Consciousness, complexity and chronic pain: Exploring the occurrence and implications of incongruent beliefs about 'important' chronic pain treatment components

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Abstract

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Background: The biological sciences have contributed an extensive volume of research in efforts to resolve the issue of chronic pain. An expanding body of research, focusing on the psycho-social aspects of chronic pain, is also now evident. Paradigms applied to chronic pain appear to compete and lack an integrative framework.

Aims: The original aim of this study was to identify and explore patterns of congruence that exist between service users and providers in relation to beliefs about which treatments for chronic pain are important. At the outset this research took a constructivist position, based within existing research which demonstrates that beliefs about chronic pain and its treatment are individually constructed and that lack of agreement between people with pain and treatment providers may contribute to negative treatment outcomes. As the iterative process of the research unfolded the aims of determining if a complex adaptive systems (CAS) analysis was appropriate for chronic pain and whether recommendations for change could legitimately be generated using a CAS paradigm, emerged.

Methods: The literature was reviewed to identify conceptualizations of, and interventions for, chronic pain. Based on this information the Stage one postal survey, gathering service users' and providers' opinions about important treatment components, was designed. The survey also included Skevington's standardised Beliefs About Pain Control Questionnaire (BPCQ). The second stage employed Delphi methodology. A series of iterative questionnaires explored the original questions about congruence of beliefs, perceived impact of disagreement and suggestions for action. As additional information emerging from each Delphi round the analysis employed firstly a constructivist framework and ultimately explored the usefulness of reframing chronic pain within a CAS framework.

Findings: The participants in this study had very little inter and intra-group congruence of beliefs. While service users believed that their decision-making was influenced by four domains of the Chapman's Consciousness model (*coherence, purposiveness, affect* and *self-image*) as derived from constructivist theory, service providers stated that *affect* and *self-image* were not strong influences. Participants agreed that some action should be taken when there is disagreement about important treatments and the overwhelming majority of recommendations focused on actions the service providers should take. Very few recommendations were made of actions for the service users. Participants' responses in Delphi 3 indicated that chronic pain had a number of elements consistent with a CAS but that more linear and conflicting beliefs were also strong.

Discussion and Conclusions: A constructivist perspective in itself proved insufficient to explore chronic pain's resistance to change and the implications of this for intervention. By applying CAS theory to the three key features that emerged from Delphi 1 and 2 (incongruent beliefs, differential access to information and paradoxical beliefs and behaviours) the phenomenon of chronicity was reframed. Interventions, based on complexity science principles, can effect change in the highly interactive systems that constitute the chronic pain experience. A complexity science paradigm can serve as a meta-framework, integrating the currently competing theoretical models employed in chronic pain. The NHS Modernisation Agency, and other researchers and theorists, have provided complexity science based policy statements and recommendations for affecting change in a range of healthcare settings. These can be examined for patterns and examples of how dissent and conflict can be a positive generative force for change. Examples and patterns in turn, can form templates to guide reframing the practice and operating paradigm for chronic pain service delivery.

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Related publications and presentations

Refereed journals

Can Complex Adaptive Systems theory be applied to occupational and physiotherapists' beliefs about chronic pain? Disability and Rehabilitation (2005) in review.

Trojan mice in global health issues (Gallery Article). Journal of Epidemiology and Community Health (2005) in press.

Relationships, context and embedded systems: illustrating complexity science (Gallery Article). Journal of Epidemiology and Community Health (2005) in press.

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May 2005	**Implications of diversity of therapists' beliefs about treatment for chronic pain: Evidence-based or Chaos?** (parallel session paper) Canadian Association of Occupational Therapists National Conference, Vancouver, Canada.
March 2005	**Reconceptualising 'professionalism': The imperative of changing perspective on the value of the affective domain** (Poster), Kawa Challenge and Change Conference, Sheffield Hallam University, UK.
Oct 2004	**Meaning construction in chronic pain.** (Workshop) National Occupational Therapy Pain Association, annual general meeting. St. Albans, UK
Sept 2004	**Chronic pain and complexity: the beliefs of people with pain and service providers** (parallel session paper), 4th Complexity Conference: Health and Social Care, University of Exeter
Sept 2003	**Service users and occupational therapists beliefs about important treatments for chronic pain** (Poster) Annual Pain Management Programme Conference, Norwich UK
April 2003	**Service Users Beliefs about Important Treatments for Chronic Pain**. (Poster) Pain Society, UK Annual Conference, Glasgow.
June 2002	**Beliefs and Attitudes of Occupational Therapists Regarding Chronic Pain.** (parallel session paper) World Federation of Occupational Therapists Conference, Stockholm, Sweden.
June 2002	**Occupational Therapists and Beliefs about Treatments for Chronic Pain; Should We Be Worried?** (parallel session paper) College of Occupational Therapists Annual Conference, Brighton, UK.

Table of Contents

1. Introduction

2. The nature of chronic pain

3. Pain intervention and evaluation

4. Constructivist theory

5. Complex Adaptive Systems

6. Methodology and study design

7. Stage one findings

8. Delphi 1 findings: the decision-making process

9. **Delphi 2 findings: the Consciousness model**

10. **Delphi 3 findings: complex adaptive systems**

Chapter 1
Introduction

1.1 Initial study rationale

Chronic pain is an expensive and growing problem within the United Kingdom (UK) and other industrialised countries [1-4]. As the demand for intervention accelerates, socio-economic forces have driven a parallel growth in demand for rigorous research into the efficacy of resource utilisation. An expanding, and sometimes extensive, body of chronic pain research is now evident within the scientific literature of most health-related disciplines.

A preliminary review of the literature identified that several streams of research prevail. The impact of the multidisciplinary approach is one stream. Strong support has developed during the last 20 years for the multidisciplinary approach to management of chronic pain [5]. In this model of service delivery, "...programs employ a host of various cognitive-behavioral approaches, as well as approaches from other disciplines such as physiotherapy and occupational therapy" [6]. Although this approach is now subject to growing scrutiny [7-10], a multidisciplinary structure continues to be the model recommended by both the International Association for the Study of Pain (IASP) [11] and the British Pain Society [12]. The multidisciplinary/multimodality approach to treatment makes for unique research design challenges in attempts to isolate components and to determine their relationship to the model of practice claimed by a program (for example, if a program states it has a cognitive-behavioural philosophy, why does it include massage therapy?). As Freeman and her co-authors point out, multidisciplinary teams experience a range of problems with different interpretations and philosophy of practice being of particular concern [13].

A second stream was identified in the literature that focused on the pain experience from a psycho-social framework. Themes emerging from research into the perspectives of people with pain include the relationship of chronic pain to beliefs about pain's temporal nature, how individuals construct an understanding of the cause of pain, the extent of self-blame, and how coping styles affect response to pain [14-17]. Additionally, the impact of peoples' beliefs in the effectiveness of treatment and their own self-efficacy and coping style has been extensively explored [18-21]. There is also growing attention to the areas of post-traumatic stress [22], fear-avoidance issues [23] and stages at which a person with pain is more receptive to change [24].

A third stream is that of biomedical research. Biomedical research remains the strongest presence in the available evidence-base as demonstrated by the overwhelming majority of basic science research articles in journals specific to the study of pain (for example Pain and the European Journal of Pain).

There is an ever-growing volume of research in the area of chronic pain. Chapter 2 (sections 2.5 and 2.6) describe in detail the wide range of physiological and particularly, biopsychosocial explanatory models for chronic pain. Chapter 2 also proposes that the debate between neurophysiological models and more holistic, biopsychosocial paradigms is set within the wider context of social change, personal meaning and the cultural valuation of science. The scope of explanatory models is extensive but there is an apparent lack of synthesis between the different bodies of research. Scientific publications do not routinely seek relationships and connections between paradigms and yet these interrelationships seem an important point to consider. If each stakeholder, across the chronic pain experience, holds any one of a number of different theoretical frameworks for chronic pain, an extensive range of beliefs and behaviours will be exhibited. Can stakeholders assume that their model is shared by others, or, are important misassumptions being made? Are service providers' beliefs about what constitutes the most effective chronic pain intervention communicated to, and shared by, service c-users? Do service providers and service users operationalize 'importance' in the same way? Varanken proposes, "the way the medical community conceptualizes what a pain patient is and how he should be treated, exemplifies how the medical community understands pain" [25]. However, is this the way people think about their own pain? Is there such an entity as 'the medical community' and can homogeneity of beliefs be assumed? Hanley [26] indicates that there is a growing awareness of the need for programming that reflects the unique perspective of people who actually experience the services for themselves. Current trends strongly support the need for evidence-based programming. However, are outcome evaluations and development of new services evidenced-based only in terms of health care professionals' interpretations? And do all the stakeholders place the same value and faith in the evidence produced?

1.2 Initial research questions

These types of concerns prompted the research presented in this dissertation. The original research questions the study aimed to address were:

1. What do people with pain believe are important treatment components? Why?
2. What do service providers believe are important treatment components? Why?
3. How much agreement is there between service providers and service users?
4. Do service users and providers think it matters if there is disagreement and, if so, what should be done?

Determining 'what' the participant believed was seen as a necessary precursor to more qualitative, reflective questions addressing 'why'. The researcher's premise was that asking 'what' would provide a wide range of elements around which to explore emerging themes as participants discussed the values and personal beliefs about the meaning of pain required to explain 'why'.

Questions concerned with the congruence of beliefs between service users and providers about what treatments were important for chronic pain were felt to be highly relevant in light of what research in the fields of concordance and compliance is now demonstrating. Patient compliance with treatment is inextricably combined with the individual's perception of whether the intervention is relevant, meaningful and likely to be successful [27-30]. Patient beliefs regarding morbidity have, in some studies, been shown to be a better prognostic indicator than objective measurement of health status [31]. Additionally, some theorists have begun to explore the relationship between stages of readiness for change and treatment outcome [24, 32]. In this school of thought, a client's stage of readiness will influence which treatment components he ranks as most effective. If the service provider is unaware of this influence, the prioritisation of treatment components may vary significantly from the client's. The consequence of this dissonance is proposed to be to high recidivism and premature withdrawal from the program.

1.3 Approach

A multi-stage approach to these questions was indicated. The first part of Stage one was a detailed review of the literature investigating current conceptualisations of chronic pain, from both a lay and a professional perspective. This literature review informed features of the research question -specifically, what were the range of components available within treatment programs for chronic pain, how did service providers evaluate what is important in a program and how did service users evaluate the importance of the program components? The information gathered was used to design a survey to identify service providers' and users' opinions about what treatment components are important.

The concept of 'importance' was carefully considered. To define 'importance' specifically (e.g. 'reducing pain', 'being able to go back to work') potentially denied individuals the opportunity to self-define within the context of their own needs and pain experience. The rationale for using the concept of <u>importance</u> related to the phenomenon of people making decisions based on their personal assessment of over-all desirability ('importance') as opposed to the more narrow concept of benefit to health. Several models of health related behaviours suggest that people attach a relative value (importance) to health outcomes that then influences their degree of participation and compliance with treatment activities [33]. These models propose that people may acknowledge that a certain behaviour is of benefit (for example, weight loss) but at the same time assign a low level of importance to the behaviour in the context of their own lives. Additionally, focusing on *importance* allowed a more open-ended approach so that individuals could respond from a values and beliefs perspective.

The second stage of the study employed a Delphi methodology based on a series of iterative questionnaires. Delphi technique (discussed in detail in Chapter 6-section 6.5) offers many positive features and allowed for structured examination of qualitative issues across large groups of physically and socially dispersed people. Additionally, it bridges the gap between qualitative and quantitative data collection in healthcare because of its quasi-experimental nature (gathering statistical data within an iterative process). With Delphi methodology, participants are provided with a summary of the group's response to the preceding questionnaire and asked to comment on the accuracy of the researcher's interpretation or, if they wish, to revise their response based on this new composite information. The Delphi questionnaires explored the original questions about congruence of beliefs, perceived impact of disagreement and suggestions for action. Additional questions arose out of the analysis of each round of questionnaires and lead the researcher towards an examination of constructivism in relation to pain beliefs and, ultimately, complex adaptive systems theory.

1.4 Chapter outline

Chapter 2 (The nature of chronic pain) defines chronic pain and discusses the incidence and prevalence both within the UK and in comparison to other industrialised countries. The documented high personal and social costs of pain are presented to support the importance of this question at a number of inter-related levels. A range of explanatory models for chronic pain are discussed and the chapter concludes with an examination of the seeming resistance of chronic pain to resolution, regardless of which theoretical model guides intervention.

Chapter 3 (Pain intervention and evaluation) reviews the current evidence-base for more commonly employed psychological and biomedical interventions. Research pertaining to the multi-disciplinary team, complementary therapies and the self-management approach is discussed. The chapter concludes with an overview of the state of issues and practices related to outcome measurement in the field of chronic pain service delivery.

Chapter 4 (Constructivist theory) presents the researcher's justification for applying a constructivist framework to exploring people's beliefs about chronic pain. The concepts of pain cognitions and schemata are discussed in relation to constructivist theory and the manner in which a range of psychological theories about chronic pain can be consolidated through application of the Consciousness model, grounded in a constructivist paradigm, is also presented.

Chapter 5 (Complex adaptive systems) presents a definition of complex adaptive systems and examines the historical relationship between complexity theory and healthcare. Examples from the current state of healthcare and chronic pain are presented to illustrate how the principles of complex adaptive systems (CAS) apply, and to justify this approach to relevant stages of the study.

The study design and research methods employed are presented in Chapter 6. The justification for using a two-stage approach is presented and questionnaire construction, the standardised Beliefs About Pain Control Questionnaire [34], and piloting of the questionnaires are discussed. Chapter 6 also details the participant recruitment process and ethical considerations of the study. The Delphi approach is defined, its strengths and limitations discussed and the rationale for its use in this study is presented. How the content of each Delphi round was structured around the emerging theoretical constructs (Delphi 1 and 2 – constructivist model of Consciousness and Delphi 3- complex adaptive systems) and the quantitative and qualitative data analysis techniques applied to all stages of the research are explained. The chapter concludes by presenting a discussion of techniques employed to ensure methodological rigour throughout the study.

In Chapter 7 (Stage one findings) participant demographics, BPCQ scores and the amount of congruence that existed in beliefs about important treatment components for chronic pain is presented. Intra and inter-group comparisons are made and a lack of congruence is identified. The decision to present the findings of Stage one and each subsequent Delphi round in Stage two as separate chapters because of the large volume of data generated by the study, is discussed. The iterative nature of the study made it necessary for a preliminary discussion to follow each of the chapters that presented findings (Chapters 7-10) thus laying the foundation for the subsequent questionnaire content and analysis. In Chapter 7 a preliminary discussion of the implications of non-congruence is provided and the rationale behind the decision to use a Delphi methodology in Stage two (exploring 'why') is revisited.

Chapter 8 (Delphi 1 findings: the decision-making process) discusses the Delphi 1 findings in relation to the implications for decision-making. The themes that emerged in Delphi 1 from an exploration of influences on decision-making are presented and the impact of disagreement between service users and providers is explored. The influence of affect in decision-making also emerges as an important factor in decision-making and the implications are presented in the Chapter 8 preliminary discussion of Delphi 1.

Chapter 9 (Delphi 2 findings: the Consciousness model) presents participants' responses to the researcher's application of a constructivist framework (the Consciousness model [35]) in analysing the Delphi 1 findings. Participants did not uniformly validate all of the researcher's conclusions; and the implications of this and how it influenced the next Delphi round are outlined. A model of the meaning construction cycle, within a constructivist framework, is provided. This model is employed to facilitate an exploration of the dynamic nature of decision-making. The chapter concludes with a discussion of the implications of discord as a consequence of conflicting positivist and constructivist frameworks, and identifies that both paradigms fall short of providing a comprehensive explanatory model for chronic pain.

Chapter 10 (Delphi 3 findings: complex adaptive systems) presents participants' responses to the researcher's conclusions for the Delphi 2 round and the themes that emerged from participants' reflections on why service providers discount the role of affect in decision-making. Chapter 10 also highlights the coexistence of linear and complex adaptive systems beliefs as exhibited by the participants' responses about relation to chronic pain service delivery. Chapter 10 also shows how participants' responses to questions about certainty and agreement in Delphi 3, when plotted in a matrix, clearly demonstrated features consistent with a complex system [36]. Other examples where participants' responses illustrate a system that contains both linear and complex elements are identified and a framework for analysing these responses against a complex adaptive systems paradigm is outlined. Lastly, Chapter 10 presents the participants' feedback in relation to participating in this Delphi study.

Chapter 11 (Discussion) presents the case for applying CAS theory to redirect efforts away from the current emphasis on seeking 'the best' approach to chronic pain reduction. An argument is presented for reframing the question towards exploring the patterns of interactions that keep pain chronic. In other words, why is the most likely outcome for chronic pain, regardless of the range of theoretical methods employed, chronicity? Three key influences for the state of chronicity are identified from the research findings discussed in preceding chapters. These three features are incongruence of beliefs, differential access to information and paradoxical beliefs. Chapter 11 also outlines the study limitations and concludes by introducing principles for change within CAS that can be applied to chronic pain service delivery.

The concluding chapter examines what challenges and opportunities currently exist within the healthcare system to affect positive change within chronic pain service delivery and outcomes. The CAS principles of change management introduced in Chapter 11 [37] are discussed in relation to the study findings and current healthcare delivery. The benefits of making overt the inherent paradox and dissent within any CAS are presented as an opportunity to redirect energy towards constructive and creative problem solving. The chapter concludes with three key recommendations; identify existing patterns, encourage the expression of dissent and create new simple rules (as opposed to those rules that support 'chronicity' as the status quo).

1.5 The research journey

The chapters in the study reflect the research process not only in content but also in style. Earlier chapters deal with more linear aspects of research and study design. The writing style reflects this and supporting evidence for arguments put forward at the beginning of the study are grounded in a reductionist framework. A range of statistical methods, designed to reduce error and increase reliability, are employed. The research conventions of both qualitative and quantitative study design, focused on ensuring replicability, transparency and rigour are presented and dictate much of the early chapters' content. However, as the research moved into other paradigms and different ways of looking at the phenomenon of chronic pain, new sources of evidence were also required. Complex ideas are not necessarily best expressed through flowcharts and bullet points, so other ways of illustrating concepts were examined. Complexity science proposes that uncovering and exploring patterns is critical to understanding complex problems. Analogy, metaphor and story-telling are all tools that complexity theorists value for their ability to help people understand patterns and think about events from a new perspective. The latter chapters of the dissertation mirror this belief and use a wide range of literary, philosophical and popular culture sources to illustrate, and at times provoke, new perspectives and facilitate novel insights into previously unanticipated relationships.

Chapter 2

The nature of chronic pain

2.1 Introduction

Pain is nothing new to humans; evidence of our concern with it can be traced as far back as history takes us. Kleinman comments that, "pain's sheer inexhaustibility as a subject for conceptualisation and empirical study is a statement about how deeply its roots tap the sources and express the forms of human conditions" [38:122)]. Ironically, despite the ever-growing volume of literature seeking to understand pain, our grasp of this complex entity seems perpetually elusive. If we cannot understand pain, how can we then attempt to remediate it? The area of chronic pain proves particularly resistant to clear, concise analysis, with scholars and clinicians at times polarised in their beliefs [39, 40]. At one end of the continuum are those who maintain that pain's etiology lies within bio-physiological functions in the body. At the other end are those who seek to demonstrate that chronic pain is actually a socially conditioned and maintained response to life circumstances.

This chapter will briefly review predominant theoretical models to establish the context for the subsequent research study. Accepting Morris's position that "pain is always historical - always reshaped by a particular time, place, culture, and individual psyche..."[41:6], context is an important consideration. To that end, the current incidence of chronic pain will also be reviewed and a working definition of chronic pain determined.

2.2 Definitions of Pain

Butterworths' medical dictionary tells us that pain is, "...the distressing sensation excited by noxious stimuli of sufficient intensity acting on nerve-endings in the skin, viscera, muscles, bones, joints, etc." [42]. In other words, a physiological event that causes the individual distress. This viewpoint, put forward in a credible source, lies close to the biological end of the conceptual range. Even here though, the social connection cannot be avoided - pain is 'distressing'. The International Association for the Study of Pain, adopted the following definition for pain in 1986, "...an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage " [44]. Here the reader is alerted to the new element of 'potential' tissue damage. Lastly, McCaffrey & Beebe put forward a definition that exemplifies the opposite end of the scale. They conceptualise pain as a uniquely individual event, consisting of, "...whatever the experiencing person says it is and existing whenever he says it does" [43]. These features guide us to an understanding that pain is more than a sensory event. In these latter definitions pain has a perceptual component, requiring interpretation within the individual's own experience and background. A review of the literature reveals any number of definitions for pain that lie between these two poles. This ongoing debate exemplifies the conflict within the professional community and illustrates one reason why the treatment of pain is fraught with confusion and uncertainty for many professionals and patients alike.

Finding a consistently accepted definition of chronic pain is equally problematic. Indeed, this has been cited as one of the features contributing to the ongoing problems in effective intervention for people with persistent pain [25]. Depending on the theoretical perspective, definitions range from malfunctioning auto-immune systems, to conversion reactions triggered by abuse, to an adaptive response to threatened livelihood and loss of income. The two consistent features seem to be temporality and unexpectedness. In other words, pain that is unexpected and has lasted too long. The IASP defines chronic pain as, "...lasting for a period of time. It usually persists beyond the time of healing of an injury, and there is frequently no identifiable cause"[44].

Pain terminology, like all words and conversational phrases, is a product of society. It changes over time and reflects what is acceptable within the context of the time [45]. Montes-Sandoval proposes that '...to clarify the meaning of the concept of pain it is important to identify as many uses of the term as possible'. She identifies these uses through a historical review, discussing pain as the opposite to pleasure (Aristotle), pain as warning (Descarte), pain as punishment, (Merriam Webster's Collegiate Dictionary), and as an abnormal mental perception - 'psychalgia' (Maude-Muse) [46]. How the definition of pain has changed over time is evidenced within the last 20 years of the IASP's publications. In 1994 the IASP reviewed and up-dated their pain terms from the 1984 published definitions. That terminology had, in turn, evolved from the original document published in 1979. The most recent revision now includes a footnote to the word 'pain', highlighting its subjective nature; "Each individual learns the application of the word through experiences related to injury in early life" [47}. This definition more closely reflects concepts of subjectivity and emotion as components of pain. Prior to the early 1980's these beliefs were not readily supported and seldom evidenced in the mainstream literature. Chapman, et al., put forward a definition of chronic pain, strongly reflective of contemporary thinking, integrating perception and sensation. They describe chronic pain, "...as severe persisting pain of moderate or long duration that disrupts sleep and normal living, ceases to serve a protective function, and instead degrades health and functional capability" [35:35].

It is important to identify the terminology for this study. As the IASP points out, "...the usage of individual terms in medicine often varies widely. That need not be a cause for distress provided each author makes clear precisely how he employs a word" [47]. Having said this, they go on to reinforce the need for terminology to have a shared meaning. The goal of selecting a widely accepted definition for chronic pain from the extensive range available in the current literature is problematic. Chronic pain, like so many other chronic illnesses, still suffers from what Fordyce [48] described as the "illusion of homogeneity". We cannot approach the question as if each person with pain was identical to the next. "In fact, individuals suffering from persistent pain bring to the clinical situation a vast array of individual differences, including personality, character, pre-morbid level of adaptation, capacity to cope with adversity, and varying degrees of resourcefulness and resilience" [49]. The definition of chronic pain for this study will, subsequently, make no claims to universal acceptance. Rather, the author has selected the earlier cited definition of Chapman et al., as being reflective of chronic pain as a complex, uniquely individual event.

2.3 Incidence & Prevalence

Chronic pain is recognised as a significant problem within the industrialised nations [1, 50]. Prevalence has been recorded between 12-35% of the population at any one time, and between 49-80% across the life span, in European and North American studies [1]. In 1982 one of the first comprehensive reviews of chronic pain prevalence in the UK, carried out in the Oxford Health Region, reported an occurrence of 3.25% [51]. By 1991 the prevalence of chronic pain in Britain was estimated at 7% [52]. Subsequent studies in the UK have continued to reflect this trend with an 11% prevalence reported in 1995 [53] and 27-28% cited in a 1998 Manchester based study [54]. Another recent study, carried out in the Bradford Metropolitan Health District during 1997, reported an average life-time prevalence of 59% and an average annual prevalence of 41% for low back pain [55]. This variation must be viewed cautiously and it is possible that the discrepancies in prevalence are a feature of different reporting practices and help seeking behaviours across the UK, and not of actual variations in occurrence of pain [56].

Elliot et al., reported a 1998 study, based in the Grampian region of the UK where over forty-six hundred (4600) people, randomly selected from the General Practice Administration System for Scotland (GPASS) electronic data-base, received questionnaires. The response rate was 82.3% and of that group, 50.4% of respondents reported some form of chronic pain. The two most common complaints were back pain (16%) and arthritis (15.8%). Although only 15.8% rated their pain as 'most severe', 28% of the total group reported the highest degree of need consequent to their pain [50]. This discrepancy between pain intensity and level of function is consistent with other research findings specific to pain [57-59] and other chronic illnesses [60, 61]. Results of the Grampian study indicate that women were more likely to report pain than men, and that prevalence of chronic pain was higher amongst those living in rented council accommodation, the elderly, and those people reporting themselves as retired or unable to work.

2.3.1 The UK contrasted with other industrialised nations

Maniadakis et al reported a 104% increase in back pain disability between 1986 and 1992 in the UK [1]. This growth in reported chronic pain in the UK is consistent with trends demonstrated in the research from other industrialised countries [62]. A study done in Ontario, Canada found that, "...11% of respondents reported a persistent problem with pain...Women were the most commonly affected, and the prevalence of persistent pain increased with age" [63]. In an American study carried out in 1984, chronic back pain was found to be the third leading cause of disability and loss of individual productivity and it was estimated that close to 4% of the total

American population was permanently disabled by chronic back pain [64]. By 1987 it was estimated that 70 million Americans had some form of chronic pain. Of these, non-malignant back pain was the most common problem being reported by approximately 50 million people [65]. Blyth et al., [66] carried out a study of over 17,000 people in Australia and found that chronic pain was reported in 17.1% of males and 20.0% of females. The authors highlighted the similarity of their findings and other studies regarding the strong associations between chronic pain and older ages, female gender, lower educational levels, and limited access to compensation/ private health insurance. The serious nature of chronic pain is reinforced by studies such as Nachemson's extensive review of the international prevalence of chronic low back pain. These findings concluded that Sweden, Canada, The Netherlands and Great Britain, followed closely by the United States and West Germany, have the highest rates of disability from back pain of all industrialised countries [67].

Increasingly health care policy makers and researchers are stressing the importance of approaching chronic illness from a holistic, socio-culturally sensitive perspective. The studies cited previously are only a sample of the growing body of research that firmly establishes chronic pain as a condition that falls into such a category.

2.4 Direct and indirect costs of pain

The cost of chronic pain is routinely cited in the literature as being a significant burden to the individual, the health care systems and society at large. However, because of the myriad of health services provision options and inconsistency of diagnostic labelling it is very difficult to do between country comparisons [68]. Costs in the UK are associated not only with NHS treatment but also with over-the-counter medications, privately funded interventions and lost productivity. It is difficult to place a definitive cost on chronic pain given that definitions employed by physicians and service providers vary. Additionally, many people, holding an attitude that pain is an inevitable part of life, do not seek formal assistance. A report by the Clinical Standards Advisory Group (CSAG) in 1993 reported that Sickness and Invalidity benefit paid for back problems increased from 81 million days in 1991-92 to 106 million days by 1993-94 (25 million days in one year). They estimated costs to the NHS for back pain were 480 million pounds sterling, with lost productivity and DSS benefits equalling an additional 3.8 billion and 1.4 billion pounds respectively [69]. The NHS Burdens of Disease Discussion Paper [70] reported that between 1991-1992 back related pain was one of the top twenty reasons for consulting in general practice, irrespective of gender. A 1995 study [68], reported that back pain patients account for between 5.8 and 8.6 million consultations to general practitioners and in excess of 900,000 hospital bed days a year. In a recent publication Maniadakis and Gray attempt to address the need to integrate primary and secondary cost issues. They carried out a 'cost-of-illness' study of the socio-economic impact of back pain in the UK. The study estimated the direct care costs of back pain in 1998 as £1632 million. Private (patient funded) services account for 35% of this estimate. However, once the indirect costs (carers, lost wages, etc.) are included, the cost raises to £10,668 million. Maniadakis et. al, conclude that back pain is one of the most costly conditions for which economic analysis has been carried out in the UK [1]. Back pain, as cited previously in Elliott's findings, accounts for potentially as little as 16% of chronic pain and represents only the tip of the iceberg in the total economic costs of chronic pain.

Socio-political features and the capitalist economic context are seen by some authors as paramount influences in the equation to determine the costs of pain [71,72]. Loeser, for example, proposes that the goals of people with pain (pain reduction) and the goals of the state and economic structure (return to work) are often mutually exclusive and can result in maximum use of health services and escalating costs. Loeser goes on to propose that state organisations, having a vested interest in keeping unemployment low, will seek to medicalize underemployment problems, creating growing numbers of people with 'disabilities' (chronic back pain being a prevalent example) [4]. A detailed examination of medicalization is beyond the scope of this paper, however, even these few citations serve to reinforce how inextricably pain, society and economics are enmeshed at both micro and global levels.

2.5 Physiological models for pain

Much conflict and debate exists in both clinical and academic circles in relation to the etiology of chronic pain condition. To understand this, it is important to start with a historical overview. Kotarba sites western medical thought on pain in the mid-1600's, the point at which Descartes' metaphor of the universe as a machine was applied to the human body. The body was regarded as an object (machine), and pain became the signal that mechanical failure was imminent [73]. Descarte's work reflects a mechanistic image of the body; the size, number and length of 'pores' and 'tubes' for carrying messages around the body, and the valves or 'doors' responsible for regulating the flow of certain spirits around the body, were all central themes in his conceptualization of how the body worked [45].

In 1894 VonFrey published his "Specificity Theory" of pain. He proposed the existence of specific pain receptors, which were mediated by changes in stimuli. Kotarba suggests that, to date, specificity theory remains the most acceptable to health care practitioners because of its congruence with the one disease/one cause reductionism of the bio-medical model [73]. This model presents pain as physiological event where stimuli from sensory end organs (nociceptors) are transmitted through neural pathways. Biochemical events occur that modulate the process, resulting in the sensation of pain. Abnormal sensation is precipitated by failure of the regular physiological mechanisms. "The biomedical sensory neurophysiological model of pain holds that nociception, transmission of noxious signalling, modulation, and sensory registration of pain are biologically predetermined processes," [35:40].

2.6 Psychological aspects of pain

A diversity of theoretical models have been proposed in relation to the key role psychological influences play in chronic pain. The following sections will review the more prevalent thinking that has emerged from the literature.

2.6.1 Psychological trait theory

The last thirty years has seen a growing body of research based around psychological traits and their effect on the individual's experience of chronic pain. Studies from the early 1970s are cited to support the proposition that a range of personality traits predispose individuals towards chronic pain (the 'pain prone patient'). Neuroticism, hypochondriasis, and depression are common features examined in research exploring the relationship between pain and personality [74,75]. A large body of trait research has focused on efforts to develop psychometrically sound instruments that can be applied for the purposes of predicting what type of person will develop chronic pain and how they will respond to treatment. Recently, Weisberg and Keefe [75] published a comprehensive review of the literature and, despite highlighting some interesting themes, were unable to draw any clear conclusion. They stated that although the research literature does seem to support personality traits and disorders as potential influences in the development and treatment of chronic pain, and that personality disorders appear at a higher rate amongst people with chronic pain, no causal relationship between pain and personality traits has as of yet been demonstrated [75]. They conclude their review with the caution that the question of which occurs first, the personality or the pain, has only now begun to be studied.

2.6.2 Cognitive aspects of pain

The second broad category is that of beliefs and perceived meanings for the pain experience. Within these two groupings, the concepts of self-efficacy [76] and readiness for change [77-79], have featured predominantly in the current literature. Research has also focused on the concept of fear-avoidance and how a cycle of anticipated harm will result in less and less frequent participation in a certain activity. Less participation results in de-conditioning, with the consequence of decreased ability to participate without pain. Fear-avoidance thus becomes a self-fulfilling cycle [80]. Vlaeyan and Linton's comprehensive review of the issue of fear-avoidance concludes that, '...fear of pain and (re)injury may be more disabling than the pain itself [which] refutes the early notion that the lowered ability to accomplish tasks of daily living in chronic pain patients is merely the consequence of pain severity' [23:329]. These concepts will be explored in more depth in the following sections.

2.6.3 Behavioural aspects of pain

The third broad category of theory underpinning psychological theories of chronic pain is that of learned behaviours. In a behavioural model, pain behaviours are acquired through what a person has learned from experience and understood during observation of the environment. Other people's behaviours and attitudes, observed in response to a particular stimulus, are acquired as part of the individual's response to events he/she perceives to be similar. These behaviours are, in turn, modified or reinforced through personal features such as cognition, emotions, and physiological events. A clear relationship between socio-cultural influences and illness beliefs and behaviours has been demonstrated in the literature [81].

Research has also highlighted that individuals attribute a range of meanings to events in the environment and that the reaction of others is interpreted as either desirable or a negative factor in formulating a responding behaviour. 'Individuals are not likely to display a behaviour that has been learned by observation unless they perceive that the observed behaviour is likely to elicit positive rewards from others in the environment' [82:220]. Behavioural theory has generated a wide-ranging school of research on chronic pain, with current literature falling into one of two general categories (operant and respondent). These theories and intervention approaches are discussed in more detail in Chapter 3 – (sections 3.3.1 and 3.3.2). Operant theory proposes that behaviours are influenced by environmental events, and looks at such areas as medication use, coping strategies, pain reports, and health services utilization. Fordyce's work [83] is considered seminal in the application of operant conditioning principles to chronic pain. The work of Fordyce and his colleagues has been termed 'revolutionary' in Sanders [84] review of operant conditioning and laid the foundation for development of a range of clinical interventions focusing on the modification of maladaptive pain behaviours through application of reinforcement, punishment, extinction and stimulus control [84]. Back schools, modelled on operant theory, were accepted as the benchmark for chronic back pain intervention in the 1980s. The Back school model has fallen from dominance more recently in response to concerns about poor maintenance of change post-discharge, the high cost of this type of programming and the emergence of more interdisciplinary and self-management styles of intervention [85]. Respondent theory also focuses on the link between behaviour and chronic pain. In respondent theory physiological behaviours are believed to be modified through cognitive processes [9]. Specifically, it is theorised that actual physical sensation or environmental conditions are not required to provoke pain behaviour. Rather, cognitive processes (such as anticipation and fear) can act to trigger physiological responses and corresponding pain behaviours [77, 80]. This concept and related interventions is more thoroughly detailed in the Chapter 3 (section 3.3.2) discussion of interventions.

2.6.4 Emotional aspects of pain

According to the IASP, chronic pain by definition has a strong emotive component, "...an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage " [44]. Anxiety, anger, depression and fear are amongst the more common researched features of pain's affective domain [5, 6, 9, 19, 21, 23, 29]. The emotional context of pain pervades the discussion of intervention and evaluation presented in Chapter 3 (particularly sections 3.3.2 – *psychological interventions* and 3.7- *self-management approaches*) and the process of meaning construction presented in Chapter 4 (sections 4.5.1- *sense of self* and 4.5.3 – *personal nature of pain*), and will be discussed in more detail in these and subsequent sections.

2.6.5 Coping strategies and adjustment to pain

Research framed within psychological models has highlighted that coping style, self-efficacy and readiness for change are all significant features in the chronic pain experience. Jenson et al have extensively reviewed the literature examining the relationship between beliefs, coping and adjustment to chronic pain. Two consistent threads emerge from these reviews: peoples' beliefs and their level of function are related; and those who believe they can control the pain, avoid catastrophizing and believe they are capable, perform better in daily activities [76]. Recently, attention has focused on the actual definition of 'coping' with researchers proposing that the term should only be used in relation to purposeful efforts to manage and control the negative impact of stress [86-88]. Geisser's research indicates that maladaptive coping strategies are highly related to whether a person adjusts to chronic pain, as they mediate the ability to acquire and employ more adaptive techniques [86]. Thorn follows on from this to propose that it is more important to teach people *how to cope* (adaptive coping strategies) than to focus primarily on what not to do (maladaptive strategies). This is an important distinction given the focus of some pain management programs on reducing certain behaviours (grimacing, rubbing the painful area, seeking medical attention, using mobility aids etc). Efforts to extinguish maladaptive strategies are of little use unless people are concurrently taught what to replace these strategies with [88].

Another widely researched psychological aspect of social learning and of chronic pain is that of perceived self-efficacy. Bandura [89], building on concepts of social and observational learning introduced in the late 1960s, has widely informed current research on how people are influenced by what they believe about their own effectiveness in controlling and coping with pain. This concept of self-efficacy has been show by some researchers to be a more influential variable in treatment outcome than degree of pain intensity [57, 90, 91]; and self-efficacy has been shown to act as a mediator of the relationship between pain intensity and disability [92].

A third concept, derived from social learning theory, has been labelled, 'readiness for change' [24, 77-79]. Readiness for change implies that an individual's willingness to adopt new cognitions and beliefs about pain, behaviours and the environment, is moderated by specific stages involved in the change process. The five specific stages are Precontemplation, Contemplation, Preparation, Action and Maintenance. An assessment tool, the Pain Stages of Change Questionnaire –PSCQ [77] is currently undergoing scrutiny for its usefulness in helping clinicians determine if the patient's stage of change is compatible with the demands of the treatment being offered. Research is still emerging in this area but there is growing support for the Transtheoretical Model as '...prescription of 'stage matched' interventions may enhance the engagement and active participation of individuals who hold varying beliefs...' [77:55]. Patient education researchers in Germany looked at 149 administrative workers' perceptions about maintaining good body posture and demonstrated a statistically significant relationship between self-efficacy and identification of perceived benefits of the behaviour. They also saw a significant and linear increase in preventative practices related to body posture and back pain across the workers' stages of change [93].

2.7 Biopsychological models

Over the last 50 years a movement has grown within the biomedical perspective recognising the influence of non-biological events as modifying factors in the pain experience. This trend can be seen to run parallel with changes in social attitudes and beliefs towards illness and health [45]. By the 1950s Sigmund Freud's writings on the interaction between body and mind were gaining popularity, and Beecher had published his thought-provoking observations about soldiers on the battlefield.

These soldiers, although seriously injured in fighting, presented with little or no pain. Beecher speculated that this occurred because the soldiers 'gained' from their injuries by being removed from battle [94]. However, what is seen as the most significant reconceptualization of pain within the biomedical model is Melzack and Wall's *Gate Control* theory [95:6]. They conceptualised pain as a perception based on the interaction between physiology (specific pain receptors) and modifying factors. Emotional, motivational and cognitive factors are all considered to act as modifiers to the bio-physiological event [96]. Although viewed by many as an improvement over the strictly biological approach to pain, shortcomings of the *Gate Control* have been raised in the literature [97:39]. One criticism is that practitioners employing a Gate Control theory explanation for pain still often focus on determining whether organic or psychological factors are most significant in perpetuating the pain experience. Once the pain is categorised, treatment is offered either through medical or psychiatric intervention. Vranken states that, "...the patient is yo-yoed between two views, while his confusion grows. Initially, his pain is dealt with as if it were 'organic', but subsequently he is persuaded that it is 'psychic' pain. While his confusion and frustration add to his suffering, the physician will tell him he is somatized..."[25:440].

