

**How do patients and doctors make sense of  
chronic back pain in the first specialist  
consultation?**

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## Overview

Part one of this volume is a systematic review of literature about the expectations patients with chronic pain have for medical consultations within secondary care. It presents a thematic analysis of the results of eight qualitative papers and considers the quality of these studies. The review discusses the extent to which the UK professional guidelines for doctors about what consultations should offer correspond with the research about what patients want from them. The clinical implications are discussed, with recommendations for future research.

Part two is a qualitative empirical paper which investigates how patients with chronic back pain understand and experience information about pain and recommended treatment within their first chronic pain medical consultation at a specialist pain management centre. The paper also examines the extent to which patients' and their doctors' understandings of the same consultation correspond. The results are considered in the context of a biopsychosocial framework of chronic pain and recent UK healthcare guidelines.

Part three consists of a critical appraisal about conducting this thesis. It contains some personal reflections about the process of conducting the research project, including strategies that were found helpful when managing researcher biases and when attempting to represent both doctors' and patients' perspectives within the study. The appraisal also discusses the potential influence of the interviewer being a psychologist, and includes reflections about the personal impact of conducting this research.

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## **PART 1: Literature Review**

**Patient expectations for medical consultations in  
specialist pain services:**

**A thematic analysis of the qualitative literature.**

## **Abstract**

**Aim:** Patients' priorities and expectations for consultations for chronic pain beyond primary care are poorly understood. This paper aimed to summarise what the current research indicates patients with chronic pain want and expect from medical consultation in specialist pain clinics.

**Method:** This paper reviewed eight qualitative studies which sampled patients with chronic pain and reported on their expectations for medical consultations in specialist pain services. The findings were synthesised using a thematic analysis, and the quality of the studies was appraised.

**Results:** The thematic analysis resulted in 12 sub-themes, which were organised into five higher-order themes. Patients reported expecting an outcome from attending a consultation, including a cure, pain relief, a diagnosis and/or information on self-management, and considered a specialist pain doctor to be an 'expert' in pain relief. Patients were also seeking effective communication with their doctor and for their pain experience to be validated. The fifth theme described how patients' expectations changed over time from expecting a 'fix' to seeking support with self-management.

**Conclusions:** The extent to which patients' expectations for medical consultations correspond with the UK guidance for what these consultations should offer was examined. There were a number of areas of non-correspondence; it seems important for services to support patients to align their expectations with what they can offer.

## **Introduction**

The International Association for the Study of Pain (1979) defines pain as an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage. Chronic pain may be defined as pain that lasts beyond the course of acute disease or expected time of healing and may continue indefinitely. Chronic pain of moderate to severe intensity occurs in 19% of adult Europeans, seriously affecting the quality of their social and working lives (Breivik, Collett, Ventafridda, Cohen, & Gallacher, 2006). The Chief Medical Officer's (CMO) Annual Report for 2008 increased awareness of pain as a public health issue, stating that each year over 5 million people in the United Kingdom develop chronic pain, but only two-thirds will recover (Donaldson, 2009).

The CMO report stated that people with chronic pain account for a significant proportion of general practitioner appointments each year and are relatively high users of accident and emergency, diagnostic, and outpatient services. The percentage of people with pain referred to specialist pain clinics is increasing (The British Pain Society, 2005). However, patients referred to pain clinics have often followed a long and convoluted route through the healthcare system, and pain clinics are inconsistent in the quality of services they deliver (Chronic Pain Policy Coalition, 2012). The CMO report highlighted the importance for services to be better co-ordinated and designed around patients' needs.

Despite the rhetoric for pain services to be patient-focused (Chronic Pain Policy Coalition, 2012; Donaldson, 2009), there is currently sparse evidence about what patients with chronic pain prioritise or expect from treatment or pain services.

A large-scale survey found that people with chronic pain rated a wide range of outcome domains as being important, including pain reduction, enjoyment of life, emotional well-being, fatigue and sleep-related problems (Turk et al., 2008). A recent study found little correspondence between these patient- determined outcomes and the outcomes routinely measured in treatment trials (Beale, Cella, & Williams, 2011). The authors state that it is important that patients' priorities for improvement are understood, and that these form a basis for communication between health care professionals and patients about treatment targets.

It has been shown that many patients fail to express their expectations or agendas in medical consultations (Bell, Kravitz, Thom, Krupat, & Azari, 2001), or to have them heard. Qualitative studies have shown that GPs can miss the cues of patients with chronic pain that they are seeking explanations, and respond to patients' cues about psychosocial problems with explanations for physical symptoms (Salmon, Dowrick, Ring, & Humphris, 2004). If patients' expectations are met, patients are more likely to be satisfied, adhere to recommended treatments and make fewer return visits for similar symptoms (Hirsh et al., 2005). However, patients with chronic pain typically report high levels of dissatisfaction with healthcare services (Chronic Pain Policy Coalition, 2012); it therefore seems timely for services to better understand patients' expectations for healthcare services.

A systematic review conducted by Parsons et al. (2007) reported on qualitative studies examining patients' beliefs and expectations of primary care in relation to their chronic musculoskeletal pain. The themes identified included patients expecting good communication, establishing an ongoing and equal

relationship with their general practitioners (GPs), and having continuity of care. One of the review's major themes was about patients wanting to be believed and trusted when they talked about their pain, and one way of 'legitimising' their pain was to be referred to another practitioner or for further tests. It is the interest of this current review to explore what patients' expectations are once they have been referred to a specialist. Furthermore, it will examine whether patients have similar expectations of their GPs to pain specialists and, moreover, whether these are consistent with what these different services are set up to do.

In 2007, the Royal College of Anaesthetists (RCA) established a Faculty of Pain Medicine: a professional body responsible for the training, assessment, practice and continuing professional development of specialist medical practitioners in the management of pain in the UK. The Faculty of Pain Medicine has published a number of documents relating to training and professional standards in pain management. Guidelines – developed by a multidisciplinary working party – recommend that doctors within pain medicine consider treatment goals beyond simply reducing pain intensity and provide a wider management plan which is focused on reducing disability and improving overall quality of life, including supporting patients to develop self-management strategies (The British Pain Society, 2010). These guidelines recommend that goals are agreed with patients before starting treatment and are assessed at each review. The recommended curriculum for doctors specialising in Pain Medicine is consistent with this biopsychosocial approach to pain, including the requirement for doctors to learn about the physical, psychological and social aspects of pain (RCA and The Association of Anaesthetists of Great Britain and Ireland (AA), 2012). Of particular relevance for this review is

the requirement for the ‘Good Pain Medicine Specialist’ to effectively manage patient, family and carer expectations (RCA and AA, 2012). It seems pertinent for the literature on patients’ expectations to be reviewed to assist specialists with this task.

### **Relevant review paper**

Initial scoping exercises uncovered a systematic review of studies about patient expectations and satisfaction with treatment for low back pain within any healthcare setting (Verbeek, Sengers, Riemens, &Haafkens, 2004). The aim of the review was to describe aspects of care which patients had specific expectations about, or which they expressed particular satisfaction or dissatisfaction about, in order to inform an understanding of what patients expect from healthcare providers. Studies were sampled from primary and secondary care literature.

Given that the objectives of the Verbeek et al. review were similar to those of this review, their literature search results are discussed, along with a consideration of how far it meets the aims of this review. Verbeek et al. summarised the findings from twelve qualitative studies; they reported that patients wanted a clear diagnosis of the cause of their pain to prove to others that the pain was real and legitimate, as well as information and instructions, pain relief and a physical examination. Patients were reported to want what the authors defined as a ‘confidence-based association’ with their healthcare provider, which included being understood, listened to, respected and included in decision-making. Patients were reported to be dissatisfied if these conditions were not met, and consequently felt delegitimised and lost confidence in their healthcare providers.

The results of the systematic review by Verbeek et al. are clearly relevant for the present review question in providing a synthesis of studies about patient expectations and satisfaction in relation to care provided for back pain, but for several reasons their review does not answer the question posed by the present review. First, the review by Verbeek et al. included papers about patients with acute back pain and/or chronic back pain, and they synthesised the results across these studies. No comparisons were drawn between patients with acute or chronic pain, but they did note that there seemed to be a gradation between more and less ‘experienced’ patients; more experienced patients (whose pain was more likely to be chronic) seemed to expect more information and make higher interpersonal demands of their healthcare providers compared with newer patients. Given that healthcare needs are different for chronic and acute pain, the present review aims to focus on studies which only include patients with chronic pain. Second, the review by Verbeek et al. included patients who described their expectations in relation to care from a range of professional groups and services, without differentiating between these services. However, patients may have different expectations from different professions. In order to inform service provision, it seems helpful to understand patients’ expectations in relation to particular services or professional groups. Thirdly, the results by Verbeek et al. only included themes from patients’ accounts which were also considered important by the studies’ authors. It seems possible that expectations that were only referred to infrequently by patients, or which were not directly relevant to the authors’ research aims, may not have been included in the review. The present review seeks to identify all expectations of healthcare expressed by patients in studies.

In conclusion, the review by Verbeek et al. seems useful in indicating areas that may be relevant in answering what patients with back pain expect from healthcare. However, due to their broad inclusion criteria, it is not clear if the conclusions are applicable for patients with chronic pain seeking care from specialist medical pain consultations. The present review plans to use more specific search terms to capture what patients are wanting, hoping or seeking from specialist pain consultations, and will also sample literature since 2001, not covered by the Verbeek et al. review.

### **Aims of this Review**

This paper aims to answer the following question: what does current research indicate patients with chronic pain want and expect from medical consultations in specialist pain services? To address this question, it seems most appropriate to examine qualitative papers given the exploratory nature of the review question and the aim to represent patients' perspectives. A systematic literature search for relevant qualitative papers will therefore be conducted, and a thematic analysis of the results will be undertaken to synthesise the relevant data.

This review plans to compare the results of the current review with the results of the review papers discussed above. It will also examine the extent to which UK guidelines about what consultations within pain services should offer patients, corresponds with the research about what patients are expecting from them.

## **Methods**

The objective of the literature search was to identify qualitative papers which examined what patients with chronic pain wanted or expected from medical consultations in secondary care or pain services. Since services and expectations of them change with policy and with implementation of evidence and guidelines, the search focused on recent literature. This methods section will describe the review's search strategy and present the search results.

### **Inclusion criteria for literature search**

Studies which met the following criteria were included in the review:

- Exclusively researched individuals with chronic pain (pain for more than three months)
- Examined patients' experience or views of healthcare services
- The majority of the results reported patients' expectations, preferences, wants or hopes for medical consultations within secondary care or pain services
- Qualitative methods of data collection and analysis were used
- Participants were adult
- Published in English
- Published between 1995- 2012.

### **Search strategy**

A search for papers was carried out on the following electronic databases: PsychINFO, Medline and Embase. The following search terms were developed:

(persistent adj4 pain\*) or (chronic adj4 pain\*)

AND

patient\* or client\* or service user\*

AND

want\* or expect\* or expectation\* or agenda\* or communication\* or  
desire\* or preference\* or hope\* or presumption\* or assumption\* or view\* or  
opinion\* or experience\* or choose or choice\* or attitude\* or satisfaction\* or  
important\* or perception\* or seek or prefer

AND

doctor\* or physician\* or medic\* or consultant\* or appointment\* or hospital\*  
or consultation\* or (pain adj2 centre) or clinician or (doctor-patient) or (pain  
adj2 clinic) or professional\* or treatment or healthcare or (pain adj2  
management) or (health adj2 service) or (health adj2 care) or practitioner\*

The function options within each of the databases were used to limit the searches to studies of human adults published in English in a peer-reviewed journal between January 1995 and January 2012. The qualitative methodology filter

developed by Grant (2000) was used to limit the search to qualitative research: “findings or interview\* or qualitative” were entered as search terms. In line with recommendations, the search was also ran without the methodology filter to increase the likelihood of identifying qualitative research (Shaw, 2011); this did not result in the identification of any additional studies that met the inclusion criteria for this review. Therefore, the results of the literature search with the qualitative methodology filter are presented.

## Search results

Table 1 shows the number of papers identified at each stage of the search process. After the search limits were implemented 815 papers were identified through Embase, 704 papers through Medline and 129 through Psychinfo. After de-duplication, 913 papers were identified across the three databases.

Table 1

*Number of papers identified during electronic literature search*

	Number of papers identified			
	Embase	Medline	PsychINFO	Total
Search terms	9777	5966	2336	18079
Limit to English language	8256	5211	2219	15686
Limit to Humans and Adults	3679	3261	396	7336
Limit to 1995- 2012	3338	2809	369	6516
Limit to studies including in abstract, keyword or title: findings or interview* or qualitative	815	704	129	1648
De-duplicate	791	94	28	<b>913</b>

The titles and abstracts of the articles were read and screened to determine if they met the inclusion criteria for this review; this excluded 854 studies. Over a third of the papers did not meet the criteria of chronic pain: 297 papers reported on research on other medical conditions (for example cancer, kidney disease, hernias, pancreatitis, osteoporosis, sickle cell disease, pregnancy, degenerative conditions, spinal cord injuries, amputation) and 40 papers on acute pain. The majority of the remaining papers did not meet the criteria of patients' experience or views of healthcare services: 222 reported on medical interventions, 52 on clinical features of chronic pain, 41 on psychological or physiotherapy interventions, 33 on psychological or mental health variables associated with chronic pain, 31 on assessment or survey tools, 25 on the classification of chronic pain, 23 on participants' coping strategies, 16 on prevalence studies, 16 on healthcare professionals' views or knowledge, 13 on healthcare usage and 7 on audits. A further 12 papers were excluded as they researched children and 4 papers were excluded as they were conference abstracts. An additional 22 papers did not meet the criteria of using qualitative methods of data collection: the majority of these papers reported results from satisfaction surveys.

The remaining 59 studies were retrieved and read to determine if they met the inclusion criteria: this resulted in 52 studies being excluded. Table 2 presents the research topics of the excluded studies; the largest number exclusively examined the impact of pain on individuals' lives.

Table 2

*The research topics of retrieved papers which were excluded*

<i>Research topics of excluded papers</i>	<i>Numbers excluded</i>
The impact of pain on individuals' lives	19
Participants' health beliefs	9
Participants' views of utilising complementary and alternative medicine	5
Patients' satisfaction with healthcare using quantitative methodology	5
Participants' views of web-based healthcare messages	4
Participants' perceived role within healthcare interactions	3
Participants' expectations of primary care	3
Participants' views of treatment adherence	2
Participants' experience of physiotherapy	2

This left seven studies which met the inclusion criteria. The reference lists of these papers were searched which resulted in the identification of one further study which met the inclusion criteria. Therefore, eight studies were included in the current systematic review.

## **Results**

The results of the eight papers that met this review's inclusion criteria are presented below: this results section is divided into four sections. First, a summary of the studies' characteristics – including their research aims, methodological details and sampled populations – is provided to contextualise the findings. Secondly, the

thematic analysis of the papers' data is presented. Thirdly, data which was considered pertinent to the review's question but could not be included in the thematic analysis is reported. Lastly, the quality of the studies and their ability to answer this review's question is discussed.

## **Contextual Data**

This section provides an overview of the studies included in this review, including their research aims, methods of data collection and analysis and sampled populations.

Table 3 presents details of the studies' aims and data collection and analysis methodologies.

Table 3

*Details of the studies' methods*

<i>Author and Research Aims</i>	<i>Methodology and when participants were interviewed</i>	<i>Question(s) asked of participants</i>	<i>If relevant, additional measures used</i>	<i>Analysis method</i>
<p>Allcock et al., 2007</p> <p>Aim: explore patients' pain-beliefs at the point of referral to a pain clinic, their expectations of the clinic and priorities for improvement.</p>	<p>Focus groups, 1 -2.5 hours.</p> <p>Conducted prior to consultation at pain clinic.</p>	<p>Open-ended questions about patients' beliefs about their pain and expectations for the pain clinic.</p>	<p>Participants were asked to rank ten statements according to their priorities for the pain consultation.</p>	<p>A data-driven method of framework analysis to identify themes.</p>
<p>Dewar et al., 2009</p> <p>Aim: describe the perspectives of people with chronic pain as they seek relief via the health care system.</p>	<p>Semi-structured interviews, 30-90 minutes</p> <p>50% conducted over the telephone; 50% face-to-face; Convenience sampling resulted in participants being sampled at different points in their journey through the healthcare system.</p>	<p>Participants asked how they manage pain, who helped them manage it and how they sought assistance.</p>		<p>Name of analysis not given, description resembles thematic analysis.</p>

<p>Hansson et al., 2011</p> <p>Aim: investigate the meaning of the experiences of patients with chronic pain in their encounters with health care staff.</p>	<p>Unstructured interviews, between 50-70 minutes long.</p> <p>Not clear when participants had last received healthcare.</p>	<p>Experience of encounters with health service staff within secondary care, experience of being invited to participate in the care and being seen as a whole person, experience of being asked about their pain experiences.</p>	<p>Phenomenological approach, including searching for participants' meanings and categorising them into themes.</p>
<p>Katz et al., 2011</p> <p>Aim: examine similarities and differences between Hispanics and White non-Hispanics with chronic pain, in relation to medical treatment decision-making preferences.</p>	<p>Semi-structured focus groups.</p> <p>Conducted after at least two outpatient appointments at a particular teaching hospital. Duration of groups not reported.</p>	<p>Moderator-guided discussion of broad areas, including treatment decision-making process, discussions between patients and physicians, preferences for information resources and roles in decision-making.</p>	<p>Comparison between responses given by Hispanics and non-Hispanics white participants.</p> <p>Grounded theory approach to identify themes, then content analysis to compare the responses from the two ethnic groups.</p>
<p>Kenny, 2004</p> <p>Aim: explore patients' and doctors' accounts of chronic pain, at the point patients' have been referred to a chronic pain clinic.</p>	<p>Unstructured interviews, 45 minutes to 2 hours long.</p> <p>Conducted after completing a multi-disciplinary pain clinic programme.</p>	<p>Participants were asked to talk about their experiences of their pain problem, positive and negative, including their experiences of treatments, doctors and other health practitioners that they had consulted, and overall their satisfaction of how their pain had been managed.</p>	<p>Transcribed for conceptual analysis and examined for recurrent themes, including explicitly and implicitly expressed ideas.</p>

<p>Liddle et al., 2007</p> <p>Aim: explore the experiences, opinions and treatment expectations of patients with chronic low back pain in order to identify what components of treatment they consider as being of most value.</p>	<p>Semi-structured focus groups between 60-70 minutes long.</p> <p>Conducted within two years of receiving treatment from a medical professional which included advice and exercise.</p>	<p>Facilitated discussions including asking patients their expectations from treatment, and how they decide if expectations are met or not; their views and experiences of different treatments and how they thought chronic pain should be treated.</p>	<p>Name of analysis not given, description resembles thematic analysis.</p>	
<p>Petrie et al., 2005</p> <p>Aim: examine expectations of patients' first outpatient visit to a pain clinic.</p>	<p>Brief structured interview;</p> <p>Conducted prior to first pain clinic.</p>	<p>Three open-ended questions: What do you expect to come out of your first visit to the pain clinic; What outcome from the pain clinic interview will be most satisfying for you?; What outcome would be most disappointing?</p>	<p>Patients asked two Yes/no questions: if they expected further medical investigations, and if they expected to have a different medication prescribed.</p>	<p>Name of analysis not given. Categories developed from participants' responses, and participants' response to each answer was coded into a category. Description resembles content analysis.</p>
<p>Walker et al., 1999</p> <p>Aim: explore back pain patients' perspectives at the point where patients seek help from pain treatment centres.</p>	<p>Unstructured interviews, duration between 1.5 and 3 hours.</p> <p>Conducted after first appointment as a new referral at pain clinic.</p>	<p>Participants asked to tell their story from the time their pain problem began. No interview schedule used; probing non-directive questions were used to elicit how participants' feelings and thoughts about the events described.</p>	<p>Phenomenological approach to identify themes organised according to the meaning participants ascribed to their experiences.</p>	

Only two of the eight studies in this review directly sampled patients' expectations prior to their first outpatient visit to a pain clinic (Allcock et al., 2007; Petrie et al., 2005). In the study by Allcock et al., patients were asked to discuss their beliefs about their pain, expectations and priorities for the consultation within focus groups. In the study by Petrie et al., patients with chronic pain were asked open-ended questions within a brief interview: what they expected to come out of their first visit to the pain clinic, what outcomes from the clinic would be the most satisfying and what would be the most disappointing.

Three of the eight studies asked people with chronic pain – who previously had or were still receiving specialist pain healthcare – about their views, experiences and expectations about medical treatments and consultations (Hansson et al., 2011; Katz et al., 2011; Liddle et al., 2007). Each of these studies had specific research aims that were narrower in focus than the question of this review. However, the papers were considered relevant for this review as the majority of the themes identified in the papers were about patients' preferences or expectations in relation to medical consultations and treatment provision beyond primary care. The study by Hansson et al. (2011) aimed to investigate the meaning of the experiences of persons with chronic pain in their encounters with health service staff and asked participants about how they experienced encounters with health service staff. The research aim of the study by Katz et al. (2011) was to compare how similar Hispanics and White non-Hispanics with chronic pain were in medical decision-making preferences; they facilitated semi-structured focus groups, comprised of the two ethnic groups, and asked questions about the participants' views and preferences about the medical treatment decision-making process. Liddle et al. (2007) sought the views,

experiences and expectations of patients with chronic pain who had received advice and exercise as part of treatment for their pain, aiming to identify what components of treatment this group of patients considered to be of most value, and what, if any, key changes they would make to enhance treatment effectiveness.

Three of the eight studies had broader research aims than this review's question, and asked patients with chronic pain more generally about their experiences and perspectives of managing chronic pain and seeking healthcare (Walker, Holloway, & Sofaer, 1999; Kenny, 2004; Dewar, Gregg, White, & Lander, 2009). These studies were considered relevant for this review as most of their reported themes were around what patients wanted or preferred from pain specialist medical care. First, the study by Walker et al. (1999) aimed to explore chronic back pain patients' views of their lives and their worlds, in order to provide an 'insider' perspective on chronic back pain at the point where patients seek help from pain treatment centres; they asked patients to tell their story from the time that their pain problem began. Second, Kenny (2004) aimed to compare doctors and patients' descriptions about chronic pain; the part of this study which asked patients about their experiences was considered relevant to the review's question. Indeed, patients were asked to describe their chronic pain experiences, positive and negative, including treatments, the doctors and other health practitioners that they had consulted, and their overall satisfaction with the way that their pain had been managed. Third, Dewar et al. (2009) aimed to describe the perspectives of people with chronic pain who seek relief via the health care system, and they asked patients about how they managed pain, who helped them manage it, and how they sought assistance for their pain.

Table 4 presents a summary of the populations sampled within the studies, including the country and setting of the data collection, the chronic pain criteria used, and the sample demographics available from the paper. Three of the papers were conducted in the UK (Allcock et al., 2007; Liddle et al., 2007; Walker et al., 1999), one in Sweden (Hansson et al., 2011), one in New Zealand (Petrie et al., 2005), one in the US (Katz et al., 2011), one in Australia (Kenny, 2004) and one in Canada (Dewar et al., 2009). In two of the studies patients were sampled from a hospital pain clinic waiting list (Allcock et al., 2007; Petrie et al., 2005), four studies sampled patients who were outpatients of a pain clinic (Hansson et al., 2011; Katz et al., 2011; Kenny, 2004; Walker et al., 1999), one study sampled patients through a chronic pain support group (Dewar et al., 2009) and one study recruited patients through a university (Liddle et al., 2007). All of the studies reported only including patients with ‘chronic pain’: the majority of studies included patients with a range of pain diagnoses (Allcock et al., 2007; Dewar et al., 2009; Hansson et al., 2011; Kenny, 2004; Petrie et al., 2005), one study included patients with either chronic back or knee pain (Katz et al., 2011) and two studies only included patients with chronic back pain (Liddle et al., 2007; Walker et al., 1999). The sample demographics available within the papers were mostly restricted to the participants’ gender, age and employment status.

Table 4

*Participant demographics*

<i>Author</i>	<i>Country and setting</i>	<i>Sample</i>	<i>Number of participants</i>	<i>Pain criteria</i>	<i>Sample Demographics available from paper</i>
Allcock et. al, 2007	UK.  Not reported where focus groups were conducted.	Patients on the clinic waiting list of a pain management service at a hospital.	18 (3 focus groups)	Chronic pain- not defined.  Duration of pain not reported.  72% had back pain, other participants had either stomach, neck, knee, face or neck pain.	50% female, 50% male.  27- 76 years old, mean age: 54 years.  11% unemployed, 61% retired, 28% employed.
Dewar et. al., 2009	Canada.  50% interviews conducted over telephone; not stated where the interviews were conducted for the remaining 50%.	90% were recruited through chronic pain support group database.	19	Chronic back pain, neck pain or migraine, minimum of 6 months. Duration of participants' pain ranged from 4 to 52 years.	68% female, 32% male;  40-65 years;  53% unable to work because of chronic pain; other 47% either full time or part time employment.  All had government-administered health care insurance; 47% had additional health insurance.

<i>Author</i>	<i>Country and setting</i>	<i>Sample</i>	<i>Number of participants</i>	<i>Pain criteria</i>	<i>Sample Demographics available from paper</i>
Hansson et al., 2011	Southern Sweden.  Interviews conducted in participants' homes.	People who had received health services from a specific council health authority.	8	Chronic pain- not defined.  Duration 3-45 years; participants had been given a range of diagnoses including back pain, neck pain and rheumatoid arthritis.	75% female, 25% male;  29- 66 years old;  50% in employment, 12% on sick leave, 38% pensioners.
Katz et al., 2011	Boston, US.  Groups held at venue independent of hospital.	Outpatients of a teaching hospital, who had received care from specialist pain department.	90	Chronic back or knee pain. Sampled if patient had been seen at a particular hospital, at least twice in the year for this pain.  Did not state how long patients had experienced chronic pain for.	90% female, 10% male;  Median age 60 years (range 32-83 years);  Groups divided into either Hispanics or non-Hispanic white participants.
Kenny, 2004	Sydney, Australia.  Setting of interviews not reported.	Patients who had completed multi-disciplinary pain programme.	20	Diagnosed chronic non-malignant pain, and failure to improve their occupational or social functioning after participation in one or more pain programmes.	70% female, 30% male;  Age range not provided, all over 18 years old;  Employment: 40% medically unfit for work, 20% in employment, 40% fit for work but unemployed.