Kotarba links the apparent reluctance of medicine to abandon this body/mind dualism with the growth of paramedical perspectives on the treatment of chronic pain. Other health care agents have recognised the need for alternative models of intervention. Kotarba suggests that, while unanticipated, the proliferation of alternatives has fostered ideological competition and professional reductionism [73]. In theory, this debate may be interpreted as a stimulus to scientific inquiry: in reality, it contributes to the confusion and frustration of people seeking help for their pain. Research is most often uni-disciplinary, lacking the interdisciplinary focus required to generate integrated theory and interventions. Sullivan and Lewin use the biblical analogy of a group of blind men, each describing an elephant based on what they could touch to describe pain research [98]. Many disciplines touch a piece of the elephant that is called pain, but most cannot tell whether they have the trunk or the tail.

2.8 Biopsychosocial models

Biopsychosocial models focus on illness as opposed to disease. Disease is considered as a biological event and illness as an individually determined event, based on a person's interpretation of the features in relation to his or her life context. "...Patients suffer 'illnesses'; physicians diagnose and treat 'disease'...illnesses are experiences of disvalued changes in states of being and in social function: diseases are abnormalities in the structure and function of body organs and symptoms" [99:11] Evidence for conceptualising pain as illness rather than disease is found in the disparity between individual responses to often quite similar clinical pathology [82]. Biopsychosocial models propose that nociceptive sensations (prolonged stimulation which has become noxious over time) occur that are perceived by the individual as painful. Cognitive processes, beliefs and past experiences moderate this perception; and these cognitions, in turn, influence emotions and behaviour that serve to reinforce the original perception of the sensation as painful [9]. Biopsychosocial models propose that to understand pain, one must also recognise the influence of social forces. Biological and biopsychological models are incomplete unless the relationship of social forces such as economics [4], political agendas [3], behavioural norms and the mediating effect they play in fear of pain and pain avoidant behaviour [23], are also an integral component of the analysis. The relationship between pain and social factors like beliefs and attitudes has received a great deal of attention and several well-researched self-report tools exist to assess people's feelings about their pain. One example is the SOPA-B (Survey of Pain Attitudes) in which feelings about control, solicitude, medication use, disability, emotion, medical cure and harm, are assessed [100]. Other examples include the Pain Beliefs and Perception Inventory (PBPI), which examines beliefs about pain stability over time, pain as a 'mystery', and self-blame [101], the Pain and Impairment Relationship Scale [102] examining beliefs about ability to function despite pain, the Pain Information and Beliefs Questionnaire[103], which explores agreement with conservative treatment strategies, and the Pain Cognitions Questionnaire [90] which focuses on beliefs about coping strategies. These instruments have demonstrated a relationship between beliefs and behaviours such as treatment compliance, medication use, physician visits, activity levels and reported well-being.

Keefe, et al., highlighted the importance of this integrated, biopsychosocial perspective for pain in developing effective approaches to pain management. Assessment and intervention need to include not only biological, but also psychological, social and environmental factors [82]. This proposal is reinforced throughout the pain literature, as other researchers identify the inherent problems in attempting to measure complex and multidimensional phenomena with a single outcome tool [104,105] and advocate a greater awareness of pain as a dynamic process [82]. Change across time is a key consideration in most biopsychosocial models and the variable nature of pain is acknowledged, not only between individuals, but also within each person.

2.9 Integrating meaning and social context

David Morris states that, "...humankind -across cultures and across time- has persistently understood pain as an event that demands interpretation" [41]. The theme of 'meaning' recurs across theoretical models and the reader is referred to the excellent reviews of meaning in illness [106, 107] and, more specifically, meaning in pain [46, 108]. The common threads interwoven throughout these reviews, are those of: meaning, the chronic illness experience, and how the relationship between the two influences behaviour. This behaviour in turn provides feedback to influence the individual's beliefs about meaning. Many authors point out the dynamic nature of pain meaning, where the concept changes not only for the individual [109], but also within an individual's cultural and social group across recorded history [45]. Mattingly makes a strong argument for recognizing the need for meaning as an inherent part of being. "Locating ourselves within an intelligible story is essential to our sense that life is meaningful" [110]. The role of meaning will be further developed in Chapter 4 (Constructivist theory) as a key element in the construction of pain consciousness [35].

2.10 Chronic pain resists resolution

In summary, it seems that chronic pain is a complex entity, possibly triggered by a physiological event, moderated by a range of historical and socio-cultural context and psychological features. Gatchel and Epker [111] provide a skilful review of the extensive research activity that has sought to identify the underlying psychological traits that increase the likelihood of developing chronic pain and illuminate what constitutes the 'pain personality'. They caution that the search for specific personality types is a flawed construct due to how highly embedded each person's pain experience is in idiosyncratic socio-economic, cultural, environmental and political contexts. However, Gatchel and Epker also point out that some discernable patterns do seem to have emerged from the chronic pain research, indicating mediators of the likelihood of developing chronic pain. For example, people who employ maladaptive cognitive and behavioural coping stratgies (like an oversolicitous spouse and activity avoidance) are more likely to have a prolonged pain experience [17, 75, 76]. Comorbidity has been demonstrated with some consistency between pain and psychological disturbances such as depression and substance misuse [49], lack of social support, compensation patterns, and job satisfaction [111]. The coloured clinical flags system developed in New Zealand is a useful tool, providing an overview of the risk factors for developing chronic pain, and clearly highlighting the inter-related nature of the biological, psychological, social and occupational forces at play in chronic pain [112].

Many researchers caution that the notion of pain patterns should be employed with caution, and emphasise that co-morbidity should not be simplistically equated with causation [113, 114]. The experience of pain is unique to each individual and, while the underlying pathology may be the same, each person's perception of pain intensity and threat to well-being widely varies. These perceptions and interpretations for the pain also affect each individual's behaviours and coping actions. Despite the breadth of research in the area of chronic pain, successful resolution of the problem remains elusive. The incidence and prevalence statistics cited in the section 2.3 demonstrate that the occurrence of chronic pain is growing [1, 50]. Kleinman proposes that '...chronic pain syndromes highlight the fault lines of society' [115] with those people who have lower incomes, poor education and limited social resources for coping, being more at risk to develop chronic pain.

Hilbert's interpretation of chronic pain's resistance to intervention is that this type of pain defies what society defines and understands as pain. Because chronic pain does not 'go away', as we understand pain should, it eludes what Hilbert calls 'successful cultural construction' [116]. Constructivist theory assumes that there are many ways of interpreting the world (multiple realities) depending on an individual's interactions with the environment. " That is, particular actors, in particular places, at particular times, fashion meaning out of events and phenomena through prolonged, complex processes of social interaction involving history, language, and action " [117]. A number of contemporary researchers have taken up this constructivist model in their approach to chronic pain. Aldrich and Eccleston propose that to understand pain, meaning must be “grounded within moral and political domains that have been constructed and socially sedimented over time” [118]. Eccleston and other researchers have proposed that issues of responsibility, blame and protection of personal identity are important components of how people construct their pain [39]. In other chronic diseases, constructing a meaning for the illness experience has been typified as a political contest between service providers and people with the disorder [119]. " In short, a contest in which the demarcation lines between mind and body are continually assessed and re-defined, and the tenets of 'biomedicine' are constantly challenged" [120]. Wilson advocates a constructivist paradigm as the way forward when confronted with what he calls the 'paradoxical dissimilarity', which underlies the art and science of medical practice. This paradox occurs because medicine has developed into a positivist domain, which sees each disease as existing in nature, independent of the individual sufferer. In this framework, the interaction between disease and individual and society has been overlooked and the patient left vulnerable to marginalization and dismissal as 'difficult' [121].

2.11 Summary

Chronic pain is a multidimensional condition that places high financial strain on both the individual and society. A range of general frameworks for understanding chronic pain have been reviewed; physiological, biopsychological and biopsychosocial as well as the models corresponding to each framework. Despite the volume of research carried out in the chronic pain field, the condition for many people remains elusive to resolution. Constructivist theory offers insights into this resistance and will be examined in more depth in Chapter 4. Further background literature pertaining to current interventions for people with chronic pain and the relevant outcome literature are will first be explored in Chapter 3.

Chapter 3

Pain intervention and evaluation

3.1 Introduction and background to criteria

In response to a perceived rapid proliferation of (often unregulated and widely disparate) pain treatment facilities, the International Association for the Study of Pain (IASP) published 'Desirable Characteristics for Pain Treatment Facilities' in 1990. The document defines five major categories of service with *Pain treatment centre* serving as a generic term with no specific personnel or clientele implied. The term *Modality-oriented clinic* is specific to a certain form of treatment (e.g. biofeedback) and a *Pain clinic* offers a range of consultative and treatment services but this occurs in the absence of an interdisciplinary team. The *Multidisciplinary pain clinic* offers a range of assessment and intervention options, consists of a multidisciplinary team but does not routinely conduct research and teaching. Where these activities occur, the term *Multidisciplinary Pain Centre* is proposed. The IASP document outlines specific criteria for staffing and treatment components believed necessary to deliver comprehensive services within a Multidisciplinary Pain Centre [11]. The Pain Society (British & Irish Chapter of IASP) built on this classification system to develop the document, 'Desirable Criteria for Pain Management Programmes [12]. This report outlines what the Pain Society proposes as reasonable guidelines for pain management services. Accepting that the Pain Society is a legitimate leader in the field of chronic pain management in the UK, the Society's recommended treatment components are used as a framework for the first section of this chapter. Each component identified will be reviewed and relevant outcome data identified. The second section will examine self-management, alternative therapies and outcome studies related to these areas. Lastly, current issues in service provision and assessment will be discussed.

3.2 Desirable criteria for pain management programmes

According to the British Pain Society pain management programmes should integrate both biomedical and psychological rehabilitative treatment. This stand is supported in the literature where single biomedical interventions have generally been demonstrated as having weak outcomes in chronic pain. Systematic reviews of biomedical interventions excluding the psychological aspects of chronic pain have been completed and found that there were a high number of methodological problems in the research. McQuay et al. concluded that the evidence was flawed and inconclusive regarding a range of biomedical interventions. Specifically, acupuncture for chronic pain lacked high quality evidence, the results for studies of manipulation therapies and lasers were mixed and the use of certain prescription medications (NSAIDs) were found to have negative side-effects with no evidence base for their use [122]. This same systematic review, NHS Health Technology Assessment, found that TENS (transcutaneous electrical nerve stimulation) may be useful but lacks evidence, the use of quanethidine in intravenous regional sympathetic nerve blocks was not supported, and that the evidence supporting steroid injections for chronic shoulder pain 'is less than compelling'. The review included anticonvulsant drugs, which are widely used in chronic pain relief, however McQuay and co-authors found a scarcity of RCTs and cautioned that the literature did not support use of anticonvulsants as first-line interventions, particularly in light of their potential for serious side effects. Similarly, anti-depressant medication has not been rigorously demonstrated effective for all people with pain, although Fishbain et al. [123] did report a stronger relationship between antidepressants and analgesic effect in their meta-analysis. Other researchers' findings also support that a biomedical approach alone is insufficient to address the complexity of chronic pain [124]. Max [125] proposed that the sheer volume of clinical analgesic studies (over 15,000) should be seen as an indicator that pain cannot be approached in the same way as structural diseases. With pain, issues such as the large magnitude of placebo effect, difficulties of symptom measurement and frequent findings of negative results even with drugs known to be effective analgesics, all need to be considered. In summary, there appears to be a strong and growing evidence-base that biomedical interventions are often insufficient to achieve meaningful outcomes for people with chronic pain conditions. This supports the Pain Society's call for biopsychological models in the chronic pain intervention programmes. What types of psychological programme components are indicated to facilitate this non-reductionist approach are discussed in the next section.

The target group for chronic pain management programmes are those people with unresolved pain following traditional medical and pharmacological interventions.

The specific goal of a pain management programme is functional, as opposed to pain relief, and places a high emphasis on skill development through both teaching and practice. 'The aim of a pain management programme is to reduce the disability and distress caused by chronic pain by teaching sufferers physical, psychological and practical techniques to improve their quality of life'[12]. The specific minimal contents of a pain management programme are:

- psychological assessment and intervention
- physical reconditioning
- posture and body mechanics training
- applied relaxation techniques
- information and education about pain and pain management
- medication review and advice
- graded return to activities of daily living
- multidisciplinary team approach [12]

3.3 Evidence-base related to psychological interventions

The Pain Society criteria for programmes to incorporate psychologically-based rehabilitative treatment has a strong evidence-base. Dichotomous views of pain, as either corporal or psychological in origin, are inadequate [126]. Physical factors may trigger a pain event but psychosocial factors form the context for expression of that pain. The theory underpinning psychological intervention for chronic pain fall into four general categories; operant, behavioural, cognitive, and cognitive-behavioural.

3.3.1 Operant approach

In an operant approach to chronic pain, treatment would focus on pain behaviours and how their consequences and surroundings (reinforcement, punishment and extinction) influence them. This approach is congruent with *Gate-Control* theory, which proposes that sensory input is modulated at a cortical level. Research findings indicate that pain behaviours can be reduced over time with a system of verbal reinforcement and that pain behaviours and reports increase when a solicitous spouse is present [9]. While initially viewed as ground breaking when introduced by Fordyce in the late 1960s, operant therapy has now received sustained criticism as being too focused on overt behaviours to the exclusion of other key elements in the chronic pain experience [127].

3.3.2 Behavioural approach

Behavioural methods are built on many of the principles of operant theory. McQuay et al. [122], propose that there are three components of behavioural therapy that have a significant evidence-base within the psychological literature. These are the use of graded exposure to increased engagement in feared activity, the use of relaxation to affect somatic change, communication/assertiveness training. Current research has demonstrated a relationship between anticipation of pain and reduced activity. Findings also show that over time the fear of pain becomes generalised to many activities (e.g. walking, sitting, socialising) that results in increasing functional disability and social isolation [9, 97, 80]. A form of behavioural intervention includes Respondent treatment approaches. These are designed to modify physiological responses by teaching control techniques and are widely practised in many pain programmes. An example of this would be teaching a patient about the relationship between muscle tension and pain. The intervention would then focus on training in the use of electromyographic (EMG) bio-feedback to control muscle tension and ultimately reduce pain [85].

As discussed in Chapter 2, cognitive factors, such as attitudes, beliefs, self-efficacy and coping strategies, have been demonstrated through the scientific literature to be very influential in the pain experience. As Turk states, people '...appraise their conditions and decide by matching sensations to some pre-existing implicit model whether a particular sensation is a symptom of a particular physical disorder that requires attention. Thus, to some extent, each individual functions within a uniquely constructed reality' [9:13]. Several studies also support the relationship between cognitions and physiological change. These physiological events include elevated muscle tension (EMG) in subjects during discussion of painful events, increased sympathetic system arousal [9], and elevated endocrine secretions such as cortisol [128]. Interventions in these areas are evolving and existing meta-analysis have pointed out that further research is needed in this complex area [129].

3.3.3 Cognitive-behavioural approach

Cognitive-behavioural therapy can be seen as a refinement of treatment techniques drawn from all three previously discussed approaches. Cognitive-behavioural therapy is extensively used in multidisciplinary chronic pain settings and focuses on teaching people to understand the relationship between their pain and cognitive, emotional and physiological elements. It is predicated on the theory that as this new understanding evolves people will then be able to develop effective coping strategies for pain control. An evidence-based practice group from McMaster University in Canada recently carried out a structured review of the research literature on the effectiveness of cognitive-behavioural interventions. From a pool of over 1500 titles, 29 papers were finally identified that met the inclusion criteria. They found that the participants receiving cognitive-behavioural interventions, versus those in control groups, had a positive effect on pain perception and reported intensity. A weaker effect was revealed for activity level, depression and cognition. When the cognitive-behavioural interventions were compared to alternate forms of therapy (medical care, physiotherapy, hypnotherapy, social work), ' ...no short-term outcomes were found to be clearly supportive of the cognitive-behavioural approach alone' [130]. The group concluded that it was difficult to draw conclusions because of the wide variety of cognitive-behavioural interventions and multiple outcomes. This mirrors the opinion of other authors, who point out that different components of the intervention may be effective for different people and that it cannot be assumed that all people need a comprehensive combination of treatments [122]. "There is little evidence bearing on which components are necessary, sufficient or most important" [131: 532]

3.3.4 Evidence-base between approaches

A systematic review of behavioural treatment for chronic low-back pain across the evidence-base for treatment effectiveness, compared the different styles of behavioural therapy; cognitive, operant, and respondent. Only RCTs were included and of the twenty-one studies reviewed, only six were found to be of a high quality [85]. The review compared each style to the others and concluded that there is some limited evidence that cognitive and operant treatments are equally effective and that a moderate degree of evidence supports that respondent therapy is no more effective than cognitive treatment in decreasing pain intensity, improving functional status and behavioural outcomes. Regarding cognitive-behavioural versus cognitive treatment they found limited evidence supporting the two approaches as being of equal effectiveness. The other comparisons of cognitive-behavioural versus respondent, cognitive-behavioural versus operant, and operant versus respondent were inconclusive because of either insufficient RCTs to include or conflicting findings in the original data. An additional finding was that when compared with waiting list or no treatment groups, behavioural therapy had a positive effect on pain intensity, generic functional status and behavioural outcomes, although the effects were only moderate or low. These authors reiterate the caution of other researchers [92, 132] that it is still unknown which treatments are most effective, for which patients and in what settings. Likewise, the experience and qualifications of the staff providing these services was also raised as a possible barrier to generalisability of research findings.

In summary, The Pain Society's recommendation of psychologically-based rehabilitation appears to have a clear evidence-base and specific areas for attention have been identified to focus direction of future research.

3.4 Evidence-base for biomedical interventions

3.4.1 Reconditioning

In addition to psychological components, The Pain Society also recommends that a pain management programme should offer physical interventions. The first category they mention is that of physical reconditioning. This is based on the assumption that people with chronic pain gradually lose strength, range of motion and flexibility as they decrease activity levels. The literature supports the use of exercise in a pain management programme on several different levels. Simmonds' review of the literature identifies studies supporting early activation for people with back problems and avoidance of over-treatment [59], pointing out that exercise-based interventions are widely accepted by patients and insurers.

Confounding issues, such as motivation and fear, make assessment of outcome problematic. Additionally, outcome tools have been criticised as being too abstract and heterogenous (e.g. what does it mean to have twelve kilograms of grip strength if you are a forty-five year old woman, a nineteen year old man, a teacher or a long distance driver?). Many researchers are now tending towards a more functionally based form of assessment (stair climbing, timed walking, ability to dress oneself) with simple-to-understand instructions and easily understood measures [59].

A number of authors comment on the importance of exercise and postural retraining programs for people with chronic back pain and the practice of conditioning and aerobic activity for people with chronic pain is clinically well established [23, 133]. However, recent examinations of the research have raised concerns about the strength of evidence supporting the importance of exercise-based interventions for people with pain [134]. Wittink identifies several problems with assessing the effectiveness of exercise-based interventions. The first is that people do not necessarily have the same rehabilitation needs or functional goals. Function is not strictly a consequence of impairment. Thirdly, valid and reliable outcome measures of exercise and postural retraining programs are only now under development and lack a strong research history upon which to draw conclusions. Wittink goes on to point out that although aerobic fitness is often reported as having an association with pain, function and disability, the evidence to support this assumption is unclear. In a recent study Wittink and co-researchers found that the study group of people, reporting an average duration of forty months of back pain, did not differ in aerobic capacity to the pain-free, sedentary control group [135]. Other authors have also noted that although exercise programs are a common treatment component, exercise tolerance is seldom examined as a unique outcome component. Additionally, exercise is often a combination of strengthening and aerobic capacity, with no way to differentiate between which (if either) component was of most benefit [136].

3.4.2 Posture and body mechanics

The Pain Society's second criteria is that of postural and body-mechanics training. This approach is based on two assumptions. The first assumption comes from the tenets of attribution theory, which propose that people are motivated to predict and control their environments. Understanding what causes pain (from within a biomechanical perspective) increases feelings of control. Proponents of patient-education as part of pain management themselves evidence the second assumption, that chronic pain is bio-physiological in origin and therefore proper lifting and movement will assist to reduce and prevent recurrence of pain [137]. Patient postural and biomechanical training is found in many interdisciplinary treatment centres following a 'back school' approach to rehabilitation of people with chronic back pain. And, as with exercise, these treatment components suffer from a lack of clearly focused outcome evaluation. There is a growing belief expressed within the literature that patient self-management for chronic conditions is efficacious [8, 10] however, to-date, the evidence-base in support of this component of chronic pain treatment is lacking. Several systematic reviews [138] and meta-analyses of back schools for chronic pain have been published in the 1990s. Cutler and co-authors found thirty-seven studies meeting their review criteria and following analysis, they concluded that back centre treatment (non-surgical) increases the rate of return to work and the benefits are not temporary. They also comment on how difficult it was to isolate return-to-work as a variable, which may not be a shared value amongst all people with chronic pain, and caution that the overall poor quality of the studies included in the review may effect the usefulness of their findings [139]. Koes' systematic review of back schools uncovered a very poor evidence base, wide variability in outcome measurement and a mixture of studies where some of the back schools had significantly better outcomes than the single modality interventions and some did not. They concluded that back schools appear to be useful in relieving pain but the results may not persist past one year [140]. This is consistent with a literature review, also carried out in 1994, which concluded that at one year follow-up, there was no evidence in the studies reviewed of clinically important benefits on any of the outcome measures employed [141] Similar findings were recently published in a Cochrane Database Systematic Review; <u>Back schools for non-specific low back pain.</u> The review team was able to uncover only fifteen randomised controlled trials (RCTs) meeting the selection criteria. These proved to be statistically and clinically so heterogeneous that a qualitative (best evidence synthesis) review was carried out instead of the more usual quantitative systematic review. Of these, only three pieces of research were rated as high quality. The reviewers identified similar research shortcomings, as previously mentioned in discussions of exercise, and concluded only that back schools may be effective for patients with recurrent and chronic low back pain [142]. Di Fabio's meta-analysis, which reviewed nineteen RCTs, did find a significant relationship between back school participation but only when coupled with a comprehensive rehabilitation program of conditioning and spinal mobility. Efficacy of back school was supported for pain reduction and improved understanding of back pain, however, no support was demonstrated for back school as being more effective than control groups for return to work and decreased disability ratings[143].

3.4.3 Relaxation techniques

The Pain Society also recommends relaxation training as an important component of any pain management programme. As with many of the previously examined treatment interventions, insufficient, high calibre research exists to demonstrate a clear relationship between pain reduction and relaxation training. A recent systematic review was able to identify only seven trials comparing relaxation with a control group and concluded that, "relaxation does not appear to be effective in relieving chronic non-malignant pain"[144]. These findings should not be interpreted as conclusive that relaxation training is of no benefit to people with pain, since benefit is not defined solely as pain relief. As cited previously, pain intensity and function are not closely related. Relaxation is prescribed very widely in pain treatment programmes and may have a very positive effect on function or other areas related to coping with pain (e.g. feelings of control, personal beliefs about the causes of pain, physiological benefits of deep breathing/relaxation techniques, etc). To-date, there is insufficient evidence to either negate or support the practice.

3.4.4 Graded return to activities

The Pain Society's emphasis on return to functional, daily activities is in keeping with the stated goal to reduce disability and distress caused by chronic pain. The need for clear communication of this philosophy to patients and their families is evident if conflicting expectations are to be minimised and trusting working relationships are to be maintained. The literature supporting the importance of maintaining personal functional roles and coping with chronic pain is wide ranging [124, 145,146]. Most recently research has focused on the role of functional self-efficacy (the belief in one's ability to carry out a specific function) and found that self-efficacy beliefs are a more significant indicator of outcome than pain cognitions or pain intensity reports [19]. The issue of work and function is complex, meaning different things to different people depending on the context of their pain experience. " Work may at times be perceived by those who suffer with chronic pain as a palliative, an analgesic, a way to fend off or escape pain, and a way to maintain self-efficacy and achieve self-realization in spite of chronic pain" [145:51].

3.5 A multidisciplinary approach

An additional recommendation of the Pain Society is that intervention should be delivered within a multidisciplinary model. There is no shortage of literature urging a multidisciplinary approach to chronic pain [6, 12, 147, 148]. Flor et al concluded in their meta-analysis (comprised of sixty-five studies meeting inclusion criteria) that, "...multidisciplinary treatments for chronic pain are superior to no-treatment, waiting list, as well as single-discipline treatments such as medical treatment or physical therapy [148]. This approach is proposed as the most effective method for addressing the complex array of factors that contribute towards developing chronic pain and maintain its existence in opposition to conventional treatment. The roles of team members have been examined and increasingly defined through the work of the International Association for the Study of Pain and its national chapters.

While support for the multidisciplinary approach is strong, many authors raise cautions about the need for careful monitoring and long-term follow-up of outcomes. A recent review of UK multidisciplinary pain management programs found that of the centres that responded to the questionnaires only 21% were able to provide complete data and met the suggested criteria for adequate time duration and frequency of follow-up. This review also found high variability in staffing patterns and outcome tools [150]. Outcome measures ranged from non-standardised measures of activity through more widely utilized assessments such as the HAD (Hospital Anxiety and Depression) scale, MPQ (McGill Pain Questionnaire) and VAS (Visual Analogue Scale). The researchers found that the most common outcome domain focused on mood and affect. Health care use, a significant concern for fiscal accountability, measures of fitness and medication use were much less routinely assessed at follow-up. The authors (Peat et al.), call strongly for developing consistency of outcome follow-up between programs. This work has begun as a sub-committee of the Pain Society of Great Britain and Ireland with a planning meeting held at York, during the autumn of 2000.

Additional considerations raised in the literature about multidisciplinary program (MDP) evaluation include monitoring of practice and training to ensure that an effective team is in place [6]. Team members who focus on pain relief as opposed to the actual goal of return to daily function [151], therapists who continue to follow a 'no pain, no gain' approach contrary to the cognitive-behavioural model of the other team members [7], and those who 'take sides' and are poor at clarifying conflicting information between patient and other team members [6] can leave patients confused and unable to benefit from a true team approach. The other significant problem with multidisciplinary intervention is that of outcome evaluation. While clinical evidence may support the effectiveness of this approach, the multidimensionality of its nature makes evaluation very difficult. Repeatedly researchers raise the issue of 'what combinations of program components are required'? 'Are all components required by all participants'? Becker's study of two hundred and eighty-six Danes referred to a multidisciplinary pain centre revealed that patients who were not involved in disability pension claims or who were already on disability pension improved. However, patients who were involved in the application and assessment process for disability pension did not benefit from multidisciplinary program treatment [152]. The research team concluded that the socioeconomic problems encountered during the process of accessing disability pension need to be addressed before a patient could benefit from the regular multidisciplinary program. Another question raised regarding MDPs is that of how can the components be separated out for evaluation [7, 59, 85, 131, 153]. Also, Eccleston and co-authors [39] have commented on the struggle a service provider must undertake to reflect on his or her own beliefs and practices in relation to the philosophy proposed by the multidisciplinary team, or what Morris [41:283] calls the 'Babel of competing tongues'. Additionally, the issue of defending/defining good practice versus cost-containment is becoming an increasing pressure in the examination of multi-disciplinary teams. A qualitative systematic review of economic evaluation of multidisciplinary pain management for chronic pain patients concluded that a lack of standard measures of costing and outcome measurement prevented a conclusion as to the cost-effectiveness of multidisciplinary teams [154]. As LeFort [8] points out, because services are expensive and often inaccessible to many, prudent resource utilization becomes imperative.

3.6 Complementary therapies

The Clinical Standards Advisory Group (CSAG) discussed the delivery of complementary therapies in the document, Services for Patients with Pain [69], and revealed that although complementary therapies are usually provided outside of the NHS, Health Authorities and Trusts do pay for small amounts of these treatments. Nationally, 25% of chronic pain services have access to complementary therapies (acupuncture, chiropractic care, reflexology, aromatherapy, hypnotherapy and naturopath), either contracting for a certain number of hours from an outside practitioner or supporting the training of NHS staff (e.g. nursing) to assume these functions [69]. They also found that GPs varied widely in their feelings about the usefulness of complementary therapies. The clients surveyed indicated that 77% had self-referred to private complementary therapists and that they were, for the most part, willing to try alternative treatments for their pain. Both GPs and clients raised concerns about the lack of regulation and research into the effectiveness of different treatments.

The current literature includes systematic reviews of aromatherapy [155], acupuncture [156], massage therapy [157], relaxation [144] and chiropractic therapy [158] in the treatment of chronic pain. These reviews uncover the recurrent theme of insufficient numbers and quality of RCTs to provide an evidence-base for the use of complementary therapies in chronic pain treatment and all conclude with a call for more rigorously conducted outcome studies. Research into these and other forms of alternative therapies, such as spiritual healing and therapeutic touch, have responded to the challenge through more rigorous studies. Findings, however, remain inconclusive and conflicting [159].

3.7 Self-management approaches

Self-management as a chronic pain treatment strategy is becoming increasingly evident in the literature [160, 161]. In the last five years self-managed chronic pain programs, modelled on the ASMP (Arthritis Self-Management Program) [162], have emerged. Self-management is seen by some as an important tool in addressing the common criticism of the multidisciplinary team approach as having limited access because of referral process, geography and cost. In 1996 it was estimated that only 1% of people with chronic pain in the UK participated in speciality pain programs

[163]. Self-management, community based programs have been put forward as a cost-effective, readily accessible alternative that can be delivered by trained lay-leaders. Turk et al [164] stress that cost-effectiveness is an important consideration in program evaluation and suggest that even if lay-person led, self-management programs are over-all less effective for each person with pain, their economical nature allows for wide dissemination and ultimately, greater impact on patient care than treatment restricted to a fewer number of people.

Self-management programs focus on engagement in health-promotion tasks (for example, exercise, maintaining daily activity, and strategies for monitoring and managing changes like pain flare-up and stress). A recent randomized trial in the United States using a modified ASMP found that when compared to a usual care group, the self-managed program for chronic pain was more effective in reducing anxiety and increasing self-care and positive attitude towards self-care at six and twelve month follow-up [10]. Other studies reported similar findings of improved vitality, social roles, life-satisfaction and self-efficacy [8, 165] and propose that locus of control may be an important indicator of what type of person benefits the most from self-managed programs [166]. Kung's work revealed that people with a high internal locus of control may prefer programs that offer options and allow for personal choice in treatment and that, following education about available options, people will change their minds about what they believe would be best. When pre-education testing was carried out, 15% of the group felt a pain clinic would be best and 15% selected self-managed programs. Following an educational session, only 9.5% selected a pain clinic and the selection of self-management was greatly increased to 41%.

The findings were less consistent in the area of actual pain reduction. In the two previously cited studies, Lorig reported no reduction in pain as opposed to LeFort et al., who do report a decrease in pain. LeFort also concludes that the standardized protocol, allowing for training of lay-people to reliably deliver the program in a variety of settings, is a significant, cost effectiveness benefit of the self-managed programs.

3.8 Evaluation of services for chronic pain

3.8.1 Service user involvement

It has been pointed out that the service user's voice is under-represented in the evaluation of treatment for people with chronic pain because outcome measurements are usually based on scales developed by physicians with no input from service users [167]. The Agency for Health Care Policy and Research (AHCPR) in the United States stated, "...the mainstream of pain assessment should be patient self-report" [168]. This focus on the service user is echoed by The Consumers in NHS Research Support Unit document, titled Involving Consumers in Research & Development in the NHS: Briefing Notes for Researchers [26], and a recent article published in the British Journal of Therapy & Rehabilitation [169] which reviewed the wider political and social context of a shift towards patient/consumer collaboration in health care research. While focusing on the history, benefits and range of consumer involvement possibilities, the article stresses that translating the rhetoric of consumer involvement into reality is still much in the preliminary stages and will be a costly process, demanding a strong willingness of service providers to re-examine attitudes around sharing of control and the role of healthcare workers. The research that does exist, where people with chronic pain have evaluated the outcome of treatment programmes, indicates that there are a variety of factors influencing their satisfaction with treatment. These include age [168, 170], how long after treatment the follow-up is carried out, functional status at time of follow-up [171,172], and whether people felt their expectations had been met [172-176]. Additional factors influencing peoples' evaluation of their treatment include physician-client communication [177], other people's opinion about the prescribed treatment, how much responsibility the individual is expected to take in making self-care changes [170], and how strongly the person with pain feels someone else (for example an employer) is to blame for the pain [178].

A growing volume of literature emphasises that 'patient satisfaction' must be seen as a complex interaction of components dependent on each individual patient. Studies including people with multiple sclerosis (MS) [179] and psychiatric patients [174] have examined how their expectations of service influence outcome. This rapidly developing area of research interest has potential similarities with chronic pain service users. Noble [174] points out that the users of psychiatric services are often socially and economically marginalized, and this is certainly the case with chronic pain sufferers. Similarly, as with MS, the chronic pain experience can be widely variable and unpredictable between people. Both Noble and Somerset's research has demonstrated that what people expect from services is often not the same as what they want. Also, service users do not always directly convey to the service provider what it is they do want.

Research specific to chronic pain proposes that service users differ widely in their opinions about what is of benefit and when it is best prescribed [171, 173]. Current research on patient satisfaction has been strongly criticised as methodologically flawed, lacking in validity and reliability [175]. Patient satisfaction is similar to the idea of ''multidisciplinary teams" in that both are complex concepts with many overlapping and difficult to isolate components. Factors such as time and service users' individual characteristics and beliefs compound the difficulty of the task. What is lacking, at the most elementary level, is an awareness of what each individual defines as 'satisfactory'.

3.8.2 Deficit of comparable data

An issue repeatedly raised by authors of systematic and critical reviews of the literature concerns the lack of comparable outcome data between services. The lack of standardised assessments and wide variation in outcome domains is clearly identified in the literature. What constitutes success and from whose perspective, the influence of uncontrolled socio-environmental factors (e.g high unemployment), pervasive lack of program fidelity and varied practices for including or excluding program drop-outs are identified as important and often over-looked questions [132]. Additional concerns include the need for closer scrutiny in the evaluation process of referral patterns, attributes of those not entering treatment, attrition [180], relapse, and the impact of non-compliance [181]. Relapse rates range between 30-60% and non-compliance with long-term treatment prescription are reported as high as 75% [181]. However, as Turk and Rudy point out, non-compliant patients still report improvement and the question remains to be answered of what are the minimal levels of a treatment adherence to ensure positive outcome?

3.8.3 Selection of outcome measures

Further issues of outcome evaluation have been identified in the debate regarding the use of generic versus disease-specific tools [58,150]. Generic assessments are considered to be applicable to people with a range of conditions and are generally concerned with quality of life (QoL) and individual perception of health status. Two widely accepted tools of this sort are the Sickness Impact Profile (SIP) and the SF-36 Health Survey [58]. Examples of these tools' usefulness in exploring whether certain social science theoretical models remain consistent between groups are widely distributed in the literature. Research as diverse as carer needs in the community [182] and the perceived health status of different age cohorts utilizing Medicare health programs [183] all made effective utilization of the generic SF-36 QoL measure. Interestingly, it is the research itself that provides the clearest demonstration of generic tool limitations. Velanovich's study of two thousand, four hundred and seventy-four (2474) surgical patients with varied diagnosis, found that while 77% of the subjects believed the SF-36 to accurately reflect their health status, only 45% of the respondents believed it gave a true indication of the problem for which they were seeking assistance [184]. This lends support to Kopec's [58] assertion that there is a strong need for disease specific measures which assess aspects of health believed to be directly affected by the disease process. His review of existing back-specific functional outcome measures highlights key issues for researchers in determining which domains should be measured, the shortcomings of composite scoring and methodological flaws in assuming that pain and function are proportionally related. Kopec concluded that, although scale design has progressed since 1980, with most tools now having been tested for validity, reliability and responsiveness, the data generated is not comparable across different studies. The study identifies that there is a role for both generic and disease-specific measures but that the proliferation of new instruments may prove counterproductive [58].

A pivotal question in the discussion of program evaluation is that of *what* should actually be measured. Malone and Strube's [129] meta-analysis of non-medical treatment for chronic pain revealed that many types of treatment showed short-term benefit. They proposed that instead of searching for the key difference making one better than the other, research should focus on identifying the similarities. Their research proposes that effectiveness of treatment may be attributed to the features treatments have in common. Specifically they identified, the installation of 'hope', contact with a caring professional and attention to psychological factors of the chronic pain experience. More recent follow-up studies of people with fibromyalgia (which has many parallels with chronic pain), have similarly concluded that while multidisciplinary teams may be effective, there are large individual differences in response to treatment and that programs may benefit from a more customised approach which considers specific client characteristics [185].

3.8.4 Economic consideration in outcome measures

As mentioned previously, economic considerations are a feature in program evaluation. The costs of programs are driven not only by the service provided but also by the response of service users. When dissatisfaction is high, compliance is low and requests for more tests and to consult other physicians grows [186]. This awareness, coupled with the increasing demand for fiscal accountability and evidence-based interventions, have flagged several key questions for current researchers. Firstly, which is more effective, in-patient or out-patient chronic pain programmes? Findings of recent study within the UK suggested that people who received inpatient programmes maintained greater levels of outcome at one-year follow-up for functioning, coping and low use of health care resources [187]. However, these findings are not strongly endorsed by other studies that have demonstrated out-patient programmes are equally effective in long-term follow-up [7,188]. Reviewers report that current research is inconclusive because the vast majority of people with pain are referred to neither in or out-patient treatment programmes and this makes for selective study populations and unrepresentativeness of most samples [7, 8]. Additional problems include the high dropout rates from programmes (between 30-61%) and strong likelihood of recurrence after treatment (14-80%) [7].

A second question driven by the current emphasis on accountable health services is that of cost-benefit. The literature appears to support that, for both in-patient and out-patient structures, pain management programmes are cost effective. McQuay et al [122] concluded, as part of a systematic review of chronic pain services, that the cost to the National Health Service for people referred to pain programmes was one half that of those people not referred and using other services within the NHS. Given that recently estimated costs of chronic back pain alone in the UK, (factoring in informal costs and lost productivity), amount to in excess of £10,600 million [1] the need to establish what is the most cost-effective method of service delivery becomes imperative.

3.9 Summary and conclusions

While there is much clinical support for comprehensive chronic pain service delivery, problems with conflicting frames of reference, poor communication, the need to demonstrate effective utilization of limited resources, outcomes based on a possible misleading composite versus individual components, and assessment tools that neglect the service user's perspective, remain unresolved. A stronger evidence-base, addressing the identified short-comings in research, is required. It has been proposed that a critical barrier to building this strong evidence-base exists in that there is no primacy of theory within the treatment and study of chronic pain. Paradigms range from biomedical to psychological and their conflicting positions are often taken into the arena of treatment [39] making it difficult to identify what frame of reference is being operationalised and what part of treatment it is exactly that can be evaluated. Social scientists propose that chronic pain will continue to prove resistant to accepted medical and psychiatric interventions because they fail to address an individual's inherent need to create meaning for events in life, to understand what is happening and why [109, 189]. Osterweis [72] suggests that pain is not an objective event, but rather is inseparable from personal perception and social context . Pain does not exist outside of personal interpretation and subjective experience. Instead, it "...draws the researcher towards a cultural critique of biomedicine and of societal values that are embedded deep within its concepts and practice "[145 :6].

The following two chapters will examine the emerging theoretical frameworks of postmodernist constructivism and complex adaptive theory that address the shortfalls of the traditional biomedical and biopsychosocial approaches in issues of chronic illnesses, like chronic non-malignant pain, in western cultures.

Chapter 4

Contructivist Theory

4.1 Justification

A basic PubMed ® literature search of 'chronic pain' for the period between January 1980 and March 2001, uncovered 4851 publications. To put this figure in perspective, the same search strategy was employed for two conditions identified as national priorities in the British government's National Service Framework for Health [190]. Publications related to the first area, myocardial infarct, occurred 5061 times, and the second area, osteoporosis, 5887 times. The volume of research generated around the issue of chronic pain closely matches these national priorities and demonstrates not only pain's significance as a healthcare concern but also, possibly, its complexity and continued resistance to understanding. As discussed in previous chapters, a number of theoretical models have been proposed to explain the dynamics of chronic pain. However, as the review of evaluation and outcome research presented in Chapter 3 highlights, a clear evidence-base remains elusive. The call for theoretical frameworks that integrate the biological, psychosocial and environmental aspects of chronic pain is a consistent theme in current research. One such framework, informed by the disciplines of anthropology and sociology, is that of constructivism. The goal of a constructivist analysis is to gain an understanding of the multifaceted nature of a life experience from the perspective of the person living it. Basic assumptions of this model are that people create knowledge based on their own perspective. Reality is not an objective and universally shared entity but rather a construction based on the beliefs a person holds about an event and the meaning assigned to those beliefs.

> *...constructivism means that human beings do not find or discover knowledge so much as construct or make it. We invent concepts, models, and schemes to make sense of experience and, further, we continually test and modify these constructions in the light of new experiences'*
> [117:125].

This chapter will explore the theoretical argument put forward by proponents of the constructivist perspective of chronic pain. The examination will include a review of the literature that more specifically identifies contextual factors predisposing an individual to develop chronic pain.

4.2 Consciousness and the construction of pain

Many theorists construe chronic pain not as a sensation, dependent on intensity and duration of neural stimuli, but rather as a perception [35, 117, 121, 191-193]. This perception requires the brain's processing of sensory information, in conjunction with association and memory, to create a subjective reality. This reality is dynamic and modified by forces both internal and external to the individual. Chapman and colleagues [35], propose that consciousness is a key component in this perception formation and that without consciousness (for example. during coma or an anaesthetised state) pain does not exist. In their work, consciousness is characterised by four key features: coherence, sense of self, purposiveness and personal nature and affect.

The first feature, *coherence*, is seen as the individual's tendency to organise experiences into meaningful patterns with a temporal (sequence of time) component. *Sense of self* is what this coherence and organisation is structured around. This holds for the temporal aspect as well, people organise their meanings around temporal markers in their own lives – present, past, future. An example of this would be a person telling you that, "when I was a child I enjoyed mowing the lawn because it meant I was trusted by my parents. Now, as an adult, I find it a chore, more of an obligation and not pleasurable. In the future, when I am retired, I will look forward to using the lawn mower because I will enjoy the exercise and feeling that I am still capable of looking after my own home".

The third feature is *purposiveness.* This is seen as social, biological and psychological forces that drive an individual's attention to select certain events requiring consciousness and to remain unaware of others. (" All I focused on was winning the race, I didn't even realise we ran past that big fire until I saw the newspaper the next day"). The final feature proposed by Chapman [194] as required for consciousness is the uniquely personal nature of the event and resulting *affect.*

‘My back pain is mine alone’ as are the resultant emotions and the intensity to which one experiences them.

4.3 Cognition and the construction of pain

Sharp [193] proposes that the current cognitive-behavioural analysis of chronic pain remains too focused on behaviour (e.g. limping, grimacing, rubbing the painful area) and has failed to evolve to the level of cognitive theory in other disciplines, (such as education). This work maintains that cognitive-behavioural therapy needs to be reformulated with a stronger emphasis on the essential nature of the meaning people ascribe to their pain and behaviours subsequent to this meaning construction. Applying cognitive processes within a constructivist model does not deny the existence of physiological or psychological features in the development of chronic pain. Rather, it recognises that through the process of becoming conscious of these features, individuals must do one of two things. Either they are able to develop an acceptable understanding and coping strategy for what is happening or they are unable to integrate the experience and thus remain unresolved and in pain. This lack of resolution serves to increase the discord within an individual's attempts to self-organise, which will then allow a negative cycle of effort and outcome to become established [193]. Additional influences on attempts to resolve the pain event are wide ranging. Personality, support network, an individual's social group, the political climate for health and social benefits, economic issues related to productivity and life-style choices are only a few of the features composing the dynamic internal and external context of a pain experience, which can further destabalize the likelihood of successful resolution.

4.4 Schemata

The process of filtering sensory input though a network of past experience, influences and memory to determine degree of conscious awareness and subsequent action plan has been called *schemata* and is widely addressed in the clinical and cognitive psychology literature [35]. Schemata involve both cognitive and motor patterns (as involved, for example, in riding a bicycle) and it is believed that each time schemata are retrieved and brought to a conscious level they are altered by the new context and experiences occurring at that point in time. The bicycle riding schemata formed as a child for example, may be dramatically altered when retrieved during an emergency situation when an adult is required to us a bicycle to ride for urgent assistance. For successful resolution of this emergency situation, the individual must be able to modify his or her existing schemata and construct a new meaning and awareness of bicycle riding that allows for different behaviours to occur. The range of internal and external forces that interact when an individual activates personal schemata for pain is vast. It is possible that when there is a barrier to activating consciousness (such as lacking a cohesive explanation for the pain), the individual cannot modify his/her schemata and therefore cannot construct a contextually relevant meaning for the new pain experience. Without this new meaning construct, efforts for resolution will remain ineffective.

4.5 Consolidation of theories through the Consciousness model

The subsequent discussion of features that present as barriers to schematic modification and construction, will be organised around the four features of consciousness [35] previously identified, *sense of self, purposiveness, personal nature and affect,* and *coherence.* The majority of the following studies highlighting issues preventing resolution of the chronic pain experience are not built on a constructivist model. Their theoretical underpinnings are as diverse as the range of issues presented. The following review will serve to illustrate that this range of issues, which at first glance appears to bear little relation to each other, can actually be organised and linked within the four features of consciousness in a constructivist analysis.

4.5.1 Sense of self

There are two general aspects in developing and maintaining a sense of self. The first is physiological (mediated by the body systems) and cortical (particularly related to perceptual functioning in the parietal lobes). Basic functions such as respiration, heart rate, and strength all supply information about one's self. Of equal importance is the brain's ability to translate incoming sensory data into awareness of position in relation to surrounding objects, where one's individual body parts are in relation to other parts (proprioception) and overall body image. Damage to any of the cortical areas responsible for perception can result in an altered or incorrect sense of one's own body. Examples of these problems are readily evident in the medical literature related to strokes and head injury. Sack's book, The Man Who Mistook His Wife for a Hat, is one widely recognised treatment [195] of this topic in the popular press.

Chapman and Gaurin [97] propose that persistent stimulation to the sensory pathways can result in sensitization of peripheral nerves and transmitter cells in the spinal cord so that abnormal neural firing patterns and lowered firing threshold occur. A neuroendocrine response to this stressor occurs in the hypothalamo-pituitary-adrenocortical (HPA) complex that will flood the system with maladaptive levels of neuroendocrine substances and stimulate an immune system response. The net result of this process can be to trigger an illness response. This response is similar to having influenza- fever, sleepiness, reduced respiration, decreased libido, muscle-ache, mood and cognitive functioning depression. Chapman et al outline how this promotes a cyclical process of pain, sensitisation, stressor, more pain and so on. Although a more in-depth discussion of this complex area is beyond the scope of this current work, there is a growing volume of research that supports the proposals outlined above [128, 196].

The second aspect of *self* is that of the social self. How we assume our roles within that society is affected by who we are, how others interact with us, what society as a whole expects and what it allows . Cravey and colleagues' [197] recent work explores the concept that self is influenced not only by 'what' society tells us, but also by 'where' the telling occurs. They examined whether people were more receptive to information received in a location that matched their self-image. For example, for someone who sees himself as a strong, dedicated worker, is information about back pain more readily accepted from colleagues in the workplace as opposed to the GP's surgery? The study concluded that the health information people accessed to understand and explain events occurred in different locations dependant on a variety of socio-economic factors such as employment, access to close family members, and religious homogeneity of an area. People isolated from their usual socio-spatial knowledge networks through events such as loss of job, relocation, or impaired mobility will experience difficulty in adapting to experiences like chronic pain that are perceived as threats to their self-image.

The importance of social context in the construction of self and pain is illustrated through David Morris's thought-provoking story of the 1920s vaudeville performer Edward H. Gibson. Gibson claimed to feel no pain and his stage performance was a graphic demonstration of this (e.g. having himself nailed to a board and allowing the audience to stick hatpins into him). Morris states that, 'Audiences responded to Gibson in ways that tell us something about our acquired habits of thought. A person who cannot feel pain seems a kind of freak or outsider' [41:13]. People's reactions created Gibson as abnormal, a freak. Morris proposes that it is not the experience of having pain that unseats a person's sense of self. Rather, it is other people's interactions with that pain that shape an individual's understanding and behaviours. Pain is not constructed in isolation but rather within a complex social context.

There is an extensive volume of literature examining the social influences on an individual's pain experience. Issues of social conflict, normative influences, socially legitimised disempowerment and social consequences of complaining about pain are frequently recurring themes. Encandela [198] proposes that an individual's scope and creativity in creating a social construct for his or her pain is limited by what is permitted within the social context. The components of social context (ethnicity, age, gender, and socioeconomics) all influence the individual's understanding of pain as it relates to him or herself. He states that the range of interpretations available to an individual is contextually bound and uses a study of two similar retirement communities in the northeastern United States to substantiate this premise. Encandela reports how living situation was a key influence in how peoples' self-image was normed by the community. In both communities people were expected to be active and pain-free if they lived in unsupported (no nursing assistance) accommodations. These residents expressed a need to 'conceal' their pain and not 'bore other people'. They gave examples of 'being left out' and 'losing your friends' as consequences of not complying with these norms of behaviour. People living in the supported units, in the same community, were expected to be less well and were able to openly verbalise their pain and aspects of ill health. For these people, pain was a more medicalized experience, not something to fight off but rather a justification for decreased autonomy and less active participation in the social expectations of the community. Encandela also discusses how some residents used a form of 'colluded silence' about their pain experiences as a strategy to maintain personal control and privacy.

A study examining instances of when patients chose to consult a physician versus a nurse presents findings in a similar theme [199]. The researchers found that only 14.3% of people with issues related to chronic care (eg. prescription renewal) agreed with the doctor's view as to whether they needed to be seen by a physician or a nurse. They also reported that 27.7% of chronic patients felt the nurse could see them, but in the doctor's opinion only 10.2% were suitable to be seen by the nurse only. Kernick suggests that doctors and patients construe health differently; doctors are more focused on the technical aspects and patients are more concerned with psychosocial issues. If this is the case, patients who only consult with a physician may find their expression of the pain experience channelled in a bio-technical direction regardless of any issues they perceive to be more significant. Help-seeking behaviours can become less direct and the person with pain may alter his or her self-image to coincide with the physician's view as opposed to a more individualised construct. Some research indicates that service users actually have improved self-efficacy and more positive affect when their perception of pain intensity is not congruent with that offered by their physician [200]. Charles et al [201] points out that passive acquiescence to the doctor's opinion is a philosophical underpinning of the paternalistic bio-medical model. Despite calls from social organisations, such as the NHS, to move toward a more informed process of shared decision-making, there continue to be physician, patient and caregiver socially mediated barriers to this change in direction.

Social scientists have proposed that suffering is often politicised into a medical condition. Torture and poverty can become delegitimised as social issues through a process of medicalisation [38, 202, 203]. The tortured are no longer victims of political oppression and warfare but become people with post-traumatic stress. The solution no longer demands a wider social context; it is now the individual's problem. Kleinman [202] proposes that members of society find it easier to remove themselves from the overwhelming task of fixing social wrongs through medicalization of issues, and this serves to allow the status quo to remain unchallenged. Other authors have drawn similar conclusions regarding women's suffering during life changes [204], and social response to the atrocities of 20th century western history [41]. "The genocidal programs of mass murder carried out under Hitler or Pol Pot inevitably affect how we think, we act, how we feel...the mind simply blocks what it cannot comprehend...quite literally we can make nothing of it" [41:51]. These authors maintain that to resolve this inability to comprehend, western cultures have recreated suffering as an individual's own pain and medical problem, requiring personal, not political, resolution. When this social construction of suffering as personal pain comes into conflict with the individual's self perception of having suffered as a result of political activities or social negligence (unemployment, lack of education, poverty, violence), development of a consciousness and an acceptable schema is precluded and the event remains unresolved. When meaning for an event is incongruent with a person's self identity ('I was a war hero, now I am suspected of trying to cheat the welfare system'), it leaves the individual's self identity vulnerable with no acceptable repertoire of responses and behaviours [106]. Some recent research suggests that when communication issues are interpreted as dehumanising, devaluing and disempowering within the medical encounter, people feel their personal identity is threatened. When this occurs, reported dissatisfaction with healthcare increases [205].

4.5.2 Purposiveness

The second category of factors affecting consciousness is that of *purposiveness* [35]. Purposiveness, underpinned by the basic needs of adaptation and survival, is what captures our attention. The purpose we ascribe to the features of our internal and external environment serve to focus our attention. Focused attention (consciousness) allows for selective activity and efforts to obtain goals. Chapman and colleagues also remind the reader that we do not achieve awareness in a vacuum. Awareness of pain is a mediated state, dependent on the interaction between the individual and the bio-psycho-social context of his or her environment. Research also demonstrates that attention and cognitive functioning is affected by physiological changes during chronic pain and pain related medication. A recent study of 275 chronic pain patients in a large American urban hospital reported 20.5% of the participants stated they had difficulty finishing tasks and 18.7% felt they had problems with attention [206].

This section will review key features of the individual's psychosocial context that serve to direct or filter attention towards the experience of pain. These key features are identified as *pervasiveness, vigilance, expectation*, and *search for cure*. Lastly, the issue of acquired self-awareness for people experiencing pain is addressed.

Fife [106] proposes that *pervasiveness* is one of the features in how a person conceptualises the meaning of chronic illness. As the impact of illness on the number of areas of a person's life grows, so does the attention it receives by that person. Fife uses the example of cancer patients who are undergoing chemotherapy. The 38 adult participants in her study reported that a form of compartmentalisation is possible; the cancer did not demand all of their attention because it did not affect all aspects of life (e.g. their social life) [106]. However, when treatment caused hair loss, many people reported that their total attention was now focused on the cancer experience. The hair loss was a visible sign of cancer that was carried into all aspects of daily life. The cancer, subsequent to visible hair loss, became pervasive and highly attended to.

A number of recent theorists' work suggests that the pervasiveness of pain as a global feature of life is reinforced through personal vigilance. They propose that once an event (e.g. pain) is brought to awareness, a complex of interactions occur that serve to maintain and actually intensify vigilance to the event [80, 207-209]. Aldrich et al [80] describes a cycle of attention, worry, maladaptive coping and problem solving, inability to resolve worry, increased vigilance, decreased activity for fear of re-injury, increased pain, increased worry and so on. People with pain may perceive that they have limited options to affect change in the situation because of financial, social or cultural issues. The only action available, according to Aldrich, remains worry. The consequence of this escalating vigilance to pain can be both psychological (diminished self-efficacy) and physiological [210]. Diagnostic uncertainty is also seen as a feature in heightened vigilance. Stenner and colleagues [209] examined patient/clinician communication and concluded that an uncertain diagnosis increased some patients' persistence in information seeking. The consequence of this was reported to be increased frustration and distrust between both parties, and an ultimate breakdown of the therapeutic relationship.

Lastly, there is the relationship between illness narrative and vigilance to pain. Hyden [207] detailed problems encountered by individuals who, for numerous reasons, were unable to construct an account of their illness. He suggests that narrative is what allows individuals, and the people who listen to the narrative, to organise understanding, formulate response and evaluate actions. When an individual is consumed by attention to pain, the narrative process suffers. Information is in constant flux, understanding is not clear and communication breaks down. Once an individual has become conscious of pain he or she needs to be able to construct an effective narrative for the experience. When this fails, positive self-evaluation and interpersonal relationships, dependent on clear and trust-worthy information exchange, will suffer. The literature regarding doctor-patient communication proposes that these exchanges are already primed for miscommunication secondary to a range of sociocultural background variables. Miscommunication in turn has an effect on patient outcomes [208]. For people whose consciousness is consumed by vigilant attention to pain, the consequences can have far reaching negative impacts.

Expectation, in terms of what people want and believe should be done to achieve what they want, is a third feature of purposiveness. A discussion of expectation follows logically from the preceding ideas of vigilance. For people with pain, the two are closely interrelated. Contemporary researchers propose that fear of pain and the consequent avoidance of potentially painful activities serve to heighten some individuals' attention and consciousness of pain [21, 80, 211, 212]. Eccleston and Crombez [211] state that pain, through its novelty, interrupts attention to other aspects of daily life. For individuals who are unable to put the pain in an understandable and acceptable context, the pain experience remains dominant and does not allow functional attention to other aspects of life. People in this scenario of pain's chronic interruption will experience a range of negative consequences, one of which may be heightened fear of doing anything to increase the already pervasive pain experience [211]. This expectation of pain, paradoxically, sets up a self-perpetuating dysfunctional cycle of activity avoidance, biological deconditioning and escalating fear of activity.

Another important aspect of understanding how expectation heightens the intrusion of pain into consciousness is the patient/service provision dynamic. Research exploring the area of patient expectations has suggested that where expectations are incongruent with service provision, outcomes will be poorer [174, 176] and that dissatisfaction with service provision can have an iatrogenic affect [213]. Although these researchers do not deal specifically with a chronic pain population, there are parallels between the characteristics of social and financial marginalisation Noble et al. [174] describe in their critical review of empirical studies and the experience of people with long standing psychiatric conditions. Noble's review is also noteworthy for its citation of several of studies concluding that what people expect is not necessarily the same as what they want and that people often use indirect routes to communicate their wishes to clinicians.

Search for cure is a further theme emerging from the literature regarding peoples' attention to the pain experience. Vrancken's provocative review, *Schools of Thought on Pain* [25] proposes that in a consciousness analysis of pain the individual is unexpectedly forced to recognise (be conscious of) the body in a way not previously experienced. A part of the body (Vrancken uses the example of a painful foot) suddenly consumes here-and-now awareness. This in turn, may restrict awareness of other life events and interfere with personal self-concept. She goes on to propose that the individual now stops being a person and instead becomes a pain patient. The patient assumes the role of searching for cure and while this fulfils the person's need to take action it also becomes all-consuming. Stenner et al [209] relates the search for cure to how resistant a condition is to understanding. They suggest that in disorders with uncertain aetiologies, people respond through hopeless resignation or anxious, persistent, attention consuming search for cure. Stenner and colleagues compare their study of sixty people with Irritable Bowel Syndrome (IBS) with a study of chronic pain patients [39] and report a strong resemblance between the two studies' participants in their belief that there is an undetected physical cause for their current illness. Perceived efforts by health care providers to move patients away from a search for cure towards a problem management model are strongly resisted and Stenner et al.[209] concluded with a caution for clinicians to develop more sensitive communication skills to prevent further deterioration of the healthcare relationship.

Finally, the issue of *self-awareness* should not be overlooked in this exploration of the role purposiveness plays in consciousness. Steen and Haugli [214] propose that chronic pain programmes should be structured around the philosophy that a person must be *taught* how to be truly conscious of their body. Rather than allowing unstructured and conflicting perceptions to be forced upon the individual trying to come to terms with the painful body's intrusion on daily life, they suggest that people with pain be shown how to reflexively tap into self-knowledge based on past experience and in that way arrive at an acceptable understanding for the meaning of current event. Their analysis draws heavily on Dewey's [215] concept of *awareness* and Leder's [216] proposal of the split between the body and self, leading some people to experience their body as 'separate' and alien [214]. Steen's work, based on a programme of twelve sessions, every fortnight for four hours with between eight and ten participants, reports that participants learned to be aware of their bodies through a variety of techniques - movement, metaphor, guided imagery, art and written approaches to self exploration. The study concluded that in an RCT, the intervention group reported less pain and better coping ($P<0.05$) as compared to the control group at one year follow-up [214]. Unfortunately, the training of the programme leaders and the outcome measures employed are not identified in the paper. Despite these short falls, the work points in an interesting direction of facilitating the individual with pain's access and control over aspects of pain consciousness.

4.5.3 The Personal Nature of Pain

Chapman's third feature in bringing pain to consciousness involves *affect*, the emotional interpretation each individual places on the pain event. The social science literature is rich with narratives and research related to the affective dimension of the pain experience. The Culture of Pain [41] and The Body in Pain [203] can be considered seminal works in any exploration of the affective nature of pain. Morris relates a complex relationship between pain and society and gives rich examples of how pain emotions, both negative (fear, suffering, loss, stigma) and positive (pleasure, justice, penance), are contextually bound to social events at any given time. Scarry's work explores the political and spiritual dimensions of pain and suffering. She contends that western society lacks the ability to communicate the experience of pain, making it easy to discount in others. '*To have pain is to have certainty, to hear about another's pain is to have doubt*' [203:4]. This section will discuss *fear of pain* and the *consequences of others' disbelief* as influences on the affective domain of consciousness.

Research highlights how complex the relationship between pain and fear can be. Increased pain can be a consequence of an individual acting on his or her fear of re-injury and therefore becoming deconditioned and physiologically vulnerable [21, 80, 211]. An individual may use a personal interpretation of how severe the pain is to evaluate the degree of concern or fear that should be expressed, and the 'perceived threat or damage to one's biological integrity' [97]. Other research has focused on the wider range of consequences related to fear and anxiety about pain. Aldrich's review of this literature highlights that the outcome of pain and fear may be decreased self-confidence, inability to set future goals, deterioration of support systems, work incompetence and maladaptive problem-solving attempts [80]. Fear about pain is compounded by additional fears about social isolation, economic hardship and an uncertain future. Eccleston et al [39], suggest that these additional fears do not remain as separately identified issues but rather are amalgamated and added to the intensity of pain experienced. They propose that this occurs because of how strongly people with pain endorse the dominant cultural belief that pain is attributable to disease or illness. In other words, people with pain believe that increased pain is caused by worsening physical condition and not by becoming unemployed. Chapman's recent review of the relationship between physiology, consciousness and pain examines how once pain is brought to a conscious level and an affective response (like fear) is triggered, physiological mechanisms (responding to perceived biological threat) then serve to maintain consciousness and the pain experience. The mechanisms for this defence response are the physiological processes occurring at the hypothalamopituitary-adrenocortical axis (HPA) [210].

Affect is also influenced by *disbelief*. Social science research has highlighted the power imbalance between people with health conditions and service providers and how this imbalance impacts on communication, satisfaction with services and concordance with treatment [208]. Ong et al., propose that when there are communication problems, patients tend to rely on their personal interpretation of non-verbal behaviours and that these interpretations tend to be negative as a consequence of the heightened affect experienced during health related interactions. In a recent study of 96 chronic pain patients on treatment in a university based American hospital, 74% of the participants reported feeling angry towards themselves and 64% stated they were angry at healthcare professionals [217]. The researchers propose that there are significant secondary issues consequent to anger; depression, isolation, and perceptions of decreased functional ability. Their findings suggest that anger is targeted and in some cases can actually be helpful to motivate action (for example more committed participation in rehabilitation and engagement in advocacy related activities).

It is also possible that this power imbalance contributes to people feeling disbelieved by service providers. Kouyanou et al., looked at iatrogenic factors in chronic pain and found that in a two-site sample of one hundred and twenty-five chronic pain outpatients, 25% reported the doctor had directly disputed the patient's reported pain intensity and that 41% stated they were made to feel that the doctor doubted their report [218]. Another study, looking at the communication issues between doctors and patients with irritable bowel syndrome (IBS), suggests that physicians dealing with difficult to diagnosis conditions like IBS may be frustrated when the condition proves resistant to treatment. In cases such as this, personal beliefs may over-ride professional 'knowledge' and behaviours, resulting in an adversarial relationship between patient and physician. The doctor blames the patient for failure to respond to treatment and the patient comes to believe the physician doubts their honesty [219]. Although this study focused on a different clinical group, it bears examination because IBS is similar to chronic pain in its resistance to diagnosis and treatment. Pain specific research has revealed similar issues with physician frustration and patients' feelings of being distrusted and blamed [39]. Sullivan proposes that while patients bring their first-person accounts (the experience of pain) to the encounter, the physician is interpreting their accounts into the third-person (pain as a disease entity). When the translation breaks down for some reason, the first-person account, by nature of its subjectivity, becomes suspect and open to doubt. Sullivan identifies patient behaviours incongruent with physician expectations, social stereotypes, and the social negotiation process around accounts of other people's pain, as being key barriers to the move from subjective reports to professionally recognised disease [31].

From the preceding discussion, disbelief and the emotions it engenders presents as a significant issue in maintaining pain at a conscious level. As Chapman points out, emotions related to pain are individual and often difficult to communicate [35]. It is this very individualism that places such a barrier on others' comprehension, and for the person with pain the consequent weight of negative emotion serves to reinforce his or her consciousness of pain.

4.5.4 Coherence

The forth and final feature of human consciousness that Chapman et al., propose is *coherence*. In his analysis consciousness is self-organising and directs effort towards integrating the fragmented internal and external elements that come to awareness. This integration is required for the individual to assign meaning to events and experiences, relying on past understanding and awareness of events across a time span. Chapman calls this 'our model of reality' [194]. The literature on chronic pain is rich with discussion related to meaning construction and the socio-political and biological factors that present barriers to an individual arriving at a coherent meaning for pain that is congruent with past experience and beliefs.

Many features influence coherence and there is a wealth of social and biological scientific literature to examples draw from. Issues that have been raised relate to lack of or misinformation [220], and withholding of information as a political strategy by health care providers concerned with maintaining the professional status quo [221]. Hunt et al. [222], demonstrated that people's concept of illness has a strong temporal component and that their explanatory models for illness fluctuated over time. Interestingly, these researchers concluded that changes people made to their explanation for an illness were more strongly linked to changes in personal circumstances and interactions within the social environment as opposed to the influence of physician/patient interactions. The importance of time is also highlighted by Jenson and Kern's [24, 77] work on pain stages of change. In this model people's ability to take on new information and beliefs is related to where they are in the readiness for change stages (precontemplative, contemplative, preparation, action or maintenance). Stages of change research suggests that for treatments to be effective they must be matched to the individual's current stage [24, 77].

A third feature of coherence is related to control of treatment decision-making. A number of authors propose that there is a significant relationship between increased perception of control and treatment outcomes [203, 223-225]. There are a number of influences on peoples' feelings of control; family and social network, access to accurate information, and the perceived seriousness of a problem, balanced against the effort required to exert control. On the service providers' part are issues of professional identity, time for information sharing and the expense of resources to do this work [201]. Additionally, as Bailis [223] points out, there are varying degrees of ability and desire to assume control and it may be that the impact of social inequality needs to be addressed as a precursor to shared decision-making in the clinical setting.

Perhaps the area of coherence that has received the most attention is that of differing beliefs and values between service providers and service users. As discussed in Chapter 2, the meaning a person ascribes to his or her pain is constructed through a complex interplay of socio-cultural and political factors including class, gender, economic environment, socialisation and the family. 'Human pain does not exist apart from meaning' [108:118]. What the literature is also beginning to demonstrate is that, just as each individual with pain formulates a personally congruent meaning for the pain experience, so service providers also develop a meaning for the service user's pain. This meaning derives from an individual's own past experience, socio-cultural background, political and economic demands and other environmental contexts of the service user. It is now well demonstrated that the meanings that are constructed are not necessarily shared [121, 167, 199, 207, 209, 219, 226-228].

In the study of service users' and service providers' beliefs about irritable bowel syndrome (IBS) mentioned previously [209] disagreement was found between service users' and providers' beliefs regarding aetiology of the disease, the role of diet, exercise and psychological issues such as stress and childhood trauma. Other researchers have proposed that medical practitioners are inculcated to be 'detached observers' but are in fact, as strongly influenced by their own subjective biases and beliefs as by the scientific evidence [121]. It has been suggested that even the assessment tools used by clinicians are flawed because they are designed by service providers and predominantly reflect what the tool creator values as opposed to the service user's desired outcomes [167].

Some research has found that while service users rated areas like size and accessibility of the practice, the variety of treatment options offered, and social issues (such as housing and employment), as important aspects of service delivery, these areas were judged as less significant by service providers [227]. A study using focus groups of service users and providers found that, although there was agreement about the 10 most important topics in healthcare service provision, there was disagreement about the priority of each topic. For example, only 7% of service users rated the physician's knowledge as most important where as 17% of the physicians' group rated knowledge as most important [226].

4.6 Summary and conclusions

Chapman [35] proposes that within a constructivist framework pain is a conscious process and that features of consciousness can either act as barriers or as facilitators of successful resolution. Some researchers propose that in addition to the previously identified barriers to meaning construction, an increasing awareness of the limitations of current medical 'knowledge' creates discord. A growing voice in the healthcare literature proposes that conventional medicine can no longer be seen as the definitive reality and that social values are now reflecting a shift towards more holistic thinking where consumer rights, access to information via electronic media, and self-responsibility are seen by many as essential components of well-being [229-230]. Individuals attribute a range of meaning to the events they experience, interpret others' reactions as either desirable or negative and than adjust their behaviour accordingly. These theories are consistent with postmodernist thinking which proposes there are many realities depending on the lens through which an individual views the world [34]. This concept underlines that it is not only service users but also healthcare workers who are subject to the social forces in which healthcare service is provided. In postmodernist thinking there are no universal givens and personal reality changes in relation to the socio-political, temporal and environmental context in which an individual lives [36]. The emerging social phenomenon in western cultures of challenging biomedicine's superiority has seen a growing exploration and endorsement of interventions that previously were held to be from the fringe, and 'alternative' [36-38]. Personal meaning construction may be blocked for some people as they struggle to resolve these concepts within their personal belief systems and the conflict it presents around a biomedical system that controls a large component of their access to care.

The preceding discussion has attempted to demonstrate how research evidence from varied schools of thought can be incorporated within a constructivist framework and the conceptualisation of pain consciousness. Lastly, the emerging influence of post-modernist thinking was identified as a potentially strong influence on individual pain constructs.

Chapter 5

Complex Adaptive Systems

5.1 Introduction

The director of the NHS Modernisation Agency, David Fillingham, stated that ' the NHS is the epitome of a complex adaptive system. Such systems do not always respond well to mechanistic formulae' [232]. A growing number of theorists and researchers echo this sentiment in relation to many aspects of healthcare in the 21st century. It is increasingly emphasised that people are complex biological systems that do not behave in a linear fashion [233-236] and that effective healthcare for the growing number of chronic disease and lifestyle issues (like chronic pain) must be grounded in a non-reductionist paradigm focused on understanding relationships and taking a flexible approach to problem-solving [237-240]. Chapman et al. have predicted that for pain research, '...the principle challenge will not be technological advancement but rather the generation of a theoretical framework that can guide complex scientific inquiry' [241:138].

This chapter will discuss the theory of complex adaptive systems (CAS) as it relates to healthcare. It will also, through identifying the congruence between the characteristics of a CAS and features of the chronic pain experience, demonstrate that CAS theory is an appropriate framework for seeking to understand chronic pain.

5.2 Defining complex adaptive systems

> " *A Complex Adaptive System (CAS) is a collection of individual agents with freedom to act in ways that are not totally predictable, and whose actions are interconnected so that one agent's actions changes the context for other agents.* " Plsek and Greenhalgh [242: 625]

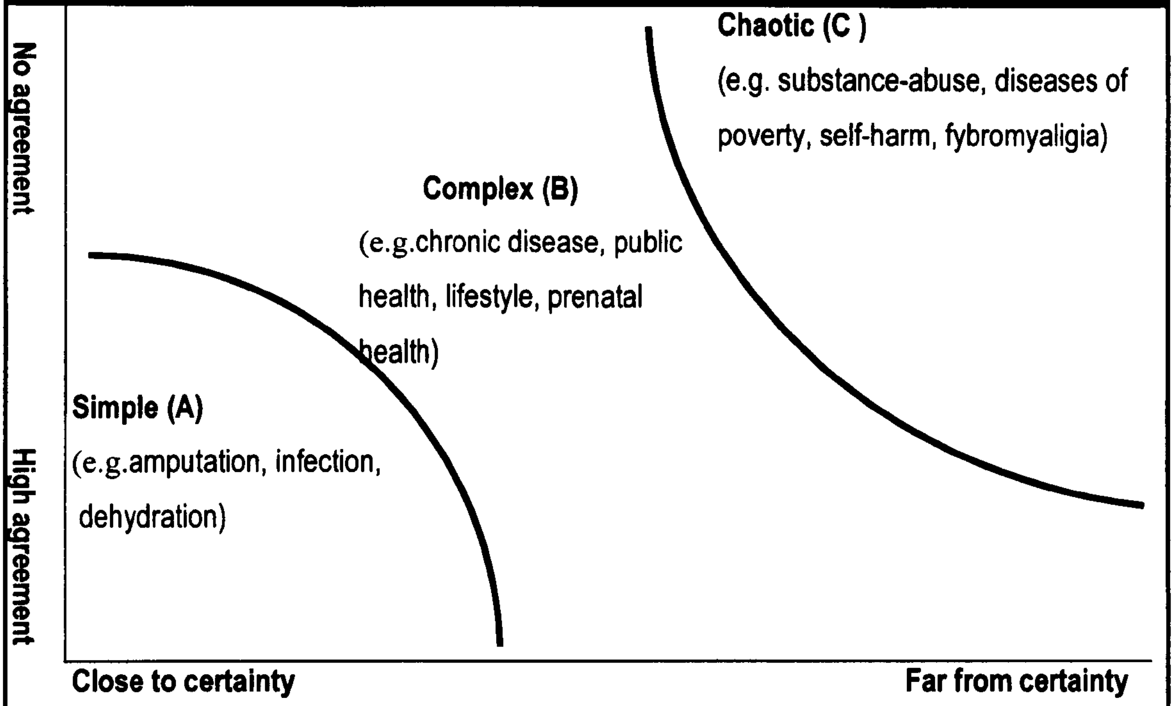
Cilliers [243] suggests that attempting to reduce and define a multifaceted concept like complex adaptive systems is contradictory. Instead he leads the reader to explore the concept as a dynamic composite of multiple elements. Zimmerman et al [244] suggests that the concept of CAS is best understood through examining the significance of each term; 'complex'- implying diverse relationships between many elements, 'adaptive' – reinforcing the dynamic capability for change and 'system' – highlighting the interconnectedness of the individual elements.

Complexity theory places events within a matrix recognising that while simple relationships between two elements can occur, more complex interrelationships between multiple dynamic influences occur as well. Within this matrix very chaotic events, often with undetected and deeply embedded influences, can also emerge. Simple events have a linear relationship in which the cause of an event is directly proportional to the effect. The greater the magnitude of the causative agent, the larger will be the effect. An example of this would be the body's response to external temperature. The body's thermal regulatory system increases in activity as the external temperature deviates from the body's normal temperature. In linear relationships there tends to be a high agreement amongst stakeholders about the correct course of action (for example a child chokes on a sweet, you remove the sweet). Complex events on the other hand are multidimensional and have the features of high uncertainty and disagreement (the current multiple measles, mumps and rubella (MMR) vaccination debate in the UK would be an example). These events, because they are embedded in so many contexts (social, political, cultural, economic, temporal, affective etc.) require non-linear strategies for decision-making [236]. In complex adaptive systems a small input can have an unanticipated large effect. The huge infusion of funds into spinal cord research after one person's injury (actor Christopher Reeves) is often cited as an example of this complex phenomenon. The resistance of cancer to 'cure', despite the vast financial and human resources channelled into research internationally, is another example. These types of events can be construed as evidence of non-linear relationships where the outcome is not proportional to the input.

Complexity theorists propose that when linear thinking and searches for 'the one-best solution' are applied to complex problems the system becomes immobile and de-stabalized [235, 238, 239]. The 'one-best' solution imposes too many controls to allow for the flexible responses necessary to incorporate new information as it becomes available and to provide feedback to the existing problem. Complex problems require a range of strategies that facilitate timely implementation of 'good-enough' solutions that can be modified as feedback and new information become available. Searching for a global 'best' solution is seen as a futile, counterproductive exercise in which it can take so long to formulate the solution that the dimensions of the original problem have long since evolved and often compounded into a new issue.

The agreement/certainty matrix model of complexity (Figure 5.1), generally attributed to Stacey [245], has been used widely to illustrate the range of events when relationships shift from predictable and agreed upon towards high uncertainty and demonstrating a range of idiosyncratic opinions. Events where there is high agreement and certainty about outcome respond to the conventional scientific model with a linear notion of causality (Point A in Figure 5.1). As events become less predictable with more and more contextual influences needing to be considered the event becomes complex (Point B). Complex events are still governed by basic rules (people with diabetes have problems regulating insulin production) but are also influenced by a myriad of conditions, features and forces. A day in EuroDisney, eating unhealthy food to avoid being singled out by peers as different, combined with fatigue consequent to travel, time change and the high energy levels exerted for a prolonged period in a theme park, presents a very different situation for a child with diabetes than the usual predictable school day. Environment, social pressures and parental awareness all become important influences that modify and, in turn, are modified by one child's diabetes. Complex events are understood by focusing on the relationships between the multitude of influences as opposed to seeking reductionist rules. Complex systems are constantly being influenced by, and adapting to, their environment. They respond to and, at the same time, act upon the extensive range of elements that comprise their unique context [236]. In addition to simple and complex events, a system can also become chaotic (Point C), where no discernible pattern emerges and the system appears to fluctuate randomly and is not longer adapting to the environmental context.

Figure 5.1: Complexity Matrix



Modified from [245-246]

5.3 History of complexity and healthcare

'If things were that simple, word would have gotten round'

Derrida (1988) in Cilliers [243]

In the 8th century B.C. the Greek poet Hesiod wrote of how the earth and order emerged from chaos, 'order comes from disorder' [247]. However, the concept of chaos and its relationship to order was not widely explored until mid-20th century advances in the ability of computers to manipulate previously impossibly large and complicated calculations. This computer capacity facilitated examination of irregular (less that predictable) phenomenon such as apparently random changes in weather, the outbreak of epidemics and fluctuation in populations of animals and birds [247]. The principles of chaos theory that began to emerge from this point have been explored and refined in a diverse range of disciplines. For example Edward Lorenz's attempt to create a computer model of a global weather pattern in the late 1950s found that very small changes in initial conditions could produce widely varied and unpredictable responses. This concept has become known as the

'Butterfly Effect' (a butterfly beats its wings in Brazil and a tornado occurs in Texas) and has been so well assimilated into western culture that it forms the basis of the widely popular Jurrassic Park movie series[1][248]. A second example of the application of chaos theory comes from the field of biology and population dynamics. Robert Mays' application of chaos theory principles in this area [247] is credited with demonstrating that the size of a population in the wild will not necessarily remain predictable dependent on predators, food and the environment, but rather will oscillate periodically between two states. This concept (bifurcation) demonstrates that systems are not all linear in nature. Putting more food into the system (input) will not necessarily result in more fish (output). Rather, some systems will increase to a certain point and then split or cycle [247, 249]. These types of non-linear systems examples emerged from a range of different scientific disciplines and their application to real life problems has become collectively referred to as complex adaptive systems theory [247]. Contemporary theorists see chaos and complexity theory as a revolutionary advancement in science, allowing for the interdisciplinary integration of non-reductionist creativity and ideas required to deal with the problems of the 21st century. "Chaos breaks across the lines that separate scientific disciplines. Because it is a science of the global nature of systems, it has brought together thinkers from fields that have been widely separated" [249:5].