<i>Author</i>	<i>Country and setting</i>	<i>Sample</i>	<i>Number of participants</i>	<i>Pain criteria</i>	<i>Sample Demographics available from paper</i>
Liddle et al., 2007	Ulster, Ireland;  Focus groups conducted in private room at university.	83% employees of a specific university, 17% students of same university.	18 (3 focus groups)	Episode of non-specific low back pain lasting three months or more, and received treatment for it from a health professional.  Did not state how long patients had experienced chronic pain for.	78% female, 22% male;  Occupations: manual, clerical, technical, academic or student.  Ages: <20 6%, 20-40 years 28%, 41- 55 years 50%, 56-65 years 16%.
Petrie et al., 2005	Auckland, New Zealand.  Interviews conducted in hospital prior to consultation.	Patients who were first time referrals as outpatients of pain clinic.	77	Chronic pain for 6 months or longer;  34% had multiple pain sites; 23% head, neck, and facial pain; 20% back pain.  'Average' duration of pain: 6 years (SD 7.9).	55% female, 45% male;  'Average' age: 51 years (SD 16).  Earnings-related compensation payments were being received by 30%.
Walker et al., 1999	South England, UK.  Interviews conducted at participants' homes.	Patients who recently attended pain clinic as new referrals.	20	Diagnosed with chronic benign low back pain;  Duration of pain between 2 and 50 years.	40% female, 60% male;  28- 80 years old.

## **Thematic Analysis of the papers**

### *Method of synthesising literature*

The Cochrane Qualitative Research Methods Group (CQRMG) guidance was consulted to determine the most appropriate method of synthesising the qualitative papers (Noyes & Lewin, 2011). The primary aim of this review was to aggregate and summarise the qualitative papers which addressed a specific question about patients' expectations, so an integrative method of synthesis was adopted. A thematic analysis without theory generation was considered the most appropriate method to answer this review's question. This method offers an organised and structured way of synthesising the literature and results in the identification of prominent or recurrent themes from the source papers (Dixon-Woods, Agarwal, Jones, Young, & Sutton, 2005). Given the exploratory nature of the research question, a data-driven approach was utilised, that is, the themes within the synthesis were determined by the themes identified in the literature itself. It is unclear from the current literature whether thematic analysis should reflect the frequency with which particular themes are reported, or whether the analysis should be weighted towards themes that appear to have a high level of explanatory value (Noyes & Lewin, 2011). For the purpose of this review it was decided that any data within the papers that referred to what patients wanted or expected from services outside general practice was included in the synthesis and, for transparency, the number of papers which mentioned each theme is stated. The thematic analysis was limited to summarising the data reported in the studies and the primary data was not accessed; as participants' responses in each study were analysed according to the individual studies' research aims, it does

not seem helpful to place too much importance on the frequency with which particular themes are reported. The results present a descriptive account of the thematic analysis.

There is currently no agreed guidance for the process of conducting a thematic analysis synthesis (Noyes & Lewin, 2011); the published examples provided by the CQRMG were consulted as methodological guides (Carlsen, Glenton, & Pope, 2007; McInnes & Askie, 2004; Noyes & Popay, 2007). The methodology adopted within this review was akin to the approach used in qualitative research (Braun & Clarke, 2006). First, the researcher became familiar with all the papers by reading them several times. Second, all the data which related to the research question was underlined: any reference to patients' preferences, expectations, views or wishes of consultations beyond general practice was included. Thirdly, a list of all the identified data was generated. It was noted that the majority of the papers reviewed had different research questions from this review: patients' expectations of services were only one aspect. It therefore did not seem helpful to be restricted to the way the papers had grouped their data; if only one sub-theme from a theme was relevant to this review, only that sub-theme was included in the synthesis. When data was extracted from a theme, notes were made about the theme to provide contextual information with which to understand the meaning of the included data. Fourthly, the data was organised into themes; this was an iterative process which included consulting the papers to ensure that the themes reflected the original meaning and that all relevant data was included. Fifthly, the themes were named using the language used in the papers as far as possible.

## *Results of thematic analysis*

The thematic analysis of the papers identified 12 sub-themes, which were organised into five themes: these are described below.

### *1- Outcome*

All of the studies described patients reporting that they expected an outcome from the consultation: this theme describes three outcomes: seeking a cure or pain relief, wanting a diagnosis and wanting information on self-management.

#### *1.1 Seeking a cure or pain relief*

All of the papers reported that patients wanted a cure or pain relief as an outcome from consultations. Several of the studies described how patients wanted from their consultation a complete cure or fix for their pain: a fifth of patients in one study stated that this would be the *most* satisfying outcome of a pain clinic consultation (Petrie et al., 2005). Patients described how on referral to a pain clinic, after having experienced a number of ineffective treatments within primary care, they now wanted a '*solution*' (Walker et al., 1999, pg. 624), a '*quick fix*' (Hansson et al., 2011, p. 446) or to '*get rid of the pain*' (Liddle et al., 2007, p. 1904).

The studies also described how, if a 'fix' was not possible, then patients wanted to know that there was a possibility of improvement (Petrie et al., 2005) or that something could be done (Walker et al., 1999). This is exemplified in the following extract: "*I'm hoping for some- I can't say pain-free because will I ever be pain-free?- but just some relief*" (Allcock et al., 2007, p. 253). However, two studies emphasised that patients did not want pain relief to be offered just through analgesics

and muscle relaxants, as patients wanted the source of the pain condition to be addressed (Allcock et al., 2007; Liddle et al., 2007).

### *1.2 Wanting a diagnosis*

The majority of studies reported that patients wanted to have an accurate diagnosis for their pain. Several reported that patients thought that a diagnosis would enable doctors to treat their pain (Allcock et al., 2007; Hansson et al., 2011; Liddle et al., 2007; Walker et al., 1999); this is exemplified by the following patient quote: “*if they can't put their finger on what it is... then they can't sort of... you know... treat it*” (Liddle et al., 2007, p. 1903). Furthermore, four studies also described how patients wanted a diagnosis from the doctor because it would ‘validate’ that their pain experience and distress was ‘real’ (Allcock et al., 2007; Dewar et al., 2009; Kenny, 2004; Liddle et al., 2007). The patients in two of these studies reported wanting to know why they had the pain and it seemed to be assumed that a diagnosis would provide this understanding (Allcock et al., 2007; Walker et al., 1999). In the study by Petrie et al. a quarter of patients reported expecting from a pain consultation an explanation or improved understanding of their pain; it was not reported what constituted an explanation, for instance if a diagnosis would fulfil the same purpose.

### *1.3 Wanting information on self-management*

Four of the studies also reported that patients hoped to have advice or guidance around managing their own pain (Allcock et al., 2007; Dewar et al., 2009; Liddle et al., 2007; Petrie et al., 2005). In the study by Petrie et al., one tenth of participants said the *most* satisfying outcome of the pain clinic consultation would be

advice on self-management. In line with this, another study reported that patients wanted to be provided information about the best practices for pain management strategies (Dewar et al., 2009), and one study reported that the majority of patients preferred that the physician provided such information, as opposed to being offered other information sources, such as leaflets (Katz et al., 2011). Furthermore, another study reported that patients wanted advice about lifestyle adaptations and exercise programmes to be tailored to them individually, and that they wanted to be followed up to ensure that they were carrying out the advice properly and to enhance their motivation (Liddle et al., 2007). One focus group within this study, for example, discussed how they wanted advice to be ‘modified’ to them individually and they agreed when a participant described how a group format was ineffective because “*what suited one person, didn’t suit another*” (Liddle et al., 2007, p. 1903). The hope that visiting the pain clinic would enhance motivation was also mentioned in another study, as one participant stated, “*when you’re on your own, there’s not much motivation*” (Allcock et al., 2007, p. 253).

## *2- Pain doctor as expert*

Four studies reported that patients expected doctors outside primary care to be ‘expert’ and to be able to provide additional treatments for their pain from those their general practitioners prescribed (Allcock et al., 2007; Hansson et al., 2011; Katz et al., 2011; Liddle et al., 2007). One of these studies, for example, reported that patients wanted diagnosis and treatments to be provided by a specialist in pain, rather than by their general practitioners who were not ‘expert’ enough: “*diagnosis is a specialist subject... I don’t think GPs should take that on board... I pushed to see a*

*professional and not take advice from a GP”* (Liddle et al., 2007, p. 1903). Hansson et al. reported that patients expected that specialists would know of new revolutionary discoveries to alleviate their pain.

The study by Katz et al., reported that three quarters of all patients’ comments about who should make health care decisions were in line with the theme that the doctor was the ‘expert’ and so should be the primary medical decision maker. The authors reported that patients described how they considered doctors specialising in pain to be expert and knowledgeable, trusted sources of information and that consequently they would be prepared to follow their recommendations.

### *3- Communication*

The third theme describes the importance patients attributed to effective communication within the consultation: they wanted to understand the language the doctor used and to be understood by the doctor.

#### *3.1 Wanting understandable language to be used*

Two of the studies described that patients wanted doctors to talk to them using terminology that they could understand, rather than using medical terminology (Katz et al., 2011; Walker et al., 1999). At the same time, patients in these studies also described wanting to be spoken to as though they were at the same level as the doctor, and that the way doctors communicated with them was a key source of potential satisfaction or dissatisfaction. This is exemplified in the following quotation: *‘I don’t want to be talked down to. Don’t throw out a bunch of medical jargon to me... to be dismissed because you’re just a patient’* (Katz et al., 2011, p.

82) In the study by Walker et al., patients described wanting professionals to use consistent language so that they could understand the terminology being used.

### *3.2 Wanting to be listened to when describing their pain*

Four of the studies reported that patients wanted doctors to listen and understand them, in particular when describing the intensity and impact of their pain (Allcock et al., 2007; Hansson et al., 2011; Katz et al., 2011; Kenny, 2004). A central theme within one of the papers was the importance of patients being listened to, including having space in the consultation to share their agenda for the consultation, and for the doctor to incorporate the patient's experience into their understanding of the patient's pain (Kenny, 2004). In line with this theme, two studies described that in order for the doctor to adequately listen to the patients, this required enough time in consultations for patients to describe to their doctor their pain experiences (Katz et al., 2011; Hansson et al., 2011). Indeed, patients stated that when there was not sufficient time within consultations to discuss what they had wanted to talk about, or they felt that they were not listened to when describing their pain, this left them feeling that the doctor was uninterested in them and did not understand them (Hansson et al., 2011). Patients within this study suggested that one way that they could quickly, but effectively, indicate their pain intensity was on a visual analogue scale, given how hard it was to show their pain physically. However, some patients in the same study felt such an approach was used too much and that they felt they needed to be 'strategic' when rating their pain in order to ensure their pain was taken seriously.

#### *4- Wanting their experience to be validated*

This theme describes two sub-themes that seem connected to patients wanting their experience to be validated: not wanting pain to be attributed to psychological causes and wanting to be considered as an individual.

##### *4.1 Not wanting pain to be attributed to being 'in the mind'*

A sub-theme present in four studies, which seemed connected to the sub-theme of wanting to be listened to, was patients wanting to be believed when they described the physicality of their pain (Allcock et al., 2007; Hansson et al., 2011; Kenny, 2004; Walker et al., 1999). One of the sub-themes within one of the studies was 'all in the mind' which summarised how patients did not want an absence of pathological findings to be used to imply that their pain was in their minds and to divert responsibility away from physicians (Walker et al., 1999). Furthermore, central to the results within another paper was how patients wanted to be believed when they described their pain in physical terms, and that this was central to feeling 'legitimate' as a patient (Kenny, 2004). Patients wanted to be taken seriously when describing the intensity of their pain and for it not to be attributed to psychological distress; if the physicality of their pain did not seem to be believed, this left patients feeling 'discredited' (Hansson et al., 2011). In the study by Petrie et al., for 5% of patients the *most* satisfying outcome of a pain consultation was validation or acknowledgement of a pain problem.

#### *4.2 Wanting to be considered as an individual*

Two studies reported how patients emphasised that they wanted to be considered holistically and as an individual within consultations, rather than just as a patient with pain or, for example, just in terms of what their spine looked like (Hansson et al., 2011; Walker et al., 1999). This is exemplified by one patient who described her frustration that *“in the orthopaedic department, they don’t look at the whole person, just bits and pieces...to a surgeon, it looks like a minor injury, but the fact that you are in pain all the time and they can’t do anything about it, they don’t see what you should be depressed about”* (Walker et al., 1999, p. 623). The authors discussed the importance of services addressing all of patients’ needs, not just the medical aspects. Furthermore, Hansson et al. reported that the central meaning for patients when they are approached by health service staff, was expecting to be encountered as a human with self-worth and dignity, and not just patients in pain. These authors describe how being treated as a ‘human’ included patients wanting to be considered as a whole person, for instance by doctors taking into account other physical problems that the patient has or how well he or she is coping. Moreover, they reported that patients wanted to be asked about how they experience their current situations so that practitioners can acquire knowledge about their world and the impact of pain in their lives.

#### *5- Patients’ expectations as transitional*

Two of the studies reported on change over time in what patients wanted or expected from consultations (Liddle et al., 2007; Dewar et al., 2009). Firstly, Liddle et al. (2007) described how there seemed to a turning point for patients when they

realised that it was unrealistic for doctors to administer a ‘quick fix’ treatment, and they moved towards wanting doctors to assist them in bringing about and maintaining their own recovery or rehabilitation . Researchers described how patients seemed to reach a point when they accepted the importance of an active involvement in their own recovery, and consequently appeared to be more satisfied with the pain treatment programmes that they were offered.

Secondly in the study by Dewar et al., the authors described the most prominent theme as ‘coming to terms’ in which patients themselves described a transition from searching for a cure and being dependent on the medical system to realising that the pain was unlikely to remit. They described initially expecting to have the cause of their pain determined and their pain relieved; when these expectations were not met, patients reported feeling disillusioned with the healthcare system and then reaching a level of acceptance of the realities of their pain and limitations of what healthcare can provide. In this later stage patients reported that they wanted information to assist them to manage their pain, whilst keeping their treatment options open. However, Dewar et al. (2009) reported that most patients did not want professionals to tell them that they must accept the situation and ‘live with their pain’ as this was equated with physicians not trying to find a solution. It was not clear in either study how prevalent the theme of transition was in participants’ responses, or at which point in the healthcare journey participants reached the latter stage of acceptance.

## **Other relevant data from the papers**

This section discusses data which was considered relevant to the review's question but was not included in the thematic analysis.

The study by Petrie et al. (2005) reported that a third of participants explicitly stated that they had no expectations for their pain clinic visit, and about a quarter of participants were unsure whether to expect further medical investigations or different medications to be prescribed (it was not stated if the same participants did not provide an answer to each of these questions). The authors hypothesised that this finding may be a reflection of the high rate of previous treatment failures and, although there may be a number of reasons for this finding, it could be due to '*a defensive process to guard against another poor treatment outcome*' (Petrie et al., 2005, p. 300). The study does not report what patients said in relation to having no expectations or being unsure about the likely outcome, and the authors' hypothesis does not seem to be grounded in literature or what patients themselves reported. Given the high rate of patients who did not provide any expectation, it seems unsatisfactory that this finding is not discussed more comprehensively. One possibility is that the finding is a result of the methodology used as patients were only asked within the context of brief interviews; indeed, the other studies which utilised longer interviews or focus groups reported richer data about patients' expectations and preferences. In the study by Allcock et al. the authors reported that most participants had difficulty saying what they wanted from the pain clinic, partly because they knew nothing about it and that patients were surprised by the notion that there was such a thing. Unfortunately, the results did not contain any further

details about what patients actually said. However, it seems possible that the reasons provided in this study might explain the absence of expectations expressed in the study by Petrie et al.: patients did not know what would be possible to expect from a pain clinic.

In the study by Allcock et al. (2007) participants were asked to rank ten statements about pain according to their priorities for improvement. Having less pain or some pain-free times were ranked highest by all participants. Statements which the authors described as being associated with psychological or emotional improvement, such as wanting to feel less depressed or more in control of life, were ranked lower than the statements around physical improvement. It was not clear from the authors the basis for the choice of statements or why priorities for the consultation were not asked about through open-ended questions, as the rest of the study was. It seemed a rather arbitrary distinction to distinguish 'physical improvement' from 'emotional and psychological' improvement, and the statements seemed to make *a priori* assumptions that patients did feel, for example, depressed or not in control. The constrained nature of this aspect of the study seemed to elicit less rich or meaningful data, compared with the open-ended questions.

The study by Katz et al. (2011) compared Hispanics and non-Hispanic whites; there were a number of differences between the two groups in regard to health-related decision-making, including Hispanics being more likely to be influenced by word-of-mouth communication of negative experiences of certain treatments, making them disinclined to want those treatments. Hispanics were more likely than Whites to comment on strategies for coping, such as faith, religion and

family support. These are not directly related to what patients expect from consultations, but do seem important contextual information for doctors to take into account when offering treatment options: how previous knowledge of treatments and patients' coping strategies may influence their healthcare experience and willingness to try treatments. Although the authors highlighted these differences between the two groups, it is not clear the extent to which they are due to ethnicity as there were also important differences between the two groups, such as education level and socio-economic status. Moreover, due to the relatively small number of participants and the absence of statistical analysis, any conclusions can only be considered tentative. Nevertheless, this study does highlight the possibility that ethnic or cultural factors may influence patients' preferences in relation to healthcare. It seems surprising that none of the other studies reported participants' ethnicity: demographic information was usually limited to gender, age and employment status.

One of the studies that was conducted in the UK discussed the context of most patients being reliant on incapacity benefit, or currently seeking compensation for their injuries (Walker et al., 1999). The results described that patients were 'battling for benefits' and attempting to 'establish a legitimate claim'. The authors concluded that for some patients the need for medical professionals to designate that they are 'genuine and deserving' of benefits or compensation contributes to patients seeking medical help. It seems possible that patients' expectations of specialist services may therefore include the need for benefit or compensation claims to be supported by medical evidence. The other studies did not discuss this context, although four studies did provide in their participant demographic data that a

proportion of patients were on sick leave (between 12% and 53%) (Dewar et al., 2009; Hansson et al., 2011; Kenny, 2004; Petrie et al., 2005).

## **Quality appraisal**

Quality assessment of qualitative research studies remains a contested area and there are currently no agreed quality assessment criteria (Hannes, 2011). This review did not use quality assessment criteria to filter studies given the potential risk that valuable insights would be excluded from the synthesis, especially given how few studies fulfilled the search criteria. Moreover, all the studies met a minimum criterion of describing the sampling strategy, data collection procedures and the type of data-analysis (Hannes, 2011).

This section discusses the quality of the studies within this review, with particular focus on the impact the studies' quality had on the ability to answer this review's question. Guidance from the Cochrane Qualitative Research Methods Group (CQRMG; Hannes, 2011) and the Mays and Pope criteria (Mays & Pope, 2000) are used as a framework of 'quality'. The four evaluation areas described in the CQRMG guidance – credibility, confirmability, dependability and transferability – are considered in relation to the studies in this review; although they are discussed in turn, there is overlap between the areas.

### *Credibility*

A key criterion for ensuring the rigour of qualitative research is that the researcher has undertaken procedures to check the credibility of his or her conclusions, that is whether the representation of the data fits with the views of the

participants studied (Hannes, 2011). A number of ways to evaluate credibility have been proposed. A strength of all of the studies, except for the study by Petrie et al. (2005) is that themes were supported by verbatim quotations from participants and the data was judged to 'fit' the interpretations drawn by the authors: this was helpful in increasing the 'credibility' of the process of analysis, but also to further understand participants' perspectives. Indeed, the conclusions one could draw from the study by Petrie et al. seemed to be limited by the lack of descriptions of or extracts from participants' responses; responses were coded into rather broad categories, such as 'expecting explanation or improved understanding of pain problem'. The descriptions of the themes and participant extracts within the other studies enabled richer insights into reasons underlying patients' expectations, for instance that one reason for seeking a diagnosis was to validate that their experience was 'real' (theme 1.2).

Two other 'credibility' checks that researchers can conduct are either having another researcher examine an 'audit trail' of the research process or to independently analyse the data to reach a consensus as to how best to represent the data. Both of these are intended to reduce the researcher bias in the process of analysing the data (Barker & Pistrang, 2005). All of the studies, except the study by Hansson et al. (2011), included additional researchers to examine the 'audit trail' or independently analyse the data. However, two of the papers were very vague about their process of 'auditing', stating that another researcher 'assisted' in the data analysis (Dewar et al., 2009) or independently 'validated' the themes (Walker et al., 1999, p. 622). Three other papers stated that the data was analysed by an independent researcher and any discrepancies were 'resolved' (Katz et al., 2011, p. 80) or the

themes were discussed and a consensus of opinion was reached (Allcock et al., 2007; Liddle et al., 2007). It would increase confidence in the process of these ‘credibility checks’ if the papers were more transparent and detailed about how differences were resolved. Only two papers seemed to provide adequate detail about how independent ratings of the themes were conducted, including reporting the inter-rater agreement (Kenny, 2004; Petrie et al., 2005).

The majority of the studies did not seek respondent validation of the findings, that is, they did not ask participants to comment on the interpretations made by the researcher. The one study which did seek respondent validation reported that no-one disagreed or added to the themes (Liddle et al., 2007): this could be taken as evidence of the ‘credibility’ of the study’s results. However, the lack of any suggested changes begs the question of whether participants felt able to disagree; indeed, Hill et al. (2005) question the utility of respondent validation, arguing that participants rarely provide feedback because of a power imbalance and, if they do, it can be problematic because results sections tend to report only typical responses and thus may not fit any single participant.

Another method to improve the ‘credibility’ of data is for researchers to search for, and discuss, elements in the data that contradict the emerging explanation of the phenomena under study: such ‘negative cases’ help to refine the analysis and increase the reader’s confidence that the views of a range of participants are represented in the data (Mays & Pope, 2000). The majority of the papers in this review included ‘negative cases’ and represented different perspectives within their results (Allcock et al., 2007; Dewar et al., 2009; Hansson et al., 2011; Katz et al.,

2011; Liddle et al., 2007; Walker et al., 1999). The inclusion of ‘negative cases’ seemed to enrich the results presented within the papers: for example, Dewar et al. described patients’ different responses to being encouraged to ‘accept’ and ‘manage’ their pain: this emphasised the importance of doctors checking with patients their perceptions and reactions to the advice being provided. It also helped to contribute to the understanding that patients’ expectations can develop and change over time.

### *Confirmability*

One way of evaluating whether the data is qualitatively ‘confirmable’, that is, it is grounded in the data, is to assess the effects of the researcher during the research process (Hannes, 2011). Indeed, given that the researcher influences the process of research and the interpretations of the data, it is recommended that the researchers disclose their perspectives so that the reader can better evaluate the conclusions drawn (Barker & Pistrang, 2005). Five of the papers in this review provided the names and professions of the researchers who conducted the interviewing and analysis (Allcock et al., 2007; Hansson et al., 2011; Kenny, 2004; Liddle et al., 2007; Walker et al., 1999) and three of the papers reported who analysed the data, but not who conducted the interviews (Dewar et al., 2009; Katz et al., 2011; Petrie et al., 2005). However, in all studies, information about the interviewers or analysers was restricted to their professions and whether they had experience of working with patients with chronic pain. It seems a shortcoming that none of the papers disclosed information on the researcher’s perspective, *a priori* assumptions about the research topic, or personal characteristics which might have influenced how the data was collected or analysed. Only two of the papers mentioned that the researcher could

influence the results; these two studies were the only ones using a phenomenological approach to data analysis and described it as an integral part of the process to remain '*faithful to the meaning of participants*' (Walker et al., 1999, p. 622) and '*not be governed by preconceived notions*' (Hansson et al., 2011, p. 445). It is a limitation that the studies using other methods of analysis did not discuss the need to be self-reflexive during the research process.

Despite a number of limitations being identified, it seems important to note that the studies in this review span twelve years, were conducted in seven different countries, and used a range of qualitative methodologies. However, themes identified in individual studies converged and there were no apparent discrepancies between the results presented in the studies. This convergence seems to indicate that the studies represented something fundamental about participants' experience, and that patients' expectations for pain services appear to be relatively consistent across a range of settings.

### *Dependability*

Dependability evaluates whether the process of research is logical, traceable and clearly documented, particularly on the methods chosen (Hannes, 2011); it is important for any research to be transparent about its process and to choose appropriate methods to answer its aims (Barker & Pistrang, 2005).

All the papers clearly documented study aims, data collection methods and analytic method and, for the majority of the papers, the results were easy to access. Two of the papers embedded literature within their results sections, presumably to provide context with which to make sense of their results, but this sometimes made it

difficult to distinguish between what patients' said, what the authors' interpretations were, and what previous literature was reported to have found (Kenny, 2004; Walker et al., 1999).

For all the papers, the authors' choice to conduct qualitative research was considered appropriate given the exploratory nature of the research topic and, for the most part, there was a clear rationale for the choice of methodology. The main exception seemed to be the study by Petrie et al. (2005) in which the rationale for the method of data analysis was not clear: participant responses to each of the three questions were coded into a category and if a participant's answer covered two or more categories, it was coded into the category which best captured the response. This enabled patients' 'expectations' to be ranked in terms of which were reported most frequently, which provided some useful information: for instance, that 'explanation' and 'cure' were expected much more frequently than advice on self-management. However, it seems rather simplistic to assume that patients only had one expectation for a consultation or one preferred outcome, and this choice of analysis seems unlikely to capture the complexity of patients' expectations. It may have been that this rather reductionist method of analysis was a 'trade-off' for the significantly larger number of participants interviewed in this study: if this was the case, however, it would have been helpful to report it. In addition, it was not clear why in the study by Katz et al. (2011) the authors chose to tally the number of times a statement was mentioned in the focus groups as a 'rough gauge' of the comparative importance of themes; as the authors acknowledge, this does not account for the possibility that one or two participants can contribute a large number of statements.

This seems a particular limitation given that the tallies were used as the basis by which to compare the preferences of the two ethnic groups.

The three papers which conducted focus groups provided a rationale for choosing focus groups over individual interviews, for instance, that they have been shown to reveal '*attitudes, values and beliefs which may not emerge during one-to-one interviews*' (Allcock et al., 2007, p. 254). However, these studies did not discuss whether using focus groups met these expectations. The papers which conducted one-to-one interviews did not explain their decision to collect data through interviews rather than focus groups. There did not seem to be obvious differences – in terms of the content or richness of the data – between group or interview data. However, it would have been helpful if the papers had stated their reflections on their choices of data collection, for example, to assist readers to plan research which is most likely to capture patients' experiences. For example, the study by Dewer et al. (2009) conducted half of their interviews over the telephone and half face-to-face; they did not report whether there was a difference between the data elicited. If there was no difference, this seems a useful finding as future research could reduce costs by telephone interviews; but if there were differences, this is important for the reader to know in order to interpret their results accordingly.

### *Transferability*

The criterion of 'transferability' evaluates whether research findings are transferable to other settings and other groups of individuals (Hannes, 2011). It is important that sufficient contextual details are reported to enable readers to determine whether the findings can be applied to other settings.