The growing acceptance of post-modernist thinking in western industrialised culture has fostered the application of CAS thinking to a wide range of contemporary social issues. One such area is healthcare where, since the mid-1990s, theorists have applied the principles of complexity and chaos theory [236, 239, 244]. Theorists propose that while the scientific model of illness (consequent to the historical foundations of philosophers and scientists like Newton and Descarte) is effective for understanding certain disease states, it is an inappropriate framework to apply to many contemporary lifestyle and chronic health problems [236, 250, 251]. Complexity science maintains that a flexible range of approaches to healthcare problems is essential. For straightforward issues (like a ruptured appendix) a scientific model should be applied and conventional healthcare implemented. However, other health conditions like rheumatoid arthritis have multiple interrelating

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[1] Jurassic Park is so well accepted that it is actually being used to teach 10-14years olds about the concepts of chaos and fractals http://www.challenge.state.la.us/k12act/data/jurassic_park.html

influences (such as lifestyle, social context and chronicity) and the way forward is not easily reduced to one solution. Theorists point out that the history of medicine is rich with examples of when 'scientific' reductionism failed and what was once widely accepted medical 'fact' proved to be a flawed construct. A recent example of this is the reconceptualising of gastric ulcers. The long held belief was that they resulted from an inflammatory process. However, the dramatically different opinion currently held is that ulcers are a bacterial infection [252] and clinical practice has shifted accordingly.

Post-modernist thinking assumes that there are a multitude of truths dependent on the viewer's context and influences [253] and how the viewer constructs his or her personal reality. Taken to the extreme this thinking is seen as a rejection of orthodox medicine and can ironically contribute to both the over-zealous pursuit of a positivist generated evidence-base to the exclusion of all other forms of evidence [254-256] and, the opposite side of the same coin, resistance to implementing evidence-based change in practice [257- 261]. Complex adaptive systems theory however, fosters the view that healthcare decision-making occurs within a matrix of influences and certain approaches are more effective at certain times in certain conditions. Figure 5.1 shows examples of this range of conditions.

Martin [253] proposes that orthodox medicine's response to challengers will result in new ideas either changing practice or being labelled heresy and marginalised. There is a growing weight of evidence that traditional medical establishments are open to change and new ways of thinking about chronic health conditions. For example, the UK Medical Research Council (MRC) has stated, " The greater the difficulty in defining precisely what, exactly, are the 'active ingredients' of an intervention and how they relate to each other, the greater the likelihood that you are dealing with a complex intervention" [262 :1]. In an effort to guide medical researchers in addressing these types of issues the MRC produced A Framework for Development and Evaluation of RCTs for Complex Interventions to Improve Health [262]. The document falls short of a clear call for abandoning the traditional hierarchical positioning of RCTs as the 'gold-standard' for many healthcare issues. However, as the MRC is the largest public sponsor of RCTs in the UK, the guidelines have the strong potential to legitimise researchers' efforts to address complex problems from a wider perspective. Other widely respected and influential voices of the medical establishment have expressed support for reconceptualisation of health and illness within a complexity framework. The British Medical Journal (BMJ) series on complexity science in 2001[242, 250, 263, 264], the World Health Organisation's call for a reconceptualization of healthcare needs of the 21st century in: Innovative Care for Chronic Conditions: Building Blocks for Action [265] and the NHS Modernisation Agency's clearly articulated stand that healthcare is a complex issue [266] requiring innovative and creative solutions, demonstrate that many in the medical establishment are ready to look at a new framework for contemporary healthcare needs.

The following section outlines the characteristics of complex adaptive systems in healthcare, applying examples from the chronic pain experience and demonstrating that chronic pain is a condition well suited for examination within a complex adaptive system framework.

5.4 Properties of complex adaptive systems

> *'Our meddling instinct mis-shapes the beauteous form of things*
> *we murder to dissect '* Wordsworth [267]: lines 26-28

Complex adaptive systems are more than the sum of their parts. Both poets (like Wordsworth) and theorists alike warn of the danger of taking elements in isolation as opposed to focusing on the relationships between the elements. Magnification of elements in isolation will result in an obscured perspective. For example, the researcher who focuses only on the pancreas will not develop an understanding of diabetes. The multidimensionality of complex systems dictates that it is essential to have a way to organise and guide examination of complex adaptive systems. As discussed in Chapter 2 the range of research and theoretical paradigms on chronic pain are vast and ever growing. Griffiths [268] proposes that complex adaptive systems theory should be seen as a meta-theory that provides a way of organising and relating a range of other theories. In this way, complexity theory reconciles potentially conflicting analytical models by demonstrating how each theory is of value in certain contexts at certain times and for certain people. Griffiths compares complexity theory to the development of the periodic table in the mid 1800s. The many techniques for examining minerals were in existence prior to that time but the theory of essential elements (earth, air, fire, water) employed by alchemists was flawed. With the development of atomic mass theory, existing techniques were employed to quickly gain new insights into chemistry. Griffiths proposes that a similar process will occur when existing healthcare research data is viewed from within a complexity framework, thus allowing new and revised insights to emerge from existing theories.

Plsek [239] proposes one method of organising an examination of CAS in healthcare. He identifies eight key properties of complex systems and these are listed in Box 5.i.

Box 5.i: Key Characteristics of Complex Adaptive Systems

5.4.1	Relationships are central to understanding the system
5.4.2	Complex systems are described by their structure, processes and patterns
5.4.3	Actions are based on internalised simple rules and mental models
5.4.4	Underlying attractor patterns explain complex behaviour
5.4.5	Complex systems are in constant adaptation
5.4.6	Experimentation and pruning must occur for the system to adapt
5.4.7	Complex systems are inherently non-linear
5.4.8	Complex systems are embedded within other systems and co-evolve

The following section will examine a range of research theory and findings in the area of chronic pain as they relate to Plsek's key properties. Evidence for the proposal that chronic pain is not so much an experience or syndrome but rather a CAS will be developed in this discussion.

5.4.1 Relationships are central to understanding the system

The ant colony is frequently used as an example of the competitive and cooperative nature of interrelationships within systems. Complex organisations are maintained by the dynamic interplay between competition (for reproduction) and co-operation (for food). Understanding how these forces are balanced to ensure maximum system integrity offers insights that can be applied to other complex systems [269].

In a CAS behaviour is generated by interaction between the stakeholders. Stakeholders are guided by their own personal meaning constructs for the event and as such their behaviour is not always predictable to others [243]. Additionally, miscommunication is highly possible as stakeholders do not necessarily share beliefs, culture and opinions, come from different linguistic groups [270], do not feel the need/comfort/ability to share these opinions overtly, may not be allowed to speak for themselves [271], and may be suffering iatrogenic effects of past miscommunications [272].

Relationships can also be negatively affected by the agents' idiosyncratic beliefs and coping style with regard to change. Many of the interactions concerning chronic pain focus on changes in behaviour and belief (for example a service provider trying to assist a service user to move away from a belief that pain is best dealt with through bed rest). As discussed in detail previously (section 2.7.3), research now demonstrates that the approach taken by the change-agent needs to be consistent with what has been termed the recipient's 'stage of readiness for change' [79]. Efforts to affect change that do not consider barriers and fears about change can be met with resistance and potentially serve to hinder the establishment of effective relationships [273,274].

The chronic pain experience is highly interactive and, because of its impact on productivity, social roles and public resources, the numbers of stakeholders are high. Communication issues are well documented [74, 209, 275], as is the significance of personal meaning construction within the chronic pain experience [29, 108, 116, 189, 276].

5.4.2 Structures, processes and patterns

All three components of a system (structure, processes and patterns) must be considered as highly interactive. Changing one will result in change in the others. It is flawed thinking to assume that consistency in two components can predict consistency in the third. The narrowly averted Cuban missile crisis is cited in the complexity literature as an example. Although the structure (government decision-making mechanisms) and processes (protocols for progressing between stages of military preparedness and pre-emptive strike) during the Bay of Pigs crisis were stable and predictable, the third element of the system (pattern) was not. The Russian leaders' patterns of behaviour were perceived by President Kennedy to be inconsistent with that to which the structures and processes were pointing [269]. Consequently his response was not consistent with what would have been the logical behaviour in a linear system, where the assumption exists that if 'A' and 'B' are true, then 'C' must also be true.

The Clinical Standards Advisory Group's (CSAG) [69] review of services for people with pain in the UK concluded that how services are delivered *(structures)* for people with chronic pain are quite varied. They also identified that treatment options range from single modality and condition specific clinics through to inpatient intensive multidisciplinary programmes and that the human and material resources available within these options are also widely varied. Additionally, the *processes* for accessing services differ from region to region, the routes for referral are unclear, and public versus private sector options are not clearly apparent. Although communication of understandable and usable information amongst stakeholders is essential for healthcare, structures and processes guiding this communication have many tiers; government policy, healthcare directives, healthcare structures and process, and the ethno-social realities of multicultural service users and providers [277]. In many circumstances this confusion is further compounded by a lack of enforcement of existing regulations and guidelines that are intended to ensure access to healthcare information for a range of stakeholders [277].

Lastly, there are barriers to changing the *patterns* of interaction that emerge from the power dynamics and socio-political forces at play. Despite guidelines from the Pain Society [278] and the International Society for the Study of Pain [11], and a growing evidence-base in the literature that strongly supports a bio-psycho-social approach to chronic pain, many chronic pain interactions continue to occur within an exclusively biomedical paradigm. Service providers continue to be inculcated with the professional values of objectivity and pursuit of the scientifically reductionist 'correct' answer to problems [279-281]. Research has also demonstrated that some healthcare professionals are slow to change clinical practice to incorporate new scientific findings (like the bio-psycho-social approach). Reasons for this include difficulties accessing research literature [282, 283], lack of time or knowledge required to search for, read, interpret, and evaluate relevant reports [259, 284, 285], the belief that experience and expert opinion are more important to competency than knowing the results of research [286], failure to recognise the existence of guidelines based on evidence, and institutional barriers to changing current practice [258]. It has been reported that clinicians find the "current style of research articles unhelpful and unreadable with recommendations few of them are realistically able to work with let alone understand" [287]. Additionally, for certain clinical conditions (like chronic pain) the literature is diverse, extensive and at times, contradictory. When this happens the problem of accessing and evaluating the ' evidence' is compounded presenting a further barrier to modifying the traditional professional/patient pattern of interaction.

The traditional patient/professional relationship, which places a high premium on 'objectivity', is still strongly evident in interactions between service users and providers. However, there is increasing discussion about how important it is for healthcare providers to be able to employ reflective practice not only for their patients but also in the interests of their own health [288-290]. Healthcare professionals, working with service users that have complex problems requiring frequent attendance, are considered at particular risk from the heavy emotional content of these interactions (frustration, guilt, hostility and anxiety) [279]. People with chronic, non-malignant pain are one such group of service users who bring a range of emotions to the clinical encounter [96, 291]. This range of potential emotions is also related to the wide variety of processes and structures within which service is offered and received. Anecdotal evidence suggests that any number of people may attend a clinic over the course of a day, having the same age, gender and with the same diagnosis, but each encounter will be unique for the service provider and service user alike.

5.4.3 Internalized simple rules and mental models

> *"Simple, clear purpose and principles give rise to complex, intelligent organisational behaviour. Complex rules and regulations give rise to simple, stupid organisational behaviour".* Dee Hock in Pierce [292:12]

Complexity theorists use the examples of migrating flocks of birds (discussed in depth in section 12.3) and of the game 'tic-tac-toe' to illustrate the concept that simple rules can result in very complex outcomes. In the case of this 3-by-3 game there are in excess of 50,000 possible legal configurations [248]. If this complexity is possible from the simple rules of a children's game, the implication for interactions between people and organisations is vast. In human interactions internalised rules are not static and linear but are reconstructed with experience and reflective cognitions. The significance of this personal meaning construction in chronic pain has been previously discussed. Literature supports that the biomedical model is still a widely held assumption for people with chronic pain and service user and provider patterns of behaviour are strongly influenced by the 'search for cure' metaphor [293]. However, as this search becomes more extensive, so do the search results become more and more complicated and fragmented. Simple internalised rules (*the doctor will give me a pill to take the pain away*) no longer operate or offer solutions to existing problems. The search for cure leads people into an ever-expanding field of practices and processes, policies and procedures. New and complicated information about waiting lists, treatment regimes, locations of clinics and claims' forms presents additional demands on the resources of service user, family members and service providers. Additional to the mechanical complications of seeking treatment is the confusing variety of reasons put forward for that treatment. It has been pointed out that even highly trained and specialised pain management programme teams may not share a uniform understanding of the primary goal of intervention [149]. Some team members believe that the primary goal of intervention is pain relief, while others state the goal is improved physical function, and yet others may operate with a focus on self-expression and psychological insight. Service users themselves have internalised expectations and goals about treatment and when these varied (and often uncommunicated) beliefs collide, the treatment process becomes complicated and frustrating. This conflict has been shown to contribute to iatrogenic problems for people with chronic pain [13, 213, 294].

5.4.4 Attractor patterns

The concept of attractor patterns comes from the field of mathematics and refers to underlying forces that attract behaviours towards a consistent outcome regardless of what type of input is exerted [247]. "An attractor is the area that a system moves towards and where it will tend to stay" [295]. A simple analogy is that of pouring pebbles into a bowl. The pebbles, regardless of size, number, colour, weight and a multitude of other factors will move towards the lowest point in the bowl. The attractor is the bottom of the bowl and regardless of what the pebbles look like or where they are placed in the bowl to begin with, they will be attracted to the lowest point in the bowl. An example of a biological attractor is the common cold viral infection. Most common colds in western industrialised society follow the same trajectory regardless of the input exerted. Whether the person drinks chicken soup, takes aspirin or has a massage, the outcome is most likely to be the same and eventually, the cold symptoms resolve.

Attractors are not always straightforward and the term 'hidden attractor' is applied to systems where the likely point of outcome is not necessarily evident [295]. For example, a social services' agency may believe that its attractor is equity of service delivery. Guidelines and procedures are setup based upon this principle. However, the reality for the organisation is that there are limited financial resources and provision of services and equipment needs to be rationalised based on age, disability or employment potential. In this situation the formal attractor of equity of service is not correct. Regardless of the policy statements and guidelines, the system will always fluctuate in terms of equity of service delivery across the community. The hidden attractor is actually fiscal restraint. Attempting to modify the wrong attractor results in wasted input. As Burton points out the hidden attractor may have been there all along, 'it just wasn't obvious until we looked in the right way' [295].

In the history of illness there are numerous examples where resources were misdirected and did not actually target or influence the true attractor in the problem. To determine the attractor in an event, complexity science focuses on examining patterns and relationships. However, relationships and how we look at them are socio-culturally embedded and so change with the thinking of the time. Often social-political forces actually work against uncovering hidden attractors and it is not until thinking changes that new ways of looking at events are possible. With those new ways of looking what was once obscure becomes clearly apparent.

Medicine's view about cholera traced across the centuries is a good example of how attractors in a system can change dependent on the acceptable social thought of an era. When religion was the tool through which society understood events and constructed meaning, cholera was seen as a divine punishment. However, over time people came to see that cholera was indiscriminate in afflicting both sinners and saints. Therefore, people concluded, cholera must be the output of some other system, not grounded in spirituality. Also, by the 16th century, secular leaders were emerging who wanted to be seen as 'scientific' and modern (as opposed to guided by religious leaders they perceived as superstitious and too powerful). Cholera then came to be viewed as a disease found only amongst the poor and labourers. When it crossed social classes (coinciding with vast rural out-migrations and over-crowding in urban areas) to affect the affluent, thinking shifted again. Social and political leaders speculated cholera was a consequence of the poor being in closer proximity to the affluent. This proximity resulted in the forced sharing of a common resource – air (miasmic theory). In 1854 Filippo Pacini, an Italian doctor, identified the cholera bacteria but his findings were rejected as fanatical by the medical community who still ascribed to the class conscious miasmatic theory. That same year, because of an interest in statistics and epidemiology, the English doctor John Snow identified the now famous Broad Street pump in London as a source of cholera and the scientific gaze slowly shifted once more [296]. As technology, public sentiment, political power and scientific orthodoxy changed so did how people understood cholera. Efforts to prevent cholera that aimed at improving the quality of the air were probably effective at times because as people moved from 'miasmic' areas to the countryside the water supply would also change. Efforts aimed at the wrong problem inadvertently still resulted in positive consequences. The attractor for cholera remained hidden until such time as a complex array of social, political and cultural forces interacted to facilitate a new way of looking.

A parallel situation could be proposed for current approaches to pain management. It appears that chronic pain has as yet hidden attractors. Regardless of which of the wealth of interventions is inputted to the system, chronic pain still remains an expanding, unresolved health and social issue. Much effort is being exerted, and positive outcomes occur, but the pattern of the system remains elusive. The efforts may be less than effective because the hidden attractors are obscured in current ways of thinking about and understanding chronic pain. As discussed in Chapter 2 much of current thinking about chronic pain is firmly entrenched in the biomedical model.

However, over the last thirty years a shift of attention has been evidenced by the focus of national and international pain organisations on the importance of functional outcomes, rather than pain reduction, as a treatment goal [11, 12]. It is possible that previously hidden attractors will be uncovered as the pervasive influence of biomedical thinking readjusts and professionals and the public construct new models of health and illness.

5.4.5 Constant adaptation

A complex adaptive system is functional when it is able to adapt. When strict regulation and linear problem solving are imposed the system becomes less adaptive. Theorists propose that central control can stifle adaptive responses and throw a functional system into stagnation, inertia and ultimately chaos. Complexity theorists use the example of the Red Queen's comments in *Alice through the Looking Glass*, where the Red Queen explains to Alice that they must keep running just to stay in one place. To stop running is to fall behind [269]. The argument here is that too much central control in the form of rules and regulations can prevent participants from not only adapting to new demands on the system but from even maintaining their current position.

This situation occurs in treatment for chronic pain where efforts remain focused on arriving at 'the best solution' across the board, and on the national standardisation of intervention programmes [63, 69, 278, 297-299]. While guidelines and identification of good practice are important, these types of policy statements often make little or no recognition of the need for local problem-solving within a community context. Because health issues, like chronic pain, are deeply embedded within multiple contextual dimensions, high degrees of central control may be an undesirable barrier to creative, pragmatic problem-solving. In addition to requiring flexibility, problem-solving within a CAS is iterative, requiring access to high amounts of information and the resources for feedback and reflection.

5.4.6 Experimentation and pruning

> *"Ships can't steer if they are not moving, and living systems – such as organisations – can't survive without change, challenge, variety and surprise."* Flower and Guillame [300:17]

CAS theory is rich with examples of how experimentation and pruning have resulted in the emergence of exciting and effective innovations. Experimentation with putting telephone lines and binary code together set the stage for the internet. Pruning of less robust contenders in the same product system (like the Betamax recorder and the 5 ½" computer disc) resulted in superior product design and efficiency [245, 247]. In healthcare the pruning component of innovation is considered a critical and yet often overlooked issue. Zimmerman [301] proposes that, currently, letting go of the outmoded is a key problem for healthcare systems as new approaches are forced into pre-existing structures and processes. A system needs to be able to adjust to maintain its balance and conserve energy. Systems that have the freedom to take on new methods and abandon others allow for this dynamic interplay and can self-regulate. Loss of self-regulation (because rigid external control mechanisms have been applied) prevents the system from being adaptive. Petros argues that this type of external control, imposed consequent to a linear approach to healthcare, creates dysfunction and iatrogenic disease [294]. The balance in health has been lost through exclusive application of the scientific reductionst model and other complex influences have been devalued. He suggests the evidence that this scientific biomedical approach has failed is demonstrated through the increasing numbers of patients who are, "...voting with their feet, to iridologists, reflexologists and any other 'ologist' who can supply their needs" [294:176].

The reluctance to abandon what has been routine practice and to implement new approaches (introduced in section 5.4.1) is evident within chronic pain. An example would be the resistance of stakeholders to take up new information about the use of opioids and self-administered medication systems for non-malignant pain because of persistent beliefs (fear of addiction in this example) in the face of evidence to the contrary 87, 302]. This finding is consistent with other studies where lack of uptake amongst healthcare professionals for evidence-based interventions has been repeatedly highlighted [257, 260, 283] and practices that lack an evidence-base continue to be viewed as desirable treatment components. For example a review of the back pain literature revealed that relaxation, acupuncture, homeopathy and biofeedback all remain commonly employed forms of intervention despite systematic reviews all of which concluded that there was no evidence-base for the treatments' effectiveness [122, 156, 303, 304].

5.4.7 Inherent non-linearity

A principle of CAS is that, unlike linear systems where effort and return have a direct relationship, small events can effect major, and not necessarily predictable, change. Conversely, large highly regulated and centrally controlled efforts will bear little result [236, 250, 305] and can even have negative, iatrogenic effects [294]. Holland uses the example of an ant colony to explain non-linearity from a biological perspective. Specifically, he points out that while a colony may for a period grow more efficient with increased numbers of ants, this relationship (more ants = more efficient) does not hold ad infinitum. Rather, a point occurs at which the colony becomes too big, competition for resources outweighs the benefits of collective gathering and splinter colonies emerge [248]. Kauffman illustrates this same point with the example of automobile innovation. In the early twentieth century a wide diversity of sizes, shapes, wheels and drive linkages existed. Creative effort resulted in innovative improvements. Over time however, actual improvements required more and more effort to be inputted to the system and the effort/outcome relationship was no longer linear in nature but rather required dramatic shifts in thinking to achieve any true change beyond asthetics [306].

Perhaps the best example of this non-linearity in the treatment of chronic pain is the outcome of multidisciplinary programmes. These programmes are resource and labour intensive for both the service provider and the person with pain. However, it is not strongly supported in the evidence that a multidisciplinary approach has any additional advantage over other less intensive forms of service delivery [307, 308] and the degree of effectiveness of different features of these programmes remains unclear [309]. A systematic review of fourteen studies concluded that the outcome methodologies employed were for the most part flawed and no claim of economic effectiveness could be made in relation to the multidisciplinary team approach for chronic pain intervention [154]. Thunberg [310] cautions that poorly functioning teams, consequent to poor communication and a lack of shared values, can be less effective than sole practitioners. In Thurnberg's review the healthcare providers in one chronic pain setting had concluded that effective treatment requires an organisation that is "...loosely coupled, decentralized and organic in design...the character of a problem should determine the knowledge that is needed- not who has most power" [310: 758]. These service providers' conclusions and the features of other studies highlighted by Thurnberg et al. are all characteristics of a complex adaptive system.

For people with pain, treatment interventions do not follow a linear model. For example, the consultant interrupting a patient to take a phone call at the wrong time or a service user finding a support-group phone number pinned up at the local newsagent, are both very small actions, but they can nudge the event towards large-scale positive or negative outcome. There are examples in public health of very large-scale, centrally coordinated initiatives resulting in very little return. An example widely cited in the health promotion literature is that of the growing number of homosexual men currently engage in unsafe sex. Researchers propose a range of explanations for what is, given the large national programmes that have targeted this practice, a surprising phenomenon. Increased scepticism in healthcare, resistance to 'authority', an overall lack of personal responsibility in society, message 'over-kill', and trait theory have all been proposed as mediators against achieving change through large public health campaigns [311]. Crossley proposes that resistance to health promotion cannot be reduced to a single explanatory model but rather that it is embedded in the context of particular situations and interactions. Information presented about safe sex practices, for example, needs to be individualised to the group and venue. An identical pamphlet about condom use may be received very differently by a group of 14 year-olds in a school health class then by sexually active homosexual men in a nightclub. At this point it is difficult to speculate whether this contextually bound acceptance/resistance to intervention occurs for people with chronic pain because large, centrally controlled initiatives have not widely been developed.

5.4.8 Systems are embedded within other systems and co-evolve.

Sardar and Abrams [247] use examples from economics to explain the concept of embedded, co-evolving systems. They discuss how computers and electronic transactions have created a society where currency has evolved to become a virtual as opposed to a concrete object that can be held and moved from location to location. The printed monetary note is no longer the tangible representation of pension dividends, stock premiums, salaries and savings. This state was made possible through advances in computer technology. This computer technology meant that criminals no longer focused on physically stealing notes but instead applied this same advanced computer technology to divert/steal other people's virtual money. Law enforcement agencies were forced to evolve along with the new technology to prevent computer theft. Financial institutions are amongst the major funders of educational institutions training students and researchers to develop anti-theft software. In turn, the software can be applied for either legal or illegal gain. As one aspect of the system evolves, so do the others. It is the interaction between the aspects that allows creative new behaviours to emerge and create a system greater than the sum of its parts.

The proposition that systems are embedded and co-evolve is strongly evident in the arm of pain research that focuses on biopsychosocial frameworks as ways of conceptualising the chronic pain experience. Emotions [312], race and ethnicity [313], psychological well-being [314], the influences of partners [315] and employers [178] have all been shown to affect the experience of pain. Roberts' [270] study of Welsh-speaking people with pain and their interactions with English-speaking care providers offer some interesting insights into the erroneous assumptions about the language of the clinical encounter and chronic pain. Kalvemark et al [316] suggest that advanced medical technology, organisational reform, the evolving 'business' ethos of healthcare and a more educated and consumer-focused population have contributed a new and growing element of ethical dilemma to the complexity of health services delivery. The list of elements embedded within systems pertaining to healthcare and chronic pain is extensive and ever expanding as new research is reported. Time, place, cultural expectations, financial situation, social roles and responsibilities, learned behaviours from childhood and access to healthcare services have all been identified as features acting on and, in turn, being influenced by the person with chronic pain. The recent World Health Organisation publication Innovative Care for Chronic Conditions: Building Blocks for Action [265] highlights the growing imperative to reframe healthcare. The challenge of the 21st century is the management of chronic, lifestyle-related disease as opposed to the 'battle against bacteria' for which the biomedical model evolved over the last centuries.

5.5 Summary

The preceding chapter has described the growing awareness within the community of health researchers and policy makers of a need for refocusing medical care within a complex adaptive systems framework. The chapter has also highlighted ways in which the characteristics of complex adaptive systems can be applied to healthcare and the chronic pain experience. Complexity theory may offer a route for reconciling and legitimising the diverse range of theoretical perspectives discussed in Chapter 2 that are currently applied to the field of chronic pain management. Applying a complexity theory framework can also help stakeholders avoid the counterproductive sparring inherent in '*either/or*' linear thinking. Complex adaptive systems theory stresses that systems, made up of a myriad of interacting and idiosyncratic elements, require a range of explanatory models depending on the circumstances and context. The focus is on '*this/ as well as that*' and on understanding the relationships that move these systems in certain directions. A theory however is only as useful as its application and CAS theory offers many examples of how innovative and pragmatic management strategies can be applied to produce a positive outcome. Emerging management strategies for influencing outcomes in complex systems focus on flexible simple rules as opposed to highly structured and detailed engineering of solutions. The concepts of 'good enough vision', balancing between control and flexibility, adjusting to the needs of both safety and risk, valuing diversity and free flow of information, accepting paradox and dissent as opportunities for innovating new ideas, and implementing small actions as opposed to applying one big solution, are all seen as tools for effecting change in complex adaptive systems. Additional tools include accepting the power of, and working with, informal organisational systems (for example, conversations around the coffee machine) and seeking solutions through local level initiatives as opposed to central control [235, 326, 244, 251, 263, 317, 318]. The literature emphasises developing simple rules that can be creatively applied in ways that accommodate local context and circumstances. Simple rules specify what is desired for healthcare on a national level but leave the route free to be plotted at the frontline within a community context. If everyone in the country had to travel to London, complex adaptive systems theory would say that what matters is not whether they all travel in the same way, but whether they all get there. The NHS has clearly articulated this philosophy in the Modernisation Agency that specifies five simple rules:

1. *See things through the patient's eyes.*
2. *Find a better way of doing things.*
3. *Look at the whole picture.*
4. *Give frontline staff the time and the tools to tackle the problem.*
5. *Take small steps as well as big leaps.*

(NHS Modernisation Agency [266:5]

The preceding chapters have examined current thinking about the aetiology and management of chronic pain. Chapter 4 discussed why, from a constructivist perspective, beliefs and behaviours related to chronic pain are highly idiosyncratic. This chapter begins the discussion of how CAS theory can act as a meta-framework with the potential for legitimising and reconciling these apparently competing belief systems. The defining principles of CAS as they relate to chronic pain have also been presented and a brief discussion of management strategies for influencing CAS has been introduced. The background theories presented in this and the previous chapters guides the methodology and design for this study's exploration of the occurrence and implications of congruence between service users and service providers about what treatments are important for chronic pain. The next chapter will describe the design and process of the study.

Chapter 6

Methodology and Study Design

6.1 Introduction

"Can researchers ever know that what they are measuring exists beyond how they measure it?" Ogden [319:60]

Several very clear directions are emerging within healthcare research. The first is that a new relationship between researchers and the people they are researching needs to be developed. It is no longer acceptable or desirable for one group (researchers) to decide what needs to be known about another group (service users) and how this information will be collected. Rather, research must be designed to allow for sharing of information and decision-making to ensure relevance and legitimacy for all stakeholders. Bastian [320] explores how one of the most influential tools for evidence-based research, the Cochrane Collaboration, can be interpreted as supporting researchers in this process. The Cochrane Collaboration focuses on developing knowledge and states that ensuring access is one of its guiding principles. While currently many researchers interpret this to refer to the end-product of research, Bastion proposes that these goals can be widened beyond the narrow definition of sharing the final results to also include elements of both how studies are designed and carried out. Recommendations for Cochrane Collaboration participants include focusing on patient identified outcomes, supporting capacity building at the community level so that meaningful public participation can occur, developing mechanisms to seek out dissenting voices in addition to 'expert' patients, and addressing issues of terminology, not as an exercise in political correctness, but as an opportunity to challenge outdated role expectations and educate professionals. Addressing ways to make information accessible to people with different levels of ability, cultural backgrounds and access to technology are also identified as concrete issues in achieving the Cochrane Collaboration's goal of ensuring access [320].

The Department of Health, through its *Expert Patient* programme, has also taken a clear stand on the need for service users to be involved in all aspects of healthcare research, service delivery and evaluation.

> *"The era of the patient as the passive recipient of care is changing and being replaced by a new emphasis on the relationship between the NHS and the people it serves – one in which health professionals and patients are genuine partners seeking together the best solutions to each patient's problem, one in which patients are empowered with information and contribute ideas to help in their treatment and care"* DOH [321:9]

Operationalising this type of fundamental reform, where peoples' roles change from *subject* to *participant,* requires new skills from all involved. How can values and outcomes of relevance to service users be elicited, how should service users be recruited [322], what types of outcome measures are significant to service users [323], how can information be made accessible and understandable [270] and how can the inherent positivist bias held by researchers trained within the biomedical model be addressed [324], are only a few of the current challenges. Significant resource has been channelled into developing tools and providing information to guide this reconceptualised work. The Consumers in Health Research Support Unit of the NHS R&D programme has provided strong support and guidance to researchers in the form of publication of guidelines (for example Involving Consumers in Research & Development in the NHS: Briefing Notes for Researchers), and the INVOLVE network's regular newsletter that contains examples of good practice and skill development opportunities [26]. Additionally, the NHS Research and Development Health Technology Assessment (HTA) Programme has produced and widely disseminated reviews of techniques for eliciting public preferences in healthcare [325], consensus development methods [326], evaluating patient-based outcome measures [327] and structured reviews of research methods appropriate for qualitative [326, 328].

The second development evidenced by contemporary healthcare literature is that researchers must move beyond the perspective that positivist findings generated in randomised control trials are the gold standard for healthcare evidence.

> *"If practitioners were to use exclusively the standard levels of evidence model in their selection and use of information, they would be making sub-optimal decisions based upon less information than that which is relevant, valid and available for making the decisions"* Tickle-Degnen and Bedell [256: 234]

Because peoples' idiosyncratic natures have a strong influence on their health and well-being, research must be able to reliably and systematically examine related questions. Positivist research examines causality and probability and is essential for certain questions of medicine. There is therefore no suggestion that quantitative methods should be abandoned, but rather that additional tools (well established in other disciplines such as anthropology and education) be viewed with equal enthusiasm. Patterns and possibilities, values, beliefs and human relationships seldom pose questions that can be addressed through reductionist methods [107, 329]. The British Medical Journal (BMJ) has added a strong and unequivocal voice of support for expanding the healthcare community's repertoire of research approaches to include qualitative methods. Evidence of this support is apparent in BMJ's publication of Qualitative Research in Healthcare [330] as both a hardcopy and a free, downloadable publication from its website. Since that work the BMJ has published additional support for qualitative research methods [255, 331] and patient participation in research design [201, 227, 332]. BMJ has also fostered the ongoing debate and education needed to develop a more sophisticated awareness amongst practitioners as to the definition and generation of evidence-based medicine [191, 257, 331, 333]. The competent researcher of contemporary healthcare problems has incorporated the need for matching the question being examined with the best method possible.

> "*... Evidence based medicine is not "cookbook" medicine. Because it requires a bottom up approach that integrates the best external evidence with individual clinical expertise and patients' choice, it cannot result in slavish, cookbook approaches to individual patient care*" Sackett et al [333: 71].

The literature supports that it is counterproductive to look for one 'best' approach to healthcare questions and that increasingly a combination of both qualitative and quantitative methods are employed within the same study, addressing different dimensions of the question [325, 334]. The debate over the superiority of qualitative versus quantitative methods is passé and counterproductive. As Buck [335] eloquently points out; *"It is clear nonetheless that qualitative and quantitative research fulfil quite contrasting roles, thereby supplying different types of information and answering different types of questions"* [335:111].

There is significant and growing support for abandoning the qualitative/quantitative dichotomy and instead applying a pragmatic perspective driven by the questions and objectives of the study as opposed to the popular rhetoric of any given school of thought [335-337]. Bowling [334] proposes that researchers should focus on the historical foundations of thinking about any type of research. She states that the aim of understanding a phenomenon is best served by systematic examination. Whether it is carried out through observation, measurement, experimentation or a combination of techniques, the key features of this systematic examination are always rigour, validity (are you measuring what you say you are measuring) and reliability (the evidence that someone else would arrive at the same findings in the same conditions and context) [334]. This chapter will detail how a multi-stage approach, using a combination of both qualitative and quantitative methods was applied to examine the initial question of congruence between chronic pain service users and providers and to provide a structured iterative process for exploring emerging issues in greater depth. The chapter will also outline the strategy employed to insure that stakeholders were involved on an interactive basis through out all data collection and analysis stages.

6.2 Justification for two-stage design

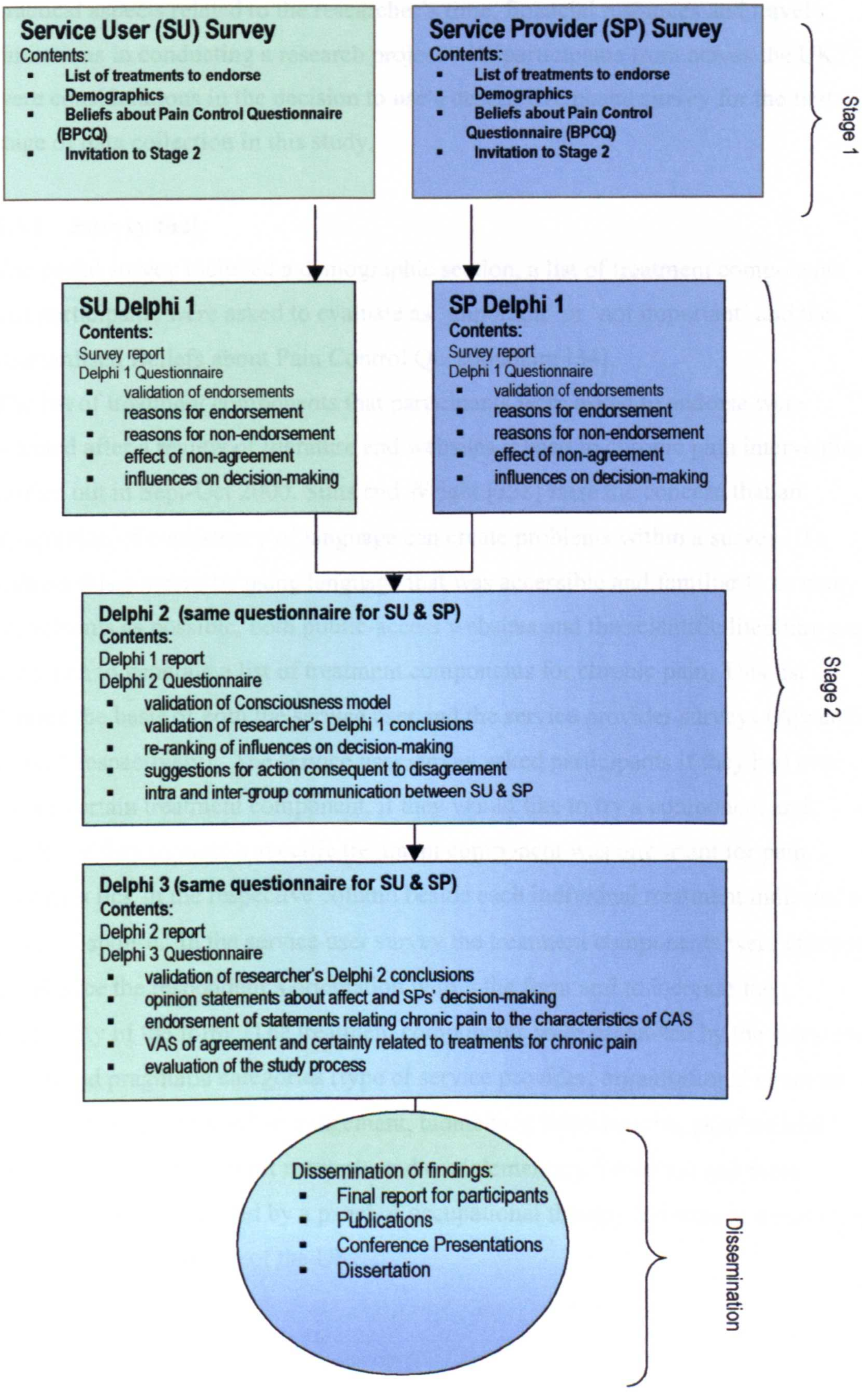
A two-stage approach was selected to explore the issues around congruence of beliefs between service users (SU) and service providers (SP) regarding what treatment components for chronic pain are 'important'. Within a constructivist analysis the researcher examines not only the quantifiable 'what?' but also the 'why?' of any question. Current research methods' literature points out that the two questions are not mutually exclusive within a research project. Rather, applying qualitative and quantitative data collection together can be a complementary process [192, 334] influenced by the research question rather than dictated by any methodological school of thought. The issue of congruence in beliefs about pain treatments is complex. Shiell [228] emphasises that values and preferences are not interchangeable concepts and a person may identify a certain treatment as important (preferred) but actually assign minimal value to it. To fully understand the question the study must look first at what people endorse as important treatments. This then needs to be followed by an examination of what personal meaning they have constructed to justify that endorsement and lastly, the relevance of this to decision-making in their lives. The first question can be explored for large groups of people using a survey. However, the second and third require a more in-depth phenomenological examination. The stages of this study are graphically presented in Figure 6.1.

6.3 Stage one: treatment endorsement survey

Starting with the 'what'....

Sims and Wright [338] point out that selecting a survey design is predicated on several key assumptions. One assumption is that discernable patterns exist in society. There is also an assumption that the terms used in a survey are interpreted consistently by all participants, that respondents will be honest in their replies, and that social and physical context are not major determining influences in participants' responses. Many of these assumptions are consistent with the goals of Stage one of the research. The researcher was interested in patterns that might emerge within and between respondent groups. The structure of a descriptive, anonymous postal survey lends itself to respondent candour and is flexible enough to allow respondents control over the time and environment in which they complete it.

Figure:6.1 Flowchart of study process



Accordingly, a survey was employed for the first stage of data collection in this study. This had the advantage, highlighted above, of offering participants the flexibility to respond at a personally convenient time and place. Additionally, practical aspects related to the researcher's time, financial resources and travel limitations in conducting a research project with participants from across the UK, were considerations in the decision to use a descriptive postal survey for the first stage of data collection in this study.

6.3.1 Survey tool

The postal survey included a demographic section, a list of treatment components that participants were asked to evaluate as 'important' or 'not important' and the standardised Beliefs about Pain Control Questionnaire [34].

The list of treatment components that participants were asked to endorse were selected after a review of literature and websites related to chronic pain intervention, carried out in Sept-Oct 2000. Sims and Wright [338] raise the concern that an assumption of consistency of language can create problems within a survey. To address this concern by using language that was accessible and familiar to as many participants as possible, both public-access websites and the scientific literature were drawn on to generate a list of treatment components for chronic pain. This list formed the basis of both the service user and the service provider surveys (Appendix 5 and 7 respectively). The service user survey asked participants if they had ever tried a certain treatment component, if they would like to try a component and thirdly, if they thought a specific treatment component was important for pain. Placing a tick in the respective column beside each individual treatment indicated a 'YES' response. In the service user survey the treatment components were grouped to enhance the respondent's orientation within the form and to increase the readability of the form. The treatment components were organised by the researcher into broad pragmatic categories (type of service provider, organisational structure of service, education for self-management, biomedical interventions, psychosocial interventions, peer-support network, and complementary therapies) and these categories were validated by a panel of occupational therapy lecturers at a university in the Northwest region of the UK.

The final survey had a Flesch-Kincaid reading grade level of 6.2 (computed with the grammar check option in Microsoft Word 2000). A grade level of six is within the recommendations for written health education materials [339]. The Department for Education and Skills in the UK estimates that 6.8 million adults have reading skills comparable to or below that expected of nine to eleven year olds [340]. A Flesch reading grade level of 6.2 is similar to or slightly above that of an 11 year old in the sixth year of education.

Two visual analogue scales were also included. The first scale was anchored at 0= '*no pain*' through to 10 = '*worst pain ever*'. The second scale was anchored at 0 = '*the doctor's choice of treatment is best*' through to 10 = '*I want to make my own choice*'. Demographic information was gathered following the treatment endorsement section in keeping with Moser and Kalton's [341] recommendation to put less interesting but more personal questions towards the final stages of the survey. Demographics included age, gender, job status, duration of pain, duration of membership in a support group and how they came to join the group.

The service provider survey asked age, gender, profession, years in practice, type of pain experience, pre and post qualifying training in pain, sources of information about pain and whether the respondent was currently working in a pain management programme. The survey asked participants who were currently working in pain programmes to indicate whether their programme provided, or would provide if there were the resources, each individual treatment component. They, along with any service providers currently not working in pain programmes were also asked to indicate if they thought the treatment component was important or not, by ticking the appropriate box. Individual treatment components were presented in random order within the service provider survey so that respondents would not be influenced by researcher-identified categories. The Flesh-Kincaid grade level for the service provider survey was 8.3 and is below that which it is reasonable to expect of a diploma or degree qualified healthcare provider.

6.3.1.1 Beliefs about Pain Control Questionnaire

The Beliefs about Pain Control Questionnaire (BPCQ) was selected as a standardised tool to explore the participants' pain control constructs [34]. Skevington's psychometric testing on the BPCQ included 6 groups so that comparisons could be made between i) people with pain and people who were pain –free, ii) patient versus non-patient groups, and iii) ill versus healthy participants. People with cancer, arthritic and unspecified pain as well as undergraduate students, university applicants and people attending an acupuncture clinic were included in the study. The BPCQ contains three sub-scales: Internal control (IS), Powerful Doctors (PD), and Chance Happening (CH). The 13-item scale (IS-5 items, PD- 4 items and CH-4 items) has an internal consistency of 0.73 (IS), 0.82 (PD) and 0.56 (CH) using Cronbach's alpha. In Skevington's research the test-retest reliability F-test ($p< 0.01$) results ($IS - r = 0.585$, $F = 0.14$; $PD - r = 0.243$, $F = 0.48$; $CH - r = 0.590$, $F = 2.36$) showed no significant changes in the three subscales for chronic pain patients after nine months [34].

The BPCQ does not appear to have been widely employed since its development in the early 1990s and its internal consistency is less then optimal, particularly for the CH scale (0.56). Higher internal consistency would have been desirable to reduce the chance of Type I or Type II errors (where existing relationships were either overlooked or falsely assumed). However, although there are numerous instruments available for assessing beliefs held by people with pain [342], the researcher was unable to uncover any standardised tools designed for use with service providers as well as people with pain. Additionally, normative BPCQ data exist for a range of groups and that was considered an asset for this study. It was critical to the study that the beliefs of service users and providers be collected in a comparable fashion. While recognising the limitations of the tool, it was nevertheless determined the best of the limited options available for meeting the study design goal of employing a consistent evaluation tool, applicable to all groups in a study, so as to increase the validity of comparative analysis. The BPCQ was only one component of many that collected data related to agreement between service users and providers and as such should be viewed as a tool to strengthen the triangulation of findings and not as conclusive in itself.

6.3.1.2 General design guidelines

All aspects of the survey development stage (and subsequent questionnaires) were guided by the recommendations outlined in Design and use of questionnaires: a review of best practice applicable to surveys of health service staff and patients [343] and by the principles outlined in the Plain English © Campaign [344].

6.3.2 Pilot of service user survey

The co-ordinator of the National Office of Arthritis Care, UK agreed to approach volunteer staff at the organisation to pilot the service users' survey (Appendix 3). Volunteers who were interested e-mailed their request for a survey to the researcher. Fifteen surveys were requested in total and 10 were returned. Participants provided both specific and general comments. The following list is indicative of the range and type of comments.

- *What is a recreation therapist?*
- *Don't use the term 'physician'.*
- *Add analgesics and Muscle Relaxants to the medication categories*
- *Are vitamins the same as supplements?*
- *What is biofeedback?*
- *Include a column 'I would NOT try if offered'*
- *Should I comment on services I arrange my self or only what the NHS offered?*
- *What is Capsaicin ointment?*
- *Am I responding that it is generally good for people or only things for myself?*
- *Add reflexologist*
- *Somewhat cramped and small print*

Additionally some problems were identified with the layout of the tick boxes and it became clear that the design could be simplified by eliminating the 'do not' columns.

6.3.3 Pilot of service provider survey

The service provider survey was piloted with a group of six allied health profession lecturers at the University of Liverpool. Their comments related to grammar and some wording they felt was ambiguous. The appropriate changes were made to the final draft.

6.3.4 Participant identification

6.3.4.1 Service users

The sampling strategy should both match the research question and meet the criteria of being relevant, and likely to generate return, enhance generalisation, produce behavioural descriptors, and be ethical and feasible [345]. Given these criteria, members of special interest groups (either lay or professional) were felt best suited to the aims of the study. It seems likely that different responses would be elicited from people who have pain but do not access support groups and from professionals who do not belong to specialist pain management organisations. The option of a sampling strategy based on the general population of NHS users and healthcare service providers was considered, but discarded on the grounds that too diverse a sample could potentially obscure any emerging patterns. Also, because people in support groups and specialist service providers are more likely to be involved in policy setting exercises, identifying patterns that existed within and between these groups was seen as a priority over focussing on a more general population. This sampling strategy, like all sampling, runs the risk of introducing bias and efforts were taken, consistent with the qualitative research design philosophy of trustworthiness and authenticity, to insure the participant description was as detailed and transparent as possible. Limitations of the sampling strategy are discussed within the context of the overall study methodology in section 11.5.2. The study design thus addresses only a small piece of the jigsaw; and representativeness is not implied.

Three support groups for people with chronic pain were identified as active in the Merseyside area. The organisers of all three groups agreed to distribute the researcher's survey through a combination of handout at group meetings and mailings (Appendix 1). None of the groups were willing to allow the researcher direct access to mailing lists, labels or membership demographics, so sampling was opportunistic as opposed to representative. Each group identified how many surveys they felt were required and the researcher added an extra 10 surveys to the requested number to ensure adequate availability for new members over the period of the study. In total 110 surveys were distributed between November and December 2001.

6.3.4.2 Service providers

Service providers were recruited from a range of organisations (Appendix 2). At the beginning of 2001 health professionals' pain-related special interest groups were approached for permission to use the membership mailing lists for survey distribution. The response of the interest groups/organisations is detailed in Box 6.i.

Box 6.i: Service provider special interest groups/organisations

Group	Membership number	Disposition of request
1. The Physiotherapy Pain Association	Unknown	Refused permission
2. National Occupational Therapy Pain Association (NOTPA)	Known	Approved request
3. Royal Collage of Nursing Pain Forum	Unknown	Refused permission
4. Pain Society (UK & Ireland)	Known	Approved request
5. British Psychological Society	Unknown	Stated they have no pain special interest group

The National Occupational Therapy Pain Association (NOTPA) and the Pain Society (International Association for the Study of Pain- IASP Chapter UK and Ireland) were willing to allow the researcher single-use access to their membership lists. The Physiotherapy Pain Association (PPA) and the Royal Collage of Nursing – Pain Forum Special Interest Group declined the invitation to participate. Reasons given for not allowing access to Special Interest Group mailing lists included gatekeepers' perceptions that members were 'tired' of being surveyed and that only acute pain (versus chronic) was of specific interest to the majority of members. The British Psychological Society stated they had no special interest group for pain and declined to participate. It was decided to proceed with the membership of the Pain Society (plus any NOTPA members who were not members of the Pain Society), as this would provide a multidisciplinary sample of sufficient size for statistical analysis to determine whether there was congruence of pain treatment beliefs between professional groups. It would also allow the researcher to solicit volunteers for the second, qualitative stage of the research.

Once the mailing was adjusted to remove duplicates (nineteen occupational therapists who were members of both organisations), twenty-four non-UK/Ireland members and fourveterinarian members of the Pain Society, the final mailing went to one thousand, four hundred and twenty-six (1426) service providers during the months of October-December 2001.

6.3.5 Ethical considerations

The survey pack sent to each service user and service provider included an introductory letter of invitation and explanation, a stamped return envelope, and the respective service provider or service user survey form (Appendix 4 and 6). The study population were individuals involved in special interest organisations and self-managed support groups as opposed to NHS employees and patients in receipt of NHS services. The NHS medical research ethics review process (MREC) was not considered applicable in this situation and, instead, the committees elected by the members of each organisation to act as gatekeepers on the members' behalf were approached about the study. To ensure participant confidentiality only single-use mailing labels or second-party distribution was used for the first survey and gatekeepers did not receive any indication of which specific members of their organisation had or had not replied to the survey. Consent to participate in the second stage required the respondent to first indicate in a tick-box that they were interested in participating in Stage two. They manually filled in a blank box with their contact details in the space provided on the survey form. At a later point in the survey they were again asked to provide contact details if they wished to participate in Stage two. This redundancy (first asking for contact details and then again later seeking an indication of willingness to participate in Stage two) was deliberate to safeguard against having participants' intention to volunteer for future stages misinterpreted. An information sheet was incorporated into the introductory letter (Appendix 4 and 6) and participants were provided with the following information:

- why they were being approached
- how the researcher received their name (if a direct mailing)

- the purpose of the study
- why it was relevant to them
- what was involved and an estimate of time required
- who was supervising the researcher
- what would happen to the findings
- how the data would be safeguarded and kept confidential
- how to contact the researcher
- assurance that participants could withdraw and have all data returned if they wished.

6.3.6 Analysis

The survey had two discrete response sections; the BPCQ scales and the treatment endorsement section (Appendices 5,7 and 8). All surveys that had both or either one of the sections completed were entered in the findings. Surveys that were returned with neither section completed were recorded in the count of returned surveys but no findings were recorded. During the statistical analysis no estimation was attempted for this missing data. All statistical analysis was carried out with SPSS Version 11.01 ®. When small within-sample sizes occurred non-parametric tests (i.e. tests where no assumption that the sample has a normal distribution can be made) were employed. Pallant [346] points out that while non-parametric testing is most suitable for nominal and ordinal scale data where there are small sample sizes, it is less sensitive to between-group differences than parametric testing. This means that statistically significant differences between groups may not be detected (Type II error).

The BPCQ consists of three subscales; Internal Control (IS) has a total possible score of 30, Powerful Doctors (PD) and Change Happening (CH) each have a possible score of 24. All BPCQ raw scores were weighted and entered as separate domains (IS, PD & CH) for comparative purposes. Chi-square analysis of endorsement for whether a treatment was 'Important/Not Important' required aggregation of the BPCQ scores into 'Hi/Low' ('Hi' representing all converted scores above the group mean and 'Low' consisting of any scores less than or equal to the mean).

6.4 Survey report

Stage two of the research involved a series of three Delphi questionnaires that allowed participants to comment on findings from each previous questionnaire. To facilitate reflection and discussion in the Delphi 1 questionnaire, a report from the Stage one survey findings was generated. The report, intended for both service users and service providers, was presented as a four-page booklet, on light yellow coloured paper. The paper was coloured so that it would stand out from the Stage two Delphi questionnaire it would be mailed with. The report, ***Beliefs about treatment for chronic pain: views of service providers and service users*** (Appendix 9) was prepared in September 2002 and included a brief introduction to remind the participants about the study, a profile of who had responded to the survey (gender, age, professional sub-group or service user) and a list of treatments that the participants (by sub-group) endorsed as important. A final section presented the finding that service users and providers had very weak agreement about what treatments were important and identified patterns in responses that had emerged. The complexity of the information made it difficult to write at a lower grade level and despite refinements to several pilots of the report the Flesch-Kincaid score was grade 10.2. This is higher than desired and may have affected some participants' comprehension of the report.

6.5 Stage two: Delphi round

looking at the 'why'…

The original plan was for Stage two to be carried out as a series of in-depth interviews with volunteers in the North-West of England and employing a grounded theory methodology [347]. However, there were many more volunteers for Stage two than had been anticipated and it was decided to select an alternative research method that would allow for all of the volunteers to participate while still staying within the resource limits of the researcher. A review of the literature identified that Delphi technique offered many positive features and allowed for structured examination of qualitative issues across large groups of physically and socially dispersed people. Although Delphi technique was originally designed in the 1950's as a rapid consensus building tool for industry and the military [348], over the last twenty years it has been applied with increasing frequency for the purposes of information sharing and expanding awareness amongst people who do not routinely share ideas and issues [326]. Walker and Selfe [349] propose that Delphi technique bridges the gap between qualitative and quantitative data collection in healthcare because of its quasi-experimental nature (gathering statistical data within an iterative process). They report that a CINAHL (Index to Nursing and Allied Health Literature) search identified eighty-one studies using Delphi technique in the thirteen years prior to 1988. The same search strategy found one hundred and thirty-four studies in the period 1991-1996. These studies have focused on a wide range of healthcare issues involving policy formation, decision-making, curriculum development and treatment outcome prioritisation. Walker and Selfe present a table of research questions to illustrate the diverse scope of topics for which Delphi methods have been employed. These include: perceived roles of allied health professionals, criteria for teaching therapeutic techniques at the undergraduate level, research prioritisation exercises, development of a uniform classification system for people with back pain, guidelines for clinical practice placements and orthotic management protocols [349]. They offer this increase in use of the technique as evidence of its growing acceptance as a valid research tool. Other evidence for its usefulness includes the discussion of Delphi technique in research offered on the Scottish Network for Chronic Pain Research website [350] and its inclusion in a recent Health Technology Assessment Review [326] of consensus development techniques.

6.5.1 Definition of Delphi technique

Delphi technique has been described as a, 'reliable and creative exploration of ideas or the production of suitable information for decision-making' and as, 'a series of questionnaires interspersed with controlled opinion feedback' [351]. Delphi involves a number of 'experts' in a subject field completing a series of iterative questionnaires and is considered an excellent tool to explore underlying assumptions and information leading to differing opinions [352]. A Delphi study occurs in several rounds with the first round being used to generate ideas that are then used to structure the questions for subsequent rounds. The responses to each round are analysed (either quantitatively, thematically or a combination of both) and the analysis is sent back to each participant in an anonymous form, along with the next questionnaire in the series. This iterative process allows each round of questionnaires to be designed to focus on emerging themes and ideas [348, 349].

6.5.2 Strengths of Delphi

Adler and Ziglio [348] point out it is not uncommon to have large numbers of people on committees involved in health policy and planning. With the expanding role for service users in healthcare committee sizes can be expected to grow still larger. Large group sizes bring a range of problems. Pragmatically where and when to meet becomes more complicated. Transportation, room availability, conflicting schedules and unexpected events that take precedence need to be juggled. Deadlines add an additional element of unwelcome pressure. Less concrete issues exist as well in the form of group dynamics, level of facilitation skills required, and communication channels. In face-to-face meetings issues of status, power and communication skills can exert considerable negative influence over interactions and are particularly resistant to change because of the covert nature of these characteristics [334, 353, 354]. The literature identifies that Delphi methods can redress a number of problems such as these. For example, because people do not meet face-to-face in a Delphi study there is much less chance of feeling intimidated by other professional groups or strong personalities. Participation bias is reduced when people are free to reflect at their own pace and without the pressure of others' scrutiny. The traditional hierarchal organisation of healthcare systems is reduced in a Delphi study. Additionally, the group dynamics that can lead to unassertive and less confident members of a group withholding or modifying their comments because of perceived (or actual) sanctions are not present. Delphi studies can be more cost-effective because participants and the researcher do not have to travel, regular work schedules are not disrupted and transcription costs for interview or focus groups data are avoided. However, printing and postage can be a factor (especially in large studies) and this needs to be weighed against the costs of traditional interviewing and focus groups. Focus groups as a rule include no more that twenty participants [334], whereas a Delphi study can accommodate a much larger group of people, thus resulting in a more representative sampling of opinion. Participants are more in control of the time and place they complete Delphi studies as opposed to feeling the pressures of scheduling more common during in-person data collection approaches [334, 350, 353-356].

6.5.3 Limitations of Delphi

Researchers must also be conscious of potential limitations of particular research methods and design the study appropriately. Over time the term 'Delphi' may have come to be misused and it is cautioned that careful and detailed descriptions of the process must be provided when applying the Delphi method to ensure issues of validity, rigour, and credibility are properly addressed [357-359]. Crisp et al [360] stress it is not the Delphi technique itself that is unreliable but rather that term has been incorrectly applied to a range of poorly designed studies to justify less than systematic research. Delphi methods must be subject to the same rigours of design (such as triangulation, researcher transparency and reliability checking for coding) as guides any form of qualitative research [334]. These issues concerning rigour have been addressed in the design of the present study and will be discussed in greater detail in section 6.9 (Rigour of the study).

Researchers have identified other practical limitations to employing a Delphi technique:

- High organisational demand to co-ordinate the 'paper-trail' and keep careful records.
- The time between rounds can be lengthy and participants may lose interest.
- The process is structured and lacks flexibility, compared to an interactive and dynamic interview.
- Non-verbal clues (facial expression, sighs etc) to respondents' opinions are not evident and so cannot be explored [352, 358, 359].

6.6 Delphi 1 – the decision making process

The first Delphi questionnaire provided feedback to participants about the survey findings (these findings will be presented in detail in Chapter 8). The questionnaire then asked specific questions based on these findings, with the goal of exploring why they had made the choices they did. Because service providers and service users had different endorsement patterns in the first survey, a separate Delphi 1 questionnaire was developed for each group (see figure 6.1). The questionnaires followed the same overall format but were modified to reflect the variation in each group's responses to the Stage one survey (Appendix 10 and 11).

6.6.1 Delphi 1 questionnaire

The questionnaire forms were eight-page booklets on blue, A4 paper so that participants could easily separate them from the report (which was reproduced on yellow paper). There were separate booklets for the service users and the service providers although the overall style and appearance was the same. Flesch-Kincaid reading grade level for the service provider questionnaire was 8.5 and for the service user questionnaire it was 6.5. Each participant was assigned a unique code number so that response/non-response could be tracked across the Delphi questionnaires. All questionnaires were accompanied by an information sheet on headed notepaper from the University of Liverpool (Appendix 12 and 13), the initial survey report and a stamped return envelope. The researcher's phone number and e-mail were presented in several locations though out the documents to facilitate ease of access to assistance if any questions arose. After one month reminders were sent to service users who had not returned the survey. Because of the small number of participants in the service users' group it was felt that reminder letters were warranted. Costs precluded sending reminders to the larger group of service providers who had not responded.

Both SU and SP questionnaires began with an introductory statement and reminder that participants did not need to fill in each section, and that they were free to provide as little or as much detail as they chose. Participants were also reminded that non-response at this round did not exclude themselves or others from receiving reports and questionnaires for subsequent rounds. This opt in/opt out option is considered to be one of the benefits of Delphi technique [349], potentially leading to higher response rates overall. Both the SU and the SP questionnaires included two open-ended questions requiring written comments on a total of thirteen separate treatment components, one question with a list of eight separate influences requiring ordinal scale responses, and one question which required selecting the three most important elements out of a possible ten. All questions invited participants to write in any additional information they wanted to give.

Question 1 listed the ten treatment components for chronic pain most frequently endorsed in the first survey. The question asked participants to write their opinion about why other participants ranked these treatment components as important. Each treatment component was highlighted in **bold** and the percentage of participants who selected the treatment as important was given in brackets ( ). Question 2 was structured in the same manner and identified the three least endorsed treatment components. Question 3 asked service providers whether, in their opinion, it mattered if service providers agreed on what are the most important treatment components. The response options were 'Yes' or 'No'. Service users were similarly asked about whether service user agreement matters. This filter question then directed people who had answered 'NO' to go onto Question 4. People who answered YES completed the remainder of the question and selected from a group of ordinal, unidirectional scales how much effect disagreement would have within each of the following categories:

- Financial
- Emotional effect on service provider (in service provider questionnaire only)
- Emotional effect on service user (in service user questionnaire only)
- Treatment outcome
- Relationship with patient/client (in service provider questionnaire only)
- Relationship with service provider (in service user questionnaire only)
- Public perception of treatment for pain
- Range of available treatments
- Relationship with co-workers (service provider questionnaire only)

For each statement the 5 point scale was anchored at 0 = '*No effect*' through to 4= 've*ry marked effect*', and participants were invited to write in comments if desired.

Question 4 asked participants to select and rank order (from 1=*strongest*, 2 = *2nd strongest*, and 3 = *3rd strongest* influence) what they believed to be the three most significant influences on their decision-making about whether a treatment is important. The lists of potential influences were different for service users and providers and are identified in Box 6.ii.

Box 6.ii: Ranking of influences on decision-making

Service user influences	Service provider influences
1. past experience	1. past clinical experience
2. advice from healthcare provider	2. patient preference
3. advice from complementary therapist	3. government and NHS guidelines
4. what family and friends recommend	4. clinical protocols developed by service provider's team
5. what I believe is causing my pain	5. philosophical framework of treatment programme
6. what I have read in magazines or seen on TV	6. internet search
7. information from someone else with pain	7. readings in current journals
8. what I can afford on my budget	8. information from pharmaceutical companies
other (write in)	9. what the patient is willing to try
other (write in)	other (write in)
other (write in)	other (write in)

Participants were reminded at the end of the questionnaire to mail the form back within the next two weeks and that a report on the findings from this Delphi round would be mailed to them once data analysis was complete.

6.6.2 Analysis

6.6.2.1 Coding Question 1 and 2

These questions asked participants to give their opinion about why certain treatments were rated as 'important' or 'not important' by the participants in the first survey. Bowling [334] suggests that, when a study is exploratory and is concerned with theory building, it is preferable to use inductive coding rather than working to a predetermined coding framework. This approach has the flexibility for development of new sub-themes that may not have been anticipated prior to the data collection. This is consistent with the aim of this study to allow for theory building work and consequently inductive coding was carried out. It was also recognised that, as the questions were open-ended, comments relevant to more than one grouping and subsequent sub-theme could emerge from each participant's responses.

Grouping of statements into sub-themes was carried out for all of the treatments listed at questions 1 (*Why is this treatment important*?), and 2 (*Why is this treatment not important*?). The written responses for each question were read a minimum of twice, then grouped and given a group label. For example in response to Question 1 – 'Why is education about what causes pain important?', service users made statements like *'if you are informed you know what you can do that does not cause pain (participant 418), knowledge that you will not make things worse is so important (832)* and *'without some form of education [you can] carry on for years and it can be too late to rectify or ease the original condition' (836).* These statements were given a grouping title of ' **Knowing to not hurt yourself**'. This process was followed for each statement made regarding all 10 of the treatments discussed at Question 1 and the 3 treatments in Question 2. Each grouping of related statements was given a title and identification number (1A, 1B, 1C, 2A, 2B etc). The number indicated which treatment component the grouping was related to and the letter identified the different groupings that emerged from all comments regarding that treatment component. For example, in the service users' survey, eight discrete groupings emerged from the Question 1, treatment component 1 ('education about pain') comments. These groupings are represented as 1A, 1B, 1C through to 1H. Each grouping cross-referenced with the relevant respondents' code numbers is shown in Appendix 14.

Related groupings were then coded into sub-themes. For example the groupings **1C**- *'you need accurate information'*, **2D**- *'You need to know what is right'*, **3D** –*'you need the correct information'* and **5B**- *'Learn how you should do things'* were all groupings organised into the sub-theme of '**Doing it right**'. This means that for treatment components 1 (education about pain), 2 (education about posture), 3 (physiotherapy) and 5 (graded activities of daily living –ADL) the service users made comments that contributed to the overall sub-theme of **'Doing it right'**. This is presented diagrammatically in Box 6.iii.

Box 6.iii: Delphi 1, Question 1 coding examples

Groupings	Number of groupings in sub-theme	Sub-themes	Theme
▪ *you need accurate information (1C)* ▪ *you need to know what is right (2D)* ▪ *you need the correct information (3D)* ▪ *learn how you should do things (5B)*	4	Doing it right	**Coherence**
	4	Being informed	
	9	Keeping pain free	**Purposiveness**
▪ *exercise and keep fit (3B)* ▪ *exercise programmes (6C)*	2	Keeping fit	
	2	Keeping able	

The final organisation of sub-themes was theoretically driven and employed a constructivist paradigm, within which the underlying assumption is that each individual constructs a personal reality consistent with the context of his or her own life. This reality may be in conflict with that of others around him and is flexible, dependent on the interaction between experience, new learning and the form of feedback received consequent to the actions a person takes in response to his reality [117]. It is widely accepted in the literature that pain is a multidimensional phenomenon with sensory, affective, social and cognitive components [6, 361]. It follows then that a range of similar components will mediate the individual's judgement and construction of the importance of certain treatments for this pain. The Consciousness model [35] (discussed in Chapter 4); is consistent with this line of thinking. This framework proposes that pain is an internal construct based on the personal representation of reality and that personal representation is temporal, dynamic and requires a complex interplay of physiological, psychological, social and learning dimensions. As discussed in detail in Chapter 4 Chapman proposes that pain exists only through consciousness and that consciousness has four key themes: *coherence, sense of self, purposiveness* and *personal nature/ affect.* All of the sub-themes that emerged from the analysis in Question 1 and Question 2 responses were therefore organised against these four themes in the Consciousness model [35].

6.6.2.2 Validation of coding

Both interpretive and descriptive labels were employed for grouping the data. Interpretive groupings are highly dependent on the researcher's judgement of statements that form common categories. For example, a range of statements (*'I wanted to hit him', 'they really make me fume', ' I just see red')* may all be interpreted to relate to a common sub-theme of data (in this case 'Anger'). However, it is possible that different researchers would make different interpretations and the researcher needs to acknowledge that the groupings are contextually bound and subject to personal bias. Descriptive coding is generally more straightforward, describing an action (for example 'Not sleeping'*)*. However, apparently straightforward descriptors are also influenced by context and should not be assumed to be completely value-free [334]. Two academic colleagues who were not involved in the researcher's project validated the coding (see Appendix 15). The average agreement with the researcher's coding was 64.3% and 68.1% for Questions 1 and 2 respectively. This indicated that the original categories were not discrete and so these were refined subsequent to discussion with the reviewers. The potential for insufficient information for confidently coding all data and for identifying negative cases is an inherent problem when dealing with short, written responses to open-ended questions, as opposed to interview data. It is possible that negative cases were overlooked because the researcher failed to interpret the responses as they were intended. It was not possible to interpret comments that offered too little information (for example respondents who wrote in '*nonsense*', *'!!!'*, and *'this is too much trouble'*) and these type of comments were excluded from the coding. Although clarification of these comments would have been desirable and could have added to the depth of the information, pragmatic concerns about distance and cost precluded pursuing additional input from these respondents.

The coding, as discussed above, is subjective on the researcher's part. However, the Delphi's iterative process acts to increase the reliability of the interpretive process. In this Delphi study a report summarising all participants' responses and detailing the researcher's interpretation was provided at the end of each round. Questions in the subsequent questionnaire specifically asked participants if they agreed with the researcher's interpretation or not and space to elaborate was always provided. This process provided the opportunity for participants to accept or refute the interpretation offered by the researcher. In this way participants were able to provide clear direction that the coding was either acceptable and representative of participants' intent or that the researcher needed to re-examine the information and formulate a clearer analysis.

6.6.2.3 Organising quantitative data

For Questions 3 and 4 SPSS version 11.01 [362] was used to compute frequencies and relevant analysis that will be discussed in detail in Chapter 8 (*Delphi 1 Findings*). Participants also included comments on each question and these were compiled in text boxes of related groups to illustrate points that will be discussed in depth in Chapter 8.

6.6.3 Delphi 1 Report

A report was prepared summarising the findings of the Delphi 1 questionnaire (Appendix 16). The report provided a short background to the study up to this point and briefly presented the findings for Questions 1 through 4 from the Delphi 1 questionnaire. A combination of text, charts, graphics and bullet points was used across the eight-page report. Key points were highlighted in blue to help break up the information into more manageable 'chunks'. These strategies were consistent with the guidelines for increasing the readability of surveys as outlined in a recent review of best practice for survey design in healthcare [343]. The report concluded with a summary of its purpose and a reminder that the questions in the Delphi 2 questionnaire would ask whether the participant agreed or not with the findings in the report. The report was printed in booklet format with eight, A4 size pages. The Flesch-Kincaid reading grade level was 10.9 which was higher than optimum. the Flesch-Kincaid is intended for use with primarily text documents and the use of tables and bullet points as opposed to sentences may have been an influence on the higher score. To meet the goal of sharing information between all participants only one report, which contained both service user and service provider responses, was prepared. In that way, each group could reflect on their own answers in relation to those held by others.

6.7 Delphi 2 – the Consciousness model

The Delphi 2 questionnaire (Appendix 17) was designed to share information with the participants about responses to the Delphi 1 questionnaire and seek their validation of the conclusions (presented to the participants in the Delphi 1 report) drawn by the researcher when applying Chapman's Consciousness model [35]. The questionnaire also explored participants' opinions about what actions, if any, should be taken when service users and providers do not agree about what treatments are important. Participants were asked to identify who was responsible for taking these actions. Participants were referred back to information presented in the accompanying Delphi 1 report to help them reflect on their own and other people's beliefs and opinions.

6.7.1 Questionnaire design

The questionnaire was printed as an eight-page A4 booklet and the Flesch-Kincaid reading grade score was 7.4. Although the service users and providers received different coloured questionnaires to facilitate ease of data entry and sorting, the questionnaire content and structure was identical.

The seven-part Delphi 2 questionnaire comprised three ordinal scale questions, two questions requiring ranking with an optional 'comments' section and two open-ended questions requiring written comments with a sentence completion prompt. Questions 1 and 2 used ordinal unidirectional 5-point scales to determine whether people thought their reasons for selecting a treatment as important were guided by each of the four components of consciousness previously discussed in Chapter 4. Each of the components was stated in 'ordinary language', as opposed to Chapman's terminology [35], to improve the reliability of each statement. For example, the concept of 'coherence' was represented by the statement, '*whether the treatment makes sense to me*'. Both parts 1 and 2 had a space for write-in comments if the respondent wished to add anything to his/her answer.

Question 3 asked participants to use a 5-point unidirectional scale to indicate their level of agreement with the conclusions drawn by the researcher in the Delphi 1 report. A section for comments was provided. Question 4 asked participants to reflect on how service users had ranked the influences on their decision-making and then to state their own ranking for the same influences. Both service providers and users were asked to complete this section. Question 5 asked participants to do the same, this time reflecting on the influences that service providers had rank-ordered. Each sub-section had space for written comments if the participant wanted to offer any additional thoughts.

Question 6 asked participants if they thought any action should be taken when service users and providers had different opinions about what treatments are important. Those who agreed action should be taken were asked to list any actions they thought were needed, regardless of whether they believed the actions to be possible or not. The final part of Delphi 2 offered participants an opportunity to communicate with each other through completion of an open-ended statement to service users and a statement to service providers.

The questionnaire concluded with a summary of what would happen next in the process and a reminder to return the questionnaire in the addressed, stamped envelope within the next 3 weeks. Contact information for the researcher was also provided in case of any questions. Each volunteer for Stage two of the study, regardless of whether or not they had responded to the Delphi 1 questionnaire, received the Delphi 2 questionnaire pack. This included a covering letter (Appendix 18) with a Flesch-Kincaid score of 8.3, the Delphi 1 report, the Delphi 2 questionnaire and a stamped, addressed envelope. After one-month service users who had not responded were sent a prompt letter and duplicate survey.

6.7.2 Analysis

A similar format of analysis was followed for the Delphi 2 questionnaires. SPSS Version 11.01 was used for descriptive analysis and statistical testing in Questions 1-5, and written comments in Questions 6 and 7 were grouped by themes and presented in tables and charts to better display relationships and compare opinions across groups.

6.7.3 Delphi 2 report

A report was prepared presenting the findings of the Delphi 2 questionnaire (Appendix 19). The material was presented as an eight-page booklet with A4 size light green pages. As before a combination of text, bullet pointed lists, graphs and tables were used to increase the interest and readability of the document. The Flesch-Kincaid reading level was 9.1 and the same report was prepared for service users and providers. The first page of the report presented an introduction to remind people about the study and what had already taken place and then summarised the findings. Parts 1 and 2 presented the respondents' agreement with applying Chapman's Consciousness model [35] to organise influences on judgements about pain treatments. A bar graph was used to illustrate the differences between service user and service provider responses. Part 3 identified which five of the twelve conclusions drawn by the researcher from the Delphi Stage two questionnaire both service users (SUs) and service providers (SPs) agreed with. It also presented the four statements they jointly disagreed with and finally, the two statements where SUs agreed but SPs disagreed. Part 4 discussed how participants' ranking of the influences (*most important* to *least important*) had changed over subsequent rounds of the Delphi and contained a table to illustrate this shift.

Part 5 reported the percentage of respondents who felt action was required if there was poor agreement between SUs and SPs. Part 6 presented recommendations for action in relevant categories (who should be responsible for the action), a table identifying how often the recommendation was made (represented by numbers in brackets ( ) at the end of the statement), and which group of participants made the recommendation.

Part 7 reported the participants' comments to each other. A four-column table was used to organise these data and present:

- Service user comments to service providers
- Service providers comments to other service providers
- Service user comments to other service users
- Service provider comments to service users

A short conclusion, brief reference list and reminder about the next step in the Delphi study completed the report.

6.8 Delphi 3 – complex adaptive systems

> *"There are three principal means of acquiring knowledge available to us: observation of nature, reflection and experimentation. Observation collects facts; reflection combines them; experimentation verifies the results of that combination."*
>
> Diderot, 1753 in [363]

The focus of Delphi 3 arose from the iterative process of reflecting and exploring the data generated so far in the research process, in relationship to its theoretical underpinnings. The study had started from the relatively straightforward, more linear process of gathering information about 'what' participants believed. In Delphi 1 and 2 the focus moved into the area of 'why' people held certain beliefs and opinions. To look at the 'why' the research needed to reflect that pain beliefs are contextually embedded and subject to a wide range of idiosyncratic influences. The research turned from quantifiable units of behaviour (how many people stated that 'X' is an important treatment) to an exploration of the patterns and relationships that emerged from the data. The first theoretical framework employed to facilitate that process was Chapman's Consciousness model [35] as discussed in Chapter 4. The final stage of the research (Delphi 3) drew on complex adaptive systems theory (Chapter 5). The design and analysis of the Delphi 3 questionnaire was intended to gather information in relation to the principles of complexity as applied to chronic pain treatments and this is discussed in the following section.

6.8.1 Delphi 3 questionnaire

The questionnaire (Appendix 20) was comprised of three questions with ordinal scaling, two visual analogue scale questions and two open-ended questions requesting written answers. It was presented as an eight-page booklet on buff coloured 4A size paper and the introduction reminded the participant about the purpose and history of the study to date. Action statements were included at both the beginning and the end of the questionnaire regarding what to do with the completed questionnaire and how to contact the researcher. The final page also included a description of how information from the study had been disseminated (journal articles, scientific posters and presentations). This was provided to illustrate that respondents' participation in previous questionnaires was valued and was being shared. The researcher also wanted to encourage continued participation in the final round. The Flesch-Kincaid reading level for the Delphi 3 was 9.0 and the same questionnaire went to both service users and providers. As before, efforts to improve the ease of completion included use of scales with optional 'comments' sections and frequent ' white space' to decrease congestion of the pages.

Question 1 asked respondents to validate a series of statements based on the conclusions the researcher drew from Delphi 2 responses. Participants ticked a 4-point scale (*1 = strongly disagree* to *4 = strongly agree)* for each question; a '*don't know*' option was not provided. McColl et al's [343] systematic review of evidence related to questionnaire design identified that the debate between questionnaires with 'forced opinion' (through the absence of a 'don't know' option) and those providing a middle ground ('no opinion') is extensive and inconclusive. Poe et al [364] concluded that it is preferable to construct self-administered questionnaires without 'don't know' options because the absence of this option does not affect overall response rate and the questionnaire is easier to follow and less cluttered. Other researchers have drawn opposing conclusions [343]. In this case the researcher was guided by the goal of making the scale as simple as possible and the assumption (underpinning the original participant recruitment strategy) that people who were members of professional special interest groups and service user support groups could be considered as 'expert' and more likely to hold an opinion. This scale construction decision was applied to Questions 1,3 and 7 in Delphi 3 questionnaire.

Question 2 was an open question that asked for opinions about why service providers stated their decision-making about treatments was not influenced by affect and self-image. Question 3 sought participants' endorsement of twenty-three statements based on the eight key characteristics of complex adaptive systems discussed in Chapter 5 [239]. Statements (based on the principles of complex adaptive systems) were drafted by the researcher and then reviewed by the Director of the Centre for Complexity Research at the University of Liverpool. Feedback from this review was incorporated and the final series of twenty-three statements was developed. Question 4 also focused on applying a complex adaptive systems framework. As previously discussed in Chapter 5 (section 5.2) healthcare can be plotted within a matrix moving from high certainty and high agreement (indicating a linear relationship) towards increasing uncertainty and disagreement (indicating a complex relationship). Participants were asked to indicate their beliefs about these two features in relation to chronic pain treatments on two 10 cm visual analogue scales. The first scale was anchored at '*no agreement – total agreement*' and the second scale at '*no certainty – total certainty*'.