All the studies provided some information on participant demographics with which to contextualise the sample, including age ranges, gender mix and participants' site of pain. Overall, the gender mix reported in the studies (mean proportion of women was 65%) and age range (median age across the studies was around 55 years old) was broadly representative of the chronic pain population (Donaldson, 2009). However, the majority of the papers did not report the demographic characteristics of patients who described different themes. It could be helpful to develop hypotheses if such details had been provided: for example, to examine whether certain patient groups – such as patients who were on sick leave or experiencing pain in a particular location – may have different expectations. The main exception within this review is the study by Katz et al. (2011) which offered insights into the differences between two ethnic groups in relation to healthcare decision-making preferences. In addition, only a minority of the papers reported the recruitment rate and so it is difficult to determine the extent to which the participants in the studies were representative of the populations they were sampled from, for example, if they were a self-selecting sample who were particularly satisfied or dissatisfied with healthcare provision. Although qualitative studies do not typically aim for representative samples or to generalise to a whole population, it is possible that particular perspectives may not be included if the recruitment rate is low: it may be, for example, that one point of view – for example, satisfaction with healthcare – is also a reason why patients might opt in or out of studies.

For the purposes of this review, it seemed helpful that the papers sampled patients at different points in their healthcare journeys. Two papers – which had sampled patients who had been under specialist services for different lengths of time

– reported that patients’ expectations for services changed over time from initially seeking a ‘fix’ from pain specialists to then wanting support with self-management, once they realised that a cure was unrealistic (theme 5). This finding seems particularly pertinent in understanding what patients expect from services; it may be that the patients who were seeking a ‘cure’ (theme 1.1) were at a different point in their journey through the healthcare system from the patients who wanted information on self-management (theme 1.3). It seems a limitation that papers which included patients at different points in their healthcare journey did not provide details of the duration of these journeys, or discuss encounters patients had experienced within the healthcare system which may have moved them along this journey or just perpetuated the idea that a ‘fix’ was possible. Additional contextual information might have been helpful in establishing if there was a specific time frame within which participant expectations progressed from the ‘quick fix’ to the need for advice on self-management. It also would have enabled clearer comparisons to be made between studies, for instance, whether the patients who sought a ‘quick fix’ in other studies were at an earlier stage of their healthcare journey, or represented a group of patients who persisted in the belief that a cure is possible.

It seems a limitation that most studies did not provide details about the healthcare system on which the participants were expressing their views, for example, the process to accessing specialist pain services. For readers who are unfamiliar with different health services, it is difficult to infer whether insights from a study based in one country can be considered relevant to another country. Indeed, there are important distinctions between the healthcare systems discussed in the studies within this review, including whether they are insurance-based or state-

funded, which may impact upon patients' expectations. The discussion of the UK benefit system within the study by Walker et al. (1999) for example, was a helpful context with which to understand patients' need for doctors to consider their pain is 'legitimate'.

## **Discussion**

### **Summary of findings**

This systematic review synthesised themes from eight qualitative studies which sampled patients with chronic pain and reported on patients' expectations for medical consultations in secondary care or pain services. A thematic analysis of the papers identified twelve sub-themes, which were organised into five themes. First, all the papers reported that patients expected at least one outcome from the consultations: a cure, pain relief, a diagnosis and/or information on self-management. Second, half of the papers reported that patients expected doctors specialised in pain to be 'expert' and able to prescribe additional treatments to those already tried. Third, the majority of studies described that patients reported wanting effective communication within the consultation, in particular being able to understand the doctor and for the doctor to listen to them. Fourth, patients wanted their pain experience to be validated, not attributed to psychological causes, and they wanted to be considered holistically. Lastly, two studies reported that patients' expectations seemed to be transitional, moving from seeking a cure to then seeking support with self-management. It appears important to note that the majority of the studies had a

different primary research question from this review and so it is possible that there may have been data relevant to this study which were not included in the papers; it therefore does not seem helpful to place too much importance on the frequency of the reported themes.

### **Comparison of findings with literature**

The results of this review are mostly consistent with the review conducted by Parsons et al. (2007) of qualitative studies examining patients' expectations of primary care, including the importance patients attribute to effective communication (theme 3), being taken seriously and believed (theme 4), and a diagnosis being a key way to have their pain legitimised (theme 1.2). Parsons et al. stated that GPs reported 'giving in to' patients' demands for (sometimes unnecessary) tests and referral in order to be seen to be doing something and to maintain patients' trust; the authors hypothesised that this may perpetuate patients' belief that a diagnosis and medical cure is possible. The current review suggests that this may be the case as the majority of papers reported that patients were seeking pain relief and a diagnosis from pain services. There were, however, several discrepancies between the two reviews. Parsons et al. (2007) reported that patients wanted continuity of care with their GPs; this theme did not arise within the current review, which perhaps reflects the difference between the expected duration of relationship with the doctor in question. In addition, Parsons et al. reported that patients wanted an 'equal relationship' with their GPs, whereas this review indicated that pain doctors were positioned as being the 'expert' and decision-maker.

The results of this review were also consistent with the review conducted by Verbeek et al. (2004): patients in both reviews reported expecting a clear diagnosis to demonstrate the legitimacy of pain and pain relief. Both reviews also demonstrated the importance for patients of being understood, listened to and respected as individuals. This seems to indicate that these expectations are fundamental to patients with acute or chronic pain when seeking healthcare from different professional groups. The need for patients to demonstrate that their pain is 'legitimate' is consistent with literature examining the notion of the 'sick role': if doctors perceive patients to be objectively healthy, patients can be labelled 'difficult' and blamed for 'illegitimately' claiming the 'sick role'. However, if patients are deemed to be 'legitimately' sick, they can expect to not be held responsible for their sickness and be relieved from routine social obligations, such as employment (Koekkoek, Hutschemaekers, Van Meijel, & Schene, 2011).

The current review also identified several additional patient expectations to the ones reported in the reviews by Verbeek et al. and Parsons et al. First, this review highlighted the importance of considering how other contexts – such as ethnicity or patients being reliant on incapacity benefit – may affect patients' expectations for healthcare. Second, papers in this review detailed the importance to patients of being considered holistically and doctors understanding the impact of the pain on their lives. Third, patients in the previous reviews only mentioned seeking medical treatments; whereas patients in the current review reported also wanting information on self-management (theme 1.3). A theme within this review described how patients' expectations change from just seeking a 'cure' to wanting support with self-management (theme 5). The Misdirected Problem Solving Model of chronic pain

offers a way of understanding this transition: when the problem of chronic pain is framed only in terms of abolishing pain, problem solving is misdirected towards the search for a cure and patients can become trapped in a vicious cycle of trying to solve the unsolvable (Eccleston & Crombez, 2007). If patients reframe the problem from being one of purely pain relief to how to live a valued life in the presence of pain, they can become open to other ways to problem-solve: for example, learning how to self-manage and function despite the pain. It is not clear from the current evidence base when this transition occurs within patients' journeys through the healthcare system, or what proportion of patients make this transition.

This review highlights that patients' expectations include, but are not restricted to, pain relief or diagnosis; all the papers, for example, reported that patients valued clear communication and feeling that their experience was validated by the doctor. This is consistent with literature examining patient satisfaction ratings with treatment for chronic pain in which patients give significantly different satisfaction rates for 'quality of care' to 'quality of treatment' (Hirsh et al., 2005). The study by Hirsh et al. indicated that patients' satisfaction is not achieved merely by pain reduction; satisfaction with the patient-provider relationship significantly predicts patients' overall level of satisfaction with the care they receive. This review provides further details of aspects of the 'patient-provider relationship' that seem important to this patient group.

## **Clinical and Research Implications**

This section discusses a number of clinical and research implications from this review's findings, with particular focus on how patients' expectations for

medical consultations within pain services correspond with the UK guidelines for what these consultations are set up to offer patients.

Patients within the current review described wanting to be considered ‘holistically’: they reported wanting to be considered a whole person and for doctors to understand the impact of their pain on their lives. This patient expectation seems in line with current guidelines which recommend that pain specialists conduct biopsychosocial assessments (Royal College of Anaesthetists (RCA) and The Association of Anaesthetists of Great Britain and Ireland (AA) 2012) and that treatments which aim to reduce pain intensity are provided as part of a wider management plan focused on reducing disability and improving overall quality of life (The British Pain Society, 2010). Literature from primary care has found that GPs tend to respond to patients’ cues about psychosocial problems with explanations for physical symptoms (Salmon et al., 2004) and that medical and psychosocial explanations for pain are often not integrated (Ring, Dowrick, Humphris, Davies, & Salmon, 2005). One possible explanation for this finding is that GPs do not feel that they have the time or training to identify and manage both physical and psychological aspects of pain (Parsons et al., 2007). It seems relevant for future research to examine whether doctors within specialist pain services are able, in contrast to GPs, to formulate and offer interventions within a biopsychosocial framework, in line with recent guidance. Furthermore, it would be helpful to examine whether patients are having their expectations met and feel that they are treated as individual rather than just ‘a patient with pain’.

Several of the papers reported that patients expected a cure or ‘fix’ for their pain. To be referred to specialist services, it is likely that patients would have had experienced a number of ineffective treatments. However, some patients in the reviewed papers stated that they thought their GPs were not sufficiently competent to treat their pain and expected that the pain doctor would be more ‘expert’ and know of new treatments to alleviate their pain. Although there are a number of medical treatments that patients can be prescribed, most of these have a relatively high failure rate for most people with chronic pain, particularly in the long term (Williams, 2007). Recent UK guidelines state that medical treatments should therefore be considered as only one of the methods for relieving pain; non-pharmacological methods, including self-management, should be explored with patients as over-reliance of pharmacological treatments can result in physical side-effects and provide patients with the inaccurate message that a cure is likely (British Pain Society, in press). It therefore seems that a number of patients in this study had unrealistic expectations of pain specialists and the treatments they could provide, and one could hypothesise were likely to be disappointed when ‘revolutionary new’ treatments were not available. One could also hypothesise that if patients are seeking a cure for their pain and they are recommended non-pharmacological treatments, this may reinforce patients’ belief that the physicality of their pain is not being believed and taken seriously.

A number of papers also reported that patients wanted information on self-management, including two papers which sampled patients prior to their first pain consultation. This seems consistent with the current guidance to provide patients with chronic pain information about self-management principles and support them to

develop skills to maintain their everyday functioning and reduce the impact of pain (Donaldson, 2009). The current review indicated that at least some patients reported a change in their expectations over time, from previously just seeking a cure to now also wanting information about how to self-manage. Research has shown that patients who already have beliefs that self-management could be helpful benefit much more from rehabilitation programmes than patients whose notions of pain management remain focused on medical management (Burns, Glenn, Lofland, Bruehl, & Harden, 2005). Indeed, rehabilitation programmes often require a substantial patient commitment and lifestyle change and so it is important that patients are in agreement with the rationale of the approach in order to be motivated to fully engage (Liddle et al., 2007). It is therefore important for research to understand further what enables some patients to 'reframe' their problem from one that can only be solved by a medical fix to one which can benefit from engaging in self-management. In particular, it seems helpful for future research to investigate whether there are ways which healthcare professionals can deliver explanations and information about chronic pain to patients which will help broaden patients' perception of 'pain management'. Papers in this review suggested that some patients did not have a clear understanding of what to expect from a 'pain management' service, and consequently they did not know what to expect from attending. It may be, therefore, that GPs can play a vital role in educating patients about what they can realistically expect from secondary care services. Alternatively, it may be that pain services can deliver pre-consultation information about the likely assessment and treatment process to help align patients' expectations with the service's standard practice.

The recommended delivery of self-management and rehabilitative strategies is through pain management programmes; these use cognitive behavioural methods, usually in a group format and provided by a multi-disciplinary team (The British Pain Society, 2007). There are discrepancies between such a programme and the preferences patients expressed within the reviewed papers: patients reported wanting strategies to be tailored and explained to them individually, as opposed to within a group, and preferably by the physician. It seems that there may be tension between the guidelines and service pressures to deliver self-management in the most effective and efficient format, and patients' preferences. It may be helpful to examine whether patients' expectations, for example to have tailored advice, can still be met within a group format.

UK guidelines state that doctors should be aware of the pain management needs of different patient groups, including those with different cultural beliefs or who speak a different language (RCA and AA, 2012). The study by Katz et al. (2011) highlighted differences in how two ethnic groups – Hispanics and non-Hispanic whites – make health-related decisions. It seems a limitation in the current evidence base that studies are not routinely recording the ethnicity of participants when researching patient expectations of healthcare or examining whether there are differences between patient groups. It seems important for this research to be conducted to enable doctors to better understand the expectations and pain management needs of different patient groups.

Guidelines for pain doctors consistently emphasise the importance of effective communication with patients, including doctors providing clear

explanations and information about treatments in ways that patients can understand. Patients' concerns and anxieties should be listened to, their questions answered and information given in a way which enables patients to feel confident about the care being provided (RCA and AA, 2006). This importance of effective communication within consultations is consistent with the 'communication' theme in this review: patients reported wanting doctors to use language they could understand and to be listened to when describing their pain. However, patients reported that in their experience there was often insufficient time in consultations for them to discuss what they felt they needed to in order for the doctor to understand their pain. Patients also stated that doctors sometimes used inaccessible language and inconsistent language to that of other professionals, which prevented them from adequately understanding the messages within the consultation. Within the current UK financial climate there is increasing pressure for specialist pain services to quickly refer patients back to their GPs, along with treatment recommendations. It seems challenging for specialist doctors to fulfil their responsibility to conduct an assessment, provide a diagnosis and formulate a treatment plan, while also ensuring there is sufficient time for patients to describe aspects of their experience that they think are important, and to ensure patients have had time to understand the messages being communicated. There is currently no agreed way across services as to how best to explain diagnoses, formulations or treatment plans for patients with chronic pain and there is little research on how patients with chronic pain understand consultation messages within specialist services. It appears timely for research to examine how best to utilise specialist pain consultations to meet both service and patients' needs.

## **Limitations of Review**

It seems important to consider the results of this literature review in the context of several limitations.

First, it is possible that relevant studies were not included within the review. A range of subject headings for each concept were used to try and identify as many relevant studies as possible. Nevertheless, due to limited resources it was necessary to limit the search by ‘adding’ a number of fields together and only retrieve papers that contained all of them. Second, only UK guidance for pain services was examined and discussed. Given the reviewed studies were conducted in different countries it would have been preferable to have compared patients’ expectations and the guidance and service remits for their own healthcare system.

Third, most papers reporting meta-syntheses do not provide detailed accounts of the methodological processes they adopt, for example, simply stating that themes ‘emerged’. It was therefore difficult to be confident that best practice was being adopted when thematically analysing the papers for this review; guidance from the qualitative research literature was utilised to supplement the limited guidance available on meta-synthesis (Braun & Clarke, 2006; Joffe, 2011). In line with recent guidance, it seems important for future syntheses to provide more detailed descriptions of how methods are applied to improve transparency and provide an ‘audit trail’ for the reader (Noyes & Lewin, 2011). Moreover, this would be helpful for other researchers to learn about the methodological process of synthesising data and, hopefully, to contribute to consistent procedures being adopted.

## **Conclusions**

This review demonstrates that patients have a number of expectations and preferences for medical consultations within pain services which include, but are not limited to, receiving pain relief. It seems important that pain specialists understand patients' expectations to enable them to tailor consultations to try to fulfil them, for instance, ensuring effective communication and validation of individuals' experiences of pain. However, this review indicated that for some patients their expectations are not consistent with what pain services are set up for and able to deliver; it is important for future research to examine how best to support patients to align their expectations with services available in order to get the best from specialist consultations.

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## **PART 2: Empirical Paper**

How do patients and doctors make sense of chronic back pain in the first specialist consultation?

## **Abstract**

**Aim:** This paper aimed to examine how patients with chronic back pain understand and experience the messages about pain and treatment in their first specialist medical (pain clinic) consultation. It also aimed to compare what doctors believe they communicated with patients' own 'take home' messages.

**Method:** Sixteen patients were interviewed immediately after their first consultation at a pain clinic, and their corresponding doctors were interviewed shortly afterwards. Thematic analysis was conducted on the patient interviews to address the first research aim, and then framework analysis was employed to compare understandings of the consultation within the patient-doctor dyads.

**Results:** Thematic analysis of patient interviews resulted in four higher-order themes: the central role of medical treatments in the treatment of pain; a dilemma about hoping when there are 'no guarantees'; the importance of trying all recommended medical interventions and, for a minority of patients, relief to be recommended non-medical pain management. Although there was considerable overlap within the patient-doctor dyads, clinically relevant areas of mismatch included the explanation of pain, the likely long-term treatment plan, and patients' role in their treatment.

**Conclusions:** Patients' understandings of the consultation messages seemed to influence their beliefs about the likelihood of their pain being relieved, and their sense of control over it. There seemed notable areas of mismatch between doctors' and patients' understandings of the consultation which are likely to impact upon treatment success and patient satisfaction.

## **Introduction**

The Chief Medical Officer's Annual Report for 2008 (Donaldson, 2009) increased awareness of chronic pain as a public health issue, affecting 7.8 million people with enormous negative impact on individuals, their families, businesses and the economy. It described how chronic pain reduces individuals' quality of life; for example, 49% of patients with chronic pain experience depression and 25% lose their jobs. Back pain is the most common site of pain, affecting 1.6 million adults per year in the UK, and costing an estimated £12.3 billion per year, mainly in work days lost.

### **Models of chronic pain**

Historically, chronic pain was conceptualised within a biomedical model with the extent of patients' perceived pain severity considered to be proportionate to the amount of tissue damage, and relief of pain relying on eliminating the cause of the pain. It has become clear that most chronic pain is neither associated with distinct physical signs nor diagnosable disease, and when there is disease or damage, its extent is not related to the severity of pain in any simple way (Williams, 2007). However, research into lay health beliefs indicates people often still conceptualise pain as being synonymous with physical pathology (Newton-John, 2002). Pain is the archetypal warning of danger and is a survival mechanism: it interrupts, distracts and demands attention to respond to potentially harmful and life-threatening situations (Eccleston & Crombez, 1999). As with any alarm system, the cost of efficiently detecting threat is a number of false positives (Daniel & Williams, 2010). In Western medicine in the 20<sup>th</sup> century, pain that was considered 'disproportionate' to the identifiable physical pathology was generally attributed to psychopathology. Several

different psychogenic aetiologic models, such as the ‘psychosomatic’ model were proposed. The theoretical basis for these remain highly abstract and unrelated to pain mechanisms (Sharpe & Williams, 2002). Such models – which partition pain into being somatic or psychogenic – are unsupported by evidence and anachronistically simple given the last 50 years of scientific exploration of pain (Wall, 2000).

The gate control model which described sensory, motivational and emotional components to pain (Melzack & Wall, 1965) provided the basis for a biopsychosocial model which conceptualises pain as the result of the dynamic interaction among physiologic, psychological, and social factors. On this foundation, a cognitive-behavioural perspective for understanding chronic pain (Turk, 2002) was imported from mainstream psychology. The basic premise of cognitive behavioural therapy (CBT) is that a person’s interpretation of events, rather than the events themselves, determines the subjective experience and behavioural response to the event (Beck, 1987). In the context of pain, the critical determinants of individuals’ emotional and behavioural adaptations to the pain are their cognitions –appraisals, expectations and beliefs about the origin and consequences of pain – rather than the nociceptive and biological events *per se* (Morley, 2007). The immediate meaning of the pain to the individual is considered crucial in determining whether the individual is able to dismiss the pain as non-threatening and return to a task, or becomes preoccupied by the pain and its possible implications (Eccleston & Crombez, 2007).

### **Pain-related cognitions**

There is a body of research on the influence that cognitions have on pain experience, including distress and disability. If pain is interpreted as signifying on-

going physical harm, avoiding situations or behaviours that are expected to produce pain is an attempt at adaptation and recovery. However, avoidance of activity may lead to the maintenance or intensification of pain and disability, through several pathways (Vlaeyen & Linton, 2000). Through the process of stimulus generalisation, more and more activities are avoided to prevent exacerbation of pain; inactivity produces physical deconditioning, its consequences are not disconfirmed, and positively reinforcing activities are lost. Distorted movements and postures to avoid pain can cause further pain unrelated to the initial problem. Over the longer-term, losses of role and of valued activities can impact adversely on personal identity, social and work life, and contribute to depression (Harris, Morley, & Barton, 2003).

Catastrophising is currently one of the strongest predictors of distress, depression and disability in chronic pain (Sullivan et al., 2001). It is described as a tendency to attend to pain, overestimate its threat value and underestimate the capacity to manage that threat. Increases in perceived control over pain and decreases in catastrophising are associated with decreases in self-reported patient disability, pain intensity, and depression (Jensen, Turner, & Romano, 2001).

There is a body of research demonstrating that if patients shift their attention and efforts from symptom reduction to valued living, this can lead to better emotional, physical and social functioning, and reduced healthcare use (McCracken, MacKichan, & Eccleston, 2007; McCracken, Vowles, & Eccleston, 2005). Indeed, the Misdirected Problem Solving Model of chronic pain proposes that when problems are framed only in terms of abolishing pain, problem solving is misdirected towards the search for pain relief and patients can become trapped in a 'perseverance

loop', trying repeatedly to solve the unsolvable (Eccleston & Crombez, 2007). Reframing the problem involves broadening the target from pain relief to how to live a valued life in the presence of pain.

## **Current healthcare context**

Although there is a growing number of practitioners with a special interest in pain management, the vast majority of GPs are non-specialists. Guidance for non-specialists state that doctors should try all reasonable medical treatments which might abolish or reduce pain (National Institute for Health and Clinical Excellence, 2010). There is, however, a relatively high failure rate of medical interventions for most people with chronic pain, particularly in the longer term (Williams, 2007). Guidelines also highlight the importance of weighing up the potential benefits against the potential adverse effects; for example, 80% of patients having opioid therapy experience at least one adverse effect (The British Pain Society, 2010).

National guidelines recommend that medications and other treatments that aim to reduce pain intensity should be provided as part of a wider management plan which is focused on reducing disability and improving overall quality of life (The British Pain Society, 2010). The Chief Medical Officer's Annual Report for 2008 (Donaldson, 2009) emphasised that services should address pain using an integrated approach, including medical and psychological approaches, and recommended supporting patients' development of skills and coping strategies to maintain their everyday functioning and reduce the impact of pain. Discussions at a "Pain Summit" in 2011 developed these recommendations and highlighted the need for pain management services to be of a higher and more consistent quality (Chronic Pain

Policy Coalition, 2012). A theme running throughout the summit was the importance of improving information for people living with pain, including information about treatment options, strategies around positive coping and self-management principles. It was recommended that self-management principles should be embedded in the quality standard for pain services. These guidelines are consistent with the current emphasis across chronic illness on self-management being a major goal (Department of Health, 2005). In response, The British Pain Society detailed care pathways for patients presenting with pain. Latest guidelines highlight that pharmacology is only one method of relieving pain and related problems and that non-pharmacological methods, including self-management strategies, should be explored with patients, as an over-reliance upon medication can be misplaced (British Pain Society, in press).

The pinnacle of rehabilitation services in chronic pain is the CBT pain management programme, supported by several systematic reviews and meta-analyses (e.g. Eccleston, Williams, & Morley, 2009; Guzmán et al., 2001). Reviews of interventions for back pain have placed CBT in the highest category of evidence of effectiveness above analgesics, antidepressants, spinal manipulation and exercise (Koes, Van Tulder, & Thomas, 2006). CBT for pain management works towards improving patients' level of function, and is typically provided by a multidisciplinary team in a group format (The British Pain Society, 2007).

The costs of effective CBT pain management programmes and their limited availability has led to an interest in the development of briefer interventions which utilise CBT principles. Providing targeted information about the neurophysiology of pain and nociception can result in significant changes in pain beliefs in patients with

chronic back pain, and related improved physical performance (Moseley, Nicholas, & Hodges, 2004). However, trials of education in general practice have been disappointing (Jellema et al., 2005), and the specialist setting might be more suitable. It seems timely to research whether specialist consultations could be utilised to communicate helpful messages about pain and help promote patients' functioning, for example through the provision of targeted information. Within a CBT perspective, gathering new information about pain mechanisms and the role of treatments could help patients to re-evaluate unhelpful beliefs and fears about the pain's aetiology, the meaning of increases in pain and the likelihood of pain relief.

### **Chronic pain and medical consultations**

No studies were found examining how best to deliver information and explanations of pain within medical consultations for patients with chronic pain. The literature exploring the content and process of consultations for patients with chronic pain has mostly been limited to GPs' consultations with patients who fall in the umbrella category of having 'medically unexplained symptoms' (MUS). There is no agreed criterion for patients with MUS; they are often defined as patients whose symptoms are considered unexplained by their doctor, who are psychologically disturbed and attribute their own symptoms to a physical cause (for example, Ring, Dowrick, Humphris, & Salmon, 2004). Within the primary care literature, patients with chronic pain are often one of the largest groups in this broad category. It has often been reported that patients with MUS receive disproportionate levels of symptomatic investigation and treatment, which is largely ineffective and may worsen the problem; this has been attributed to doctors perceiving that patients are

pressing them for somatic treatment and cure (Ring et al., 2004). Research has found that physical interventions are proposed more often by GPs than patients (Ring et al., 2005) and self-report data has consistently demonstrated that patients with MUS describe that they are seeking support or convincing explanation rather than medical treatment (Peters et al., 2009). Furthermore, qualitative studies have shown that most patients provide cues that they are seeking explanations, and that they acknowledge emotional or social problems, and indicate uncertainty over whether they have a physical disease (Salmon et al., 2004). This study also found that GPs often responded to patients' cues about psychosocial problems with explanations for physical symptoms. It seems that GPs rarely integrate physical and non-physical explanations for MUS patients; it has not been reported what patients understand when different explanations are provided. It has been suggested patients receiving responses to somatic problems when they are seeking explanation or responses to psychological problems are likely to alter their beliefs and behaviour, encouraging future somatic presentation (Salmon, Ring, Dowrick, & Humphris, 2005). There is, however, no research on how patients understand doctors' explanations or suggested interventions, or the impact consultations have on patients' beliefs or behaviours.

Little research has been conducted about patients' experience of pain services within secondary care, outside cancer and post-operative pain management. The majority of studies conducted with patients with chronic pain have examined patient satisfaction; patients have reported seeking an explanation of their pain problem and cure or relief of their pain from pain consultations (Petrie et al., 2005).

Guidelines for practitioners in chronic pain state that effective doctor-patient communication is a prerequisite for effective medical provision; doctors are encouraged to provide clear explanations about diagnosis and treatments in a language which patients can understand (Royal College of Anaesthetists and The Association of Anaesthetists of Great Britain and Ireland, 2006). There has been no research examining the correspondence between doctors' and patients' perceptions of pain explanations, and other information, communicated within chronic pain consultations. There is evidence from mainstream health literature that patients often leave consultations with insufficient information or understanding of their presenting problem (Weinman, 2007) and effective doctor-patient communication has been associated with higher patient satisfaction and treatment adherence (Khalib & Farid, 2010). Evidence indicates that doctors do not routinely check patient understanding within consultations (Campion, Foulkes, Neighbour, & Tate, 2002).