Question 6 reminded the participants that most of the suggestions in Delphi 2 ('*what action should be taken when SU & SP do not agree*?') focused on what the service provider should do, with very few recommendations of actions that the service user should take. Participants were asked to reflect on this and offer their opinion about why it had happened.

The final question sought participants' evaluation of the study process and design. This was seen as an essential step in carrying out research that was consistent with the principles of collaboration, credibility and ethical practice inherent in qualitative inquiry [365]. Nine questions related to the usefulness of the study to each participant and their feelings about the process were presented with a 4-point scale (anchored at 1 = '*Yes, very much*' and 4 = '*No, not at all*'). Additionally space was provided for any written comments people wished to make.

The Delphi 3 questionnaire, Delphi 2 report, covering letter (Appendix 21) and stamped return envelope were distributed by post. All service users who had not responded after three weeks were sent a reminder letter, return envelope and duplicate questionnaire.

6.8.2 Analysis of Delphi 3

A similar format of analysis was followed for all three rounds of the questionnaires. SPSS Version 11.01 was used for descriptive analysis and statistical testing in Questions 1, 3, 4 and 7. Written comments in Questions 2, 6 and 7 were grouped by themes and presented in tables and charts to better display relationships and compare opinions across groups. Validity of the coding for Question 2 was conducted in the same manner as described in section 6.6.2.2 (Delphi 1: validation of coding).

6.8.3 Delphi 3 report

A report was prepared presenting the findings of the Delphi 3 questionnaire (Appendix 22). The material was presented as an eight-page booklet with A4 size pages. As before a combination of text, bullet pointed lists, graphs and tables were used to increase the interest and readability of the document. The Flesch-Kincaid reading level was 9.6 and the same report was sent to all participants. The introduction highlighted the interesting feature of participants opting in and out of the study at various times. Part 1 provided a table of the thirteen statements from Delphi 3 that both SUs and SPs endorsed and discussed the two statements where they differed.

Part 2 presented the comments made by participants in relation to SPs statements that their decisions about pain treatments are not influenced by affect or self-image. Each of the seven emerging categories was illustrated with quotes from participants. Part 3 (based on statements related to the eight principles of complex adaptive systems [239] identified that the majority of participants agreed with fifteen of the twenty-three statements presented for consideration. The eight statements where SUs and SPs disagreed were discussed and statistically significant findings presented.

Parts 4 and 5 discussed how much agreement and certainty participants believed people have about which treatments are important for chronic pain. The responses were plotted in a Stacey diagram [245], illustrating the trend towards high levels of uncertainty and disagreement. Part 6 discussed the general themes that emerged in response to ‘why are most suggestions for action directed at service providers as opposed to service users?’ The themes were presented as a bullet point list. Finally, Part 7 presented the participants’ evaluation of the research process. A conclusion, thank-you to participants, researcher’s contact information, references and a list of publications based on the research were provided on the final two pages. The Delphi 3 report and covering letter was mailed to all participants. This completed the Delphi cycle of information gathering, validation and dissemination.

6.9 Rigour of the study

> *" It is becoming clear that the principles of post-modern research are sliding quietly but determinedly into the mainstream, challenging, subverting and becoming part of accepted practice"* [366: 52]

Bowling proposes that rigour is a key principle that can be used as a measure of quality in both quantitative and qualitative research. The criteria for determining rigour include reliability, validity, a systematic approach to data collection, the transparency of interpretation, maintenance of detailed records and use of triangulation [334]. The rigour of non-linear research is also judged by its trustworthiness and authenticity [367]. Each strategy for increasing the rigour of the initial survey and subsequent Delphi rounds has been discussed in the relevant preceding sections. A summary of these actions is presented in Box 6.iv.

Box 6.iv: Evidence of rigour in study design

Criteria	Evidence
Reliability	▪ BPCQ psychometric testing :internal consistency of IS (0.73), PD (0.82) and CH(0.56) using Cronbach's alpha. In Skevington's research the test-retest reliability of coeffecients range from 0.59 (IS), 0.24 (PD) and 0.59 (CH) with chronic pain patients to 0.29(IS), 0.15(PD) and 0.22 (CH) for an undergraduate sample [34]. ▪ Statistical tests matched to type of data gathered (categorical or continuous) and population size (parametric or non-parametric) [346] ▪ Thematic coding checked against 2 validators external to the study
Validity	▪ Content validity: use of public access websites to generate treatment options list. ▪ Pilot test of survey. ▪ Criterion validity: iterative Delphi process of participants reviewing and verifying researcher's conclusions for each round. ▪ Questions representing elements of complexity reviewed by an external expert in the field. ▪ No claims of external validity (generalizability) are made in this study.
Systematic data collection & maintenance of detailed records	▪ Survey & questionnaire design decisions guided by structured review of the evidence [343] ▪ Research log detailing all decisions related to questionnaire design and analysis. ▪ Evidence-based justifications provided for design decisions. ▪ SPSS data-base tracking all facets of participation
Transparency of interpretation	▪ Reports and information about publications for each successive round provided to participants ▪ On going efforts to increase the readability of all reports ▪ Consistency of reports between participant groups.
Triangulation	▪ Delphi process uses participants as regular source of triangulation ▪ Membership in key e-alerting services to ensure the research was grounded in current developments in the literature
Trustworth-iness	▪ The research process, data analysis and supporting evidence in the literature was explained to participants at each stage ▪ Use of Flesch-Kincaid reading level tool to enhance accessibility of documents.
Authenticity	▪ The researcher worked towards the explicit goal of information exchange between diverse groups. The anonymous process allowed for uncensored exchange of information.

6.10 Summary

To answer the aims of the study in as rigorous and feasible manner as possible the study design included a preliminary survey of all members of the Pain Society (UK and Ireland) and three Merseyside support groups run by people with chronic pain. The preliminary survey asked for volunteers for Stage two. Stage two was a more in-depth examination of the question applying an iterative Delphi-type method. The Delphi consisted of three rounds and participants received reports summarising the findings from each round. The principles supporting design rigour and sound psychometric data management were applied throughout all stages. The research was theoretically driven with the Consciousness Model (discussed in detail in Chapter 4) informing the Delphi 2 questionnaire content, and Complex Adaptive Systems theory (as detailed in chapter 5) informing Delphi 3. Both the survey and Delphi stages used a combination of qualitative and quantitative question formats. The mixed methodology was applied consistent with the growing acceptance of a post-modern emphasis in healthcare literature. Without this balancing between two forms of inquiry much important information can be overlooked. As Thorne points out,

> *"...illness is experienced not as a factual clinical event, but rather as a lived, cognitive, emotive, social and even political event that is entered into by thinking, feeling and interpreting beings individually and collectively"* [107:398].

To study illness in a meaningful fashion then requires a diverse range of tools. The researcher also needs to be responsible and employ these tools in a manner capable of providing a tangible return for both researcher and participant alike.

CHAPTER 7

Stage one findings

7.1 Introduction

Between October 2001 and March 2002, surveys were distributed to one thousand, four hundred and twenty-six (1426) chronic pain service providers and approximately one hundred and ten service users. The aim of the surveys was to gather information related to which treatments both groups endorsed as important for chronic pain. The following sections will outline the findings of these surveys, starting with the service providers, then the service users and finally, a comparison of the views of the two groups.

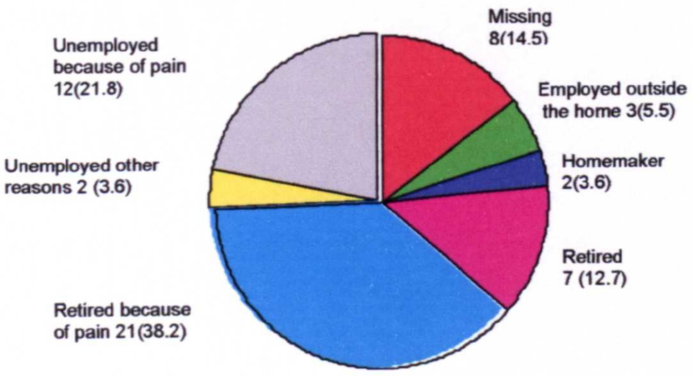
7.2 Respondents

7.2.1 Service users

One hundred and ten surveys were distributed between November and December 2001 and fifty-nine (53.6%) were returned before March 2002. As noted in section 6.3.4.1 it was not possible for the researcher to obtain specific numbers for members of the service user support groups, so the one hundred and ten surveys distributed to the gatekeepers may or may not have all been distributed and/or some duplication may have occurred. Equally, it is possible that one hundred and ten was an under-estimation and some members did not receive initial invitations to participate. This is less likely because the research contacted the gatekeepers several times to ask if they required additional copies of the survey. Four of the returned surveys were not usable because both BPCQ and treatment component endorsement sections were incomplete. Analysis was carried out on the final group of fifty-five respondents. The respondents to the service users' survey included thirty (54.5) women and twenty-five (45.5) men. The average age for women was fifty-one years and fifty-seven years for men. In terms of the demographic data gathered (age, length of pain, current pain intensity, number of treatments endorsed and BPCQ scores) an independent sample t-test revealed no statistically significant difference between genders except a small variation in age (*p*=.045) with men being on average six years older. Consequently, the data were reviewed as a composite group with no gender breakdown required. These data are detailed in Table 1 and present a picture of respondents as in their fifties, having pain for more ten years, with current pain intensity reported about midrange of the Visual Analogue Scale (between 'none' to 'worst ever'). The majority had belonged to a support group for about two years. The respondents' VAS scores for '*Who should choose treatment?*' (mean = 4.9, median = 5, on a 10 point scale anchored at 0='*Doctor is best*' and 10=' *my choice is best*') showed that they believed the choice should be shared between service provider and service user. Nearly 60% stated that they were retired or unemployed because of pain (Figure 7.1).

Figure 7.1

Service Users' Occupational Status



7.2.1.1 BPCQ scores

As discussed previously (Section 6.3.6) the total possible raw scores in the three BPCQ sub-categories were unevenly distributed (IS-24 points, PD-24 points and CH-30 points)(see section 6.3.6) and therefore the raw scores were weighted to allow for between group comparisions. Service users' weighted BPCQ scores were IS (Internal Control) = 3.75, PD (Powerful Doctors) = 4.53 and CH (Chance Happening) = 5.73 (Table 1). In the BPCQ higher scores indicate stronger belief. The range of scores for service users is graphically displayed in section 7.3.1 (Figure 7.2).

7.2.1.2 Treatment component endorsement

The survey contained sixty-two possible treatment components about which SUs were asked to comment. The number of treatment components endorsed by service users in the postal survey ranged across all options from 0 (none) – 62 (all) with a mean value of 24.75 and median of twenty-one treatment components endorsed as *Important* (Table 2). The left hand column of Table 2 shows the frequency of service users' endorsement of treatment components as either *Important* or *Not important*. The highest rate of agreement between participants was used to determine which column (*Important/Not Important*) to assign the treatment component. For example, 68.5 % of service users endorsed *Education about pain* as *Important* and 31.5% agreed it was *Not Important*. Because the number agreeing that education about pain was important was higher than the number who agreed it was not important, the treatment component was placed in the '*50-79% agreement*' row under the '*Important*' column.

The highest levels of agreement between service users were for ten treatment components selected as *Not Important (* capsaicin ointment, post-discharge support groups, biofeedback, anticonvulsants, Pilates, a social worker, creative therapies, internet chatrooms, corticosteroids and homeopathy service). These ten were all endorsed as *Not Important* by 80-99% of the service users. The agreement rate was much lower for endorsing *Important* treatment components. The highest rate of endorsement for *Important* was in the treatment component '*Education about pain*'. Thirty-seven (37) of the fifty-four respondents (68.5%) endorsed this as an important treatment component. In total, only fifteen treatment components were selected as important by greater than 50% of the respondents. The treatment components identified as important tended to cluster around pain self-management and education. In relation to type of staffing and the location in which services should be offered, only *Physiotherapy* and *Modality Specific Clinics* were selected.

When the relationship between service user demographics and the likelihood of endorsing specific treatment components was examined (Pearson's chi-square), several statistically significant relationships were found (Box 7.i):

- Male respondents were more likely than females to endorse the psychologist as an important member of the treatment team.

- People who scored higher in BPCQ-CH (Chance Happening) were less likely to think that outpatient programmes, advice on accessing information about pain and receiving lifestyle counselling were important treatment components and; were also more likely to endorse analgesics as an important intervention.
- People who scored higher in BPCQ- IS (Internal Control) were more likely to endorse the use of TENS (transcutaneous electrical stimulation), and less likely to endorse the discussion of current issues related to chronic pain (e.g. cannabis use) as *important.*

Box 7.i: Relationships between gender, BPCQ, and treatment component

Characteristic	High endorsement	Low endorsement	Pearson Chi-Square*
Male	Psychologist		.051
Hi BPCQ – CH		i. Outpatient Programmes ii. Lifestyle Counselling iii. Accessing to information	.001 .007 .020
Hi BPCQ – CH	Analgesics		.031
Hi BPCQ - IS		Current issues discussion	.033
Hi BPCQ – IS	TENS		.011

*Asymp. Sig. (2-sided)

7.2.1.3 Relationship between endorsement and experience

The data were examined to see if service users were more likely to endorse only treatment components they had experienced. There were very few examples of when the majority of people who had tried one of the sixty-two treatment components went on to endorse it as '*Important*'. There were twenty-five of the possible sixty-two (40.3%) treatment components that over 50% of all service users had experienced 'tried') (Table 3). However these twenty-five most frequently tried treatment components were not necessarily endorsed strongly as '*Important*'. As shown in Box 7.ii, only sixteen of the twenty-five treatment components that service users had tried were endorsed as ‘ *Important*’ by 50% or more of the respondents. The other nine treatment components were endorsed as *‘Important’* by less than half of the participants. This suggests that service users do not base their endorsement of ‘*Important*’ simply on experience.

Box 7.ii: Treatment components ‘Tried’ by ≥50% of all SUs & frequency of endorsement as ‘important’ by all SUs

		% of all SUs endorsing the treatment component as ‘important’	
Component	**Tried%**	**≥ 50%**	**≤ 49%**
Tai Chi	85.4		45.4
Physician	83.6		45.4
TENS	83.6		40
Physiotherapy	83.6	58.1	
Outpatient treatment	80		41.8
Stretching	80	54.5	
Education about pain	80	67.2*	
Relaxation	76.3	54.5	
Education about posture	76.3	65.4	
Print/video materials about pain	76.3	54.5	
Thermal modalities	70.9		34.5
Support group	70.9	56.7	
Pacing	67.2	57.4	
Antidepressants	65.4		29.6
Lifestyle counselling	65.4	53.7	
Graded return to ADL	65.4	59.3	
Self-management	65.4	55.6	
Massage	61.8	50.0	
Psychologist	58.1		46.3
Acupuncture	58.1		35.2
Hydrotherapy	56.3	53.7	
Education about anatomy	56.3	53.7	
Psychological assessment	54.5	50.0	
Use of Humour	54.5	57.4	
Creative therapies	52.7		19.1

* Most frequently endorsed treatment component

7.2.1.4 Service User summary

Service users tended to be in their early fifties, and were not working or were retired because of their pain. They reported an average chronic pain duration of over ten years and they were of the opinion that treatment decision-making should be shared between service provider and themselves. Several areas of specific interest can be identified within the survey results for service users:

- Firstly, congruence between service users is very low. The most frequently endorsed treatment component *'Education about pain'* was identified as *important* by only thirty-seven (67.2 %) of the respondents. Forty-seven (75.8%) of the sixty-two possible treatment options were endorsed by less than half of the service users.
- There are statistically significant differences between male and female service users regarding the importance of a psychologist.
- Significant differences also exist between higher BPCQ-CH scores and low endorsement of outpatient programmes, access to information about pain and lifestyle counselling.
- People who scored high in BPCQ-IS made high endorsement of TENS, and low endorsement of topical issue discussion groups.
- And lastly, there does not appear to be a relationship between a service user having tried a treatment component and his or her endorsement rate.

7.2.2 Service providers

The exact distribution of the postal survey cannot be reported by professional group because the Pain Society's mailing list was organised by clinical area (e.g. acupuncture, paediatrics, palliative care) rather than professional group. Many clinical areas could include professionals with different professional backgrounds. People were asked to identify their professional training on the survey and the final group of three hundred and eighty-six respondents was composed of one hundred and twenty-two anaesthetists (31.6%), one hundred and three nurses (26.7%), fifty-two occupational therapists (14.1%), thirty-five physiotherapists (9%), thirty-two general practitioners (8.3%), twenty-four psychologists (6.2%), three pharmacists and fifteen 'other' (not specified) participants (Table 4).

The inter-professional demographics were not homogeneous in all aspects and attention should be paid particularly to the gender imbalance across all professional groups (female = 62.3%, male = 37.6%) and the high amount of undergraduate training in pain that anaesthetists reported they receive compared to all other disciplines in the study (see Table 4). The median score for undergraduate training is actually zero (0) hours (50.3% of sample) even though the anaesthetists' and psychologists' amount of training skews the mean to 8.34 hours. This can give a distorted impression of most professionals' entry-level knowledge base and it is preferable to use the trimmed mean[2] of 3.47 hours and the median (0) to reflect the group's undergraduate preparation.

Service providers tended to be in their mid-to-late forties, 77.5% had more than thirty hours of continuing professional development (CPD) on the topic of pain, and the group mean was eighteen years of work experience in chronic pain treatment. While a low majority of physiotherapists (65.7%) and pharmacists (66.7%) worked with condition specific pain patients, the majority of all other SPs worked with people who had a range of pain related conditions and diagnosis. The range of frequency for endorsing a treatment component as *important* was wide (0-58), and the mean across all professional groups was 44.33 (71.5%) of the sixty-two possible treatment components.

7.2.2.1 BPCQ scores

BPCQ Scores [34] were gathered as part of the survey. Because there were so few respondents in the 'pharmacist' (n=3) and 'other' (n=15) categories, they were eliminated from the comparative analysis of BPCQ Scores (Table 5). As a group, service providers tended to believe most strongly in 'Internal control for pain' (IS), followed by 'Chance Happening' (CH). They believed least of all in pain as being under the control of 'Powerful Other' (PD).

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[2] SPSS removes the top and bottom 5% of cases and recalculates the mean value (trimmed mean). This is recommended as a strategy to decrease the influence of extreme scores within a group mean [336].

A one-way between-groups analysis of variance (ANOVA) with Bonferroni post-hoc testing [3] was carried out to explore the impact of professional group category on BPCQ subgroup scores. Statistically significant differences at the $p<.05$ level were found to exist between groups for BPCQ-IS (Internal Control) [F (5,322) = 2.872; p=*.015*], BPCQ-PD (Powerful Other (5,324)=2.345; p=*.041*] and in BPCQ-CH (Chance Happening) [F (5,322) = 3.923; p=*.002*]. In the BPCQ-IS category physiotherapists had higher scores than nurses (p=*.025*) and in the BPCQ-CH category anaesthetists had statistically significant higher scores than occupational therapists (p=*.013)* and nurses (p=*.014)*. This indicated that nurses were less likely than physiotherapists to endorse internal control regarding pain solutions. This is consistent with the philosophical backgrounds of both professions where physiotherapists strongly advocate exercise and activity-based programmes whereas the traditional nursing ethos stresses care and support. The BPCQ-CH findings also seemed to indicate that anaesthetists were more likely to believe in pain as a chance event as opposed to nurses or occupational therapists.

7.2.2.2 Treatment component endorsements

The endorsement rates across professional disciplines (Table 6a) revealed that as a group, the general practitioners (GPs) did not respond with any answer (either *important* or *not important*) to fifty-four (87.09%) of the treatment components. This lack of response precludes confident use of the few endorsements made by some members of the GP group for comparison with other professionals[4]. To that end, only those treatments where over 80% of the GPs (25/32) ventured an opinion are included in the following analysis. The specific areas where 80% or more GPs offered an opinion are as follows:

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[3] Bonferroni post-hoc testing for ANOVA uses t-tests to perform pair-wise comparisons between group means, but controls overall error rate by setting the error rate for each test to the experiment-wise error rate divided by the total number of tests. Therefore, the observed significance level is adjusted for the fact that multiple comparisons are being made [352].

[4] It is difficult to speculate as to why this occurred. It is possible that GPs in this study did not have the time to complete all sections of the survey. This assumption is partially supported by GPs' concerns expressed in the professional literature regarding the growing volume of 'paper work' in the NHS that leaves decreasing time for patient contact [358, 359].

- Treatment components related to staffing:
  - Psychologist
  - Nurse
  - Physiotherapist, and
- Treatment components related to organisation:
  - Inpatient
  - Outpatient
  - Multidisciplinary.

7.2.2.3 Areas of congruence

The agreement within groups of service providers about *Important* and *Not Important* treatment components ranged from moderate amongst the psychologists to high amongst the nurses. When the frequency of a treatment component being endorsed by 80% or more of any professional group was examined, nurses showed the highest agreement at 59.6%. In other words, 80% or more of the nurse respondents agreed in their ratings of thirty-seven of the sixty-two treatment components. Occupational therapists were second highest in agreement (31/62 = 50%), followed by anaesthetists (28/62 = 45.2%), physiotherapists (26/62 = 41.9%) and psychologists (17/62= 27.4%)[5]. Between the groups there were eighteen treatment components (29.0%) endorsed as *Important* by 80% or more of all group members (Box 7.iii and highlighted on Table 6a). Box 7.iii details these eighteen treatments components (designated as *Important* by 80% or more of all groups of service providers) and shows them organised into general categories of who (professional training), where (the organisational setting), and what (type of treatment).

Box 7.iii:Treatment component endorsed as *important* by 95-100% by all SPs

Category	Treatment component
Who- professional group	Psychologist
	Physiotherapist
	Occupational therapist
	Physician
	Nurse
Where-organisation setting	Outpatient
	Multidisciplinary
What	Posture/Body Mechanics
	Education about pain
	Graded return to ADL
	Medication review
	Relaxation
	Psychological assessment
	Pacing
	Self-management
	Reconditioning
	Print materials
	Family advice

There were no treatment components endorsed as *Not important* by 80% or more across the service provider groups (Table 6a).

The preceding analysis identifies that there was a small group of treatment components where the different service providers were congruent; and a wide range of options where endorsement was incongruent between service provider sub-groups. A chi-square analysis of service providers and treatment options revealed several statistically significant differences (Table 7). In general, nurses and anaesthetists displayed the highest rates of non-congruence with other service providers. Nurses tended to be high endorsers of many treatment options and anaesthetists were low endorsers. 'High endorsement' and 'low endorsement' were terms used to describe endorsement patterns that chi-square analysis identified as deviating from the expected response rate. 'Low endorsement' identified a negative trend (i.e. the

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[5] GPs frequencies were not computed given the high level of missing data discussed above.

treatment component was selected less often then expected) and ‘high endorsement’ indicated a positive trend.

7.2.2.4 Service provider summary

As shown in Table 6a the congruence of service providers’ opinions about the importance/non-importance of the various treatment components is moderate *within* most professional groups and low *between* the groups. Preferences for composition of the team, organisational structure of the service and the types of treatments endorsed varied between the members of different professions. And although a multidisciplinary team was strongly endorsed, there was little agreement about who should actually make up that team. Occupational therapists included the greatest number of professions with 100% agreement that a psychologist, occupational therapist and physiotherapist should make up the team. They were less united in the need for a physician (88.2%) or a nurse (84.3%). Physiotherapists had 100% agreement that a psychologist and a physiotherapist were needed. General practitioners has 100% agreement that a psychologist was needed, anaesthetists had no unanimous agreement about staffing and nurses had 100% agreement that a nurse was required. Similarly, there was little between-group agreement about which professionals were *Not important*. For example 80% or greater of the occupational therapists and physiotherapists agreed that chiropractors were *Not important* but the ranking of chiropractors as *Not important* was less consistent across the other professional groups. Psychologists and anaesthetists (70% and 56.4% respectively) stated that chiropractors were *Not important*. However, 54.8% of nurses did think that chiropractors were *Important,* which is markedly different from the other professional groups.

Lastly, the beliefs about pain control (BPCQ scores) across all service providers tended to reflect a higher emphasis on internal locus of control (IS) and lower expectations of an external power figure (PD) as providing the solution. However, BPCQ scores were not consistent across all groups and statistically significant differences were revealed.

7.3 Comparing service users and providers

Service users and service providers (when not sorted by profession) were comparable groups in terms of gender distribution. Service providers (SP) were found to be significantly younger (*p <.000*) in a 2-tailed t-test for equality of means.

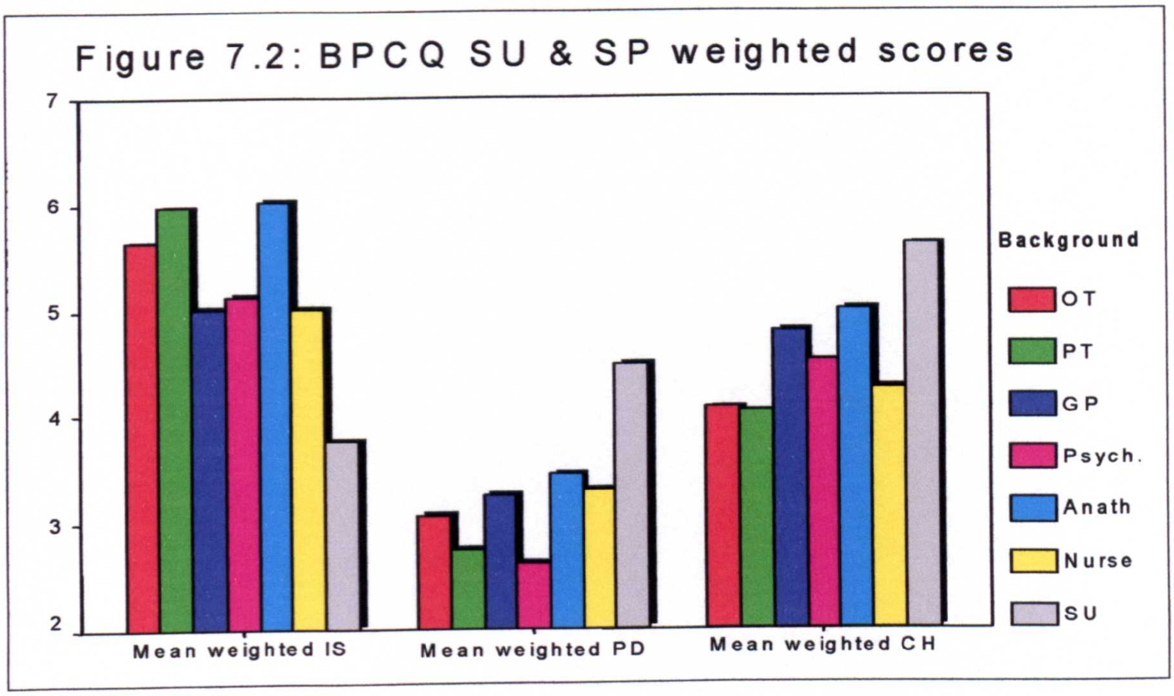

Figure 7.2: BPCQ SU & SP weighted scores

7.3.1 BPCQ scores

Figure 7.2 shows the range of BPCQ weighted scores between SUs and SPs. In relation to BPCQ scores 2-tailed t-tests reveal a significant difference (*p*<.000*)* between service users and providers in all three BPCQ subcategories. When the service provider group was sorted into professional groups [6] and analysed (one-way between-groups ANOVA with Bonferroni post-hoc testing to adjust for multiple comparisons) against the BPCQ scores of service users, significant differences were found in all three categories: IS-Internal Control [F (6,372) = 10.159; p<*.000*], PD-Powerful Others [F (6,373) = 8.512;p<*.000*], and CH-Chance Happening [F (6,372) = 7.313; p<*.000*]. The most marked differences between service users and providers were in the IS and PD categories although there were also significant differences in the category of CH (Box 7.iv). This suggests that service users believe more strongly than all of the service providers that pain control rests with an outside agent (PD-Powerful Other). Conversely,

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[6] Pharmacist and 'Other' were not included because of the few numbers in these sub-groups.

service providers believe more strongly than service users in the importance of internal control (IS) to control pain. Additionally, anaesthetists, GPs and psychologists appear to share the opinion of service users regarding the role chance happening (CH) plays in pain control. Occupational therapists, physiotherapists and nurses, on the other hand, do not endorse chance happening (CH) to the same high level.

Box 7.iv: Differences between SU & SP BPCQ unconverted scores

BPCQ	Mean Score Service User	Mean Score Service Provider*	Significance **
Internal Control- IS	11.49	16.94 Occupational Therapist	<.000
		17.83 Physical Therapist	<.000
		15.27 General Practitioner	.007
		15.52 Psychologist	.008
		16.12 Anaesthetist	<.000
		15.03 Nurse	<.000
Powerful Doctor – PD	10.88	7.33 Occupational Therapist	<.000
		6.57 Physical Therapist	<.000
		7.81 General Practitioner	.003
		6.57 Psychologist	<.000
		8.28 Anaesthetist	<.000
		7.92 Nurse	<.000
Chance Happening- CH	13.76	9.77 Occupational Therapist	<.000
		9.68 Physical Therapist	<.000
		10.15 Nurse	<.000

*Small sub-group size indicate that caution should be employed in interpreting these findings.

**One-way Between-groups ANOVA with Bonferroni post-hoc testing

7.3.2 Endorsement of treatment components

Service users and service providers had very weak congruence in relation to the treatment components for chronic pain they endorsed as '*Important*' (Table 8). Of the fifteen treatment components most highly endorsed by service users and providers, only six were common to both groups. These six treatment components for chronic pain were:

- Education about pain
- Posture/body mechanics training
- Physiotherapy
- Graded return to ADL
- Print materials
- Relaxation training

As a group of treatment components they belong primarily to the biomechanical and rehabilitation models of practice. These models focus on returning the individual to maximum functional potential through exercise, and receiving education in compensatory and protective techniques.

A chi-square analysis was carried out to examine relationships between service users' and providers' endorsement patterns. Prior to the statistical analysis the service provider subgroups of general practitioner (GP), pharmacist and 'other' were filtered from the data set. The GPs were removed because their low response rate for treatment components (as discussed in section 7.2.2) distorted the response patterns of other professionals in the survey. Pharmacists and 'other' were filtered because of their small subgroup numbers (N=3 and 15 respectively). Testing revealed no statistically significant difference in the endorsement patterns of service users and service providers for seventeen of the sixty-two treatment options (listed in Table 9). However, for all of the forty-five remaining treatment components there was a statistically significant difference in rate of endorsement. The consistent pattern was for service providers to be stronger endorsers of treatments as *Important* than the service users. The rate of statistical significance for each treatment component is detailed in Table 9.

7.4 Stage one findings summary

The service users' and providers' surveys demonstrated that there is little intra- or inter-group congruence in regard to what treatments are believed to be important for chronic pain. In general there was higher agreement between the service providers;

however they also tended to highly endorse a wider range of treatment options. The service users were less congruent but more selective, tending to endorse a much smaller range of treatments as *Important*. Because there was often a minimum of 6 different sub-groups being examined the statistical analysis of the survey data required a high number of repeated computations. Bonferroni post-hoc testing was applied to control for this problem. This may have resulted in the occurrence of several Type II errors (rejection of significant relationships)[346]. However, even with this degree of rigour, sufficient findings were revealed to illustrate that there was low inter- and intra-group agreement.

7.5 Stage one preliminary discussion: implications of non-congruence

7.5.1 Service users

Two areas of specific interest were identified within the survey results for service users. Firstly, the lack of agreement between respondents was very high. The most frequently selected treatment component *'Education about pain'* was identified as *Important* by only 67.2 % of the respondents. Over three-quarters (75.8%) of all possible treatment options were endorsed by less than fifty percent of the service users.

Secondly, although there were statistically significant differences between a number of treatment components and service users' scores in all three subscales in the BPCQ (Table 1), service users tended to score higher in beliefs that their pain was controlled by chance (CH), than by professionals (PD) and least of all by internal control (IS). Overall, the majority of participants in this study, despite their membership in peer-lead support groups, seemed to ascribe to a more traditional biomedical model where the physician has the responsibility for controlling the patient's pain. This was mirrored in the trend towards endorsement of more biomechanical interventions (for example, posture, pacing, relaxation and physiotherapy). The respondents appeared to be a strongly heterogeneous group, each with a unique interpretation of what treatments are *important*.

This heterogeneity amongst people with pain is consistent with what numerous other researchers have found [9, 24, 213, 370-372] and appears logical given the complex bio-psycho-social forces and interactions between service users and providers at play within any chronic pain experience.

Emerging literature suggests the need for caution in accepting the 'one-size' fits all approach inherent in a medical-political climate which strives to derive clinical decisions and guidelines exclusively from within the positivist definition of 'evidence-base'[372-375]. However, there are also significant counter-forces acting to dampen the influence of this growing evidence base for more individualised treatment. For example, the lack of sufficient, good quality information needed for service users to assume a greater role in treatment related decisions [376] has been identified as an issue when service providers try to provide more individualised treatment options. Additionally, service providers who are responsible for facilitating these treatment options increasingly confront the conflicting demands of balancing their responsibilities between beneficence, duty of care and changing social demands for patient autonomy and shared decision-making [377]. The clinical encounter is traditionally of very short duration and the service provider may find they have insufficient time to attend to diagnosis, treatment and providing patient education. Pragmatically, education is set aside to discuss 'at the next visit' because there is only enough time available this appointment to review and adjust medications. 'Duty of care' takes precedent over 'time to talk'.

Two implications of the strong heterogeneity of SUs' beliefs about treatment *Importance* will be discussed in more detail here. Firstly traditional medical training relies heavily on experiential, apprentice/master style learning [378] where practitioners seek to predict 'cause and effect' for presenting medical problems through reflection on other peoples' more 'expert' opinions and their own past experience. In chronic pain, where service users are so heterogeneous, a service provider's assumption of predictability in treatment planning based on past experience would prove a less reliable and applicable tool.

Secondly, the lack of congruence may preclude SUs developing the sense of 'commonality' and mutual experience necessary for formation of effective groups to lobby for change and resources. An in-depth discussion of this issue in Patient power?: the politics of patients' associations in Britain and America [379] highlights that traditionally most patient associations in the UK have focused on supporting the existing infrastructure through fundraising and public awareness campaigns and have not taken an active role in political lobbying activities. Wood points out that these groups do not generally form coalitions with other organisations to address common issues and that in order to preserve funding they run the risk of 'colonisation' by government organisations and/or pharmaceutical companies. Historically, patient associations in the UK have structured themselves as 'charities' and incorporated a non-political stand into their aims and objectives. However, in the last twenty years, consumerism (legitimised in a range of NHS and DoH initiatives) is increasing as a driving force in healthcare, [26, 160, 224]. Whether this has translated into more politically focused organisations is debatable and researchers as yet lack tools by which to measure outcomes and effectiveness of these organisations' traditional roles and their emerging responsibilities as change-agents [379]. When group members hold very diverse opinions about what is *important* (as seen in this survey) the barriers to assuming a role dependent on collective action may prove too great. Additionally, the strong BPCQ scores in beliefs about Powerful Others (PD) may indicate that SUs see lobbying efforts and strategies to change service provision as the role of professionals and others vested with recognised 'power' in the healthcare system. High Chance Happening and low Internal Control beliefs about pain control, as seen in this study, seem more likely to result in service users feeling they are not in control but rather at the will of some random fate.

The agenda for change in patient associations is dependent on a complex array of social, political and indeed personal factors. Access to skills development for assuming new roles is still highly varied and not everyone wants or supports a change in direction from traditional 'supportive' patient associations. "There indeed remains much to be done before we can fully understand the politics of patients' groups and their impact on health care systems and public policies' [379:188]

7.5.2 Service providers

Overall, the service providers (like the service users) appeared to be a heterogeneous group, each bringing a unique blend of training and experience to his or her practice. This lack of consistency was mirrored in the range of options that individual SPs felt were necessary treatments for chronic pain, although a definite trend was evident towards stronger endorsement of biomedical and particularly medication related treatment components. The significance of this lack of congruence in relation to providing evidence-based practice will be the focus of the following discussion.

As mentioned previously (sections 2.7.3 and 5.4.1) there are a range of reasons why service providers fail to take up or abandon interventions consistent with what the evidence-base demonstrates as effective. This paradox, of SP endorsements not reflecting the current evidence-base, emerged a number of times across the findings of this study. For example, the evidence-base for use of antidepressants and anticonvulsants is well established in the pain literature [128] and yet 50.0% of occupational therapists and 14.6% of the physiotherapists stated that antidepressants were *Not important*. Similarly 59% of the occupational therapists and 11.5% of the physiotherapists did not consider anticonvulsants to be important treatment options. It is possible that the occupational therapists' marked under-endorsement is related to their professional core philosophy of occupation and enablement. According to Law 'enabling occupation means collaborating with people to choose, organize and perform occupations which people find useful or meaningful in a given environment' [380:2]. This type of philosophical difference is not always evident unless a specific effort is made to clarify values and beliefs amongst team members. If differences in treatment philosophy are not made explicit, a range of negative consequences can occur for both service users and providers.

The same issue emerges in some treatment components where agreement was high. For example, 96.3 % of the anaesthetists and 100% of all the other professional groups responding to the question endorsed *relaxation* as *Important*. And yet, this extremely high endorsement is inconsistent with recent reviews concluding there is no strong evidence-base for the use of relaxation to reduce chronic pain [122, 144, 381].

Additionally, it is not possible to determine whether all participants were endorsing the same style/technique of relaxation therapy nor whether they all had the same outcome objective. A Bandolier review of the evidence for relaxation techniques (*'Relax?-don't do it'*[382]) illustrated this problem with a citation from Earl St. Vincent's comments about Napoleon's invading force, " I do not say they cannot come, I only say they cannot come by sea". The Bandolier authors conclude, "Perhaps of relaxation we can say that we do not deny that it may have a benefit, we merely say it does not relieve pain" [382]. Again, the need for all team members to make their beliefs and professional values explicit is highlighted. Actions based upon a false assumption of agreement about the approach to take and the goal of intervention can have significant negative consequences. As was seen in these survey findings (Table 4) and other studies [383-386] many professional groups have a paucity of undergraduate training in pain. This may leave them poorly equipped to formulate an evidence-based argument for the pain interventions they provide and/or endorse. Pain management teams often work within large hospital-based services and individuals may adopt the values of other team members whose professional underpinnings and treatment approaches have a different theoretical grounding. It is possible to see service providers as swaying between the influences of the team milieu, the clinical evidence they have been exposed to, and their perceptions about professional role and tenets. The negative consequences of professional ambiguity and dissention related to theoretical underpinnings of practice within multidisciplinary teams have been identified in recent publications [291, 387, 388] and include poor morale, high staff turn-over, and decreased adherence to stated programme procedures and policies.

7.5.3 Service users and providers

"Pain is as diverse as man. One suffers as one can"
Victor Hugo,1802-1885 in[389]

There are a range of theoretical perspectives that offer an explanation for the diversity of opinion and belief expressed by participants in the study. Biopsychosocial models propose that cognitive processes, beliefs and past experiences moderate the perception of nociceptive sensations (prolonged stimulation which becomes noxious over time) [94]. David Morris states that humankind -across cultures and across time- has persistently understood pain as an event that demands interpretation [41] and that this interpretation is a personal activity. Constructing a meaning for pain is a dynamic process not only for the individual [109] but also, as evidenced throughout history, across cultural and social groups [45]. Social learning is also proposed to influence what one believes about pain [94]. Pain beliefs and behaviours are acquired through experience and observation of the environment. Other people's behaviours and attitudes, observed in response to a particular stimulus, also become part of the individual's response to events he/she perceives to be similar. These behaviours are, in turn, modified or reinforced through personal features such as cognition, emotions, and physiological events. A clear relationship between socio-cultural influences and illness beliefs and behaviours has been demonstrated in the literature [81].