### **Rationale and aims of the current study**

Medical consultations offer an opportunity to convey helpful messages about pain and intervention options; it therefore seems helpful to develop an understanding of how a pain consultation can be best utilised to promote positive patient outcomes. There is currently no research exploring how patients perceive or make sense of doctors' messages or explanations in pain consultations, or the impact these might have on pain-related cognitions. In addition, research has not examined if the messages doctors believe they have communicated to patients within pain consultations correspond with patients' 'take home' messages.

This study plans to address some of these identified gaps in current literature; it aims to explore how patients understand the messages of a medical pain consultation, as well as their doctors' perceptions of the same consultations. In line with current guidelines, it appears helpful to research what constitutes best practice within specialist pain services for the most common site of pain (Chronic Pain Policy Coalition, 2012). This study will therefore research first medical consultations for back pain within a specialist pain management centre.

The study hopes to address the following research questions:

- 1- How do patients understand and experience the messages within their initial chronic pain medical consultations: how do patients make sense of the doctor's messages and how do they emotionally react to them?
- 2- To what extent do patients' and their doctors' understandings of the consultation messages match?

## **Method**

This study adopted a qualitative approach to investigate patients' and doctors' perceptions of the messages conveyed within initial medical consultations for chronic back pain at a pain management centre.

## **Ethics**

Ethical approval for the study was obtained from The National Hospital for Neurology and Neurosurgery & Institute of Neurology Joint Research Ethics

Committee on 5<sup>th</sup> December 2008 and the UCLH/UCL Biomedical Research Unit on 2<sup>nd</sup> September 2008 (Appendix 1).

## **Setting and Context**

The research was conducted within a specialist outpatient Pain Management Clinic (PMC) in a major London teaching hospital. As a tertiary referral centre, patients are referred to the service by general practitioners or specialists such as rheumatologists, neurosurgeons or spinal surgeons. Patients are referred if they report persistent pain which has not been responsive to medications or physiotherapy, or if the pain itself is causing substantial disability or distress. Referred patients are offered an initial consultation appointment at the centre with a Pain Medicine consultant. The consultation lasts between 40 minutes and one hour; the length of the appointment is designed to allow sufficient time for a diagnosis to be made, for the doctor to explain and discuss the diagnosis and treatment options with the patient, and for a treatment plan to be agreed. The majority of patients are offered further appointments at the centre for interventions; a minority of patients are referred back to their GP with treatment recommendations.

## **Participants**

All four consultants who offer initial consultations for patients referred for back pain agreed to participate. The referral letters for patients on the waiting list for initial consultations were scanned by the researcher and one of the doctors to identify patients who were referred for back pain, were aged 18 or above, and who could speak English fluently. Patients were excluded if they had previously had an initial

medical consultation at the centre. As the researcher met participants prior to and after their consultation, if patients with consecutive appointments met the inclusion criteria, only the first patient was invited to participate.

## **Procedure**

The researcher discussed the study with the doctors individually, and informed consent was obtained from them (Appendix 2). Patients who met the inclusion criteria were sent an information sheet inviting them to participate in the study: this detailed the objectives and procedure of the study, and informed them that they were under no obligation to take part (Appendices 3 and 4). The researcher telephoned patients who were invited to participate to ask if they had received the information sheet and answer any questions. Patients who expressed an interest in participating on the telephone were approached by the researcher when they arrived at the centre for their appointment, and invited into an interview room. The information sheet and the consent form were discussed and patients were given an opportunity to ask any questions. Patients were reminded that their participation was voluntary and that their decision would not affect the care they received. If patients agreed to take part, they signed the consent form (Appendix 2). The researcher invited patients to the interview room immediately after their medical consultation for the post-consultation interview. Patients were again reminded that their participation was voluntary. Patients' interviews were audio-recorded and lasted between 25 and 50 minutes.

If patients consented to participate their corresponding doctor was interviewed at the earliest time they were available after the patient interview. All of

the doctors' interviews were completed within three hours of the index consultation. Doctors' interviews were audio-recorded and lasted between six and 14 minutes.

### **Semi-structured interview**

The researcher designed the semi-structured interview schedules (Appendices 5 and 6) in consultation with the research supervisor. The aims of the patients' interviews were to elicit patients' perceptions of what the main messages of the consultation were and how they experienced these. The interview schedule therefore included the following areas:

- The patient's interpretation of the consultation's main messages
- The patient's expectations for the consultation
- The patient's account of how the doctor explained their pain
- The doctor's recommendations, suggestions or advice about their pain, including the likely effectiveness of any treatments
- The patient's thoughts and feelings about the consultation's messages
- The patient's perception of the impact the consultation might have on their future decisions or behaviours
- Any other aspects of the consultation that he or she thought were important

The aims of the doctors' interviews were to elicit the doctor's perceptions of what the main messages of the consultation were and how they thought the patient experienced these. The interview schedule therefore covered the following areas:

- The main messages conveyed to the patient, including any diagnoses or explanations for the patient's pain
- Any recommendations, advice or suggestions offered to the patient, including any discussions about their likely effectiveness
- The doctor's perception of what the patient understood from the consultation
- The doctor's perception of the impact, if any, of the consultation on the patient, including how they imagined the patient felt after the consultation
- Whether there were any aspects of the consultation that retrospectively they would change
- Any other aspects of the consultation he or she thought were important.

The interview schedules were piloted on two doctor-patient pairs. The researcher's supervisor provided comments on the interview transcripts, and as a consequence minor changes were made to the researcher's interviewing style.

### **Researcher perspective**

Guidelines for qualitative methodology recommend that researchers disclose their perspective so the reader can better evaluate the results (Barker & Pistrang, 2005). The researcher is a white female in her late twenties, born into a working-class family and conducting the current study as part of her doctorate in clinical psychology. She has worked in two health psychology departments, but had not previously worked in a department specifically for adults with chronic pain. She had an *a priori* assumption that sometimes doctors' and patients' perceptions of the main

messages of consultations did not correspond. The researcher has a preference for working within a biopsychosocial approach and endorses the policy of patients being supported as active partners within medical decision-making. Whilst conducting the research, the researcher utilised regular supervision and reflection through a research journal to support the ‘bracketing’ of her assumptions and beliefs (Hill et al., 2005). The research supervisor is a Consultant Clinical Psychologist who works at the PMC.

## **Data analysis procedures**

A qualitative research approach was utilised as the study was exploratory and focused on participants’ perspectives and personal meanings. A pragmatic perspective was adopted in choosing to apply a different data analysis procedure to answer each of the two research questions (Pistrang & Barker, 2012).

### *First Research Question: Thematic Analysis*

The first research question was focused on patients’ experience of the messages within their initial consultation at the centre, including how they made sense of and emotionally reacted to them. A thematic analysis (TA) was considered most appropriate to answer this question due to its systematic and transparent approach and potential to provide a rich and detailed account of data (Braun & Clarke, 2006), with minimal constraints on content. As the researcher is interested in patients’ feelings, thoughts and understandings of the consultation messages, a particular advantage of TA is its potential to describe affective, cognitive and symbolic dimensions of the data (Joffe, 2011). TA is also not constrained by pre-existing theoretical frameworks as are other possible approaches such as Grounded Theory and Interpretive Phenomenological Analysis. TA has often been considered

an umbrella term for a number of qualitative methodologies (Pistrang & Barker, 2012); however, a number of researchers have promoted it as a distinct methodology in its own right (e.g. Boyatzis, 1998; Braun & Clarke, 2006; Joffe, 2011). Given the exploratory nature of the research question, an inductive, data-driven approach to analysis was taken (Patton, 1990). A realist/ essentialist epistemological approach was adopted as the study is focused on patients' own experiences and meanings.

Guidelines for conducting TA were followed (Braun & Clarke, 2006), and are summarised below. First, the researcher became familiar with the whole data set by transcribing the patients' interview audio recordings verbatim, reading through the data several times and making notes of initial ideas about meanings. It was noted that the patients often described their experience of pain, medical history and experience of other consultations; although these narratives were not directly relevant to the research question they were considered within the analysis as contextual information. Second, the researcher generated a list of all the features of the data which seemed related to the research question. Third, the features were organised into potential sub-themes and themes; this was an iterative process and included re-reading the transcripts for context and intended meaning. Fourth, the themes were reviewed to ensure they were internally homogeneous and externally heterogeneous (Patton, 1990) and a thematic map was constructed (Braun & Clarke, 2006). The entire data set was thematically coded to ensure all relevant features of the data set were included, and that the themes reflected the meaning of the data set as a whole. Fifth, the themes were named and defined, using the patients' language as far as possible. Finally, the account of the data was written, including verbatim quotes.

The credibility of the analysis process was regularly ‘audited’ by the research supervisor who is experienced in qualitative analysis (Barker & Pistrang, 2005). The supervisor also provided feedback which helped refine and enhance the themes; for example, the supervisor emphasised the value of reflecting the affective components of the themes, and of considering in detail the relationships between themes.

#### *Second Research Question: Framework Analysis*

The second research question aimed to identify the extent to which patients’ and their doctors’ understandings of the consultation corresponded; the patient and doctor transcripts were therefore analysed and compared in dyads. A Framework Analysis (FA) approach, a structured method of qualitative thematic analysis, was considered the most appropriate method to answer this question (Ritchie & Spencer, 1994). The doctor’s interview responses were relatively short, concrete and often based directly on the interview questions; a purely inductive approach to analysis was therefore not appropriate. However, the patient’s responses and some of the doctor’s responses about consultation messages were not restricted to the interview question topics, and therefore a purely deductive approach could potentially miss the richness and nuances of the data. The data was analysed using FA as it enabled themes to reflect both *a priori* idea and ideas spontaneously raised by participants. Further, the matrix-based analytic method of FA facilitated a systematic and transparent approach to comparing themes within and across patient-doctor dyads.

The guidelines for conducting Framework Analysis were followed (Ritchie, Spencer, & O’Connor, 2003); this analysis process is summarised below. Firstly, the researcher became familiar with the data by transcribing the interview audio

recordings, reading the patient-doctor transcripts in their corresponding dyads, underlining relevant data and generating a list of all the potential themes relevant to the research question. The second stage consisted of the researcher developing a thematic framework for the data to classify and organise the data; the framework was organised so that 11 sub-themes were grouped under three broader, high-order main themes (Appendix 7). Numbers were assigned to the different themes and sub-themes. The process of developing the thematic framework was iterative, with the framework being revisited and refined several times. Thirdly, the data was 'indexed': the researcher applied the thematic framework to all of the data set by colour-coding data which corresponded with the framework's themes, and annotating the margin with the relevant numerical codes. The fourth stage involved rearranging the indexed data into thematic charts in order for the doctor-patient dyads to be systemically compared. Each sub-theme was 'charted' into its own table comprised of three columns, one corresponding to patient data, one to doctor data, and one for comments. The first two columns consisted of summaries of the transcripts' key points related to the sub-theme, illustrative verbatim quotes, and page references to all relevant data. The last column consisted of comments about the extent to which the patient-doctor dyad corresponded, and any other observations. An extract from one of the charts is in Appendix 8. Each transcript was examined in relation to each sub-theme; if a patient or doctor did not make reference to a sub-theme, this was stated in the relevant table cell. Fifthly, the thematic charts were analysed to identify patterns within the data, including the match within patient-doctor dyads and associations across sub-themes.

As with the first analysis, the researcher's supervisor examined the 'audit trail' as a credibility check (Barker & Pistrang, 2005), and provided feedback which enabled refinement of the thematic framework.

## **Results**

The results section is organised into three sections: contextual information is provided to situate the findings, the results from the thematic analysis are reported and then the findings from the framework analysis are presented.

### **Contextual Data**

Sixteen patients and four consultants participated in the study. Eight patients who were invited did not participate in the study; four did not attend their consultation, three did not meet the inclusion criteria and one declined to take part.

#### *Demographic Data*

Table 1 presents the demographic details of the patients who participated; nine women and seven men, aged between 18 and 88 years, with a median age of 54.5 years. The self-reported duration of back pain was between 6 months and 50 years, with a median of 6.5 years. Patient participant numbers were allocated to all patients who were invited to participate in the study and attended the clinic, including those who did not participate; therefore in Table 1, the participant numbers are not consecutive.

Table 1

*Demographic Details of the Patient Participants*

<i>Patient Participant Number</i>	<i>Age (years)</i>	<i>Sex</i>	<i>Ethnicity (as defined by participant)</i>	<i>Duration of chronic back pain (as reported by patient)</i>	<i>Employment</i>	<i>Doctor conducting consultation</i>
P1	48	Female	Black African	35 years	Retired	Dr1
P2	68	Male	Asian British	6 years	Retired	Dr1
P4	60	Female	Anglo-Indian	2 years	Payroll Assistant	Dr1
P5	61	Male	White British	40 years (worse last 4 years)	Retired	Dr1
P6	82	Female	White British	50 years	Retired Civil Servant	Dr1
P7	69	Female	White British	1 ½ years (and 35 years low grade back pain)	Academic	Dr2
P8	55	Female	White British	30 years	Security Officer	Dr3
P9	26	Female	White British	6 months	Nurse	Dr1
P10	50	Male	Black European/ Caribbean	6 years	Carer, retired Fashion Designer	Dr1
P12	88	Male	White British	5 years	Retired	Dr4
P14	31	Female	White British	4 years (low grade pain before)	Management Consultant	Dr3
P15	33	Male	Malaysian Chinese	5 years	Shop Assistant	Dr2
P17	54	Male	White British	3 ½ years	Prison Officer	Dr3
P18	18	Female	White British	7 years (also 4 years pelvic pain)	Support Worker	Dr3
P20	37	Male	White British	15 years	City Trader	Dr4
P22	84	Female	Indian	12 years (also 2 years groin pain)	Retired Nurse	Dr3

Table 2 presents the demographic details of the four consultant doctors who participated. Two of the doctors were female, and two male, aged between 37 and 60 years. The mean number of years they had specialised in Pain Medicine was 13 years, and the mean number of years they had been a consultant was seven years.

The uneven distribution between how many participating patients each doctor saw was due to the researcher's availability to attend different clinics and an uneven distribution of patients who did not attend their consultations. The doctors were part of the same team, were all supervised by the lead consultant and attended weekly clinical meetings. It was expected that there would be no fundamental differences in the model of pain held by doctors and therefore available to describe to patients.

Table 2

*Demographic Details of the Doctor Participants*

<i>Doctor Participant Number</i>	<i>Age in years</i>	<i>Sex</i>	<i>Ethnicity</i>	<i>Number of years practising as a Doctor</i>	<i>Number of years specialised in Pain Medicine</i>	<i>Number of years as Consultant in Pain Medicine</i>	<i>Number of patients seen who participated in study</i>
Dr1	48	Male	Sino-English	23	13	12	7
Dr2	60	Female	White British	38	19	12	2
Dr3	37	Female	Indian	13	12	1	5
Dr4	44	Male	Persian (Asian)	18	8	3	2

*Patients' descriptions of their experiences of pain*

Participants all spontaneously described that their pain interfered with their daily functioning and ability to participate in important life domains, including work life, social life and daily living tasks. Patients who were in employment described

that they were frustrated at not being able to work as effectively as they had previously or being unable to work at all due to their pain.

Most patients reported that the pain was currently the most severe and debilitating that it had ever been. However, three patients explained that their pain was not currently at its worst; two patients had constant low-grade back pain with intermittent flare-ups and they were currently not experiencing a flare-up, although they had been at the time of referral (P7, P14). One patient reported that her pain had started to 'lessen' over the preceding few weeks (P9).

A few patients described positive relationships with their GPs and/ or specialist doctors, but had been referred to the PMC when the prescribed treatments proved ineffective or were shown to provide only temporary relief. The predominant experiences for patients, however, were that doctors had not believed the severity of their self-reported pain; that GPs and/ or other doctors consulted lacked sufficient expertise to treat their pain competently; and that referral to the PMC had been unnecessarily delayed. All the patients reported that they had wanted the referral.

#### *Patients' descriptions of the consultation messages*

Table 3 summarises patients' descriptions of their expectations for the consultation and their description of the doctors' explanation of their pain and treatment recommendations.

Table 3

*Summary of patients' hopes for the consultation and description of the doctors' explanations and treatment recommendations*

	<i>Patients' self-reported main priorities or hopes for the consultation</i>	<i>Summary of patients' description of the doctor's explanation of their pain</i>	<i>Patients' description of the doctor's treatment recommendations</i>
P1	Hoping to have some pain relief so can be more mobile and able to do household tasks independently.	To do with the spine and the brain; the nerve and the spine are used to the pain. The disc scratches the nerve, that is when I am in pain.	Injections New tablets to work on the nerve; continue with tablets already using for pain relief.
P2	Wanted a proper fix and to be able to do more and be more mobile, in particular to be able to walk without continually stopping.	Prolapsed disc and friction on the nerve ending.	Medication Injections to ease the inflammation Surgery as last resort
P4	Hoping to be able to walk further, hope to feel better and at least not worse.  Hoping to have treatments which do not have side-effects (unlike current medication).	It is all nerve related, even the sciatica.	Medication- pain killers Scan to understand more Maybe in future, an injection
P5	Not sure what to expect from consultation- did not know what 'pain management' referred to.  Treatment priority: to be able to walk without 'continually needing to sit down'.	Wear and tear of the spine;  Scan showed L4 and L5, which means damage to the base of the spine.	Series of injections to locate the problem, and to relieve the pain  Possibly surgery

	<i>Patients' self-reported main priorities or hopes for the consultation</i>	<i>Summary of patients' description of the doctor's explanation of their pain</i>	<i>Patients' description of the doctor's treatment recommendations</i>
	Hoping would not require injections as heard negative stories from others.		
P6	Hoping for an 'answer' as to why I have the pain and what help they can offer.  Treatment priority: to increase activity level, especially how far she can walk. Goal is to be able to walk and stand long enough to attend an upcoming public event.	Doctor knew the problem from the MRI;  Doctor did not say, but I think it is because my bones are arthritic.	Injections  Maybe acupuncture  Told could do classes, think they were to do with exercises
P7	Wanted a strategy for dealing with and preventing future pain flare-ups and have some sensible informed advice.	The muscles are extremely tight; when the muscles get tighter, it squashes the sciatic nerve.	See osteopath more frequently  Make sure I am doing the full range of helpful stretches; physiotherapist appointment to discuss stretching.  Continue activities I am doing  Possibly acupuncture or drugs if pain becomes acute again.
P8	Wanted to know what can and cannot do activity wise.  Wanted pain relief.  Hoped to find out what is wrong with back.	Diagnosis: Degenerative disc problems;  When the disc is bulging it presses on the nerve.	Carry on with exercise I'm doing and lose a bit of weight.  Short-term: try pain management injections.  Longer term: Doctor wants me to go

<i>Patients' self-reported main priorities or hopes for the consultation</i>	<i>Summary of patients' description of the doctor's explanation of their pain</i>	<i>Patients' description of the doctor's treatment recommendations</i>
<p>P9 Wanted to know if and how could return to work and playing sport. Wanted to know if could have another flare-up.</p>	<p>Disc is protruding out, and it is not quite touching the spinal cord; Diagnosis: slipped disc.</p>	<p>on the course, like back management pain. Return to work and sport slowly and in a staged way; know own limitations and stop activity if it starts to hurt. If acute pain returns again- may have a nerve route injection or epidural for temporary relief.</p>
<p>P10 Have 'zero' expectations for the consultation Wanted to know what other interventions could try to alleviate pain: did not want surgery and have preference for non-medical interventions.</p>	<p>Started as sciatica; Trapped nerves and nerves dying because of diabetes.</p>	<p>Tablets to relieve pain Maybe can wear a plastic frame Lead to further tablets or other treatments, possibly an epidural.</p>
<p>P12 Wanted an injection for pain relief. Goal to walk without as much pain, and feel less tired.</p>	<p>Not explained as explained before, understand that the two bones are rubbing together, it's all crushed and snarled up.</p>	<p>Injection</p>
<p>P14 To have someone give me some practical ideas and some reassurance about how I can get the right lifestyle and routine to stop some of the major flare-ups.</p>	<p>No diagnosis given; they have previously said they are not sure with me.</p>	<p>Told better to stop activities before pain, need to fine-tune what activities I am doing. Arranged physiotherapy appointment</p>

	<i>Patients' self-reported main priorities or hopes for the consultation</i>	<i>Summary of patients' description of the doctor's explanation of their pain</i>	<i>Patients' description of the doctor's treatment recommendations</i>
	Wanted to keep it fairly practical and outcome orientated.		to discuss pacing and stretching. Mentioned a group option.
P15	Hoped could have some advice or suggestions about ways to manage the pain.  Wanted encouragement and reassurance that the pain will lessen.  Did not want any medical interventions, due to cultural beliefs.	Very stiff and tight in muscles, muscle is weak because I stopped exercising and movement for so long.	Exercise, paced approach  Try learning to relax or meditate  Can use acupuncture or massage, but this will only be for short-term relief.
P17	Wanted to check if previous hospital had missed an intervention that could alleviate the pain.  Wanted to be prescribed a physical intervention that offered more than short-term relief.	Pain is no longer short- term.	The medical interventions available have already had at previous hospitals, including physiotherapy, injection, TENS, acupuncture- was told could try some of these again.  Offered pain management group.
P18	Wanted to be told something about my pain; wanted to be given something that takes the pain away.	I also have chronic pelvic pain, as well as back pain; muscles in whole pelvic area are too tight.	A nerve block injection, then physiotherapy  Muscle relaxant medication
P20	Not sure what expecting; hoping for a magic wand and for them to do something to take the pain away.	Vague explanation, not specific, is it the nerve or brain?	Told medical interventions are likely to not be very effective; offered acupuncture and TENS.

<i>Patients' self-reported main priorities or hopes for the consultation</i>	<i>Summary of patients' description of the doctor's explanation of their pain</i>	<i>Patients' description of the doctor's treatment recommendations</i>
Expect them to know latest treatment research which can help my pain.		Prescribed steroid injection Suggested pain management group programme. Continue exercising and losing weight
P22 Want something to be done to relieve the pain; happy to try anything. Want to feel better and have less pain.	Something to do with the nerve Muscles are not very strong To do with groin, as well as back.	Injection Acupuncture possibly, but only for short-term relief

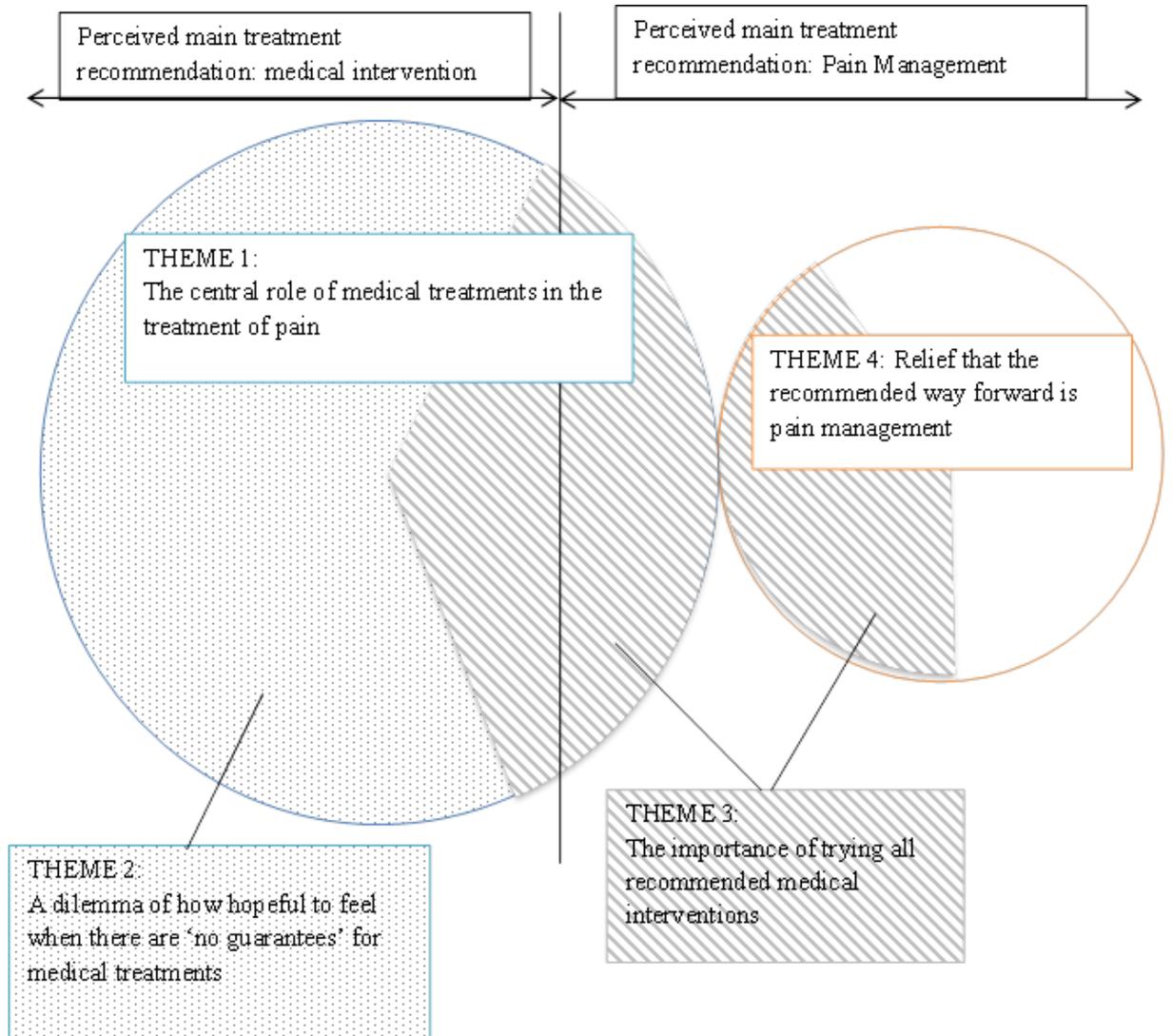
## **First Research Question: Thematic Analysis**

Patients' descriptions of the doctors' main treatment recommendations were divided into two broad categories. The first category referred to the only or main treatment recommendation being a medical intervention, typically medication and/ or analgesic injections. The second category denoted when the only or main treatment recommendation was a 'pain management approach'. Pain management approaches, for the current purpose, refer to strategies that are non-medical and require patients' active engagement, including exercise, stretching, pacing and adapting activities.

The thematic analysis of the patient transcripts was conducted to examine patients' understanding and experience of the consultation messages: this resulted in nine sub-themes which were clustered into four higher-order themes. The thematic map, shown in diagram 1, illustrates how the four themes are organised and how they relate to the two treatment recommendation categories. The left-hand and larger circle represents the 11 patients who expressed the belief that medical interventions play the central role in the treatment of pain (theme 1), ten of whom reported that the main treatment recommendation was medical. This circle, or theme, is divided into two sections: the dotted section represents eight patients who conveyed a dilemma of how hopeful to feel when there are 'no guarantees' for medical treatments (theme 2); the lined section signifies three patients who felt hopeless about treatment success but expressed a belief that they should try all recommended medical interventions (theme 3). The right-hand and smaller circle represents the five patients who expressed relief that the recommended intervention was a pain management approach (theme 4). As indicated by the lined section, two of these patients also expressed a belief that it was important that they had tried all recommended medical interventions before adopting a pain management approach (theme 3).

Diagram 1

*Thematic Map*



*Theme 1: The central role of medical treatments in the treatment of pain*

The first theme, comprised of three sub-themes, describes how the majority of patients perceived medical interventions as central in the treatment of pain. This theme was evident in the accounts of 11 of the 16 patients, 10 of whom perceived the main treatment recommendation as being medical.

*Sub-theme 1.1: Pain requires medical treatment*

Patients perceived that medical treatments were required to alleviate their pain, in part because they considered pain to be a result of a physical problem.

*The herniated disc is pointing to some sort of medical treatment. (P2)*

All of the patients reported that they had previously had medical treatments which had proved ineffective. They expected that they would continue to have medical treatments until they found one which was effective in alleviating their pain.

*So she is going to try the nerve blocker, and then if the nerve blocker doesn't work, she is going to try something different, and just keep going...if it don't work, just get more doctors' appointments. (P18)*

Patients appeared frustrated at the likelihood that the next treatment would not work, but also comforted by the belief that there were further interventions to try.

*Sub-theme 1.2: Doctor as the decision-maker*

The majority of patients positioned the doctor as being central in deciding their treatment plan. The doctor was described as being the expert in their pain, and having knowledge that the patient did not have that could offer relief for their pain.

It seemed striking how much trust the patients placed in the doctor, especially at their first meeting. Two patients referred to the status of the hospital as confirming that their trust was well placed.

*It's a very good hospital this, and as far as I am concerned I am perfectly happy to trust in their judgement and not argue at all. (P12)*

It seemed surprising that patients were prepared to trust doctors' recommendations when they ran contrary to their own preferences. Several patients

expressed fears about certain procedures, based on hearing others' experiences, and yet were prepared to follow the doctors' recommendations to try them.

*Surgery...is an absolutely last resort for me... but he is as a medical man, if he says cut off your finger to save your life, then I would have that finger cut off. (P2)*

Two patients who had treatment preferences, based on hearing success stories from others or from their own research, reported not sharing these with the doctor.

*I think me going in, saying have you thought about that, isn't going to change what's he suddenly going to do! (P20)*

As exemplified in the extract above, it seemed as though some patients felt that they had little agency to influence the consultation, or its outcome. It appeared that the role that patients adopted within the consultation was a rather powerless one, as a recipient of treatments prescribed by the doctor.

*I have left my legs in her hands... now she needs to take the pain out of them. (P22)*

### *Sub-theme 1.3: Irrelevance of pain management*

A few patients reported that although the main treatment recommendation was medical, the doctor also mentioned the possibility of pain management. This sub-theme examines how these patients, who were still trying medical treatments to alleviate their pain, perceived pain management as being irrelevant to their needs.

*From time to time this pain is unbearable, and thinking of it is not good enough... The doctor was talking pain management, get everything sorted out, get it in your mind, that yes I got this damage... Keep talking to me, what is there, is there, it is not going to make it any better, it is not going to make it any worse. (P17)*

The patient in the above extract was angry when recounting that the doctor had suggested a pain management group as he believed that it would have little

impact on his pain, and just wanted medical interventions. It seemed that medical interventions and pain management approaches were understood as two distinct options and, moreover, that pain management was positioned as the last option. The following patient described his frustration at being asked by the doctor whether he had tried pain management whilst he was still trying new medical interventions.

*Well I said these types of things will not help. You know from the picture you have got what the problem is, I want a proper fix...Well first of all the herniated disc is pointing to some sort of medical treatment so you cannot just suggest palliative care to me! You know, move your leg to the right, to the left, or whatever it is, that will not do, you have got to introduce enablers for me to do. (P2)*

As exemplified in the above extract, patients' belief that a physical explanation for their pain implied a medical treatment meant that pain management did not have a role for them. The patient's reference to pain management as being 'palliative' suggests that this option was perceived as being the absolute last resort, once there was no hope for improvement; this was in stark contrast to treatments being described as 'enablers' and having the potential to 'fix.' It seems that as long as patients had new medical treatments to try, they were hopeful that their pain would be alleviated, and this negated the need for a pain management approach.

*Theme 2: A dilemma of how hopeful to feel when there are 'no guarantees'*

When describing the main messages from the doctor, all patients who had been offered medical treatments reiterated that the doctor had stated that the treatment might not work, typically stating that there are 'no guarantees'. However, despite understanding what this at an informational level, the majority of patients also seemed excited and hopeful that the treatment, this time, would work for them. This theme considers the dilemma a number of patients expressed: on the one hand

wanting to prepare for the likelihood that the treatment would be ineffective, but on the other hand wanting to believe that the treatment would relieve their pain.

This sub-group of patients stated, often several times, that the doctor had said that the prescribed treatment might not help, or that even if it did it would offer short-term or partial pain relief. The doctors' comments seemed to fit with patients' own understanding about the likely success of treatments; indeed, several patients described how their prior experiences of unsuccessful treatments led them to feel hopeless about the next treatment. Moreover, they referred to not wanting to get their hopes up as they knew that it was unlikely that the treatment would work.

*I don't feel like nothing until it works, I don't believe it. I been through so many things, I had like massages, meds, none of them worked. So till it works, I don't care about it... Just think positive, but never get your hopes up...nothing ever works properly. (P18)*

*I sort of get the impression there's no magic wand for quite a lot of this...I guess I feel a bit optimistic, not majorly, just because it's now how it tends to go. (P20)*

It was striking that several patients referred to 'magic' when talking about what they expected from treatment; their choice of language seemed to indicate that they knew what they were hoping or wishing for was not grounded in reality.

*I am not saying everyone has magic hands to give me a magic touch, and I am going to be perfect again, start running again, I don't expect that...I am not expecting magicians to help me. I want someone to give me pain relief. (P17)*

Patients' descriptions of how they knew the treatment may not work were juxtaposed with vivid descriptions of what they imagined life would be like if, this time, the treatment did work. They seemed excited and energetic when allowing themselves to imagine life without pain.

*It won't work but imagine if it does...ah I wouldn't be able to feel pain, ah that's bliss! I am actually quite excited about having this injection! ... so hopefully, pray it works. (P18)*

Patients seemed to oscillate between enthusiastic accounts of how life could be if the treatment worked, and sounding quite hopeless in recalling that the treatment might not make any difference.

*Touch wood, hopefully, that (injection) may solve the problem... I am hopeful now that something can be done, I am quite upbeat about it... there could be light at the end of the tunnel, there could be improvement. But if there isn't, I am just resigned to the fact that I am going to have and sit down every so often, and not keep walking as far as I want to. (P5)*

*(The doctor) agreed that the first injection won't necessarily do the trick. It may however... And I am happy with that... it's a bit of luck really... I am assuming that it is going to work, that is the answer (P12)*

As the extracts above exemplify, when patients were imagining the possibility that treatments could work, they used words which indicated the need to have faith or belief – such as ‘pray,’ ‘touchwood’ and ‘trick’. This seemed connected to patients’ choice of language when describing how they were not expecting ‘magic’ or ‘magicians’. Overall, this group of patients seemed ambivalent about whether to believe that the prescribed medication would work, understanding intellectually it was unlikely, but emotionally wishing that it could.

### *Theme 3: The importance of trying all recommended medical interventions*

This theme explores patients’ belief that they should try all medical interventions that they are recommended by doctors, even when they think that they will not alleviate their pain. This theme was apparent for a minority of patients.

### *3.1: I should try all medical interventions*

This sub-theme was apparent for two patients who reported that the doctor had prescribed them further medical treatments. They felt hopeless about the likely success of these interventions, but thought it was important to at least to find out for sure that they would not be effective. These patients, seemed distinct from the majority of patients who were prescribed medical interventions and wanted to adhere because they believed, or at least hoped, that they would be a solution for their pain.

*I don't want to walk out of here, or anywhere, knowing that I didn't try....I would like to know that when I have time to sit down and think of everything, I can say ok at least I did try. And yes it worked, no it doesn't work, but I gave it a try, that's the most important thing. (P10)*

### *3.2 It is important I tried all medical interventions*

The sub- theme was evident for three patients who had been recommended a pain management approach. Patients conveyed two reasons for feeling that it was important to have tried all recommended medical interventions: the value of knowing in themselves that they had done all they could to alleviate their pain, and a sense of demonstrating this to others. It seems that they wanted to mitigate blame about not trying hard enough to alleviate their pain, whether it was self-blame or perceived blame from others. The patient below described feeling she needed to demonstrate to her work colleagues that she was trying all medical avenues to relieve her pain, even if this entailed an epidural analgesic injection which she was fearful about trying.

*I think I just thought if I said I am going to get an epidural, and then I can go back to work after that, then I could almost make it.... So I think I thought for a while, oh I'll just have the epidural, and then make everyone happy. (P9)*

The patient in the following extract reported being unable to work since the onset of his back pain three years ago; he had sought out a number of medical opinions to confirm that medical treatments would not enable him to return to work.

*There isn't anything that they can do to help me, because what they done in (hospital) is the same thing they are offering here... I got to explain this to the others. My employment, to the government...What I want now is to keep what I got, if I lose it there is not much I can do about it. But I don't want to blame myself at the end of it...I don't feel guilty anymore, because I am sure if there was anything else it would have been offered. (P17)*

The doctor's confirmation that there were no further medical treatments seemed to enable him to no longer feel self-blame about being unable to regain the fitness required for his job and it enabled him to justify himself to others. There was a sense that now he knew all medical options had been exhausted, he could begin to communicate this to others and make decisions regarding his future employment. A similar theme was also apparent for a patient who had been recommended a pain management approach, following years of unsuccessful medical treatments.

*Once you come to that end of that line, then you know. You're not, looking, there are not going to be more openings, that's it, I have got to cope with it, that's where it finishes. (P8)*

For this patient, knowing that medical avenues had been exhausted and she was at the 'end of the line,' seemed to represent a transitional point in her relationship with her pain in now needing an alternative way to 'cope'.

#### *Theme 4: Relief that the recommended way forward is pain management*

This theme, comprised of three sub-themes, describes the sense of relief that five patients described feeling in response to doctors' recommending a pain management approach. Pain management, for the current purpose, refers to strategies

that are non-medical and require the active engagement of the patient, including exercising, stretching, pacing activities and making adaptations to daily tasks. The majority of these patients were given the option of a referral to a physiotherapist and/or a pain management course to support the development of these strategies. The five patients described in this theme were all already engaging in some form of pain management – exercising and/ or pacing activities – prior to the consultation, and reported seeking further strategies to manage their pain. This sub-group included the three patients who reported that their pain was not currently at its worst, and one patient who did not believe in the long-term use of medical interventions.

*Sub-theme 4.1: Relief that I'm doing the best thing for my pain*

Patients expressed a sense of relief that the doctor indicated that their decision to engage in exercise and/ or pace activities was beneficial. They referred to concerns prior to the appointment as to whether they were doing the 'right' or 'best' thing for their pain and that the doctor's assurance that they were, enabled them to have the confidence to persist. It seemed that the doctors were considered to have the required expertise to confirm the patients' own ideas about managing their pain.

*She [doctor] pretty much verified more or less what I feel I am capable with. And I spoke to her about it, and she is quite happy so I am quite happy...Yeah, this is what I feel, and that is the expert, and you put the two together, and it's, yeah, you got to be doing the right thing. (P8)*

Similarly, two patients stated how the doctor approving of their exercising gave them permission to feel pleased with themselves.

One patient talked about her fears that her return to exercise might lead her to damage herself: she described vivid images of how her back might break, leading to

an inability to walk or incontinence. She sounded relieved and surprised that the doctor told her that she could continue to run, as long as she paced herself.

*Coz when I first went for a run I didn't tell anyone, because I thought people would shout at me, and say you are doing totally the wrong thing. But for him to say it's ok... now I know that by going running it is not going to (breaking sound) and stop me from walking forever... And someone else said to me, just be careful if you lean too far forward, or too far back it might just go (breaking sound) but I don't believe that can happen anymore! (P9)*

Patients also stated that it was particularly important to have confirmation that they were doing the optimum level of activity that they were capable of.

*I think for me, the main outcome that gives me assurance, is that I am doing the right things, that it is fairly normal for my situation and that I am on the right lines. And I am making the most of the health I have got, (P14)*

*She seemed to think it (exercising) was good... I do struggle but I do carry on... she seemed to think struggling to carry on, was alright... I feel less negative. (P7)*

The latter extract above was in the context of the patient describing how she felt 'vulnerable' and 'decrepit,' and it seemed to offer her great relief to know that the little activity she was doing was 'alright' Another patient described how 'frustrating' and 'slow' he had found starting an exercise programme – after years of inactivity subsequent to the onset of pain – and found it reassuring that the doctor reiterated that it was a slow process to regain strength and flexibility (P15). Such validation seemed to re-affirm patients' motivation and commitment to exercise.

#### *Sub-theme 4.2: Relief that I'm not getting worse*

Patients reported that although they knew that a pain management approach would not 'cure' them they were relieved to know that, if they engaged with the recommended strategies, their pain was unlikely to continue to worsen.

*I think that (pacing advice from physiotherapist) will really help to get the confidence that I can build up where I'm at. And I'm not going to go down, or least not significantly, which is a big part of that exercise for me. (P14)*

Patients conveyed having some hope and confidence that pain management might help them get a bit better, but that the most important aspect seemed to be having the assurance that they could prevent themselves from deteriorating. This was particularly salient for the following participant; she described how, prior to the consultation, she felt fearful about continuing to decline physically. This extract was when the patient was discussing how she felt about the doctor's recommendations.

*I have been feeling exceptionally decrepit with all of these wrong with me, perhaps I feel it's not quite so bad, I'm not rotting as much as I thought... I think it was because I was thinking it was an inevitable part of a slow rotting which would end up with me being dead as more and more bits fell off, and as a result of this, I think well maybe actually it might go away and at least it won't keep getting worse, so that's good. So maybe I'm not so old and rotting. (P7)*

#### *Sub-theme 4.3: Relief that I can now can make adaptations*

All the patients described in this theme reported being appreciative of the guidance the doctors offered them around self-management strategies, and that they were keen to learn more through physiotherapy appointments and/ or a pain management course. Patients envisaged that learning more about pain management would enable them to make positive lifestyle changes and re-prioritise how they spent their time. Patients conveyed now feeling a sense of agency over making decisions about their lifestyle.

*I am interested in the course, because that might give me more ideas, like if its relaxation, maybe I am not doing that, that might help...If it does concern more maybe relaxation, than that is what I need to give my time to... knowing what you can and can't do, and then it's up to you, if you want to do it. (P8)*

*I'm thinking about lifestyle changes and even if it means making some uncomfortable decisions about how I live my life. Because at least then I can sustain it. (P14)*

Being recommended a pain management approach enabled two patients to feel able to think about making decisions about their future employment. They indicated a sense of relief that they could now start to think through employment options which were less likely to aggravate their pain.

*When I get back today I will send them (employers) an email, to keep them updated.... so I think it will, it will be my decision as to, you know if something comes up with shorter hours, I will probably now go for it. (P8)*

As discussed in the third theme, it seems that for these patients hearing that the recommended approach was now one of pain management – and so there were no medical fixes available –enabled them to engage with making lifestyle adaptations.

## **Second Research Question: Framework Analysis**

As stated above, a framework analysis was conducted to examine the extent to which patients' and their doctors' understandings of the consultation's messages corresponded. The degree of concordance within the patient-doctor dyads for each sub-theme was categorised as being matched, partially matched or mismatched. A match was defined as the doctor's and the patient's account corresponding for all the aspects of the sub-theme. If a dyad was coded as partially matching or mismatching, the reason for the discrepancy was reported. Table 4 shows a summary of the concordance within the doctor-patient dyads for each of the framework's sub-themes. Appendix 7 presents detailed definitions of the sub-themes within the thematic framework; appendix 9 reports the full results of the dyads' concordance across the sub-themes, including illustrative verbatim extracts.

Table 4

*Summary of the concordance between doctor-patient dyads*

<i>Theme name</i>	<i>Matched</i>	<i>Partially matched or mismatched</i>
<b>1- The doctors' explicit consultation messages</b>		
1.1- The next recommended treatment or intervention	16	
1.2- The likely effect of the next treatment or intervention	13	3
1.3- The doctor's explanation of the patient's pain (for the 13 consultations which included an explanation)	7 (out of 13)	6 (out of 13)
1.4- The role patients are recommended to take within their treatment (for the 7 consultations which included a discussion about the patients role)	2 (out of 7)	5 (out of 7)
<b>2- Expectations about patients' long-term treatment</b>		
2.1- The expected outcome of the next planned intervention	6	10
2.2- The expected long-term treatment plan that would be most helpful for that particular patient	9	7
<b>3- Doctors' perceptions of patients compared with patients' own perceptions</b>		
3.1- Doctors' perceptions of how well the patient understood the main messages and patients' understanding of the messages	12	4
3.2- Doctors' perceptions of how satisfied patients were by the consultation and patients' self-reported satisfaction levels	11	5
3.3 – Doctors' perceptions about patients' experience of their pain and patients' self-reported experiences		6 (out of 6)
3.4- Doctors' and patients' perceptions of patients' 'agendas' and hopes for consultation		7 (out of 7)
3.5 Doctors' perception of patients' adherence intentions and patients' intention to adhere	4 (out of 6)	2 (out of 6)

The first theme, the doctors' explicit consultation messages, records the concordance between what the patient reported the doctor said to them and what the doctor reported saying to the patient. As shown in table 4, 100% of the dyads were

matched for what the next recommended intervention was and 81% of the dyads were matched for the likely effect of this intervention. Thirteen of the 16 dyads stated an explanation of pain was a component of the consultation; 53% of these were matched. Only seven doctor-patient dyads reported discussing the patient's role within their treatment, two of which provided matched descriptions.

The second theme describes doctors' and patients' expectations about the patient's long-term treatment. This theme reflects participants' own expectations about the treatment plan, rather than what was discussed within the consultation. As table 4 shows, only 38% of dyads were matched for the expected outcome of the next intervention and 56% were matched for the most likely optimal treatment plan.

The third theme concerns doctors' perceptions of patients' experiences of their pain and the consultation compared with how patients described their experiences. In 75% of consultations doctors' predicted accurately how well patients understood the consultation messages and in 69% doctors' impressions of patients' satisfaction with the consultation were matched. The last three sub-themes only arose from doctors' volunteered perceptions about patients. All the dyads were mismatched when doctors volunteered their perceptions about patients' pain or patients' agendas for the consultation.

#### *Summary of the main areas of mismatch*

Fifteen out of 16 patients described feeling satisfied with all or most of their consultation and, as summarised above, there was much overlap within doctor-patient dyads. However, it is areas of mismatch which are of particular clinical interest, so this section describes four main areas of discrepancy.

### *Mismatch of pain explanations*

Six out of 13 dyads described the explanation of pain differently (sub-theme 1.3). In four of these dyads, patients' explanations included the main aspects that the doctor reported conveying, but included additional aspects which were inconsistent. For example, two doctors reported conveying to their patients that the pain was related to nerves miscommunicating, not structural problems, but these patients reported explanations in terms of nerve and structural problems. Two other patients provided explanations which omitted a key part.

It seemed surprising that three of the consultations did not include a discussion of the explanation of their pain. Two of these patients already had a consistent understanding of their pain, but one patient's explanation of pain being structural was inconsistent with the doctor's description of pain mechanisms (P6).

### *Mismatch of the most likely long-term treatment plan: delaying conversations about pain management*

Nine of the 16 dyads were consistent in their expectations of the long-term treatment plans (sub-theme 2.2). These dyads fell into two groups: patients for whom a pain management approach was discussed as the main recommended treatment or patients for whom doctors were hopeful medical treatments would be effective. However, the remaining seven dyads were mismatched on the most likely long-term treatment plan (sub-theme 2.2), and the likelihood that the next intervention would be effective for them (sub-theme 2.1). All these dyads were matched on what was said within the consultation regarding the next recommended treatment (sub-theme 1.1) and were mostly matched on the doctor's description of treatment effectiveness (sub-theme 1.2). However, patients within these dyads reported believing that they

would continue to be prescribed medical interventions until one was effective, but their doctors stated that – although medical interventions might ease the pain – the most likely long-term treatment plan was a pain management approach. Asked why they did not tell patients the long-term plan, doctors reported intending to discuss pain management at later appointments if the medical treatments were not effective. Whilst there was a chance that medical interventions could relieve patients' pain, even if in their judgement this was unlikely, doctors were keen to pursue this chance.

P12 Dr: *I actually have a feeling it will not help his pain, or at least there is only a chance that it is going to help him. I think it is worth trying, because sometimes you get these strange cases, but as a whole injections aren't particularly brilliant anyway, but you do get the odd cases that it helps...I just thought it was worth trying for him.*

Doctors described perceiving that patients wanted or expected medical interventions and that it was helpful to accede to this, even when the doctors expected that medical interventions would not be particularly effective.

P2 Dr: *I think first you need the physical because I believe people want that, especially if their expectations have been set up to have a treatment then they want to have that, and it is really helpful for them, even if you have your suspicion it won't help to give them the treatment as long as you are not exposing them to a huge amount of risk. And that's a judgement that I have to make and I have to be happy with, to give them the treatment if it didn't work or it isn't the panacea, in order for them to move on to other sorts of treatment like enhancing their ability to cope on their own.*

There was also a sense that introducing pain management ideas too early could undermine patient relationship, so doctors postponed these discussions.

P18 Dr: *I knew if I said that to her about physiotherapy, I knew she would switch off and go away, so I said to her we will do the diagnostic block, it might only be short-term... So, I will do her injection and I will talk to her a little about, now you really need to keep moving, I have prioritised your physiotherapy, we are going to get this sorted, I am going to give her a bit of a positive message when I see her the second time around.*

It appears that doctors were taking a path of ‘proving’ – to themselves and the patient –that medical interventions were not going to work; they seemed to believe that patients would, once the interventions had proved ineffective, become disillusioned with medical treatments and thereby more open to pain management.

*Mismatch of patients’ role within their treatment plan*

As described above, whilst medical treatments were still being ‘tried’, pain management approaches were seldom discussed, so, patients and doctors had inconsistent ideas on the probable future role of patients in their treatment. However, the role of the patient within their treatment plan was reported to have been discussed in seven consultations (sub-theme 1.4): within these, pain management was recommended as the next main intervention. Five of these seven dyads were only partially matched: although patients described the need to keep mobile and exercise, most did not acquire an understanding of the details of a pain management approach.

*P14: She (the doctor) said as a rule of thumb that it’s better to stop (exercising) before the pain sort of kicks in, while you’re still enjoying it. And I understand psychologically that that’s more beneficial in some ways, but at the same time there is something more satisfying about finishing twenty minute....I immediately rejected that advice to be honest!... I think I’d be fine if someone said if you stop at the right time, we will then be able to expand that to the point you can hit your twenty minutes and go beyond that,*

*P14 Dr: She tends to over-achieve. I think it is more about reining herself back... I said when you are doing the exercise, and you are feeling really good, stop before you get to the point of saying you don’t want to do anymore...Researcher: Was there a sense of building up over time, or each time just listening to your body as to when to stop?) I didn’t really go into that. It takes so long for them to get what pacing means, and I’m not able to give it to her in an explanation now. But she seemed to be doing appropriate things, so I just wanted her to be able to stop sooner rather than push herself more, that it was ok to stop sooner.*

In the above extracts it seemed that the patient had accurately heard the doctor's advice, but did not plan to follow it as she wanted to expand the duration of her exercise over time and she thought the rationale for limiting her exercise sessions was to feel more satisfied. It seems striking that the patient grasped the concept of pacing but as the consultation did not include advice on how to pace, she was not planning to change her behaviour. The doctor predicted that the patient would adhere to the advice of stopping exercise before she was in pain rather than continuing to 'over-achieve' (sub-theme 3.5). Further, for this patient and one other, the lack of clarity of how to apply a pain management approach seemed to underscore lower expectations than their doctors of the effectiveness of the approach (sub-theme 2.1). Within several further dyads doctors described patients as 'over-doers' or 'under-doers', however patients report the doctor had not given any recommendations to change their activity levels and so did not intend to change their current behaviour.

*P8: So she has more or less told me to carry on with exercises that I am doing, she is quite happy that I am doing them*

*P8 Dr: I think for her it is really important that she carries on being able to be active, and I think that once we do the procedure, she is able to then do a little more...I think she can do more, I think she is a bit conservative, but hopefully I reassured her on that.*

This example connects with a mismatch between two other dyads, in which a medical intervention was prescribed and doctors assumed that patients knew they were expected to increase their activity levels following treatment (sub-theme 1.4):

*P2 Dr: I would probably have encouraged him to keep moving. I don't think I gave him any specific advice about keeping active. I think he probably would anyway but I didn't give him any advice.*

*P2: If I start to feel a pain and I'm going to the shop as it were, which is 15 minutes in my walk and 5 minutes in yours, then I have to find a low wall to sit down even if it means sort of half a kilometre distance, and I know*

*where they are. (Researcher: Did the doctor give you any ideas of what to sort of do, for example how much activity to do or anything else?) No he asked me if I am on any kind of painkillers or anything, for the on-going pain.*

The patients in both these dyads reported that they were not given advice about activity levels and they reported no intentions to change their behaviour; another patient intended to 'rest' in bed after the prescribed medical intervention, in the absence of advice from the doctor about activity levels.

#### *Mismatch of perceptions about patients*

Theme three summarised the concordance between doctors' perceptions about patients' experience of their pain and patients' self-reported experiences: two of these areas are described below. Firstly, in four instances, doctors over-estimated how much patients recalled of consultation messages (sub-theme 3.1); this was, in part, due to assumptions made as to how much the patient would already know:

*P20 Dr: I think he understood that's where we are going (a pain management approach), what we have to offer, I'd be surprised if he was not clear on that. Or didn't understand most of what I was saying, anyway. He's intelligent, works in IT or something, so he's not, you know. So I think he understood it.*

*P22 Dr: I don't know what she understood. She's a nurse so she probably would have taken it on board.*

Most patients reported that doctors asked them if they had questions; nevertheless, it seemed surprising that doctors reported not checking patients' understanding of the consultation messages, and assumed patients' understanding.

Secondly, in three dyads, doctors spontaneously described how they thought patients were coping well with their pain, which was inconsistent with patients' self-reports. These three patients were initially emotionally composed, but as the research interview progressed they described an emotional struggle to cope with pain.