Research has also highlighted that individuals attribute a range of meaning to events in the environment, interpreting others' reactions as either desirable or negative and then adjusting behaviour accordingly. This is consistent with postmodernist thinking which proposes there are many realities depending on the lens through which an individual views the world [390]. It is important to recognise that healthcare workers are also subject to the same social forces in which healthcare service is provided. Service users and providers alike construct reality based on the contextual environment and the feedback generated by actions within that environment. Increasingly service providers are being challenged within their professional literature to develop a questioning attitude towards what are traditionally held to be 'truths' about science and medicine [391]. Postmodernist thinking cautions against assumptions of universal givens and stresses that personal reality changes in relation to the socio-political, temporal and environmental context in which an individual lives[231]. The emerging social phenomenon in industrialised western cultures of challenging biomedicine's superiority has seen a growing endorsement of interventions that previously were held to be from the fringe, and 'alternative' [231, 392, 393].

It is difficult to discuss with any certainty what the consequences of the lack of congruence are for SUs and SPs in this study. It may be that the outcomes of differences in beliefs about treatments and pain control are similar to those identified in research related to the impact of patient/professional miscommunication [394] and research exploring what happens when service users and providers hold conflicting explanatory models for pain [73, 218]. These studies show that patients feel disbelieved, frustrated and are less likely to follow-through with prescribed treatments or to trust the advice of the healthcare provider when there is disagreement. Some literature suggests that an individual's judgement of *importance* may be modified by other influences. For example, a review of research findings exploring congruence between professional and patient pain intensity ratings concluded that professionals tend to under-estimate pain intensity. They also found evidence that this type of under-estimation is higher in more experienced staff [395]. Solomon et al [395] propose that the impact of disagreement ranges from under-treatment and prolonged, unnecessary suffering, to the development of iatrogenically-acquired problems that further compound the negative consequences of chronic pain.

People with pain and service providers are part of a system within which many different types, quantities and qualities of information flow. Information (some of it implicit) is exchanged between all stakeholders involved in the pain management relationship. That information in turn informs and modifies peoples' thoughts and subsequent actions. The service provider will bring opinions and behaviours from past clinical experience to encounters with new service users and vice versa. These experiences will influence future encounters and so on, and so on. To bring an open perspective to each clinical event requires extra energy on the part of all parties and it is conceivable, perhaps even likely, that anxious and fearful service users and service providers, pressurised by an over-stretched health care system, will fall back on past practice and assumptions. With the best of intentions communications can become conflicted [201, 396-398] and, as previously mentioned, even have an iatrogenic effect [112]. Recent initiatives to increase the communication skills training of under-graduate medical and healthcare students [399] and to promote a culture of patient empowerment in decision making [321] will help address these issues and additional strategies should be considered.

7.5.4 Justification of the Delphi stage

The survey data from this study highlighted that service users are a heterogeneous group regarding treatment beliefs. The potential implications of this for SUs being able to assume any advocacy or political action role were discussed. The survey also found that service providers differed between themselves in opinions and beliefs about pain treatments. The impact this might have on the team's ability to apply a consistent model of intervention and operationalise evidence-based practice was examined. Lastly, the striking differences between service users and providers were presented and the link between these findings and issues addressed in the literature related to poor communication, conflicting healthcare belief models, impaired meaning construction and potential for the iatrogenic exacerbation of problems were highlighted.

However, survey data does not provide sufficient information to understand why people make these decisions about what treatments are important. Without understanding 'Why' service users and service providers made their decisions it is not possible to comprehensively discuss the implications and clinical consequences of a lack of congruence. Additionally, without knowing the rationale behind people's decisions it is impossible to know what actions may be possible or required to influence the consequences. The Delphi rounds subsequent to this preliminary survey were critical to developing that depth of understanding.

In summary, this chapter has presented the findings of the Stage one postal survey. The survey stage of this study has served to strengthen the evidence that recognises the idiosyncratic nature of beliefs about treatments held by people with pain. The chapter has offered a preliminary discussion of the findings' implications for people with chronic pain and healthcare service providers. The chapter concludes with a justification for the following Delphi stage of the study. The findings and preliminary discussion of this will be presented in the following chapters.

Chapter 8

Delphi 1 findings: the decision-making process

8.1 Introduction

In November 2002, the Delphi 1 questionnaire was mailed to all thirty-two service users and two hundred and thirty-seven service providers who volunteered for this stage of the research. After one month, reminders were sent to service users who had not returned the survey. Because of the small number of participants in the service users' group it was felt that reminder letters were warranted. Costs precluded sending reminders to the larger group of service providers who had not responded. Final responses (as of Jan 31, 2003) were twenty-two (68.7%) of the service users (this included six responses that followed from the reminder letter) and ninty-eight (41.3%) service providers. Of the service provider responses twelve were either unusable, or the SP had returned the questionnaire but declined to participate.

The following sections outlines the findings of the Delphi 1 questionnaire that focused on exploring the decision-making process participants employed to determine if a treatment component was *Important* or *Not important.*

8.2 The decision-making process

8.2.1 Decision-making about treatment importance

As discussed in Chapter 6 (section 6.6.2.3) Questions 1 and 2 presented participants with the ten treatment components most frequently endorsed as '*Important*' and the three treatment components least frequently endorsed (Table 8), and asked for opinions about why these treatment components were rated in that manner by respondents in the postal survey.

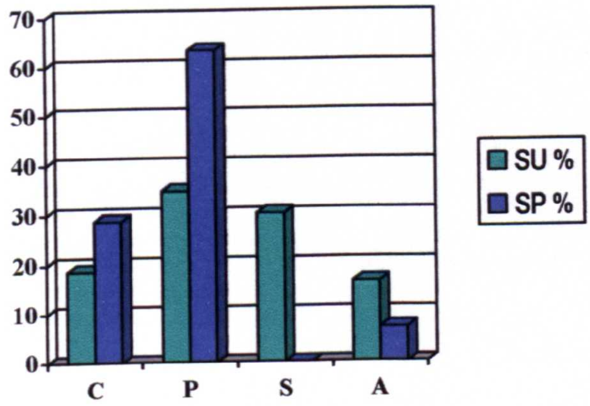
Chapman's Consciousness model [35] proposes that there are four themes that influence how conscious a person becomes of something. These themes are; *Coherence* (does it make sense), *Purposiveness* (what purpose does it serve), *Affect* (how does it make me feel), and *Self-image* (how does this relate to who I see myself to be). Our consciousness of something then influences the meaning we construct for the event and how much importance it is assigned. Participants' thoughts about why they decided certain treatment components were *Important* were analysed using the Consciousness model as an organisational framework. The coding process and detailed examples were presented previously in Chapter 6 (section 6.2.2.1).

When the raw data were grouped and organised into sub-themes and the four main themes as defined by the Consciousness model (*coherence, purposiveness, affect* and *self-image*) different patterns seemed to emerge between service users versus service providers regarding the percentage of comments related to each of the four themes. Table 10 shows themes and sub-themes for service users and providers in relation to the response to each part of Question 1 (why is *education about pain* important? why are *posture/body mechanics* important? and so on, for all ten treatment components). The responses to each part of the question were aggregated to provide a overall summation of comments related to each main theme.

The 1st (left-hand) column in Table 10 presents the four main themes – *Coherence, Purposiveness, Self-image* and *Affect*. The 2nd column, headed *Service user Sub-themes,* identifies the sub-themes that emerged when the raw data were grouped for service users. The 4th column, titled *Service provider Sub-themes*, shows the groupings that emerged from the service providers' comments. The 3rd and 5th (extreme right) columns show what percentage of the overall comments related to each of the four main themes of consciousness. For example, Table 10 shows that two sub-themes (*being informed* and *doing it right*) emerged from the service user raw data and that they relate to the main theme of *Coherence*. Of the total comments service users made for each treatment component mentioned in Question 1 (raw data), 18.6% fit into one of the two SU sub-themes for *Coherence*. Therefore 18.6% of the total comments made by service users in response to Question 1 were assigned to the Consciousness theme of *Coherence*. Similarly for service providers, four sub-themes emerged (*what others expect, how the team/programme is organised, specialised knowledge* and *what SP believes works*) that related to the main theme *Coherence*. Following coding 28.7% of all service provider comments fit into one of these four sub-themes of *Coherence*. Table 10 shows that a higher percentage of the service users' total comments were related to the theme of *Coherence* than the comments made by service users (28.7% and 18.6% respectively).

There were differences in the frequency with which service users' and service providers' responses related to each theme in Question 1. The service users' answers were most often related to the purpose of a treatment (P-*Purposiveness*) and how it affected their self-image (S- *Self-image*). The highest frequency of service providers' comments also related to the theme of *Purposiveness.* However, the second highest frequency of comments were in the theme of C- *Coherence* (the treatment makes sense with what they believe). These relationships are presented in Table 10 and graphically in Figure 8.1.

Figure 8.1: Service user & provider decision-making influences

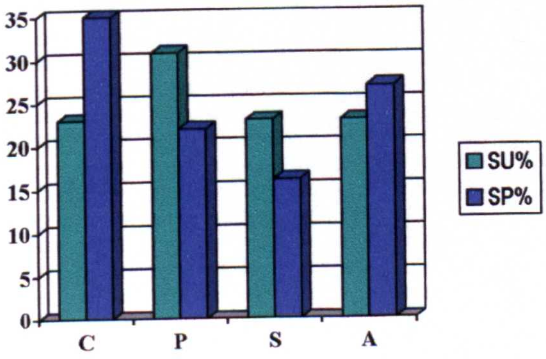


Key: C – Coherence, P- Purposiveness
S – Self image, A – Affect

Question 2 asked participants why three treatments (*social worker, homeopathy* and *chatrooms*) had received the highest rankings for *Not important* (Table 11). The responses were analysed in the same way as Question 1 following the process outlined in Chapter 6 (section 6.6.2.1). For example, five of the emerging servive provider sub-themes (*Distrust, Creates challenging SUs, Commercial interests are distasteful, Ethnocentrism/nationalism,* and *Discomfort with unknown*) related to feelings and emotion caused by certain treatment components. These sub-themes were grouped into the main theme of *Affect*. A total of 27% of all the comments made by service providers about why certain treatments were *Not important* were distributed within these five sub-themes. The distribution of all the service users' and service providers' comments, grouped by sub-theme and then main theme (*Coherence, Purposiveness, Self-Image, Affect*), are displayed in Table 11.

Similar to Question 1, the distribution of responses within each theme in Question 2 differs between service users and service providers (Figure 8.2). Service user responses are fairly evenly distributed across the themes of *Coherence* (23%), *Affect* (23%) *and Self-Image* (23%), and to a slightly greater degree *Purposiveness (*30.8%), indicating that they experience a range of influences in making decisions about what treatments are *Not important.* The comments made by service users in the raw data reflected that the weakly endorsed treatment components presented in Question 2 were not in keeping with what service users believed was needed to treat chronic pain (' *..many have tried it* [homeopathy]*and it does not work' – SU 846), ('chronic pain sufferers benefit from face-to-face contact and prefer to exchange their views on a personal level* [internet chatrooms]'– *SU 839),* and these treatments would not fit with their image of someone coping with pain *('Social workers do have a function for some people... but on the whole they are not of much use to people with pain'- SU 848), ('no need for a social worker even though you might feel like a lost cause, there is nothing they can do for us'- SU 438).*

Figure 8.2: Service user & provider decision-making influences for 'not important'



Key: C – Coherence, P- Purposiveness
S – Self image, A – Affect

Equally, the SUs' answers reflected some fear that these treatments would increase the pain and a distrust of the treatments in general (*'..people have to be wary as these are unscrupulous people (quacks) trying to cash in on others pain'* [homeopathy]– *SU 827)*. The answers reflected an overall feeling that these three treatment components (social worker, homeopathy and internet chatrooms) had little purpose in treating pain. The service user answers must be interpreted with caution given the small group size.

The service providers' responses for Question 2 covered a wider range of areas within each theme than they did in Question 1. Their replies reflected a belief that these three treatment components either were not consistent with current medical thinking in the area of chronic pain or were not considered common practice. An interesting feature arose in the theme of self-image (S) where some service providers made statements not about themselves but rather that interpreted the beliefs of service users. For example these statements, *'patients see pain as a medical not social problem'* (*SP 51*) and, *'service users will think things should be done for them instead of learning they can do it for themselves'* (*SP 309*), reflected SPs' generalisations about how service users perceive themselves in relation to treatment for chronic pain. Although not conclusive it is possible that service providers may see this as part of their role to 'speak on behalf of' service users.

The Consciousness model theme of *Affect* accounted for only 6.9% of the comments service providers made about why a treatment was important. Interestingly, the theme of *Affect* became more prevalent in Question 2 (*why is a treatment not important)* and represented 27% of the comments (Tables 10 & 11). In responses to Question 2 distrust was frequently expressed, as were concerns over protecting SUs by controlling access to information or the type of information available. Several service providers stated that in their opinion other service providers made decisions based on fear of challenges from service users and anxiety about their own lack of knowledge. For example, SP 43 wrote –"*Perhaps professionals feel suspicious/threatened by such 'uncontrolled' sharing of experience by users*".

8.2.2 Effect of disagreement

In Question 3 service users were asked to indicate on a 5-point Likert scale (anchored at 0 '*no effect*' - 4 '*very marked effect*') how much impact they believed it would have if service users did not agree with other service users. The categories they were asked to consider were *financial, emotional, treatment outcome, relationship between service user and service provider, public perception of treatments for pain,* and *the range of treatments available.* Service providers were also asked a similar question about what impact disagreement between service providers/co-workers would have. Service users' median score was '2- moderate effect' except for the variable *public perception of treatment for pain* where the median score was '3-marked effect' (Table 12). Service providers tended to rate disagreement between themselves as having a higher impact and the median response for all six categories was '3-marked effect'. An independent samples t-test (comparison of means) was carried out (SPSS Version 10) on the difference in rankings between SUs and SPs for each of the six categories and statistically significant variance was revealed for three categories: *financial effect, treatment outcome* and *SU/SP relationships* (Box 8.i).

Box 8.i Variance between service users' and providers' rating of effect of disagreement

Category affected		stat.sig
▪ financial	t (93) =-2.862	*p=.008*
▪ treatment outcome	t (95) =-3.314	*p=.001*
▪ SP/SU relationship	t (95) =-3.114	*p=.002*

In all three categories service providers rated the impact of disagreement within the group more highly then did service users (Table 12). The areas of *emotional effect, public perception of pain treatments* and the *range of treatments available* showed no statistically significant relationship.

8.2.2.1 Comments given in support of rank selected

Comments for each category are summarised and examples taken from the questionnaires are presented as italicised text in the following boxes. The first category participants ranked was the perceived **financial** effect of disagreement.

Comments differed between the two groups. Service users' comments were largely about personal finances and did not identify concerns about availability of NHS funds for pain management. Service providers were the opposite and expressed more global concerns about funding for programmes, but made little mention of the financial costs to service users or to service providers themselves.

Question 3- Financial effect

Service users who selected:

0-1(no to little effect)
Treatment is provided by the NHS- it costs me nothing; It does not take money to help with pain; Someone else's opinion costs me nothing; Money has nothing to do with pain; People come from all walks of life-finances are not on the scale

2-3 (moderate to marked effect)
Treatment is personal; Paying for treatment that doesn't work can affect you; Some people may be able to afford private treatment

4 (very marked effect)
You have a low income because of pain and cannot afford all the treatments; My work is at risk because employers do not understand pain; Allowances and benefits might not allow for expensive treatments

Service providers who selected:

0-1 (no to little effect)
(no comments were made)

2-3 (moderate to marked effect)
Affects business plan – funders will not allocate resources to a service that cannot decide what it want; May conflict with what the Trust is able to afford; Failure to focus on most effective treatment will affect results and potential for further funding; Purchasing power affect treatments available; Detrimental outcome on management and therefore wastes resources

4 (very marked effect)
Evidence-based practice must be important; Chronic pain services are grossly under-funded and are a low priority to many trusts; We still have paternalistic clinicians

The second category involved the **emotional** effect when service users did not agree with other service users and service providers did not agree with each other. Comments from the service users appear to reflect a concern over maintaining individuality and not being influenced by others' '*negativity*'. The service provider comments, however, reflect a concern for mutual support amongst professionals and for presenting a '*united front*' to service users. There were some comments about how disagreement could lead to loss of credibility to both service users and to external bodies.

Question 3- emotional effect

Service users who selected:

0-1 (no to little effect)

People all have different emotions; No two people are alike in their chronic pain experience; We all have different views on most things; I don't consider it any of my business what other people think

2-3 (moderate to marked effect)

Disagreement causes stress and exaggerates pain; I don't discuss my pain a lot with anyone who is not a professional; It can promote discussion and better information; Pain management is about using skills that are tailored to you personally; Different treatments help some and not others; Can lead to frustration

4 (very marked effect)

Someone's negative emotion can put a downer on people who do want to try something; Can cause problems between people; People who believe in something could feel a question about it; Everyone has different ideas

Service providers who selected:

0-1 (no to little effect)

(no comments recorded)

2-3 (moderate to marked effect)

Frustrating at the point of patient contact; Doesn't matter to money-holders; Especially if patient sees several service providers in the same institution which give opposite advice (demoralising); Feelings of dissonance; Dysfunctional team or professional working

4 (very marked effect)

Loss of team aim; Can create conflict between team members; We often work in isolation and don't always get support from other professionals

The third category concerned effect on the **outcome and success of treatment** when there is disagreement within the group. Service users' comments reflected a belief that treatments are individually suited to people and that disagreement with other service users has little bearing on this. Service providers were concerned that 'mixed messages' from professionals would confuse clients and perhaps prevent acceptance of certain types of intervention.

Question 3- effect on treatment

Service users who selected:

0-1 (no to little effect)

The treatments that work are unique to each person; Most people with pain agree with one another; You know for yourself what works; I will say to critics 'why don't you try it'?
People are individual and it is rare for two people to require the same treatment

2-3 (moderate to marked effect)

You will always find a treatment that works for one does not work for another; It is my pain and I try to use what is offered; Most people see their treatment as a personal matter;
Each person has to try different treatments and hopefully find the one that suits; Many people are negative and say nothing has worked in the past

4 (very marked effect)

Need to be in a group of like-minded people with positive thoughts to stay focused

Service providers who selected:

0-1 (no to little effect)

(no comments recorded)

2-3 (moderate to marked effect)

Patients may not receive optimum care; A moderate effect on an outcome that is moderate could be quite detrimental; Treatment may be compromised by not pooling resources;
Not starting from same baseline; It could influence patients' beliefs

4 (very marked effect)

Confidence levels of patients need to be reinforced by service providers agreeing on best treatment; Conflict between providers on what is best may not help the pain; User cannot have contradiction in treatment; If everyone is 'singing the same tune' it must have an effect on outcomes!?; Already mixed messages from medical mode; Consistency is essential to take on new approach; Patient receives very mixed message; Chronic pain patients will pick up the disagreement and this adds to their confusion as to what is best to do

The forth category was the **relationship between service users and service providers** when people with pain disagree amongst themselves about what treatments are important. Service users' comments reflect a belief that the relationship between a patient and a service provider is individual and not strongly influenced by other service users' opinions about treatments. Service providers' comments however seem to indicate a belief that professionals must be consistent in their treatment endorsements to prevent confusion and frustration in service users.

Question 3 – effect on relationships

Service users who selected:

0-1 (no to little effect)
There is no structure for this information to be passed along so no one would know there is disagreement; This would only happen in a group treatment where a service provider would see the disagreement; Service users will try any treatment and are glad of any help

2-3 (moderate to marked effect)
If service providers try to treat everyone the same; If I didn't have access to various treatments; People tend to put too much faith in service providers and this trust can be affected by other people's beliefs

4 (very marked effect)
If people don't agree amongst themselves they might not agree with someone trying to help them; Pain needs to be dealt with on a personal level and you need to have confidence in the service provider, disregarding people who do not.

Service providers who selected:

0-1 (no to little effect)
Should not interfere but it may subconsciously

2-3 (moderate to marked effect)
Different views may cause loss of faith in service and non-compliance with treatment; Relationship suffers, the patient needs consistency from the team; It makes justification of your preferred treatment difficult if others want to do something different – the patient gets confused and annoyed; Danger of push/pull between professions

4 (very marked effect)
If there is no relationship the patient will not be helped; Pain patients are characteristically very depressed and have lost confidence in health professionals because they have received conflicting advice and treatments; Consistency needed to get message across

The fifth category concerned the effect on **what the public believe** about pain, when service providers and service users do not agree amongst themselves about what treatments are important. Service user comments reflect a belief that pain is not of interest to anyone who hasn't got it and that this lack of interest could at times translate into a lack of support for certain treatments (for example funding reduction to programmes). Service providers' comments also indicate that they see the general public as lacking in knowledge about pain and pain treatment so that disagreement between professionals causes confusion and undermines credibility. A trend seemed to be emerging of service users valuing individuality (*pain is my own experience*) and service providers being concerned for a level of consistency that they see as increasing credibility (*'having the right answer'*).

Question 3 -effect on public opinion

Service users who selected:

0-1 (no to little effect)

If you have no pain you would not understand; people see you and think you are all right even if you are in agony; If you haven't got pain you are not really bothered about it; You don't know about chronic pain unless you have it

2-3 (moderate to marked effect)

If sufferers are seen to disagree about what they need; the public could think that they don't have pain at all; You are supposed to be knowledgeable if you have the condition; You need a positive approach because in the main, people can not see pain; People who don't suffer chronic pain don't always believe the people with chronic pain are suffering; The public could sway the balance on my choices!

4 (very marked effect)

Gives a negative attitude and can reduce treatments available; The public don't believe you have pain because you cannot see it

Service providers who selected:

0-1 (no to little effect)

The public have little understanding of what we do anyway

2-3 (moderate to marked effect)

It can cause confusion; Public don't know who to believe; They generally request what they have been told about and like the sound of; Undermines credibility; Many people cannot understand why pain services are 'part time' and why they have to wait when they are in pain

Potentially a very marked effect if public perception was influenced by good public education on pain management (eg started at school)

4 (very marked effect)

People are confused who to believe- but do we give them personal choice if we decrease treatment options or service?; Presents image of chaos and misunderstanding of pain problem; Would seem chaotic treatment; If we are not clear we cannot give a clear message to non-specialist clinicians or the public.

The sixth category related to the **range of treatments** available when service users and service providers do not agree about what are important treatments. Service users' comments reflected that they were concerned about having individually suited treatments and raised the issue of limited resources or the need for action coalitions to ensure resources were available for the treatments they wanted. Service providers were less concerned with the desire to 'customise' programmes for people with pain but did focus on how a lack of cohesion could result in resource depletion.

Question 3- effect on range of treatments

Service users who selected:

0-1 (no to little effect)

Providers should provide for individuals, not try to treat all the same; Each sufferer is an individual with her/his own problems and symptoms

2-3 (moderate to marked effect)

Surely the providers are more concerned with results rather than opinions!; Each treatment is different and might help some and not all patients; There is no structured feedback system in place to inform anyone that service users do not agree; Service providers need a consensus of opinion

4 (very marked effect)

The range of what one person likes might not be best for me; I need to be selfish and pick the treatments best for me; Service providers may stop trying new treatments;
Nobody listens to whingers anyway

Service providers who selected:

0-1 (no to little effect)

This is effected by many things – funding for one

2-3 (moderate to marked effect)

Would be compromised; Individual practitioners may offer different treatments but a lack of consensus may limit resource allocation to provide those different treatments

4 (very marked effect)

We are often limited in chronic pain programmes in what we can offer; If we disagreed some people wouldn't know what to offer; If we only use treatments that we all agree on people will be exposed to fewer and may not encounter the one that helps them move forward.

The final category targeted service providers only and asked them to comment on how **relationships with co-workers** could be affected by disagreement about which treatments are important. A majority of the comments (67.5%) reflect a concern for group cohesion, cooperation and consistency. There were no comments suggesting that multiple opinions were of value to allow the client selection from a range of individualised treatment. The median response was '3 (marked effect)'.

Question 3- effect on relationship with co-workers
Service providers who selected:
0-1 (no to little effect)
(no comments were recorded)

2-3 (moderate to marked effect)
Could be strained; Depends how good they are at negotiating and compromise;
Depend on how well the multidisciplinary team works together. We have a very democratic approach and get annoyed if the consultant 'thinks he knows best'!; Competition rather than cooperation;
Dysfunctional, people need to be valued

4 (very marked effect)
Essential to ensure people receive reinforcement of pain management principle;. If a team does not agree certain aspects will be under/over emphasised, to the detriment of the overall message.;
Arguments, discord, splitting into subgroups; If you do not work as a team it will reflect on how you treat the patient.

Finally, all participants had an opportunity to write in additional comments. These are highlighted in the box below.

'Other' (write in comments on this section) from Service Users:
People can become insular; People will stop communicating and moral is affected;
Family members can lose patience; You avoid discussing pain if you can help it;
Pain is your own, it is not about groups of people; Can lead to mistrust, frustration and misunderstanding

'Other' (write in comments on this section) from Service Providers:
Service provider disagreement can have an emotional effect on service users;
unco-ordinated approach and disagreement will give the public a message that professionals do not know what they are doing; Patients can lose confidence in conventional medicine-explore unproven methods OR become depressed AND fail to keep appointments equalling a big loss of resources (for others); causes fragmentation of care; If all providers have agreement then treatments are more likely to have effect and weight to obtain the best resources; Peer support external to the team is also effected; Disagreement can cause delays in appropriate treatment;
This all depends on how large the disagreement is and how apparent to service users

8.2.2.2 Emerging themes

Five broad themes emerged from the comments service users made related to the effect of disagreement:

1. Pain is individual.
2. If you don't have pain you cannot understand it.
3. Treatment should be customised to the individual, not offered the same for everyone.

4. Treatment that works for one person does not work for everyone.
5. Negative comments from other people can have consequences and should be avoided.

Overall, the comments reflect the low median scores concerning the impact of disagreement amongst the group of service users in regards to which treatments are important. The belief that pain is individual and that treatments should be individualised may indicate that members of the service user group felt they did not need to agree. Strategies of keeping your pain to yourself and getting support from only like-minded people were also mentioned. Several participants pointed out that there was little likelihood of people outside of the service user group being aware of any disagreement about treatment importance.

The themes generated by the responses of the service providers revealed a different pattern:

1. It is important to present a consistent approach.
2. It is important to maintain service user confidence through minimizing conflicting information from the range of service providers.
3. Lack of team agreement can have negative resource implications.
4. Conflicting service provider messages will increase service user frustration and make them search outside traditional medicine for answers.

In general, service providers' comments demonstrated a much stronger concern that disagreement would have negative consequences than did the service users.

8.2.3 Identification of significant influences on decision-making

Question 4 asked service users and providers to identify the three most significant influences on their own decision-making about treatments from a list of nine (with the option of writing in '*other*' influences if desired). The lists were different for service users and providers. As shown in Figure 8.3 service users very clearly identified that their decision- making was most strongly influenced by *1-past experience, 2- service provider advice* and *3-personal beliefs*. The other influences (*4-complementary therapist advice, 5-family advice, 6-Internet information, 7-information from magazines, 8-advice from other service users* and *9-finances)* were felt to be notably less important.

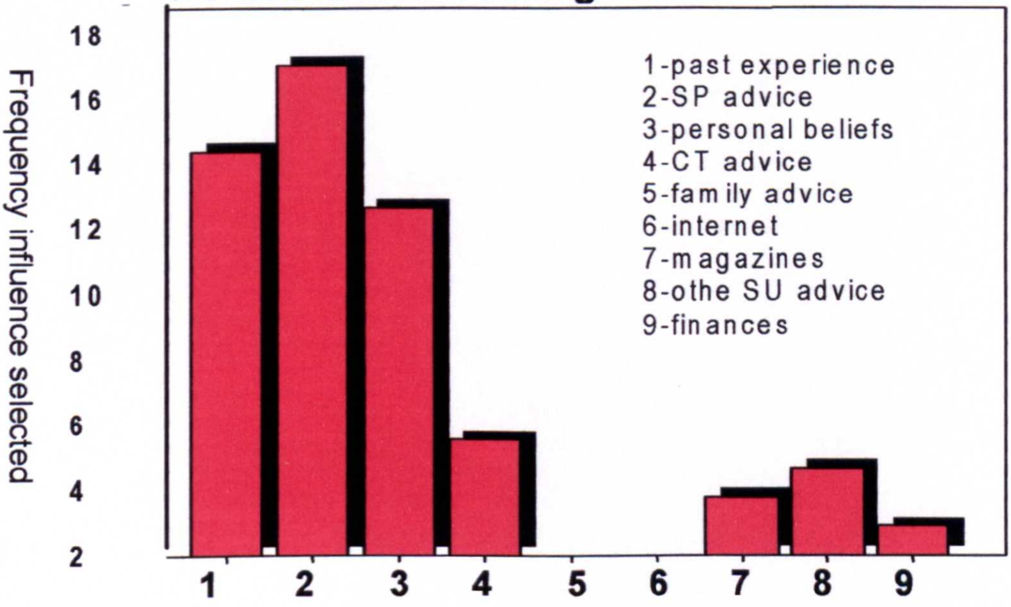


Figure 8.3: Influences on SU decision-making

Figure 8.4 shows the service providers' responses. Service providers identified that their own *personal experience* (1), *consultation with the team* (2), and what the *service user preferred* (3) were the most significant influences on their decision-making (Figure 8.4).

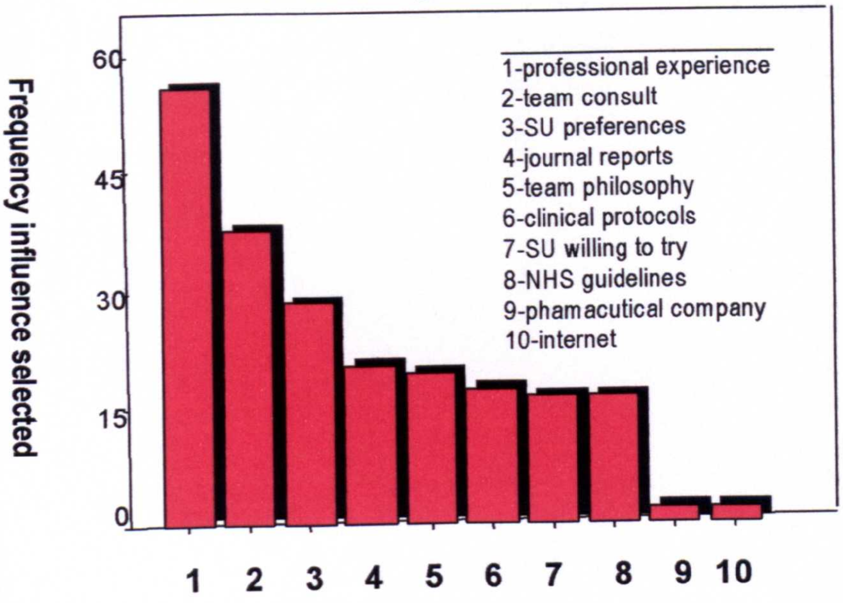


Figure 8.4: Influences on SP decision-making

All other factors were judged as less influential and are listed here in descending level of endorsement; *journal reports* (4), *philosophical framework of team* (5), *clinical protocols developed by the team* (6), *what the service user is willing to try* (7), *government & NHS guidelines* (8), *pharmaceutical company information* (9), and *internet information* (10).

8.2.3.1 Additional influences on decision-making

The data were explored to determine if a correlation existed between service providers' years of experience and the decision-making influences they ranked highest. Cross-tab computations with Pearson's product moment correlation based on all the professional groups who responded with this information in both the first survey and Delphi 1[7] revealed only one relatively weak statistically significant relationship, where service providers with greater years of professional experience were more likely to select *personal experience* (p=*.047*) as a strong decision-making

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[7] SPs were sorted into 2 groups based on their years of experience. The mean years of experience was 18.18 and the groups were defined 1 (low/average) = 21 or less years of experience and 2 (high) = 22 years or more experience.

influence. Further analysis [8] identified that service providers who selected *professional experience* as one of the three strongest influences on their decision-making were also significantly more likely to select *what the patient prefers* (p=.027) as a strong influence. It also appeared that they were less likely to select *NHS guidelines, protocols developed by the team,* and *the model of practice used by the team.* However, these relationships failed to meet statistical significance because of small numbers for the expected count in one cell of each cross-tabulation..

Finally the Question 4 data were reviewed to determine if there was a relationship between professional background and decision influences. There were insufficient participants in each professional group for reliable analysis.

8.3 Summary of Delphi 1 findings

Overall, three key findings emerged from responses to the Delphi 1 questionnaire. The first was that, while SUs' comments about why a treatment was important reflected influences distributed across all four themes of the Consciousness model (*Coherence, Purposiveness, Affect* and *Self-image*) [35], the SPs' comments contained very little *Affect* or *Self-image* content. The second key finding was the difference in opinion between SUs and SPs about how important it is to agree about treatments and the impact of any disagreement. Service users rated the impact of disagreement lower than service providers who felt that disagreement would have more negative consequences. Service users often stated that their pain was individual to them and others' beliefs were not that important. Lastly, although service users' endorsement of *service provider advice* and *personal experience* is not unusual given the predominately biomedical context of healthcare service delivery in the UK, the service provider endorsements are much more unexpected. Service providers more strongly endorsed *consultation with the team* and *professional experience* as opposed to what would be considered more evidence-based influences such as *journal reports, government and NHS guidelines,* and *protocols developed by the team.* The following section will present a brief discussion of these three key

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[8] SPSS cross-tab of SPs who selected '*professional experience*' in relation to the other influences on decision-making listed in Delphi 1-Question 4.

findings and explain how these findings were applied iteratively, guiding the theoretical underpinnings and design of the Delphi 2 questionnaire.

8.4 Delphi 1 preliminary discussion

8.4.1 The influence of affect on decision-making

The Delphi 1 questionnaire gathered participants' opinions about the effect of disagreement for what treatments are important. The data themes were identified and grouped according to the four sub-themes *(Coherence, Purposiveness, Self-image* and *Affect*) in the Consciousness model [35]. The distribution of each group's total comments within the different sub-themes showed that SUs were influenced by *affect*, *purposiveness* and *self-image* but SPs were primarily influenced by *purposiveness* and *coherence*. Service providers made very few comments in the categories of *affect* and, particularly, *self-image*. Service provider responses indicated that they believe their decisions are most influenced by *coherence* and a treatment component's *purpose* and that little influence comes from the more subjective domains of *self-identity* and personal *affect*. One possible explanation is that people misconstrued the question and interpreted 'how this makes me feel' in a physical context which would have no bearing on service providers as they are not the ones with the pain. However, the question did give a clear definition ('*the emotional feelings one has about this treatment*') and examples of participants' comments from the previous survey report were also provided. It appears unlikely then that misunderstanding could account for the nearly 80% of SPs who stated *self-image* and *affect* had little influence on their decision-making.

A growing voice in the medical literature raises the concern that, as medicine has made efforts to become more scientific and technical, service providers have become at ever-increasing risk of losing touch with their individual identities and humanity [400, 401]. Yamey suggests it is time to stop studying what makes healthcare practitioners go wrong and instead focus on what is needed to promote their well-being. He identifies attending to healthy emotional lives as necessary for service provider's own well-being and health [402].

Service providers experience many negative emotions (helplessness, frustration, hostility, hostility) in working with service users who have frequent appointments and complex, diagnosis-resistant conditions [279]. Service users with chronic pain also experience and express many emotions [21, 96, 217]. When these emotions are expressed within the context of a treatment interaction reciprocal emotions can arise for the service provider. Although healthcare providers are inculcated to deny subjectivity and strive for decision-making grounded in scientific 'objectivity' [403], the ability to do this may prove more the exception than the rule. Meier states that because feelings influence both behaviour and decision-making, healthcare providers must learn to identify their feelings consciously and accept them as normal. This is necessary in order to practice effectively in emotionally complex situations [403]. Dempsey proposes that the emotional stress of the clinical situation is also compounded by healthcare workers' concern over how their peers and co-workers will judge their behaviour to the point where this, as opposed to service user wellbeing, can drive decision-making [281]. If one accepts that there are emotional elements inherent in interactions between service provider and service user it follows that these elements would be present in the relationship between service provider and beliefs about treatment options and, also, that decisions about whether a treatment is important or not will include an affective domain.

Sweeney proposes that a positivist approach to medicine will not be responsive to the emerging conceptualisation of health as a complex issue. When health is understood as contextually imbedded in a network of social, cultural and environmental issues healthcare providers cannot 'immunise' themselves from their own values, fears and belief systems [404]. There are many examples in the professional education literature stressing the need for reflective practice based on identification and internal dialogue about personal feelings and beliefs. Fraser and Greenhalgh [263] suggest that this process is essential to effectively deal with the ongoing learning demands of remaining capable in the healthcare field. 'Reflective learners transform as the world around them changes: poor learners simply complain about it' [263].

It has been proposed that there are consequences at both the individual and the system's level when healthcare practitioners do not acknowledge or consciously examine their emotional responses. The individual service user may experience over or under-treatment, ambiguous communication, instillation of 'false hope', over-referral, excessive testing and avoidance by certain service providers [279, 281, 403]. When asked to identify sources of negative emotion, healthcare workers tend to see the service user as responsible for their frustration as opposed to looking to their own behaviour and the context of the setting [279, 398]. This perspective allows the system to maintain a status quo with efforts to improve the situation being focused on individual interactions as opposed to the 'bigger picture'. Beyond the issues of individual interactions, the pressures of the system (long hours, waiting list, understaffing, scarce resources) remain unaddressed as long as service providers are discouraged from examining the affective consequences of their daily work. At an organisational level Neuwirth states that 'society has become myopic in its focus on technical treatment to the exclusion of how we might treat each other as sublime human beings' and cautions that it is the policies and ethics of medical systems that need examination, not individual interactions [401]. To effectively contribute to the well-being of both service users and themselves, service providers need to question the usefulness of what is understood as being an objective practitioner.

8.4.2 The impact of disagreement

The second key finding from the Delphi 2 responses related to the impact of disagreement. In general, service users rated the impact of within group disagreement about treatment lower than service providers. In the categories of *financial, treatment outcome* and *relationship between the service user and provider*, the differences were statistically significant (*p=.008, 001* and *.002* respectively). On closer examination these three areas present an insight into the context in which healthcare services are delivered. Service users in the NHS are not required to pay (beyond a subsidised cost for prescriptions and some equipment). However, service providers deal daily with financial issues related to service provision and balancing the 'ideal' with the 'affordable'. Even services that have demonstrated high calibre outcomes and are recognised as leaders in the field are confronted with funding issues[9]. The Clinical Standards Advisory Group's report Service for Patients with Pain [69] noted the increasing demand on 'insecure and

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[9] For example, in early 2004 the Input Pain Management Programme at St. Thomas's Hospital in London (after more than 12 years of existence and a strong international profile) was threatened with

inadequately funded' programmes was a problem that would be difficult for service providers to resolve as the multifaceted nature of pain management makes it, "...difficult to present compelling information to hospital managers and healthcare commissioners about the value for money and effectiveness of the service" [69:6]. Service providers' concern for the financial impact of disagreement between service users and providers would appear a logical response within the economic and political context of healthcare in the UK.