*P7: I do struggle but I do carry on... I am alone, I'm scared, particularly when things go wrong it's very very difficult to cope.*

*P7 Dr: I think she is a very energetic dynamic lady who's very single minded and won't allow pain to stop her from doing things...I didn't really focus on her low grade back pain which is basically a long term problem that I think she was managing well, and it was really the more severe acute bouts that ...she wanted to focus on...so I haven't made any appointments to see her again but she knows she has an open appointment to come back.*

It seemed from the patients' and doctors' descriptions that the patients did not describe their struggle in the same terms in the consultation as they did in the research interview. One patient said that she only wanted to 'mention' the 'emotional aspects' of their pain within the context of a medical consultation:

*P14: I think when you are in pain you are much more aware of how vulnerable you are, how mortal you are...And the fact that (upset, on verge of crying) when the back pain is really bad, one of the things that is quite common when you have nerve damage like I do, is you pee yourself. Which it isn't something you particularly want either, so you get anxieties around that too, so in terms of the scary bad bits, I think that's, the whistle-stop tour through mine.... The fact that she picked up on some of the things I mentioned, and that she acknowledged those. And for me that's as far as I wanted it for that medical consultation.*

*P14 Dr: I think she was really quite an easy consultation, she knew, she came in, she was very articulate, she knew what she wanted. She wanted some help with pacing... She knew how to manage flaire-ups...Well I didn't talk about the bladder, which was also one of her anxieties. But then she then didn't come back to it either. So I kind of left it.*

It seemed that a key part of this patient's anxiety, her loss of bladder control, was missed through a combination of the patient only tentatively raising anxieties and the doctor assuming that the patient would return to issues she wanted to discuss.

## **Discussion**

### **Summary of Main findings**

All patients showed particular attributions of meaning to being prescribed medical treatment or rehabilitative approaches, with impact on their beliefs about the likelihood of their pain being relieved, and their sense of control over it. Nearly all patients who were predominantly recommended a pain management approach expressed relief at knowing more about what they could do to manage their pain. The majority of patients, however, believed that medical interventions would have a central role in alleviating their pain; they placed the locus of control with the doctor and considered pain management to be irrelevant to their needs.

There was much overlap between doctors' and patients' perceptions of the consultation messages; however, there were a number of notable areas of mismatch. A number of doctor-patient dyads were inconsistent in their understanding of the pain explanation conveyed in the consultation. For the majority of consultations doctors reported that they thought it was unlikely that the prescribed medical treatments would relieve patients' pain beyond the short-term. Doctors reported delaying conversations, about the likelihood that the long-term approach would be one of pain management, to subsequent consultations.

### **Comparison of findings with literature**

The majority of patients reported that their hopes for change were located in medicine and described wishing for a 'miracle' or 'magic'. Research from the coping literature describes such 'wishful thinking' and fantasy as a disengagement coping

strategy: it creates distance between the person and the stressor in order to escape feelings of distress. This coping style has been found to be ineffective in reducing distress over the long-term as it does not change the threat's existence or impact (Carver & Connor-Smith, 2010). For the most part, doctors thought that it was unlikely that medical interventions would offer a 'fix' for patients' pain and that the likely task for patients was one of adjustment. According to the Misdirected Problem Solving Model of chronic pain, it seems these patients have framed the problem as being purely a biomedical one which could only be solved by a medical fix. Patients can become trapped in a vicious cycle of attempts to solve the unsolvable and changing the problem frame, for example to value-focused living in the presence of pain, is necessary to exit this 'perseverance loop' (Eccleston & Crombez, 2007). It seems likely that being prescribed another medical treatment and having a biomedical pain explanation would have confirmed to patients that the problem was a physical one and fed into the vicious cycle of seeking a cure (Salmon, 2000).

A sub-set of patients expressed a belief that it was important to try all recommended treatments to mitigate self-blame about not trying hard enough to alleviate their pain, and to demonstrate this to others. This finding is consistent with literature examining the 'sick role.' Parsons defined both the obligations and rights related to legitimate sickness: the individual should do all they can to get better, by seeking and accepting help, and by cooperating with health professionals. At this price, the individual is not held responsible for his or her sickness and is relieved from routine social obligations (Parsons, 1951). In the absence of detectable underlying disease, as is often the case in chronic pain, the professional's response determines whether or not the sick role is granted (Werner & Malterud, 2003).

Research has suggested that the adoption of the sick role is rarely a conscious choice and is shaped by social reinforcement and preferred postponement of responsibilities associated with a healthy status (Koekkoek et al., 2011). This explanation is consistent with patients who stated that they felt they needed to demonstrate to employers that they were cooperating with doctors' recommendations in order to receive empathy and to be absolved of their work responsibilities. Trying all recommended medical treatments allowed these patients to demonstrate that they were 'legitimately sick'; there is currently no research examining whether following advice to self-manage pain would fulfil the requirements of a sick role.

A minority of patients reported that the main treatment recommendation was one of pain management, nearly all of whom expressed relief and described feeling motivated to make lifestyle adaptations. If one conceptualises these patients within the Misdirected Problem Solving Model of chronic pain, one could hypothesise that patients had been given options, or permission, to 'exit' the vicious cycle of searching for a cure. These patients seemed to have been able to 'reframe' their problem as functioning in spite of the pain (Eccleston & Crombez, 2007) and develop a level of acceptance that *'I have got what I got'* (McCracken et al., 2005). Inherent within the pain management messages was a sense that patients had some control and responsibility over their pain, and that the approach required patients to engage with 'active coping strategies'. Increases in perceived control over pain and the adoption of active coping strategies have both been shown to be associated with decreases in functional disability and decreases in self-reported pain (Lester, Keefe, Rumble, & Labban, 2007). One could, therefore, hypothesise that this group of patients would have better outcomes compared with the other patients in the study.

A number of patients retained incomplete explanations for their pain. Consistent with research about doctor-patient communication, doctors reported not checking patients' understanding (Campion et al., 2002) and, consequently, patients seemed to leave the consultation with an insufficient understanding of their presenting problem (Weinman, 2007). Within a cognitive-behavioural perspective, patients' understanding of their pain influences their beliefs, feelings and behaviours in relation to their pain (Morley, 2007). Several doctors reported assuming that patients would know to increase their activity level following injections; however these patients had understood their pain in structural terms, whilst their doctor described their pain in terms of pain mechanisms, and patients reported no intention of changing their activity level. It seems likely that patients who understand their pain in structural terms will interpret pain as a warning sign of further damage, a rational response to which would be to rest, to avoid strain, and to monitor pain as a sign of danger. Given that humans are hard-wired to respond to pain as a threat, it can be hard for patients to reconceptualise pain as unthreatening and more likely to be reduced by activity than rest (Eccleston & Crombez, 1999); it therefore seems important for patients to have a convincing and coherent pain explanation.

National guidelines recommend that services should address pain using an integrated approach to reduce disability and improve overall quality of life, rather than offering approaches sequentially or in isolation (Donaldson, 2009; The British Pain Society, 2010). These guidelines are evidence-based, including research demonstrating the detrimental impact if rehabilitation is delayed, since valued roles are much harder to regain once lost and time has elapsed (Harris, Morley, & Barton, 2003). However this study suggested that these guidelines are not being followed,

even within a multidisciplinary pain management centre. Within the majority of consultations pain was explained in biomedical terms and medical treatments were the only method of treatment discussed. This is consistent with primary care literature which has shown doctors rarely provide integrated explanations of pain (Ring et al., 2005). There is currently no research on doctors' adherence to the guidelines, or research examining potential barriers to their implementation. Research from primary care indicates that doctors provide physical treatments, even if they think they will be ineffective, because of a perception that patients are insisting on them (Ring et al., 2004). This was consistent with the explanation some doctors provided in this study. It could also be seen as delaying facing and discussing the likelihood that pain could not be significantly relieved. It is not an easy explanation to provide to patients, and it may be that doctors delay providing the psychosocial part of the explanation until it is needed to underpin their recommendation of pain management. Certainly, in consultations within this study, it was common for doctors to delay discussing pain management with the patient until they had exhausted all medical treatments or proved that they did not work. It seemed that doctors and patients shared the belief that it was important to try all medical interventions before pain management approaches. These findings seem to beg the question of whether it is possible to implement pain management approaches alongside medical interventions. It may have been the lack of pain management information provided to patients that left them feeling that this approach was irrelevant to their needs. Furthermore, as patients were only offered a biomedical understanding of their pain, they had no rationale for pain management. However, as patients believed that medical interventions would relieve their pain, it is

understandable that they would not have wanted to engage in the difficult process of making lifestyle adaptations. There is currently little research on how patients understand the messages of pain management, or the differences having different explanations for their pain have on how they receive such messages.

## **Clinical and Research Implications**

Given that the majority of the consultations examined within this study did not adhere to clinical guidelines, it seems important for other pain services to be audited to examine the extent to which they are following recommendations (Chronic Pain Policy Coalition, 2012). If other services are also not routinely providing biopsychosocial formulations and offering integrated care, it is important for future research to examine reasons underlying this lack of guideline adherence. To this end, it seems relevant to examine further how patients experience pain management messages, and whether patients are able to engage in both medical and pain management approaches simultaneously. It is possible that doctors are only too aware that many patients find it hard to consider pain management until all attempts at “cure” have been exhausted, as emerges here. It appears helpful for future research to examine how doctors feel about providing biopsychosocial explanations for pain or providing integrative care. One might hypothesise that it would be difficult for doctors to advocate a pain management approach as this indicates that medicine cannot fix the patients’ pain. It may be that doctors are not sufficiently trained to the task, or lack resources to help them. Indeed, within the current study doctors indicated that they did not always feel competent to explain non-medical interventions, such as pacing.

The delay in doctors discussing pain management approaches begs the question of whether patients were sufficiently informed to make treatment decisions. It is questionable whether patients could give fully informed consent since they did not know how unlikely it was that medical treatments would work or that the most helpful long-term approach was probably a pain management one. It might be that, with this additional information, patients would have decided that they did not want to try another medical intervention and risk side-effects, and instead choose to ‘short-cut’ the process and try pain management approaches. It may be that, in line with the ‘sick role’ literature, patients required the doctor to give them ‘permission’ to stop trying medical treatments (Koekkoek et al., 2011). However, there is a tension about how much information about treatments is helpful to provide patients given that in all active interventions there is a placebo effect (Price, Finniss, & Benedetti, 2008). Research examining how much information patients would like to have before making medical decisions has been predominantly limited to literature examining decisions which have major life-changing consequences, such as when to move from active treatments to palliative care (e.g. Jenkins, Anderson, & Fallowfield, 2010). There seems a need for studies about how to involve pain patients better in deciding how much information or guidance they would like when making decisions, and to explore what constitutes informed consent within the field of chronic pain.

Within this study, doctors seemed to adopt a default position of trying all medical options available; however, it seems helpful for the chronic pain literature to conduct a cost-benefit analysis of whether this is the most helpful approach. For a small number of patients, medical interventions do successfully relieve their pain, or at least sufficiently for them to function better (The British Pain Society, 2010).

Therefore, as the doctors explained, it seems important to see whether each patient can benefit from the range of medical interventions available. However, it is not possible to tell which patients will benefit; for the majority of patients medical treatments will prove ineffective and they will experience physical side-effects. Moreover, as discussed above, whilst patients are hoping medical treatments will alleviate their pain it is unlikely that they will engage in making the lifestyle and psychological adjustments required to function despite of pain.

It would be helpful to examine whether the thematic map within this study represents a process patients move through, from believing that medical treatments will work and seeking new treatments; then despite each proving ineffective, continuing for psychological and/or social reasons to try any others offered; and lastly accepting that they need to adjust to the pain rather than seeking to abolish it. This is not formalised progress, as in cancer treatment ending in palliative care, and patients may be told early on that no treatment is available, only to find further medical treatments offered when they consult another doctor. Given the benefits for patients who engage in pain management approaches, it seems particularly relevant to investigate what enables some patients to adopt these ideas. It might be that this study sampled patients at various points in this journey, including a sub-group of patients at the last stage. Another hypothesis is that there are a number of distinct journeys that patients take in relation to their relationship to treatments. Perhaps the sub-group of patients who were relieved to be prescribed a pain management approach had been able to 'short-cut' trying all medical interventions because, for example, they had different pre-existing health beliefs or coping styles compared with the other patients. Indeed, in contrast to the majority of the patients, this sub-

group of patients all reported already exercising and wanting strategies to manage their pain; it seems they had pre-existing coping strategies consistent with reframing their problem as one of functioning in spite of pain. It seems important for future research to investigate how patients respond to treatment recommendations, including self-management, at different points within their healthcare journey.

It would be interesting to follow up this study's patient sample to examine whether their emotional reactions and understandings of the messages, and behavioural intentions remained consistent. It would be helpful to examine how patients experienced doctors changing the treatment plan from a medical one to a pain management approach; one could hypothesise that this may reduce patients' trust in the doctor. One might also expect that some patients may not maintain their belief in medical interventions following further ineffective treatments. It would also be of benefit to follow-up the 'pain management' group, and whether they remained 'relieved' and were able to fulfil their behavioural intentions.

### **Strengths and limitations of the study**

This is the first study to explore how patients experience and understand doctors' messages within medical pain consultations and methodological strengths are several. First, interviewing patients immediately following the consultation seemed to capture patients' initial processing and emotional reactions to the consultation messages. Theme two, for example, describes how patients were still processing the meaning of 'no guarantees' and expressing ambivalence about how hopeful to feel. Second, comparing patients' and doctors' understandings of the same consultation highlighted a number of clinically important areas of discrepancy.

Doctors' answers tended to be brief and directly based on the interview questions; the most interesting and rich data seemed to be when doctors spontaneously described their assumptions or decision-making processes within the consultation. Framework analysis was a helpful tool for capturing doctors' different styles of responding (Ritchie & Spencer, 1994). Third, 95% of the patients who met the inclusion criteria and were invited to participate took part in the study, substantially reducing the risk that the sample itself is biased in relation to the overall population of patients attending their first consultation.

It is important that the findings of this study are considered within the context of a number of limitations. It was not possible, for practical reasons, to interview doctors immediately after the consultation. Doctors did appear to recall patients clearly and utilised their session notes. Nevertheless, it is possible that doctors' responses were influenced by recall bias. Furthermore, as the researcher had already interviewed the patient in question, it is possible that the interview questions were biased by the researcher's prior knowledge of the patient. The researcher used a semi-structured interview schedule and, as far as possible, attempted to 'bracket' her assumptions to try and eliminate this possibly (Hill et al., 2005).

It is likely that researching the consultation influenced how it was conducted. Doctors knew in advance which consultations were selected and may have tried to represent their best practice. Patients knew they would be asked about the consultation messages which may have primed them to attend differently, or influenced how they acted within the consultation. Patients' accounts were, in general, positive about their consultation experiences; it is possible that they

responded in socially desirable ways or were not confident that their answers would only be used for research. Additionally, the high recruitment rate begs the question of whether patients felt they could decline the invitation to participate. Patients stated that they wanted to contribute to research and that they appreciated the convenience of taking part. Nevertheless, it is possible that patients felt an implicit pressure to participate. It would have been preferable for the interviews to have been conducted outside of the clinic to emphasise the researcher's independence, and for a different interviewer to have conducted the patients' and doctors' interviews. Patients were asked after the consultation about their expectations for the consultation and ways they managed their pain. It is likely that their responses were influenced by the experience of the consultation and, on reflection, it would have been helpful to have asked patients prior to the consultation.

Only six patients reported being given primarily a pain management approach; given the clinical utility of understanding how patients respond to this message it would have been useful to have sampled more patients. It was unlikely that the sample size was sufficient to achieve data saturation. Caution is also required if attempting to generalise the findings outside of this study's specific context or sampled population. The study took place within a major London teaching hospital which has a prestigious reputation. One might hypothesise that patients would be more trusting and willing to adhere to doctors' recommendations within this service, compared with other services. The doctors within the current study all participate in regular professional development, including training about the biopsychosocial approach and multi-disciplinary team meetings. It would be anticipated that they are a group of doctors who are particularly familiar and supportive of pain management

approaches, and so the findings may not generalise. The study did not represent the experience of patients who are not fluent in English, and a number of ethnic minority groups were not represented in the sampled population. In addition, psychometric data was not collected which may limit the extent to which this study's sample can be compared with other chronic pain populations.

## **Conclusion**

This study indicated that doctors' consultation messages may impact upon patients' pain-related cognitions and willingness to engage with pain management. It is hoped that this study leads to longitudinal research to further understand the relationship between patients' understanding of doctors' explanations and recommendations, and patients' subsequent pain-related cognitions, behaviours and outcomes. It seems important that such research contributes to the development of explanations of chronic pain which are most likely to optimise patients' functioning.

This study also demonstrated the potential for patients to leave consultations lacking a clear understanding of their pain, their role within their treatment, the expected effectiveness of the next treatment and the most likely long-term treatment plan. These findings underscore the importance of doctors using effective communication strategies, including providing explanations in sufficient detail and checking patient understanding (RAC and AA, 2006). However, there appeared to be instances when doctors did not feel it was in patients' best interests to be transparent about the likely long-term treatment; it is hoped this finding leads to discussions to ensure medical decisions are made in line with patients' long-term needs and patients have sufficient information to provide informed consent.

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## **PART 3: Critical Appraisal**

## **Introduction**

This critical appraisal contains some of my reflections on the process of conducting my major research project, beginning with how my previous experiences influenced my decision to conduct this research. It presents my reflections about managing my assumptions about the research topic, and considers the challenges of representing both doctors' and patients' perspectives within the study. The potential influence of the interviewer being a psychologist is discussed; the appraisal concludes with a description of how the process of conducting the research impacted upon my views.

## **Background**

This section outlines the reasons underlying my decision to focus on patients' and doctors' perceptions of a chronic pain consultation.

My own experiences and being privy to family members' experiences of attending medical appointments highlighted to me the potentially large impact medical consultations can have for individuals and those in their support system. I was struck by how a relatively short meeting with a doctor can be preceded by weeks of anticipation for the patient and potentially result in life-changing decisions. Listening to consultation messages being recounted through the patient's, my family member's, words raised my awareness about how much meaning can be attributed to what a doctor says or does not say, or even his or her phrasing or tone. I noticed that sometimes there seemed to be inconsistencies within the account, or topics were not mentioned that I thought were important, such as long-term prognosis and what

activities would be helpful to do or to avoid. I wondered whether the consultation content had been explained as clearly and fully as it could have and whether difficult topics were being mutually avoided. These ponderings or concerns – depending on whether I was wearing my academic or daughter ‘hat’ – formed the basis of my wish to research medical consultations.

My work experience further fuelled my interest in how patients experience and make sense of medical consultations. During multi-disciplinary ward meetings, often led by the team’s doctor, I was curious about what messages patients were ‘taking away’ with them from the discussions. Sometimes as an observer – and perhaps being too critical – I felt uneasy about how much understanding was assumed from the patient. When my role allowed it, I would ask patients I was working with what they had understood from the ward round. I was often surprised by how although key ‘facts’ were in line with what I had heard, the meaning they made of these could be quite different from what I understood the doctor had intended.

I have a long-standing interest in health psychology, in particular in the overlap between medical and psychological aspects of care. Through my psychology training, I became aware that there is a growing body of research highlighting the beneficial role self-management can have for patients with chronic illnesses. I imagined that many patients who have chronic illnesses and could potentially benefit from information around self-management were unlikely to access psychological services, at least not with that goal in mind. I envisaged that doctors, as the health professional usually consulted, were in a pivotal position to promote self-

management. I wondered how patients consulting a doctor because of a chronic illness would experience doctors advising, or prescribing, self-management. I also was curious about how doctors would experience delivering such messages. As a training psychologist, I learnt about models of behaviour change and gained experience of working with clients who became ‘stuck’ at various points when trying to initiate or maintain changes. In contrast, I was aware that doctors often had no such training and sounded frustrated and bewildered at ‘why patients can’t just help themselves.’

At the point of choosing our doctoral projects I met with Dr Amanda C de C Williams to discuss the possibility of researching patients’ and doctors’ perceptions of medical consultations. She was enthusiastic about the potential clinical utility of such research within the chronic pain population and through our conversations, and consulting the pain literature, it became apparent that there was a lack of research about how patients perceived the content of medical consultations. There seemed a particular gap in literature examining secondary care consultations, despite how costly such specialist services were. Dr Williams organised for me to meet with a medical consultant, Dr John Lee, who worked at a specialist Pain Management Centre: he was supportive of psychology research in the clinic and we shared research interests. Moreover, I was very excited to learn that he had already been granted ethical approval for a project ‘investigating the content of the pain outpatient consultation’; the study had temporarily been shelved until he found a researcher to conduct the interviews and analysis. The ethics application had not specified the interview questions or the method of analysis, and so it left flexibility within the study design. My decision for this study to comprise my doctoral research was

cemented whilst I was shadowing John's pain clinic and my head filled with questions about what patients were thinking, feeling or understanding at different points in the consultation. I was keen to capture the essence of a patient's communication with a family member when they recount a consultation and what it means to her or him personally. Moreover, I was eager to learn the extent to which these understandings mapped onto doctors' perceptions of the same consultation. Through conversations with Dr Williams and reflecting further on the literature and its gaps, we refined the current study's research questions. Given my background in quantitative methodology, I was nervously excited by the prospect of utilising qualitative methodology to answer them.

### **Managing researcher biases and assumptions**

The quantitative research traditions that I knew aspired to objectivity. By contrast, I learned how qualitative researchers acknowledged that their data and their analytic processes were grounded in subjectivity (Morrow, 2005). Researchers have described a number of ways – somewhat dependent on their epistemological position – to limit, control or embrace this subjectivity. Qualitative research guidelines encourage researchers to make their implicit assumptions and biases explicit, as part of the process of managing subjectivity (Hill et al., 2005): this is known as 'bracketing' - the process of becoming aware of one's implicit assumptions and predispositions and setting them aside to avoid them unduly influencing the research (Husserl, Gibson, & Library of philosophy, 1962). This section describes how I attempted to bracket my biases and assumptions, and strategies I found helpful in this process.

It initially seemed that there were many new skills I needed to acquire in order to become sufficiently aware of my assumptions and then ‘set them aside’; moreover, the literature to describe these skills often seemed embedded in philosophical debates and written, at times, in inaccessible language. However, once I extracted what I felt to be the essence of the task in hand, I realised that these skills were rather similar to ones I used regularly in my clinical work. In particular, I found my training in post-Milan systemic thinking provided me with a helpful framework to guide the process of ‘bracketing’ my assumptions.

As demonstrated in the above section, even prior to writing my research proposal I had emotional investment in the topic, and assumptions based on personal experiences and from reading the literature. Qualitative guidelines recommend managing such potential bias through ‘reflexivity’, defined as ‘self-awareness and agency within that self-awareness’ (Rennie, 2004). Guidelines advocate a number of ways to become ‘reflexive’ in relation to one’s research, including using a self-reflective journal throughout the research process to record experiences, reactions and emerging assumptions and biases; self-understandings can then be examined and ‘set aside’ (Hill et al., 2005). I started my journal after my first meeting with Dr Williams and found it a great resource, and companion, during the two-year process that followed. However, I often struggled with the notion of how, once I became aware of my assumptions, I could set them aside; the ‘step-by-step’ guide I was searching for seemed to be lacking. I therefore found it useful to remind myself of how ‘self-reflexivity’ is practised in a literature that I am much more familiar with. Within systemic practice, it is understood that we come into any situation or interaction with ‘pre-understandings’: assumptions we hold, which we often take for

granted and may not necessarily be aware of (Andersen, 1995). Self-reflexivity involves our becoming curious about our pre-understandings, what contexts inform them and they relate to how we act or respond (Burnham, 2005). I found it helpful to map out the contexts that influenced my pre-understandings about the research topic (Martin & Stott, 2010); my 'contexts' included being a healthcare user, being a daughter of a healthcare user, being a trainee psychologist, being in my 20s, being a consumer of health psychology literature, being someone not living with chronic pain, and so forth. I mapped out how these contexts gave meaning to my pre-understandings and their relative influence on how I thought about the research; this process enabled me to become an observer to my pre-understandings, some of which I had 'taken for granted'. For example, my contexts of age and nationality led me to certain assumptions, including that the NHS was an entitlement and that patients should have a choice over their care. It was important to be aware that such ideas simply reflected one perspective and to be respectful that participants may have different perspectives, influenced by their own contexts. This process seemed to be one way of adhering to qualitative guidelines that researchers should stay attuned to their own perspective in order 'to recognise their own experiences as separate from the participants' stories' (E. N. Williams & Morrow, 2009).

There is discussion amongst qualitative researchers about how to 'bracket' one's assumptions sufficiently to ensure that participants' reality and experiences are represented fairly. In relation to data collecting, this involves asking for clarification and 'delving' into participants' meanings, whilst taking the stance of a naïve inquirer (Morrow, 2005). I realised that this was 'the bread and butter' of systemic – and arguably most psychology – assessments: using open questions, taking a non-

knowing stance, checking and not assuming individuals' meanings, and remaining curious about their experiences, realities and truths. This is exemplified when, during a patient interview, I summarised to check my understanding that the participant was feeling 'more positive' and she corrected me that she was feeling 'less negative' which, in her context, was an important distinction to make.

At the beginning of the analysis stage, I initially struggled with synthesising the data as I was concerned about moving too far from the details of participants' words and over-interpreting their meaning. However, I realised that there was a balance to be struck between participant detail and researcher interpretation: I needed to translate about 500 pages of transcript into a results section which coherently presented the most salient and clinically relevant aspects of participants' accounts. A helpful turning point was when my supervisor encouraged me to remember my skills as a psychologist and to have confidence in using these to 'pick up on' participants' emotions and intended meanings. I reflected upon what enabled me to synthesise – and have confidence to make inferences about – the 'data' of hours with a client to develop a formulation or write a summary discharge letter. Systemic practice encourages practitioners to have multiple hypotheses about clients and to avoid becoming too 'married' to one hypothesis (Carr, 2006). This approach seemed consistent with that of some qualitative authors who consider that greater grounding in the literature can militate against bias by expanding a researcher's understandings of multiple ways of viewing the phenomenon in question (Morrow, 2005). I tried to keep these principles in mind when analysing the meaning of participants' narratives and developing ways of organising the data into themes. I used my journal to reflect upon my pre-assumptions and I developed alternative hypothesises to the hypothesises

which came more automatically and seemed connected to my pre-assumptions. I organised the data in different ways and checked through the transcripts for examples which fitted and did not fit with each organisation. I was aware that some participants were more memorable than others, perhaps due to the way they presented themselves or the order in which I saw them or that their perspectives were more or less consistent with my own; I tried to ensure these participants' voices did not become privileged over others. I found it helpful to re-listen to the audio-recordings of less memorable participants and to keep checking that their voices were also heard within the analysis.

Qualitative guidelines recommend consulting a research team or 'peer debriefers' who can 'audit' throughout the process of data analysis and potentially propose alternative interpretations. My research supervisor was an invaluable resource and helped me think through ways of organising and capturing the nuances of the data; it gave me confidence that she felt the themes were consistent with her clinical experience of working both with patients with chronic pain and with consultants. In the interests of ensuring I considered multiple perspectives, I also found it helpful to 'consult' with others, including a clinical psychologist within the clinic, psychology peers, family members and friends who made the mistake of asking me what my research was on! In hindsight, I wonder whether certain perspectives and ways of looking at the data were privileged by my choice of 'peer debriefers' as – for pragmatic reasons – they mainly consisted of psychologists or others who were considering the research from a patient perspective. I imagine it would have been helpful to actively seek out 'peer debriefers' who were positioned within the medical profession or simply differed more in the contexts they were

speaking from. Furthermore, as recommended within qualitative guidelines, it would have been helpful to have considered seeking respondent validation of the findings (Barker & Pistrang, 2005).

### **Trying to give a voice to both doctors and patients**

My second research question examined the extent to which doctors' and patients' perceptions of consultation messages corresponded; an aim inherent within this was to understand reasons underlying mismatches which seemed clinically relevant. I was eager to make the most of the opportunity that interviewing both patients and doctors afforded me and hoped to present an understanding of both perspectives. This section briefly considers the challenges of trying to represent doctors and patients within the same piece of research and how I tried to overcome these.

I quickly became aware when consulting the chronic pain and medically unexplained symptoms (MUS) literature that a number of studies seemed to have a tendency to align themselves with either the patients' or doctors' perspective. Some medical literature, for example, discussed how these 'heartsink' difficult patients exaggerated their symptoms, 'doctor shopped', demanded unnecessary treatments and generally consumed a disproportionate amount of healthcare resources. In contrast, psychology literature often described a misunderstood group of patient whose needs were not met by doctors and were prescribed treatments they did not ask for and were, at times, iatrogenic.

When conducting the interviews, I realised how easy it could be to align myself with one position. There was, for example, a patient who arrived late and still demanded to have a full consultation, a patient who didn't let the doctor get a word in edgeways and a patient who disregarded the doctor's recommendations as they did not fit with what sounded like 'folk' medicine. There was also, for example, the doctor who completely misjudged how upset a patient was, the doctor who did not answer the one question a patient asked them and the doctor who dodged discussing a patient's emotions. Patients and doctors mostly described each other in respectful terms and these examples are, clearly, shorn of the important context in which they were embedded; nevertheless, they demonstrate how with only one side of the interaction it could be easy to misjudge the other side. Having been both a patient and a healthcare professional and having experienced both 'impossible' clients and doctors who do not appear to listen, I found I could oscillate between aligning myself with one perspective, sometimes to the exclusion of empathy or understanding for the other. This potential to take a dichotomous approach was exemplified when I told a friend about my research and she asked "so which one got it wrong, did the doctor not explain things properly or did the patient just hear what they wanted to hear?" When there seemed to be significant mismatches between a patient's and doctor's account of the same interaction, I did sometimes wonder whether I should have triangulated the research by recording the consultation itself and, in some way, answered this question.

I found it useful to take a step back and reflect upon what I was seeking to answer within the study and to remember my intention to represent both perspectives within the doctor- patient encounter. I again found appeal to my clinical training

helpful with this reflective process. Two systemic principles seemed particularly pertinent: problems are not located within people but are co-created within relationships, and we each construct the world through our personal subjective lenses (Cecchin, 2004). Although hearing the conversation within the consultation could have answered some useful questions, it seems my friend's question was a less helpful one as it implied that there was a 'truth' about what happened in the consultation which I could unearth through hearing what actually happened. I could not have been an objective observer to the consultation; I would have also constructed my own 'truth' about the consultation, albeit through a different lens from that of either the doctor or the patient. The perceptions that were the focus of this research were those of the patients and doctors. My friend's question also implied that responsibility for misunderstandings was located in either the doctor or patient, as opposed to their interaction. It did not seem a helpful exercise to blame individuals; rather, I sought to understand how mismatches occurred within the interactions.

As with clinical work, I reflected and hypothesised about the different contexts individuals were acting out of and which informed their interactions (Martin & Stott, 2010). I believe that this process developed and broadened my understanding of the multiple perspectives I was hoping to represent within this study. I found it helpful, for example, to consider the journey patients had taken through the healthcare system to reach a specialist service, and how these experiences may have influenced the way they interacted with the doctor and how they reacted to his or her messages. I also had the opportunity to hear about aspects of individuals' previous experiences and expectations directly from patients. I also

learnt about the journey doctors had taken, including their training, and the expectations they had for the consultation. I found one informal conversation with a participating doctor particularly illuminating, in which she described the service expectation of the different ‘topics’ that needed to be covered within an initial consultation and how many minutes she had roughly allocated for each of these: for example, four to five minutes to discuss each treatment option. On reflection, it would have been helpful to have had longer interviews with doctors to further understand their contexts – including service pressures – and how they made decisions within the consultation, for example what to ask about or how to explain a concept. The doctors did not have time to meet me for longer than they did on the days of the clinics, and I was appreciative that they gave up their breaks to participate in the study. However, I wonder if it may have been helpful to have tried to conduct a separate interview with each doctor, or even a focus group, to discuss more generally how they approach initial consultations and make decisions within them. I am due to present the findings to the participating doctors and this will provide an opportunity to further understand their perspectives and ensure their voices are fairly represented within the study.

### **Influence of the interviewer being a ‘Psychologist’**

I was struck by how patients described aspects of their experiences within the research interview – including their feelings about treatment options and living with pain– which they had not disclosed within their medical consultation. I was intrigued by how patients had made decisions about what to talk about within the two conversations. The empirical paper discusses potential reasons underlying why

emotions were rarely, or superficially, discussed within the consultations, including how both patients and doctors appeared to judge what was appropriate for the medical arena. However, it fell outside the research question to consider why patients did talk to me, a psychology researcher they only met once, about personal and difficult aspects of their pain experience. This section presents hypotheses about why patients described their emotions within the research interview, and outlines potential implications for future research.

I was particularly surprised by a sub-set of patients who self-reported that they rarely discussed the emotional aspects of pain with others, and whose doctors reported how well they seemed to be managing emotionally, yet in the research interview they disclosed their emotional struggles. My context of being a psychologist with certain research questions led me to be particularly interested in their experience of the consultation, including how they felt about its messages. On one hand, it seems intuitive that patients talk about emotions within an interview which asked about them, and I was probably viewed as part of the hospital system and therefore assumed to be trustworthy. However, patients were not just stating how they felt in response to direct questions; they were bringing up aspects outside of the interview schedule and becoming visibly upset in the room. When discussing the study's results with my supervisor, I mentioned my surprise at how open some patients seemed to be within the interview. She commented how I had obviously managed to use my clinical skills to create a space which enabled them to feel comfortable to disclose these feelings which, for various reasons, they had not discussed in the consultation. This led me to wonder about the difference it made to the data elicited within the interviews that I was a psychology-researcher, as opposed

to someone from another healthcare discipline or even outside the healthcare field, such as an anthropologist researcher.

The psychology professional training gives us specific competence and expertise for engaging in and managing interpersonal relationships, and arguably equips us to conduct interviews in such a way that will elicit rich, elaborated data (Haverkamp, 2005). We are trained and well-practised at engaging clients, gaining their trust and facilitating disclosure. Whilst transcribing, I realised that I had automatically used therapeutic skills such as validating patients' distress, summarising to check I had understood them and asking for their meaning of words. I wonder whether, in the absence of these therapeutic techniques, patients would have disclosed to the extent they did. Indeed, although patients initially reported taking part in the study to contribute to research that could help others, they also stated that they had found taking part was personally beneficial. Most patients thanked me for my time and for listening to them; several commented that they felt that they had been able to process the consultation more fully because of the interview and had realised that there were aspects of their care that they wanted to learn more about as a consequence. One might hypothesise that some patients also found it helpful to have a space to talk through difficult emotions, which they reported having not done so before. As Haverkamp warns, it is important to be mindful about the boundary between information-seeking and providing therapy. This begs the question of whether patients have given fully informed consent if, through the process of the interview, they end up discussing topics that they did not anticipate or they find upsetting or they become part of a therapeutic conversation. Patients had agreed to share personal information, but had not consented to a

conversation that could produce a change in their views (Kvale, 2004). Qualitative researchers have therefore been encouraged to view informed consent as an on-going mutually negotiated process rather than as a single event (Smythe & Murray, 2000). I did check if participants were happy to keep talking about the subject matter if they became upset and, in line with ethical guidelines, I stated at the outset that patients were free to leave at any time, without giving reason or it affecting their care. However, given the power dynamic that can make it hard for participants to leave a study once they enter it, if I were to conduct further qualitative research I would plan to be even more explicit during the process about the on-going nature of informed consent.

I wondered about the impact patients' perceptions of me as a psychology-researcher could make to what they chose to talk to me about within the interview. It seems possible that perceiving me as a 'psychologist' may have primed patients to discuss aspects which they considered I would be interested in, their 'psyche', thoughts and emotions. If this were the case, I wonder whether a junior doctor researcher would have been perceived to be interested in more biomedical concerns than I was. Haverkamp argues that participants have different expectations of researchers' skill, knowledge and intentions when they are psychologists compared with if they are, for example, nurses or anthropologists (Haverkamp, 2005). She states that participants expect us, as psychologists, to offer help and to not involve them in activities that do harm; as our knowledge base is about emotion and adjustment, participants will expect us to act on that knowledge in ways that protect their interests. Indeed, I was concerned about how patients perceived my relationship to the clinic and, more specifically, their care. Although I emphasised my

independence from the service and the confidentiality of their responses, I was aware that I was physically situated within the clinic and the invitation letter was headed with the hospital details. Unfortunately, for practical reasons it had not been possible to have an interview room outside the clinic. I did, therefore, worry whether patients shared ideas with me because they hoped that I would relay them back to the doctor and so, in some way, provide them with additional help. I think, and hope, this was not the case as none of the patients appeared to be seeking psychological input and they mostly believed that the clinic's role was to provide them with medical care.

I would argue that having a 'psychologist' conduct research interviews may have impact on what participants talk about, either due to the way psychology training shapes how we interview, or the lines of inquiries we choose to pursue, or how others perceive what is appropriate to tell us, or perhaps a combination of factors. If this is the case, it seems it would be helpful to investigate any differences between data elicited by interviewers according to their different disciplines. To my knowledge this research has not been conducted, although there is some research examining differences in communication styles between doctors and nurses (Lawson, 2002). If there are differences between the data elicited by interviewers from different disciplines, taking into account individual differences, this has implications when choosing who is most appropriate to conduct research interviews to answer particular research questions. This seems crucial if researchers want to justify the cost of having qualified clinical psychologists conduct research interviews in funded research.

Within my own clinical work, I hope to hold in mind the finding that patients talked about different parts of their experience in two consecutive conversations and that the doctor and I sometimes had very different impressions of how well the same patient was coping. I imagine that the different conversations patients can have with different professionals partly underlies why team members can hold contrasting impressions of the same patient. From my own clinical experience, I have found that perceptions of patients become less disparate when professionals see patients jointly, although of course this is difficult to do routinely given limited resources.

### **Personal reflections about the impact of the research**

The process of conducting a doctoral piece of research involved learning a number of skills that I had hoped to develop, for example, how to conduct a thematic analysis and a systematic literature review. There were, however, a number of less expected skills and understandings that I developed through the process, and I imagine these are likely to influence my future work as a clinical psychologist. This section summarises two aspects of the process that I was surprised by and learned from, and focuses on the impact these may have in how I work clinically and professionally.

Firstly, I realised how easy it could be to prematurely criticise other disciplines' ways of working. There were times when I became frustrated about aspects of the doctors' communication styles and it was tempting to imagine how I might have managed the consultation in a more patient-centred way. However, I realised that I was neglecting to take into account the difference between doctors' and psychologists' priorities, pressures and training. It was helpful for me to become

more familiar with the demands placed upon the participating doctors, including referrers requiring definitive diagnoses for patients' pain and commissioners increasingly pressing for specialist services to refer straight back to GPs with treatment recommendations. These service contexts are in contrast to psychologists' usual remit of providing a formulation of psychological difficulties and being able to offer an intervention over at least six to eight therapeutic hours. In addition, I realised that I had previously underestimated the influence my psychology training has on how I converse and subsequently make sense of patients' responses. Most introductory clinical psychology lectures and texts underscore the importance of summarising, checking and not assuming clients' meanings, and of being aware of our own influence upon the interaction. However, I realised that what I perceived as basic therapy skills were often absent in doctors' everyday practice. Although I was aware that doctors and psychologists had different training routes and roles within a team, having the opportunity to research a medical consultation enabled me to develop a deeper understanding of the difference our professional backgrounds can make in how we think about and interact with patients. Psychologists and doctors are both, in theory, striving to provide biopsychosocial explanations for patients; however, it seems understandable that due to our different 'lenses' the relative importance we attribute to the 'bio' or 'psych' parts of assessment, formulation and treatment differ. Furthermore, this process encouraged me to take a more critical position in relation to my own profession. It was initially rather too easy to be judgmental about doctors failing to discuss long-term treatment pathways or the realistic likelihood of treatment success. However, when I reflected on my own experiences of how psychologists manage similar situations, I think we too can often

be rather vague and shy away from talking about treatment evidence, alternative options and what happens if our therapy does not alleviate the presenting problem. There are, of course, important differences between medical and psychological treatments: for example, medical treatments have a greater evidence base about effectiveness and adverse effects. Nevertheless, reflecting on my own experiences made me mindful about the dilemmas inherent in trying to effectively fully inform patients about the pros and cons of different treatment choices, and their long-term prognosis. Moreover, it underscored the importance of not being critical of other disciplines without first understanding the challenges they too may be grappling with. I hope that these lessons will encourage me to continue to reflect upon the multiple perspectives, agendas and skills that different professionals bring to their work with clients. I also hope I remember not to underestimate the skills I bring to a team and that, as a psychologist, I can consider ways to share these with other team members through, for example, training and consultancy.

Secondly, the experience of interviewing and reflecting on patients' responses highlighted to me how patients can easily get 'caught in the middle' of professionals' conflicting explanations. Patients in this study were, for example, sometimes perceived to have 'rigid ideas' which were often simply 'truths' that they had been told by previous doctors. Patients reporting that previous doctors had told them inaccurate explanations is in line with research which shows that healthcare professionals have a tendency to use an acute pain model long after resolution of any initial injury (Linton et al., 2002). As discussed in the empirical paper, patients also sometimes seemed to have rather muddled explanations for their pain; one could hypothesise that these were a combination of different explanations they had heard

along their rather long journey through the healthcare system. It seemed confusing for patients to know which messages to believe, and understandable that they might be wary of abandoning one set of medical ideas for another. I hope that I can utilise this finding within my own clinical work, by asking clients about their previous understandings about the problem they are presenting with and taking seriously their previous 'relationship to help' (Reder & Fredman, 1996). It seems likely to be of benefit to clients to spend time incorporating their previous understandings into a formulation or, if this is not possible, providing them with sufficient information to judge which explanation is more relevant to them. This seems particularly pertinent given the current climate of stepped care within psychology services, in which clients are likely to have heard messages from a number of mental health professionals before having access to a qualified psychologist. I also hope that as a psychologist in a multi-disciplinary team, I could open up conversations with other professionals to think about where patients may be getting their 'rigid ideas' from and how they might be experiencing contradictory messages. Furthermore, I aspire to work towards developing a shared language within healthcare, rather than each discipline having its own set of patient-unfriendly language and diagnostic terms.

I am appreciative for the opportunities for reflection and learning that my research project afforded me. I also hope that I can hold on to the original observation that led me to this research at the outset: the importance one consultation can make in an individual's life. As I am soon due to embark upon my first post as a clinical psychologist in a service climate with an ever increasing demand for frequent client contacts, I can imagine it could be easy to lose sight of the importance each appointment can make to an individual. I hope that, amid a busy caseload, I can

remember to reflect upon each 'contact' as an individual with his or her own hopes for the appointment.

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# Appendix 1: Ethics Approval Letters

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## National Research Ethics Service

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05 December 2008

Dear Dr Lee

**Full title of study:** Investigating the content of the pain outpatient consultation by exploring the models doctors use to provide patients with a framework to understand chronic pain; through understanding the moments when doctors believe they are giving a learning point; and, by exploring patients' perceptions of the messages that doctors give.

**REC reference number:** 08/H0716/73

Thank you for your letter of 03 December 2008, 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 Sub-Committee of the REC held on 04 December 2008. A list of the members who were present at the meeting is attached.

### Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

### Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission at NHS sites ("R&D approval") should be obtained from the relevant care organisation(s) in accordance with NHS research governance arrangements. Guidance on applying for NHS permission is available in the Integrated Research Application System or at <http://www.rforum.nhs.uk>.

### Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
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C.V - Amanda C de C Williams	1	03 September 2008
Participant Consent Form	1.1	03 September 2008
Participant Consent Form	1.1	03 September 2008
Participant Information Sheet	3.1	03 September 2008
Participant Information Sheet	2.1	03 September 2008
Letter of invitation to participant	1.1	03 September 2008
Peer Review	3	11 August 2008
Covering Letter	1	03 September 2008
Protocol	3	15 August 2008
Investigator CV	1	05 September 2008
Application	1.0	05 September 2008
Response to Request for Further Information	1	29 February 2008
Participant Consent Form	1.2	29 February 2008
Participant Consent Form	1.2	29 February 2008
Participant Consent Form	1.0	03 December 2008
Participant Information Sheet	3.2	29 February 2008
Participant Information Sheet	2.2	29 February 2008
Participant Information Sheet	1.0	03 December 2008
Covering Letter	1	03 December 2008

#### Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

#### After ethical review

Now that you have completed the application process please visit the National Research Ethics Website > After Review

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.

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- 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.

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email [referencegroup@nres.npsa.nhs.uk](mailto:referencegroup@nres.npsa.nhs.uk).

08/H0716/73

Please quote this number on all correspondence

With the Committee's best wishes for the success of this project

Yours sincerely



**Ms Katy Judd**  
**Chair**

Email: S.Vandayar@ich.ucl.ac.uk

Enclosures: *List of names and professions of members who were present at the meeting.*

Copy to: *Mr Philip Diamond*



Joint UCLH/UCL Biomedical Research (R&D) Unit  
Professor Monty Mythen

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149 Tottenham Court Road  
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02 September 2008

Dr J Lee  
Pain Management Centre

Dear Dr Lee,

**Project ID:** 08/0278 (*Please quote in all correspondence*)  
**Title:** Investigating the content of the pain outpatient consultation

Thank you for registering the above study with the UCLH/UCL Biomedical Research Unit. I am pleased to give the approval of UCL Hospitals NHS Foundation Trust for the study to proceed.

You will be aware that as principal investigator you have various responsibilities under the Department of Health's *Research Governance Framework for Health and Social Care*. Please note that you are required:

- to comply with the UCLH Information Security Policy (the data protection toolkit "Consent and Security" will help you meet the requirements of the Data Protection Act and is available at <http://www.uclh.nhs.uk/services/research/>).
- to ensure that any co-investigator who is not an employee of UCLH has in place an up-to-date honorary contract.
- to keep copies of all consent forms with your project documentation. UCLH carries out audits of informed consent and if your project is selected for audit, you will need to provide access to the consent forms.
- To use an investigator file to store all the documentation relating to this research project (the attached list of headings is designed to help you assemble your investigator file).

This approval is conditional upon you having addressed any outstanding issues raised by the research ethics committee (REC) and having full ethical approval in place for the project. You should also be aware that your REC approval requires that you comply with all the requirements of the ethics committee regarding progress reports, notification of protocol amendments and adverse event reporting.

This approval is awarded on the basis of all the project documents you included in your submission to the UCLH/UCL Biomedical Research Unit, including any research agreements or contracts. In the event that the terms of any research contracts or agreements change or a new contract is issued this approval may be invalidated while the terms of the contract are negotiated.

Yours sincerely



**Professor Monty Mythen**  
Director of R&D, UCL Hospitals NHS Foundation Trust

Director – Professor Monty Mythen;

Assistant Directors: Dr Nick McNally; Mrs Yvonne Enever; Ms Sue Kerrison;



UCL Hospitals is an NHS Foundation Trust incorporating the Eastman Dental Hospital, Elizabeth Garrett Anderson & Obstetric Hospital, The Heart Hospital, Hospital for Tropical Diseases, The National Hospital for Neurology & Neurosurgery, The Royal London Homoeopathic Hospital and University College Hospital.

## Appendix 2: Consent forms

University College London Hospitals



NHS Foundation Trust



Centre Number (if applicable): none  
UCLH Project ID Number: 08/0278  
Patient Identification Number for this Study: .....  
Consent Form Version Number and Date: v1.2 3/12/2008

### INFORMED CONSENT FORM

Title of Study: **Investigating the content of the pain outpatient consultation**  
Name of Chief / Principal Investigator (C/PI) : Dr John Lee

#### Please initial box

1. I confirm that I have read and understand the information sheet dated.....  
(version number .....) for the above study. I have had the opportunity to consider the  
information, ask questions and have had these answered satisfactorily.
2. I confirm that I have had sufficient time to consider whether or not I want to be included in  
the study.
3. 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.
4. I understand that relevant sections of any of my medical notes and data collected during the  
study, may be looked at by responsible individuals from [company name], from regulatory  
authorities, from the NHS Trust or representatives of the sponsor for purposes of  
monitoring and auditing, where it is relevant to my taking part in this research. I give  
permission for these individuals to have access to my records.
5. I agree to take part in the above study.

.....  
Name of Patient Date Signature

.....  
Name of Person taking consent Date Signature  
(if different from C/PI)

.....  
C/PI (to be contacted if Date Signature  
there are any problems)

**Comments or concerns during the study:**

If you have any comments or concerns you may discuss these with the investigator. If you wish to go further and complain about any aspect of the way you have been approached or treated during the course of the study, you should write or get in touch with the Complaints Manager, UCL hospitals. Please quote the UCLH project number at the top of this consent form.

When completed, one form for the patient; one to be kept as part of the study documentation for the trial master / investigator site file; one original to be kept with the hospital medical notes.



UCL Hospitals is an NHS Foundation Trust incorporating the Eastman Dental Hospital, Elizabeth Garrett Anderson & Obstetric Hospital, The Heart Hospital, Hospital for Tropical Diseases, National Hospital for Neurology & Neurosurgery, The Royal London Homoeopathic Hospital and University College Hospital.





Centre Number (if applicable): none  
UCLH Project ID Number: 08/0278  
Participant Identification Number for this Study: .....  
Consent Form Version Number and Date:v1.0 3/12/2008

**INFORMED CONSENT FORM**

Title of Study: **Investigating the content of the pain outpatient consultation – consent form for NHS medical staff**

Name of Chief / Principal Investigator (C/PI) : Dr John Lee

**Please initial box**

- 1. I confirm that I have read and understand the information sheet dated.....  
(version number .....) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
- 2. I confirm that I have had sufficient time to consider whether or not I want to be included in the study.
- 3. 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.
- 4. I understand that relevant sections of any data collected during the study, may be looked at by responsible individuals from UCL Hospitals, from regulatory authorities, from the NHS Trust or representatives of the sponsor for purposes of monitoring and auditing, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.
- 5. I agree to take part in the above study.


Name of Participant	Date	Signature
---------------------	------	-----------

Name of Person taking consent (if different from C/PI)	Date	Signature
---	------	-----------

.....  
C/PI (to be contacted if  
there are any problems)

.....  
Date

.....  
Signature

**Comments or concerns during the study:**

If you have any comments or concerns you may discuss these with the investigator. If you wish to go further and complain about any aspect of the way you have been approached or treated during the course of the study, you should write or get in touch with the Complaints Manager, UCL hospitals. Please quote the UCLH project number at the top of this consent form.

When completed, one form for the participant; one to be kept as part of the study documentation for the trial master / investigator site file.



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## Appendix 3: Letter of Invitation

University College London Hospitals 

NHS Foundation Trust

Pain Management Centre

UCLH Project ID Number: 08/0278  
Information Sheet Version 1.1, 03/09/08

Dear .....

### **Research Study at the Pain Management Centre:- Investigating the content of the pain outpatient consultation**

You are about to attend your first appointment at the Pain Management Centre as a new patient who has long term pain. We are conducting a study on the new patient consultation and would be very grateful if you would consider helping us with it.

I enclose a copy of the Patient Information Sheet which I hope will explain the nature of the study. I would like to point out a few key aspects:

- you do not have to take part in the study
- whether you decide to take part or not, the care you receive at the Pain Management Centre will be the same
- your contributions will be fully anonymous in any report or publications
- the study has been approved by the hospitals Research Ethics committee.

When you arrive at your appointment a researcher will talk to you more about the study. Please be assured that any help you can provide will be appreciated and is for the benefit of research into pain.

Thank you.

Yours sincerely,

Dr John Lee  
Consultant in Pain Medicine and Chief Investigator



UCL Hospitals is an NHS Foundation Trust incorporating the Eastman Dental Hospital, Elizabeth Garrett Anderson & Obstetric Hospital, The Heart Hospital, Hospital for Tropical Diseases, National Hospital for Neurology & Neurosurgery, The Royal London Homoeopathic Hospital and University College Hospital.



## Appendix 4: Information sheet

University College London Hospitals 

NHS Foundation Trust

Pain Management Centre

UCLH Project ID Number: 08/0278

Information Sheet Version 2.2, 3/12/2008

### **PATIENT INFORMATION SHEET**

Title of study: Investigating the content of the pain outpatient consultation  
Chief investigator (CI) : Dr John Lee

We would like to invite you to take part in a research study. Before you decide, you need to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. Talk to others about the study if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

#### **What is the purpose of the study?**

The study is about the first consultation between doctors and patients during a pain outpatient appointment. It is designed to look at the first time you meet the pain doctor and is part of a larger project looking at the issue from different perspectives. Medical consultations between doctors and patients are vital for communication: for the doctor the aim is to be able to understand a patient's condition, to assess it, and to provide an explanation. It is a key time to exchange information. However, it is often more than this. In the chronic pain consultation there is an opportunity for the doctor to provide information which improves and develops the patient's understanding of what is wrong with them and why they feel pain.

Our aim is to find out your views of the consultation by interviewing you. It is important that we understand your viewpoint so that we can use it to build our knowledge of the patients' perspective of pain consultations and to try to improve it in future. We are hoping to interview 30 adult pain patients who are attending the

clinic for the first time. We will also be asking the doctor you had the consultation his/her thoughts about the consultation.

### **Why have I been invited?**

You are a patient of the [REDACTED] where this study is taking place. Occasionally there are pain clinics held elsewhere in the hospital too.

### **Do I have to take part?**

It is up to you to decide. We will describe the study and go through this information sheet. We will then ask you to sign a consent form to show you have agreed to take part. You are free to withdraw at any time, without giving a reason. This would not affect the standard of care you receive.

### **What will happen to me if I take part?**

We would like to interview you after your first outpatient appointment. The invitations to take part will be sent out at least a week before you come to the appointment. When you arrive for your appointment, a researcher will check that you received your information sheet and answer any questions you have about the study. S/he will then ask if you are happy to agree to take part in the study. The interview will take place after your new patient appointment in one of the clinic rooms.

The interview itself will take around 20 minutes when we will ask some set questions. There will also be plenty of opportunity for you to give us your opinions. The researcher will take notes about this conversation and will also make an audio recording of it so that we can check the details of the conversation at a future date. The records of the interview will be given a unique identifying number, but will not have your name or other personal information on them. You are free to withdraw at any point during the interview, or request breaks or time to consider your answer.

As part of our record keeping and the results of our research, the principal investigator is keeping a note book containing your name, age and sex. This is being recorded against your unique research number in this project so that we can demonstrate that you helped us with this work. The notes and tapes of the interview will be stored in a locked filing cabinet for the purpose of research. The note book containing your name, age and sex is being kept in a filing cabinet locked in a different office. When we undertake any analysis, report or discussion, there will be no reference to your name at all. The information we gather will be stored and maintained by UCL Hospitals. No other organisations will have access to your information.

We will provide reasonable travel and childcare expenses which are agreed in advance. Original receipts must be provided before any payment is given.

When the research team have interviewed 30 pain patients, we will begin to analyse the results. We do this by looking for similarities and differences in what participants say in their interviews. In short, we are trying to see what you, the patient, thought about the appointment with the pain doctor and how it affected you. We will also analyse the response from doctors in the same way. We will then compile a report containing our findings for publication in a medical journal and by other appropriate means such as reporting to a scientific meeting.

**Will my taking part in this study be kept confidential?**

All information which is collected about you during the course of the research will be kept strictly confidential, and any information about you which leaves the hospital will have your name and address removed so that you cannot be recognised.

**What are the possible benefits of taking part?**

We cannot promise the study will help you but the information we get from this study will help improve the treatment of people attending pain consultations

**What if there is a problem?**

If you have any comments or concerns you may discuss these with the researcher or with the chief investigator of the study. If you wish to go further and complain about any aspect of the way you have been approached or treated during the course of the study, you should write or get in touch with one of the Complaints managers of UCL Hospitals. Please quote the UCLH project number at the top this consent form when you do so.

The complaints manager of the [REDACTED] can be contacted at:

[REDACTED]

The Chief Investigator for the study can be contacted at the address at the head of this sheet.

**Who has reviewed the study?**

All research in the NHS is looked at by independent group of people called a Research Ethics Committee to protect your safety, rights, wellbeing and dignity. This study has been reviewed and given favourable opinion by the National Hospital for Neurology & Neurosurgery and Institute of Neurology Joint Research Ethics Committee.

**Further Information and contact details**

General information about research at UCL Hospitals can be obtained from:

Research and Development Directorate  
UCL Hospitals NHS Foundation Trust  
1st Floor Maple House  
149 Tottenham Court Road  
London W1T 7NF

For specific information or concerns about this research project please contact:



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## Appendix 5: Interview Schedule for doctor interviews

- From your perspective, what were the messages you said to the patient?
  - What were the main messages that you wanted him or her to take away?
- How did you explain their pain?
  - Were there any parts of the explanation that you think were more important for him or her to understand?
- Did you suggest anything that might help their pain?
  - If yes- how did you describe the likelihood this (treatment/ strategy) would alleviate their pain?
  - Did you offer any other ideas?
  - Do you think there is anything else he or she could do to help his or her pain? If yes- did you discuss this with him or her?
- How much do you think he or she understood or took on board what you said?
- What impact, if any, do you think the consultation will have on how he or she thinks or feels about their pain?
  - What impact, if any, do you think it will have on anything that he or she plans to do?
  - If advice given- to what extent do you think he or she will follow your advice?
- How do you imagine he or she left the consultation feeling?
- Looking back, are there any parts of the consultation you would have done differently?
- Is there anything that I have not asked, that you think might be important about the consultation?

## Appendix 6: Interview Schedule for patient interviews

- Check participant has the information sheet
- Describe the interview process
- Answer any questions
- Check the participant understands what participation involves
- Obtain written consent

How did the consultation go?

What were the consultation's key messages?

What were the main messages the doctor said to you?

What did the doctor say about your pain?

- What did the doctor say about your pain now? How it might be in the future?
- Did this explanation make sense to you? Did it fit with how things are for you?
- What was the most important thing for you that the doctor said?
- Did the doctor tell you anything new or anything you had not heard before?
- Anything that surprised you or stood out for you?
- Anything that doesn't fit with your understanding of your pain?
- Did they say anything that confirmed what you already thought?

When you leave here who are you most likely to talk to or call up to tell about the consultation with the doctor?

- What do you think you will tell them about what was said in the consultation?
- How do you imagine they will react? What do you expect they will ask you?
- Is there anything you might not tell them about the consultation?

Was there anything you were not sure of or confused by in the consultation?

- Were there any questions you had that were not answered?

Has anything changed as a result of the consultation?

What did the doctor say was the next step for you?

- Did the doctor give you an idea of how effective this (treatment) would be?
- Did they mention any other treatment options?
- If they mentioned a medical intervention or another appointment- did the doctor give you an idea of anything that can help your pain until then?
- How was the decision made for you to (start a particular treatment/intervention)?

Has the consultation made any impact on:

- how you think about your pain?
- Anything you might do or not do?
- How you think about the future?

- Any decisions ahead of you?

How do you feel following the consultation?

What were you hoping for from this consultation?

- To what extent has this consultation met your expectations?

How has the consultation left you feeling?

- How are you feeling about (advice/ messages given/ treatment plan)?
- I was wondering what is the most upsetting/ frustrating part for you...?
- How are you left feeling about your pain?

Conclusion-

Is there anything I haven't asked that you think might be important?

Do you have questions for me?

How have you found talking to me today?

## **Appendix 7: The Framework Analysis Thematic**

### **Framework**

The Thematic Framework, devised to address the study's second research question, consists of twelve sub-themes organised into three themes. The doctor-patient dyads were compared across all the sub-themes. The themes and sub-themes are defined below.

#### **1-The doctors' explicit consultation messages**

This theme examines the perceptions of what doctors explicitly said within the consultation; it compares what patients reported their doctors said to them, with what doctors reported advising their patients. Most of the content for this theme was derived from participants' responses to interview questions about the consultations' main messages.

All the patients and doctors identified that the consultation messages included a treatment and/or intervention recommendation and a discussion of the likelihood that it would alleviate the patient's pain. The majority conveyed as one of the main messages an explanation of the patient's pain; some also included recommendations around the role patients can take within their rehabilitation or treatment. The theme is comprised of four sub-themes which reflect these different aspects of the consultations' main messages. The sub-themes are defined in the table below; one column presents what the sub-themes consist of within the doctors' transcripts, and the other column describes the sub-themes within the patients' transcripts.

<i>Sub-themes within doctors' transcripts</i>	<i>Sub- themes within patients' transcripts</i>
<b>1.1 - The next recommended treatment or intervention</b>	
The doctor's perception of which treatment(s) and/or intervention(s) they recommended to the patient.	The patient's perception of which treatment(s) and/or intervention(s) the doctor recommended to them.
<b>1.2- The likely effect of the next treatment or intervention</b>	
The doctor's perception of how they described to the patient the likely effect of the next treatment or intervention. This includes the likelihood the patient's pain will be alleviated and the likely duration of any effect.	The patient's perception of how the doctor described the likely effect of the next treatment or intervention, including any advice around the likelihood the patient's pain will be alleviated and the likely duration of any effect.
<b>1.3- The doctor's explanation of the patient's pain</b>	
The doctor's perception of how they described or explained the patient's pain, and the aspects of the explanation that they thought were most important for the patient to understand.  When an explanation was not a component of the consultation, the doctor's explanation of the patient's pain was sought.	The patient's perception of how the doctor described or explained their pain.  When an explanation was not a component of the consultation, the patient's understanding of their pain was sought.
<b>1.4- The role patients are recommended to take within their treatment</b>	
The doctor's perception of whether and how they recommended patients took a role within their treatment, for example by pacing activities.	The patient's perception of whether and how they were recommended to take a role within their treatment.

## **2- Expectations about patients' long-term treatment plans**

This theme describes participants' own expectations about the most likely future treatment plan, rather than what was necessarily discussed within the consultation. Indeed, it compares doctors' expectations and opinions of what is most

likely to benefit patients with patients' own expectations about their future treatment plans. This theme consists of the two sub-themes in the following table.

<i>Sub-themes within doctors' transcripts</i>	<i>Sub- themes within patients' transcripts</i>
<b>2.1- The expected outcome of the next planned treatment or intervention for <i>that</i> particular patient</b>	
2.1- The doctor's expectation, or prediction, of the most likely outcome of the next treatment or intervention for <i>that</i> patient. This can be similar or different from what was discussed within the consultation.	2.1- The patient's expectation, or prediction, of the most likely outcome of the next treatment or intervention for <i>them</i> personally. This can be similar or different from what was discussed within the consultation.
<b>2.2- The expected long-term treatment plan that would be most helpful for <i>that</i> particular patient</b>	
2.2- The doctor's perception of what the most helpful long-term treatment plan for that patient is.	2.2- The patient's understanding of what the most helpful long-term treatment plan for them is.

### **3- Doctors' perceptions of patients compared with patients' own perceptions**

This theme compares doctors' perceptions of patients' experiences of their pain and the consultation with how patients described their own experiences. The theme, therefore, includes perceptions that were not discussed within the consultations, but arose within the research interview. This theme is comprised of five sub-themes, in the table below.

<i>Sub-themes within doctors' transcripts</i>	<i>Sub- themes within patients' transcripts</i>
<b>3.1 – Doctors' perceptions of how well the patient understood the main messages and patients' understanding of the messages</b>	
The doctor's perception of how well the patient understood the main messages they conveyed to the patient.	The extent to which the patient's description of the consultation's main messages were consistent with the doctor's.
<b>3.2- Doctors' perceptions of how satisfied patients were by the consultation and patients' self- reported satisfaction levels</b>	
The doctor's perception of how the patient felt or thought about the consultation, including their level of satisfaction and which aspects they liked or did not like.	The patient's feelings or thoughts about the consultation, including how satisfied they were, and which aspects they liked or did not like.
<b>3.3 – Doctors' perceptions about patients' experience of their pain and patients' self-reported experiences</b>	
The doctor's perception of how the patient experienced their pain, for example the severity of the pain, the extent the pain impacts upon functioning and the extent to which the patient coped or managed with the pain.	The patient's experience of their pain, in terms of how severe or debilitating they find their pain and the extent to which the patient felt they coped or managed with the pain.
<b>3.4- Doctors' and patients' perceptions of patients' 'agendas' and hopes for consultation</b>	
The doctor's perception of the patient's agenda, hopes or aims for the consultation.	The patient's self-identified agenda, hopes or aims for the consultation.
<b>3.5 Doctors' perception of patients' adherence intentions and patients' intention to adhere</b>	
The doctor's perception of whether the patient intends to adhere to the advice the doctor gave them.	The patient's intention to adhere to the doctor's advice.

## Appendix 8: Framework Analysis: an extract from a thematic chart

This appendix presents an extract from a thematic chart from the Framework Analysis. The first two columns consist of summaries of the transcripts' key points related to the first sub-theme, illustrative verbatim extracts and page references to the data. The last column consists of comments about the extent to which the patient-doctor dyads correspond.

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*Sub-theme name: - 1.1 The next recommended treatment or intervention*

---

<i>Patient 1:</i>	<i>Doctor 1:</i>	<i>Comments:</i>
<p>Dr recommended new medication, to keep taking Tramadol and try injections</p> <p><i>Yeah he said to me I will give you some tablets, that it not work on the pain, more that it works on the nerve (pg3)</i></p> <p><i>He said carry on with the Tramadol (pg7)</i></p> <p>Discussed re injection- pg5</p>	<p>Dr recommended injections, prescribed medication and advised to continue with Tramadol.</p> <p><i>in order to try to treat it the only mechanism we had to try and suppress her pain by different ways like doing an injection or like giving her medicines to try and suppress the pain in order that the nervous system that could be suppressed a little (pg1)</i></p>	<p>Matched on description of next recommended treatments</p>
<i>Patient 2:</i>	<i>Doctor 2:</i>	<i>Comments:</i>
<p>Three options offered- medicines, injections and surgery: both agreed to choose injection.</p> <p><i>First one was medicines, second one was injections, and the third one was surgery (pg2)</i></p> <p>Discussion about trying injection first- pg7</p> <p>Discussion re medicine- pg6</p>	<p>Offered and discussed: surgery, medication and injection. (pg1)</p> <p>Both agreed injection most likely to be helpful (pg3)</p> <p>No advice given on activity levels. (pg2)</p> <p><i>I offered him a range of different things. I said we could talk about, we talked about the possibility of surgery, the possibility of drugs, the possibility of injection. He was going to have injection at his local hospital and that's what we went for. (pg1)</i></p>	<p>Matched on description of next recommended treatments</p>

---

## **Appendix 9: Results and Extracts from the Framework Analysis**

Within the Framework Analysis, the degree of concordance within doctor-patient dyads for each sub-theme was categorised as being matched, partially matched or mismatched. A match was defined as the doctor's and the patient's account corresponding for all the main aspects of the sub-theme. If a dyad was coded as partially matching or mismatching, the reason for the discrepancy was coded. The results section reported the rate of concordance within doctor-patient dyads across the sub-themes, and summarised the most clinically relevant reasons for mismatches. This appendix reports in parenthesis which dyads matched, partially matched and mismatched within each sub-theme, and presents example extracts to illustrate mismatches.

### *1- The doctors' explicit consultation messages*

#### *1.1 - The next recommended treatment or intervention*

All 16 doctor-patient dyads matched on this item.

#### *1.2- The likely effect of the next treatment or intervention*

Thirteen doctor-patient dyads matched on this item.

Three dyads were partially matched: two where the patient expected the treatment would be effective as a stand-alone treatment but the doctor stated that the treatment would only be effective when utilised with physiotherapy (Dr-P18, Dr-

P22) and one where the patient did not report the doctor's statement that part of their pain would never improve due to a damaged nerve (Dr-P4).

### *1.3 The doctor's explanation of the patient's pain*

Thirteen doctor-patient pairs stated that an explanation of the patient's pain was one of the components of the consultation; seven of these 13 doctor-patient pairs matched for this item. Six dyads were partially matched: four patients reported additional parts of the explanation which were inconsistent with the doctor's reported explanation (Dr- P1, Dr-P2, Dr-P10, Dr-P22) and two patients omitted aspects of the explanation, which the doctor had described as being a key aspect (Dr-P5, Dr-P17).

The following extracts below exemplify the reasons for dyads being coded as partially matching for this item. In the following dyad (Dr-P22), it was coded that the patient reported an additional aspect of the explanation – that there is something wrong with her nerve – which is inconsistent with the doctor's reported explanation, that the pain is muscular.

*P22 Dr: Her pain was mainly muscular, that's the main thing I wanted her to get, that her pain was totally muscular.*

*P22: (the doctor) tried to explain to me that probably there is some nerve or something, she also said the muscles in my thighs are not very strong...She just explained that the pain is to do with the nerve or something, so I think that's why they are giving the injection.*

In the following dyad (Dr-P5), it was coded that the patient omitted an aspect of the explanation, which the doctor had described as being a key aspect: pressure on the nerves and the role of long-term pain mechanisms.

P5: (in response to ‘how did the doctor explain your pain?’) *I got a lot of wear and tear there. I had the MRI scan which showed me that, which I knew anyway. I have acquired, L4 and 5, the numbers, I don’t know what they are, but really it’s about that much damage to the base of the spine, that has been there for years...Well the wear and tear he didn’t have to explain anyway, because I had known about that for many many years.*

P5 Dr: (in response to ‘what were the main messages from the consultation?’) *So the whole thrust of it was to tease apart his symptoms in order to try and identify the likely places where his pain was coming from, was it coming from the joints, the back, or pressure on the nerves coming down to the leg. And I think it’s a combination of both... Well we looked at the scan together, and we looked at the different levels of the scan. And I showed where there was wear of the joints, and I showed where there was pressure on the nerves....And I talked about long-term pain mechanisms.*

Three dyads stated that an explanation was not a component of the consultation; when asked about their understanding of the pain, two provided a concordant explanation (Dr-P12, Dr-P14) and one a partially matched explanation (Dr-P6). The discrepancy in the latter dyad was due to the patient understanding the

pain was a result of structural difficulties, whereas the doctor described it in terms of nerves and pain mechanisms.

#### *1.4- The role patients are recommended to take within their treatment*

Seven doctor-patient pairs reported discussing the patient's role within their treatment; all patients within these pairs had been recommended a pain management approach. Out of these seven dyads, two provided matched descriptions of the recommended pain management approach (Dr-P15, Dr-P20) and five provided only partially matched accounts (Dr-P7, Dr-P8, Dr-P9, Dr-P14, Dr-P17). The patients in the partially matched dyads described the general concept of a pain management approach, but did not recount the details the doctor reported conveying: one did not recount the details of how to pace activities (Dr-P14), one did not recount the concept of modifying activities (Dr-P17), two did not recount that they were recommended to decrease their activity levels (Dr-P7, Dr-P9), one did not recount that she was recommended to increase her activity level (Dr-P8). Extracts from the last dyad are presented below.

*P8: So she has more or less told me to carry on with exercises that I am doing, she is quite happy that I am doing them and happy for me to continue.*

*P8 Dr: I think for her it is really important that she carries on being able to be active, and I think that once we do the procedure, she is able to then do a little more...I think she can do more, I think she is a bit conservative, but hopefully I reassured her on that.*

The outstanding nine dyads reported that the consultation did not include a discussion of the recommended role for patients to take within their treatment. However, two of these dyads were mismatched in how they understood the patient's role: doctors assumed that patients would understand that they would benefit from increasing their activity levels following analgesic injections, while patients were not aware of this expectation and did not plan to change their behaviour (Dr-P2, Dr-P5).

## 2- *Expectations about patients' long-term treatment*

### 2.1 – *The expected outcome of the next planned intervention*

Six dyads were matched and ten were not matched: eight patients reported significantly higher expectations of effectiveness than the doctor, and two patients (both recommended pain management) reported lower expectations.

The eight patients who reported higher expectations than their doctors had all been recommended a medical treatment as their next intervention and were hopeful it would alleviate their pain (Dr-P1, Dr-P2, Dr-P4, Dr-P6, Dr-P12, Dr-P18, Dr-P20, Dr-P22). The following extracts are from one of these dyads (Dr-P12):

*P12: He (doctor) agreed that the first injection won't necessarily do the trick. It may however, it may, it may be fine. And I am quite happy with that. No problem at all. I also know a bit about the reputation of the (hospital) and they are pretty good stuff, they are pretty good quite frankly... I am hoping that as a result of the injection, I won't be anything quite so tired, and I will be only be too happy too... I am assuming that it is going to work, that is the answer.*

P12 Dr: *I actually have a feeling it will not help his pain, or at least there is only a chance that it is not going to help him. I think it is worth trying, because sometimes you get these strange cases, but as a whole injections aren't particularly brilliant anyway, but you do get the odd cases that it helps.*

The two patients who reported lower expectations than their doctor did, had both been recommended a pain management approach and stated that they were unsure how this would improve their level of functioning (Dr-P14, Dr-P17); their doctors reported being hopeful that they could re-gain some level of functioning. The extracts below are from one of these dyads (Dr-P17):

P17: *I don't think there is anything that they can do to help me... She was talking pain management, get everything sorted out, get it in your mind, that yes I got this damage, I got this problem, and I am going to live with it, and sit down with the other people, they got the same problem, and have targets, what we going to do? I have passed that, I have passed that long ago... Keep talking to me, what is there, is there, it is not going to make it any better, it is not going to make it any worse. If you try and put it on my brain that I got to live with it, I know that, I got the pain, I got to live with it, ok. I can't keep saying count to one to ten before doing anything... I am going to ring work and tell them 'this is not short term anymore, I am not giving you any hope that I am going to be back today, tomorrow, the next day, or next year.*

P17 Dr: *So my main messages to him was unfortunately we are now in a chronic pain situation. There are things that we can help with...I think if he can accept the pain is not, the pain doesn't necessarily have to rule his life, because he is able to do other things. I think a pain management programme would be brilliant for him... I think he could go back to a different job, I think if he would be in the frame of mind to negotiate with his occupational health to say look I can do this, or I can do this amount of hours, I can't do that, I can pace myself.*

*2.2- The expected long-term treatment plan that would be most helpful for that particular patient*

Nine dyads were matched, and seven mismatched. Within the seven mismatches, the doctor reported that a pain management and/or physiotherapy approach was likely to be most effective, while the patient expected continued medical treatments (Dr-P2, Dr-P4, Dr-P6, Dr-P12, Dr-P18, Dr-P20, Dr-P22). This mismatch is exemplified in the extracts below (Dr-P6):

P6: *He came up and said, we can either offer you injection he said, or acupuncture....It seems to me as though I am here (hospital) for ever more!*

P6 Dr: *I actually think in the longer term, the most valuable thing we could offer her is the back pain management group, to actually sort of look at her expectations and goals, and try to make them realistic. I am only worried that she is quite so rigid that she might not get that.*

### *3- Doctors' perceptions of patients compared with patients' own perceptions*

#### *3.1 – Doctors' perceptions of how well the patient understood the main messages and patients' understanding of the messages*

For 12 consultations, doctors predicted accurately how much the patient recounted of the consultation messages. For four consultations, doctors overestimated the extent of agreement between their messages and patients' descriptions (Dr-P4, Dr-P14, Dr-P20, Dr-P22).

#### *3.2- Doctors' perceptions of how satisfied patients were by the consultation and patients' self-reported satisfaction levels*

For 11 consultations, the doctors predicted accurately the patients' self-reported levels of satisfaction with the consultation, all of which were positive. Doctor's overestimated patients' satisfaction in three consultations, and underestimated it in two. For the three incidences in which doctors overestimated patient's satisfaction, patients reported feeling dissatisfied as they had unanswered questions about their pain and its treatment following the consultation (Dr-P14, Dr-P15, Dr-P20).

*P14: I mean the questions are sort of left unanswered, but I hope I can pick up on them with the physio.*

*P14 Dr: I think she had her agenda met.*

For one of the cases in which the doctor underestimated how satisfied the patient was, the doctor reported how the patient probably felt rushed; whereas the patient was positive about the interest the doctor had taken in her and appreciated she

had taken the time to examine her (Dr-P17). In the other case in which the doctor underestimated how satisfied the patient was, the doctor reported that the patient had not had their agenda met as she was unable to offer him a cure for his pain, whereas the patient described how they appreciated the doctor's honesty and the value of knowing their prognosis (Dr-P22).

### *3.3 – Doctors' perceptions about patients' experience of their pain and patients' self-reported experiences*

For six consultations of the 16, doctors volunteered comments on the patient's pain. For three of these consultations, the doctors described the pain as mild which patients had described as having significant impact on their daily lives (Dr-P4, Dr-P15, Dr-P22). The following extracts are from one of these dyads (Dr-P4).

*P4: I am just about living with this pain, its the sciatica, and this worries me so much in the night... After the operation, my expectation was to be a lot more mobile, but I am not! And that makes it really bad. I find that when I walk, I just want to sit down. Otherwise I'm in pain... As I told him, when I am coming down the stairs, I always feel I am going to be falling over, because I am not able to put one foot after the other, which I used to do painfully. But I can't at all now, this one does not move, because of no feeling or whatever it is... I am desperate to get better.*

*P4 Dr: Her symptoms are, I would call them mild to moderate, not moderate to severe, or severe... her symptoms didn't sound that bad to me. I*

*listen to lots of people with sciatica, and you saw her walking here, she didn't look too incapacitated.*

For three of the consultations, the doctors described patients as coping well, which was at odds with the patients' accounts of struggling to cope with pain (Dr-P7, Dr-P8, Dr-P14).

*P7: I do struggle but I do carry on... I am alone, I'm scared, particularly when things go wrong it's very very difficult to cope.*

*P7 Dr: I think she is a very energetic dynamic lady who's very single minded and won't allow pain to stop her from doing things that she felt a commitment and responsibility to do...I didn't really focus on her low grade back pain which is basically long term problem that I think she was managing well, and it was really the more severe acute bouts that radiated to the leg that she wanted to focus on...so I haven't made any appointments to see her again but she knows she has an open appointment to come back.*

#### *3.4- Doctors' and patients' perceptions of patients' 'agendas' and hopes for consultation*

For seven consultations of the 16, doctors volunteered their perceptions of patients' agendas or hopes for the consultation; in each of these dyads, there seemed a discrepancy between how doctors' and patients' described patients' agendas. For two consultations, doctors stated that they thought an explanation was not important to the patient and that the patient already had a good understanding, whereas the patient reported wanting a clearer understanding of their pain (Dr-P14, Dr-P20). For

three consultations, doctors described patients as having ‘fixed’ ideas about what treatment they wanted, whilst the patients described having changed some of their ideas as a result of the consultation (Dr-P4, Dr-P6, Dr-P10). In each of these dyads, the patient reported being wary and worried about treatments due to hearing negative experiences from others or having previously had unpleasant side-effects from similar treatments, however all three patients then reported being prepared to try the treatment as the doctor had recommended it. In two consultations, doctors reported that the patient only wanted injections, whilst the patients described wanting whatever would best help them to increase functioning (Dr-P1, Dr-P2).

### *3.5 Doctors’ perception of patients’ adherence intentions and patients’ intention to adhere*

For six consultations of the 16, doctors volunteered their perceptions of whether they thought the patient intended to adhere to their advice about pain management. For four consultations, doctors were accurate in predicting that the patient reported they intended to adhere to the doctor’s advice (Dr-P7, Dr-P9, Dr-P15, Dr-P20). In one dyad, the doctor under-estimated the likelihood that the patient was planning to adhere to the doctor’s advice. In one dyad, the doctor over-estimated the likelihood that the patient intended following their advice (Dr-P14).

P14: (Researcher- you were saying that the doctor suggested that you stop at that point when you feel pain?) *Yeah I immediately rejected that to be honest!. I think I’d be fine if someone said if you stop at the right time, we will then be able to expand that to the point you can hit your twenty minutes and go beyond that, then I’d be fine.*

P14 Dr: *My main message to her was to try and to stop when she felt good, not to push herself that extra 10%. I think she took that away, she took that on board. I was like almost giving herself permission to stop before she got to the end of it. I think it will make a difference to how she approaches this...Well I am hoping she will pace herself a little bit more, and not do so much.*