Service providers also felt that treatment outcomes would be affected if there were disagreement between different service providers. The NHS has clearly stated that harmonious interdisciplinary service provision is a desirable quality in all service delivery and is in ongoing production of a range of policy guidelines and implementation strategies to support this initiative [405]. Principles two (*Redesign*) and three (*Respect*) of the Modernisation Agency's three guiding principles (Box 8.iii) contain a clear directive for more collaborative and multidisciplinary working.

Box 8.iii NHS Modernisation Agency principles and rules

THE 3Rs:

- Renewal: More modern buildings and facilities, new equipment and information technology, more and better trained staff.
- Redesign: Services delivered in radically different ways with a much greater use of clinical networks to better co-ordinate services around the patient.
- Respect: A culture of mutual respect between politicians and the NHS, between different groups of staff in the service and, critically, between the NHS and those we serve.

THE 5 SIMPLE RULES:

1. See things through the patient's eyes.
2. Find a better way of doing things.
3. Look at the whole picture.
4. Give frontline staff the time and the tools to tackle the problems.
5. Take small steps as well as big leaps.

[405]

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severe cutbacks. A petition to the hospital executive was widely supported at the Pain Society Annual Scientific Conference in Manchester, April 2004.

Despite the stated beliefs and efforts made by the NHS in this area, clinicians are also confronted with problems inherent in working within teams and trying to move a traditionally hierarchical system, where the physician determines both goals and the action plan [406], in a more collaborative direction. Tradition, self-interest, public expectation, a growing concern over who is ultimately responsible and culpable for team decisions, and the negative strategies many team members use to deal with conflicts (for example avoidance, miscommunication and suppression), are extensively discussed in the literature [406-409]. Service providers in the NHS exist in the paradoxical situation of needing to demonstrate adherence to a concept that not everyone is convinced works or is necessarily in the best interest of all service users.

Lastly, service providers were much more concerned than service users about the impact that within group disagreement would have on SU/SP relationships. The most obvious explanation of this may lie in the degree of experience one has with clinical encounters. As extensively discussed in Chapter 2, people assign meaning to their pain based on their personal experiences and life-context. For most service users that involves relatively limited experiences of healthcare teams and particularly healthcare teams that disagree. Service providers, on the other hand, have extensive personal and anecdotal experience with team conflict and would bring this experience to their evaluation of the impact of within group disagreement about which treatments are important.

8.4.3 Service providers and evidence-based practice

The third key finding of the Delphi 1 questionnaire was that the evidence-base is not the strongest influence in service providers' decision-making. Interestingly, this is consistent with current research. The literature demonstrates that experience, authority and expedience exert a strong influence on practice and that this influence can in some situations actually be contrary to evidence-based practices [260, 410-413]. Applying a constructivist analysis, where treatments are seen as social constructs of individual service providers, the decision to use a particular treatment or not is, to a large degree, based on the historical development of the individual's belief about each treatment component's efficacy. This is as opposed to relying on what is perceived by legislators and policy makers to be a more objective source of 'evidence', (such as the National Institute for Clinical Effectiveness [414] and the Cochrane Collaboration [415]). Decision-making regarding treatment selection is governed by what SPs are taught, what they are told, what they observe and perhaps what employers expect them or tell them to do.

Different explanations have been put forward for what has been labelled 'the research-practice gap' [260]. It has been proposed that service providers, as they become more reflective in their practice, will realise that sound, high quality research findings cannot be logically or ethically rejected because the findings do not fit with a service provider's opinions, beliefs or experiences, nor because the research is presented in a complex, difficult to access fashion [410]. Other authors propose that although service providers have actually embraced the need for evidence in shaping practice, they are becoming increasingly sceptical as to the value of the traditional definition of 'gold standard' research being comprised of randomised control trials (RCTs) [416]. Contemporary theorists now stress that while evidence arises from studying causality and probability, it also comes from an equally important examination of patterns and possibilities [256].

The World Health Organisation has cautioned that many emerging issues in healthcare, of which chronic illness is one, require an awareness of complex interrelationships between the person, society and the environment [265]. This is particularly pertinent to this discussion of influences on decision-making. Healthcare literature is beginning to explore the role these inter-relationships play, suggesting that SPs' decision-making is multidimensional and that the evidence-based as defined by RCTs is only one in a wide range of types of evidence that can guide best practice. Service providers are also concerned with patient choice [417], and that the research constituting the evidence-base is not always defined by outcomes of relevance or importance to patients themselves [411]. Upton [260] proposes that nurses are slow to take up the evidence-base generated through RCTs because they perceive a gap between this positivist approach to health care and their professional ethos of holism. She further suggests new methods of generating 'evidence' need to be developed before certain practices will be able to change. This proposal seems relevant to service providers given the growing focus on patient-centred care across all healthcare disciplines. As previously discussed in Chapter 7 (7.5.2) service provider participants in this study were very heterogrenous in their treatment endorsements and not necessarily evidence-based. Perhaps explanations for the inconsistency between the evidence-base generated through systematic reviews of the research literature and certain widely endorsed beliefs held by service providers about what treatments are important should be seen on a continuum. While some beliefs are anchored in a lack of knowledge, others should be taken as support that SPs are, either tacitly or overtly, aware of a need to inform their decision-making about a complex health issue like chronic pain in a wider range of information and sources of evidence.

8.5 Chapter summary

In summary, the results of both the Stage one survey and Delphi 1 questionnaire have identified a lack of congruence between the beliefs and the decision-making influences on service users and providers. Key issues related to the findings have been discussed. The iterative process of a Delphi study dictates the need to verify the researcher's interpretation and theoretical constructs related to these key issues. The following chapter will present the findings of the next round (Delphi 2 questionnaire) that focused on participants' validation of Delphi 1 findings and examined whether they agreed that a constructivist framework was applicable to their decision-making for chronic pain treatments.

Chapter 9

Delphi 2 findings: the Consciousness model

9.1 Introduction

The purpose of the Delphi 2 questionnaire was to seek participants' validation of the researcher's conclusions from previous rounds. It also gathered any recommendations participants had about actions required when there was disagreement between service users (SUs) and service providers (SPs) about which treatment components for pain are important. This chapter presents the findings of the Delphi 2 questionnaire.

In May 2003, the Delphi 2 questionnaire was mailed to two hundred and twenty SPs and thirty-two SUs. A reminder letter and duplicate questionnaire was sent three weeks later to the nineteen SUs who had not yet replied. By the beginning of July 2003, ninety (40.9%) SPs and sixteen (50%) SUs had replied. The reminder letter generated six of the sixteen SU replies. The demographic breakdown of respondents is presented in Box 9.i.

Box 9.i: Delphi 2 respondents' profile

Respondent	**Age (mean years)**	**Years of experience**	**Female**	**Male**
Service User (16)	54.2	12.2	9 (56.3%)	7 (43.8%)
Service Provider (90)	44.6	19.5	47 (56.0%)	34 (40.5%)
Distribution of response between professional groups				
▪ occupational therapist	10 (11.1%)			
▪ physiotherapist	8 (8.8%)			
▪ general practitioner	8 (8.8%)			
▪ nurse	24 (26.6%)			
▪ anaesthetist	25 (27.7%)			
▪ psychologist	5 (5.5%)			
▪ other & not stated	10 (11.1%)			
TOTAL	90			

9.1.1 Opt-in/out

One feature of the Delphi method is that it allows participants to opt in and opt out of subsequent rounds as their interest, time and ability to respond, alters. The responses to Delphi 2 clearly illustrate this feature. Thirty-five service providers who had not participated in Delphi 1 opted back into the study for the Delphi 2 questionnaire. Similarly, forty-three service providers who responded to Delphi 1 chose not to respond to the Delphi 2 questionnaire this round. This pattern will be more fully discussed when the findings of the final round (Delphi 3) are presented in Chapter 10.

9.2 Validating the Consciousness model

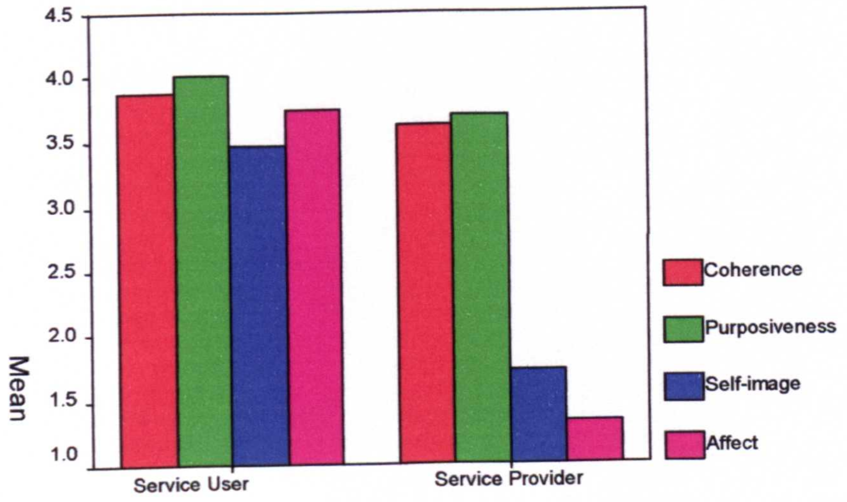
9.2.1 Part 1: decisions about 'important'

In Part 1 of Delphi 2, participants were presented with four themes representing the reasons why people decided certain treatments were important or not. The themes (*Coherence, Purposiveness, Self-image and Affect*) were derived from Chapman's model of Consciousness and pain [35] discussed in Chapter 4. The themes were defined as *Coherence* (because the treatment makes sense), *Purposiveness* (because of what the treatment does), *Self-image* (because it fits a person's idea of who he or she is), and *Affect* (because of the emotional feeling one has about this treatment). Through an ordinal scale (anchored at '0- not at all' through to '4-completely') participants were asked to identify how closely the themes matched their reasons for thinking a treatment is important. Because of the small sample size of service users (16) the data were recoded into thre categories (0-' not at all/a little', 2 – 'somewhat' and 4 – 'mostly/completely').

An independent samples t-test was conducted to compare service users' and providers' responses to the four themes. There were statistically significant differences in the scores for *Purposiveness* [(t (degrees of freedom 78) = 3.167; p=.002], *Self-image* [t (31.75) = 5.872; p= <.000] and *Affect* [t (28.764) = 7.417; p=<.000]. There was no significant difference for *Coherence*. Several interesting patterns emerged in the analysis (Figure 9.1). While the majority of service users agreed that all four themes influenced their decision-making, the service providers strongly rejected the themes of *self-image* and *affect* as having any influence on their decision-making. Only 20.5% of service providers rated the theme of self-image (*what someone like me would think)* as closely matching their reasons for thinking a treatment was important or not. Service provider ratings for the influence of affect (*how this treatment makes me feel*) were similarly low with only 19.4% of respondents selecting a rating of 3 or 4. This is in marked contrast to the service user ratings where 73.3% selected self-image and 92.9% selected affect as a strong influence.

Figure 9.1: SU/SP Mean Scores

Influences on 'Important'



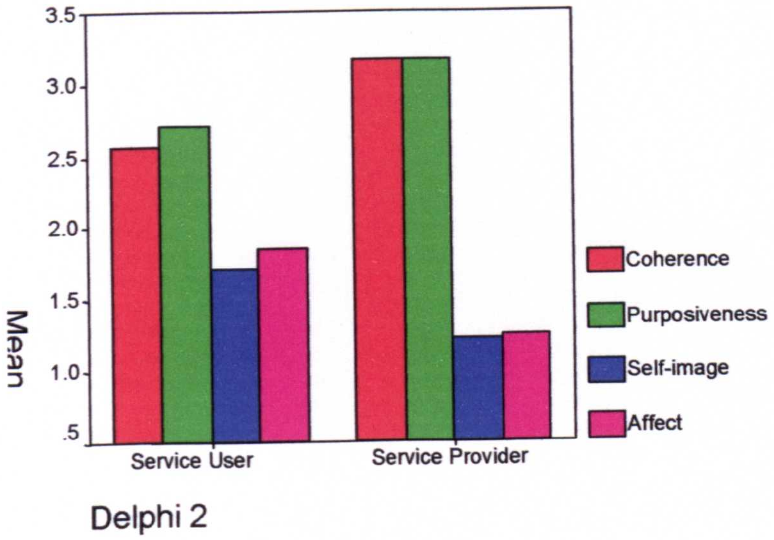
Delphi 2

9.2.2 Part 2: decisions about what is 'not important'

Part 2 asked people the same type of question as Part 1 but in relation to participants' reasons for thinking a treatment was '*not important*' (Figure 9.2). Service users in particular answered Part 2 quite differently from Part 1 ('*important*' treatment components). Service users felt self-image and affect had much less to do with deciding what was '*not important*'. Although it is possible that service users are influenced differently, for what is important as opposed what is not important, it is also possible that the question (recognised on review by the researcher, as grammatically very complex) may have been misunderstood. There is insufficient data to draw conclusions about why the questions were answered so differently. However, service providers were a much larger group and their consistent tendency to reject self-image and affect as influence on decision-making can be identified with more confidence.

Figure 9.2: SU/SP Mean Scores

Influences on 'Not-important'



9.3 Validating conclusions from Delphi 1

The researcher generated twelve summary statements, based on the responses to the Delphi 1 questionnaire. In Part 3 of the Delphi 2 questionnaire respondents were asked to verify that they agree with these statements from Delphi 1. All statements that received a median score of 3 (*mostly*) or 4 (*completely*) were interpreted by the researcher to be validated by the respondents. This resulted in eight statements being accepted as valid by the service users and five statements being accepted as valid by service providers. The validated and rejected statements are identified in Table 13. The five statements validated by both service users and providers are as follows:

1. Service providers are more concerned than service users about costs to the NHS
2. Service users are concerned about being seen as individuals
3. All service providers in a team should agree on what treatments they feel are important

4. Service users can get more resources by lobbying together
5. Service users benefit most from treatments selected individually by themselves and their service provider

An independent samples t-test revealed that there were two statistically significant differences between SUs and SPs in relation to their support for three of the original statements. Service users were more likely than service providers to endorse the following statement; *'people who do not have pain will have no opinion about what services should be provided'* [t (94) = -3.301, p =.001]. Service providers, on the other hand, were more likely than service users to endorse the statement; *'disagreement about treatments will result in lost credibility to the public'* [t (95) = -2.480, p = .015]. All of the relationships need to be treated with caution as the sample SU size is small (N=16) and the potential grammatical problems with questionnaire construction mentioned previously may have influenced some respondents.

9.4 Validating influences on decision-making

Participants in Delphi 1 had rank ordered a list of influences on decision-making regarding treatment importance. The list of influences was different for each of the two groups: service users or service providers. At the Delphi 1 stage participants were only asked to rank influences within their own grouping. Specifically, service users ranked influences on service users and service providers ranked influences on service providers. In Delphi 2 they were asked to reflect within their own group on other participants' rankings and then either indicate their agreement with the rankings or re-rank the influences on decision-making. Each group was also shown, for the first time, the rankings the other group had generated in the Delphi 1 questionnaire. In other words, in Delphi 2, service users were shown the service providers' rankings generated during Delphi 1 and vice versa. Participants between groups were asked to reflect on these rankings and then indicate their agreement with the rankings or re-rank the list of influences on decision-making. This means that SUs and SPs were shown rankings from both within their own group (thus having two opportunity to rank these influences) and between the two groups (one opportunity to consider these influences). Box 9.ii shows how each group ranked the influences on decision-making. The first left-hand column lists the influences ascribed to each group. The service user influences are listed 1-9 and service provider are listed 10-19. The 2nd column shows each within group original ranking from the Delphi 1 questionnaire (SU rankings at the top of the table, SPs in the bottom). The 3rd column shows within group re-rankings from the Delphi 2 questionnaire. Lastly, the 4th column (far right-hand side) shows the between group rankings from Delphi 2. The SP ranking of the SU influences are at the top of the table and the SU ranking of SP influences is at the bottom.

A rank of '1' indicated most important through to '10' least important. Some respondents assigned the same rank to more than one item and consequently these responses could not be entered in the data-base. The results and discussion are based on those respondents who provided discrete rankings. It is possible that some opinions are under-represented because of this.

The symbol ▲ indicates within group differences (service users' ranking compared to service users', and service providers' ranking compared to service providers'), of two or more points between Delphi 1 and 2. A ▲symbol means the influence was given more importance the second time it was rated. For example, in Delphi 1 service users ranked *'what SU can afford'* as the 7th strongest influence. In Delphi 2 they gave it a rank of 5. This means that the SUs had increased their ranking of the influence by two points thus giving it a higher weighting amongst the list of influences. The △(higher) ▽ (lower) symbols show between group difference (service user compared to service provider) of two or more rankings at Delphi 2. For example, the influence *'what SU can afford'* was rated 8th most important by the service providers in Delphi 2. This ranking differs from the SUs' by three points, indicating that the SPs think that *'what SU can afford'* is of much less importance than the SUs.

Box 9.ii: Ranking of influences on decision-making

SU Influences	**SU Delphi 1** (Original ranking)	**SU Delphi 2** (Re-Ranking)	**SP Delphi 2** (Original ranking of SU influences)
1. SP advice	1	2	1
2. SU past experience	2	1	2
3. SU beliefs	3	3	3
4. Complementary therapist advice	4	4	5
5. Other SU advice	5	5	4
6. Magazine	6	6	7
7. What SU can afford	7	5 ▲	8 ▽
8. Internet Information	8	7	7
9. Family advice	9	7 ▲	6
SP Influences	**SP Delphi 1** (Original ranking)	**SP Delphi 2** (Re-ranking)	**SU Delphi 2** (Original ranking of SP influences)
10. Professional experience	1	1	1
11. Consultation with team	2	2	2
12. SU preference	3	3	3
13. Journal report	4	4	7 ▽
14. Philosophical framework	5	6	5
15. In-house clinical protocols	6	5	8 ▽
16. SU willing to try	7	7	6
17. NHS/DoH guidelines	8	8	10 ▽
18. Pharmaceutical company info	9	9	9
19. Internet information	10	10	4 △

Service users and service providers at Delphi 2 agreed that service users were most strongly influenced by *SP advice, past experience* and *personal beliefs*. They also agreed that *SP experience, consultation with the team* and *SU preferences* were the most important influences on the service provider. These six influences are important to highlight as they indicate that there is a basis of understanding between SUs and SPs about which influences are most important in guiding treatment decision-making.

The Delphi 2 questionnaire showed that there was some shift in service users' ranking of within group influences. On reflection SUs ranked, '*what SU can afford*', and, '*family advice*' as more important influences than they did in Delphi 1. In contrast, service providers remained fairly consistent in their rankings between Delphi 1 and 2. Of particular note are the items that received quite different weighting when SUs and SPs commented on each other's list. Service providers' ranking of the service users' list showed that SPs believed the *cost of a treatment* to be less significant and the influence of *family advice* to be more significant than the ranking actually assigned by SUs. Service users, when ranking the service provider influences, believed that the *internet* was a stronger influence then journals. *Clinical protocols* and *NHS/DofH guidelines* were ranked at the bottom of the table by service users. These three items were ranked very differently by service providers who saw *journals*, then *protocols* and *NHS guidelines* as more important than the *internet.*

9.5 Recommended actions consequent to disagreement

In Part 6 of the questionnaire participants were asked if they thought that any action should be taken if SUs and SPs disagreed. Thirteen of the sixteen service users (81.3%) felt action should be taken and the remaining three SUs (18.8%) expressed no opinion. Amongst the service providers twelve (13.3%) stated "NO", sixty-seven (74.4%) stated "YES" and eleven (12.2%) had no opinion. A summary of responses is shown in Table 14.

The recommendations participants made about what actions should be taken were organised by categories of who should take action (SU, SP, or jointly) and for what ultimate purpose (for example*: to maintain or change the balance of control over treatment option decision-making*). Four categories of response were identified and related to the roles assumed by SUs and SPs for the purposes of : *supporting professional decisions*, *gaining more information, negotiating a plan,* and *sharing responsibility*. The first two categories, *Service provider action to support professional decision,* and *Service provider action to gain information* (items 1 and 2 in Table 14), contained suggestions focusing on the SP as the one who should take action with the purpose of reassuring the service user that the correct selection of treatment(s) had been made. Comments related to these two categories demonstrated an expectation that control of the situation rested with the service providers. The third category (*Service provider actions to negotiate plan)* contained comments that identified actions the SP should take. The purpose of the recommendations in this category was to negotiate agreement with the SU. There were no suggestions of actions the SUs should take independently. The fourth category contains the suggestions that were made about SU and SP joint actions for the purpose of more flexible sharing of responsibility. As shown in Table 14 very few suggestions were made about actions the SUs should take.

9.5.1 Participants who did not recommend action

Twelve SPs indicted that they felt no action was required. Eight of these SPs made no comment to elaborate their choice. The others' comments included '*it is hopeless and will take generations to educate everyone* (participant 154), *being consumer led is a 'step-backwards* ' (227), *need to have SU & SP defined more clearly before taking action* (232) and *'stop making a fuss'* (267). None of the SUs selected the response indicating no action was required although three people left the question blank.

In summary, there were very few suggestions (from either SU or SPs) of actions that service users should take in response to disagreement about which treatments are important.

9.6 Statements to other participants

In Part 7 participants were asked to share any opinions they had formed after reading other peoples' responses to the Delphi I questionnaire. An open-ended 'prompt' sentence was provided for respondents to complete (Statement 1 -'*I think service providers need to....* ' and Statement 2 - '*I think service users need to.... ').*

Responses to Statements 1 and 2 were reviewed and categorised. The categories related to issues identified in the comments and included; *communication, validation, treatment, professionalism, advocacy/lobbying,* and *paradigm shift (new ideas).* Table 15 displays the issues and samples of comments related to each issue. Many of the comments were made by only one individual and cannot be generalised to represent group opinion. However, certain consistencies emerge. Specifically, a desire for factual, mutual communication, the desire for validation and some degree of control were evident in a number of the comments.

9.7 Summary of Delphi 2 findings

The Delphi 2 questionnaire responses showed that SUs think all four of Chapman's themes within the Consciousness model (P*urposiveness, Coherence, Self-image* and *Affect*) [35] influence their decision-making. However, SPs stated they are for the most part only influenced by *Purposiveness* and *Coherence*. SUs and SPs agreed that service providers are more concerned than service users about costs to the NHS, that service users are concerned about being seen as individuals and that service users benefit most from treatments selected individually by themselves and their service provider. Most SUs and SPs also stated that service providers in a team should agree on what treatments they feel are important and that service users can get more resources by lobbying.

The comments also indicated that SUs believe more strongly than SPs that people who do not have pain will have no opinion about what services should be provided (p=.005) and that disagreement about treatments will result in lost credibility with the public (p=.012). SUs and SPs agreed that service users were most strongly influenced by service provider's advice, past experience and personal beliefs while service providers were most strongly influenced by personal experience, consultation with the team and SU preferences. When asked about what should happen when there is disagreement about treatment, both groups tended to focus on recommendations that gave service providers control over, and responsibility for, any action. When asked to comment to each other, most SUs and SPs were concerned with issues related to communication, validation, treatments, advocacy and being open to new ideas.

9.8 Delphi 2 preliminary discussion

The aim of this study was to examine whether there was congruence in SUs' and SPs' beliefs about pain treatment components. It is clear from the findings of the Stage one survey and the Delphi 1 and 2 questionnaires that congruence was low for many aspects in the study. The second aim of the study was to explore the implication of the findings related to congruence. An interesting feature that emerged in the Delphi 2 responses was that across Delphi 1 and 2 there was much greater consistency of beliefs regarding influences on decision-making about treatment importance within the service provider group than the service user group. These differences in themselves are perhaps not so exceptional. Rather, the significance lies in the implications of these differences. Service users' opinions were not static; rather, they changed about certain questions over the course of Delphi 1 and 2. This suggests that their constructs for chronic pain treatment are dynamic and alter with new information and feedback. In contrast, the service providers were much more consistent in their replies, perhaps reflecting a more positivist approach to how they approached the information generated from participants' opinions in the previous survey and Delphi 1 questionnaire. Based on analysis of the findings, an explanatory model (illustrated in Figure 9.3) for this lack of congruence was developed within a constructivist framework.

The following sections will discuss the proposed meaning construction explanatory model in detail and examine the implications of the apparent difference in the two groups' degree of dynamism within the decision-making process. The chapter will conclude with the rationale for determining that the constructivist framework is insufficient for examining the scope of the research question and introduce the shift in theoretical redirection taken in Delphi 3 from constructivism towards a complex adaptive systems (CAS) paradigm.

9.8.1 Modelling the meaning construction cycle

The model incorporates a range of features identified through analysis of the data from the study and supported by the literature. These features (thesis findings) and sources of reference (literature) are itemised as follows:

- Service providers do not acknowledge that affect and self-image are significant influences in their decision-making (Sections 8.2.1, 9.2.1).
- The outcomes of treatment for service users are concentrated in the personal/private domain ([189], Section 8.2.2.1).
- Service providers' treatment outcomes are divided between the domains of personal/private and professional/public [369, 418, 419].
- Service users have limited access to professional scientific information (Section 9.5 and 9.6, [397, 420-422].

- Service providers are constrained in their access to information about service users' affective state [423-425].

The model proposes that when a treatment option is presented both the service user and the service provider will engage in an iterative cycle of evaluation, decision-making and testing. The treatment option is evaluated against what the individual already knows and believes. Chapman's four themes of consciousness [194]; Coherence (*'does the treatment option make sense with what I already know)*, Purposiveness (*'do I understand the purpose of this treatment')*, Affect (*'how do I feel about this treatment'*), and Self-image (*'would someone like me think this treatment was important')*, characterise this process. There is a wide range of personal, public and contextual influences on how an individual responds to these questions and each person generates his or her meaning constructions based on a mixture of these shared and idiosyncratic influences [10]. Service providers and service users have different roles and self-images that influence, and are influenced by, their expectations of a treatment and what factors most affect their consciousness of the experience. As highlighted in Figure 9.3 SPs and SUs have different influences on consciousness and expected personal outcomes of their decisions about a pain treatment component. The other people and types of relationships in their environments are different (professional/colleague versus family/friend) and social roles for many SUs and SPs encourage a dependent (patient/passive versus professional/action oriented) relationship. The bullet pointed items under the headings of *Influences on consciousness* and, particularly, *Personal outcomes* (points A and B in Figure 9.3) provide examples illustrating that people with pain have access to influences contingent on the experience of 'having' pain where as service providers, for the most part, experience pain through a 'doing' perspective [41].

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[10] Chapter 4 provides a detailed review of the meaning construction process.

Figure 9.3: Flow chart of decision-making process related to chronic pain treatment importance

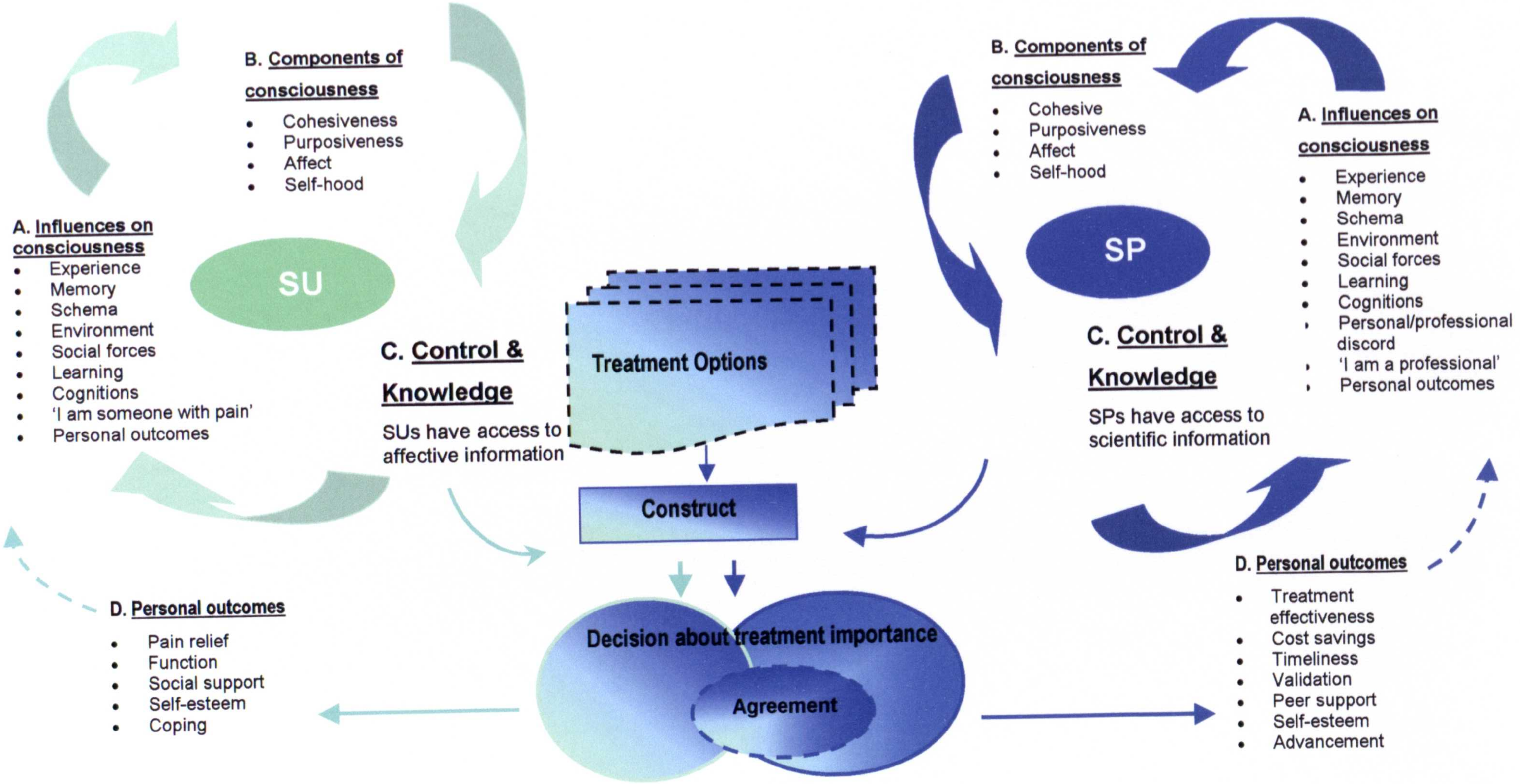

Figure 9.3 presents two possible moderators of the influences on consciousness. The first is labelled Control (C) and represents the degree of control people have (or perceive they have [19, 76]), over the outcome of actions and behaviours based on their meaning constructions. People with control are more able to engage in new behaviours, [222, 426], in turn generating additional novel information or confirming existing information that then acts as feedback into the meaning construction cycle. By nature of the role assigned to them, service providers have (and/or are perceived to have) a much higher degree of control over treatment options than service users [377, 396, 422]. This perspective that control rests with service providers is reflected in the Delphi 2 (Part 6) findings where the strong majority of recommendations about actions that should be taken as a consequence of SU/SP disagreement focused on what the service providers should do and very few recommendations were made about service user actions (Section 9.5).

The second moderator proposed in Figure 9.3 is labelled Knowledge (C). Schwandt states that the quality of constructions depend on both the degree and scope of information available and on the individual's ability to deal with that information [117]. To have one without the other can interfere with an individual's ability to formulate a construction and initiate new behaviour based on that construction. Without new behaviour the individual has limited opportunity for feedback about the construction, therefore remaining unable to evaluate and modify the existing construction in light of the new information afforded by the feedback. The model presented in Figure 9.3 proposes that SUs have access to knowledge in the affective and personal domains where as service providers have access to scientific knowledge. The findings discussed in Section 7.2.1.3 and in the literature support that service users feel that, despite concerted efforts from the NHS to improve patient-education resources [396, 397, 427], access to information and education about pain comprise important but unmet needs. Consequently, service users are unable to formulate meaning-constructs, and subsequent behaviours, because they lack sufficient scope of information. Similarly, service providers, while having a high degree of access to the scientific information, have limited structured opportunity to gain information about the affective domain of the chronic pain experience. Barriers to accessing affective information have been discussed previously and include for example, little to no education in communication skills, insufficient time within appointments, competing administrative demands, and a professional ethos that teaches students to preserve personal distance and suppress emotion [277, 398, 419, 424, 425]. How this can be interpreted then is that the meaning constructs of both service users and service providers are based predominately in information that is readily accessible to them, as opposed to a fuller perspective. Additionally, the domain of accessible information is largely unshared between the two groups, thus introducing a high degree of variation into the meaning construction.

The model proposes that the cycle begins with identification of treatment options and subsequent meaning construction moderated by influences discussed above. The next step (as shown in Figure 9.3) is decision-making about importance. Section 7.3.2 discussed that there is little agreement about what treatments are important for chronic pain. Decisions about what treatments are important influence SU and SP behaviours and lead to a range of subsequent outcomes.

The bottom left and right corners in Figure 9.3 (D) suggests that SUs and SPs seek to achieve different outcomes subsequent to behaviour based on decisions about which treatments are important. Service user outcomes are highly personal/private in nature and involve a range of physical, emotional and social elements (*can I get back to work now?, will I be able to sleep again?, do my friends think I'm 'faking'?*). Service provider outcomes also involve this complex array of elements and have a personal/private context to their meaning construction (*'this job is too stressful, I can't juggle family and work full-time'*). However, service providers' outcomes are also highly contextualised in the public/professional domain (*'would the consultant agree with me'?, 'this patient makes me so frustrated', 'how can I defend the cost of this treatment?', ' I knew I was right about that all along!'*). Morris reminds us that, "Pain seems the quintessential solitary experience....The isolation of pain is undeniable. Yet it is thus especially important to recognise that pain is always deeply social"[41:38]. Different constructs create different decisions and, in turn, produce different outcomes. These outcomes provide feedback to the meaning construct cycle thus sustaining an iterative and dynamic process.

Finally, the model in Figure 9.3 proposes the state of agreement between service users and providers. The Agreement element (centre-bottom of figure) shows more agreement overlap within the treatment components that the service providers have identified as important. The model proposes that while service users will increase their agreement with service providers about which treatment components are important, the service providers will not show the same trend towards increased endorsement. This premise is based on the existing imbalance in access to information that exists between service users and providers. Service users, through NHS patient-education initiatives and the widening availability of high quality health information on the internet [420], are more likely to be successful in accessing a degree of the scientific knowledge they previously did not have. Service providers, on the other hand, may actually be struggling to maintain what limited access to the affective domain of their patients' pain experiences they currently have. In The Paradox of Progress, Willis[11] suggests that efforts to continuously improve medical care have spawned a myriad of purportedly 'small' but essential directives and procedures. Cumulatively, these 'small' changes create an overwhelming demand on service providers and drain time and resources away from direct service provision. The demands on service providers seem to grow continually, and in each day's post, "...there is another bundle of glossy brochures about the latest additions to the ranks of mysteriously entitled bodies jostling with each other to regulate us..." [369] As a solution Willis suggests, perhaps not so facetiously, that there needs to be yet one more new government branch- The MOLWA (Ministry of Leaving Well Enough Alone) [428].

9.8.2 The dynamic nature of decisions and opinions

> *"Perspectives change, and we must give the bag a good shake*
> *and see what happens"*
> Michael Ramsey ,then Archbishop of Canterbury in [429]

Some of the Delphi 2 findings suggest that for service users, an iterative process, where they formulate a meaning construct that influences their decision-making, is

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[11] Faculty Provost of the Wessex Council, Royal College of General Practitioners.

occurring. They then act on that decision and incorporate the consequent feedback into the meaning construct. The findings do not so clearly support this process for service providers. In the Stage one survey and Delphi 1 questionnaire, participants expressed opinions based on their construction of chronic pain treatments. In Delphi 2 they were asked to reflect on these comments and validate what they had said. Some of the opinions and rankings service users had previously expressed no longer held true in Delphi 2. For example, in Delphi 2, Part 3, service users changed their ranking for two of the nine options about what influences their decisions pertaining to a treatment component's importance (Box 9.ii). Originally, in Delphi 1 they had ranked *what service users can afford,* and *family advice,* third lowest and lowest influences respectively. In Delphi 2 they increased both of these rankings by two points thus reflecting a belief that the two items had a stronger influence on decision-making. Consequently, *Internet information* and *Magazines* then became the lowest rated of all the influences. There were additional adjustments to rankings where *Service provider advice, Service user past experience,* and *Internet information* changed ranking by one point. It is possible that this is a coincidental occurrence. However, as 100% (16/16) of the service users who responded to Delphi 2 had also participated in Delphi 1 and the participants were provided with the rankings they had assigned in Delphi 1, these findings seem to offer support of an actual change of opinion from Delphi 1 to Delphi 2. It is possible that seeing other service users' opinions and having more time to reflect between Delphi questionnaires may have influenced participants' rankings. The participants were not asked to explain why they changed their rankings and it is likely that there was no one common influence that would account for all the changes.

Interestingly, the service providers changed only one of their rankings between the two Delphi rounds. *Professional experience* remained ranked as the strongest influence and *Internet information* the lowest. Between Delphi 1 and Delphi 2 *Philosophical framework of the programme* and *protocols developed by the team* changed position from 5th to 6th and vice –versa. It appears that service providers' opinions were more static. However, unlike the service providers where 100% of the Delphi 2 respondents had also responded to Delphi 1, only 60% (54/90) of the Delphi 2 respondents had also responded to Delphi 2. This means that 40% of the ranking came from service providers who had not participated in generating the Delphi 1 rankings. So, although it appears that service providers are less changeable in their opinions, this conclusion should be seen as only tentative.

A further, and less tentative, dichotomy appeared in the Delphi 2 findings regarding participants' reflection on applying Chapman's Consciousness model [35] as an organisational framework for their decision-making. Service users' responses in Delphi 1 and Delphi 2 clearly supported all four themes of consciousness. However, service providers were equally as clear in their statements that *Self-image* and *Affect* were not strong influences in their decision-making (Figures 9.1 and 9.2). This opinion is contrary to the growing literature (previously discussed in Sections 7.5.3 and 8.4.1) identifying the inherent and potentially unavoidable impact of affect in relationships between service users and providers.

It appears that while Chapman's constructivist theories about consciousness and decision-making is a useful explanatory model for the service users, it may be insufficient for fully understanding the service providers. Service providers in this study were strongly influenced by assumptions of objectivity that are more congruent with a scientific positivist paradigm. A useful explanatory model would need to more comfortably accommodate this perspective.

9.8.3 Implications of constructivism/ scientific positivism in discord

What does all this mean? Guba and Lincoln [367] remind the reader that a paradigm represents the holder's basic beliefs and way of viewing the world, and that the ongoing debate about paradigms illustrates that there is no one way to define the 'truthfulness' of these sets of beliefs. Constructivist theorists propose that even the positivist paradigm is a construction based on the individual's interpretation of the available information [367]. Scientific positivists maintain that while social forces may influence events, the world is, to the greatest extent, composed of objective reality [430]. Scientific positivism and constructivism are only two paradigms amongst many that allow one to organise thoughts about the world and experiences within it. The point is not so much that different paradigms are at play, that in itself need not be problematic. Rather, the concerning issue is; 'what happens when potentially different world-views exist for different groups in a shared experience like chronic pain?'

Previous chapters have extensively explored the literature discussing the possible outcomes of difference of opinion between service users and service providers (for example; negative affect- Section 2.7.2, 4.5.1, and iatrogenic disease- Section 4.5.2 and .3). However, reframing the issue as differing paradigms (as opposed to differing opinions) helps illustrate why, despite concerted effort and expenditure by the NHS to increase the amount and quality of patient education available through programmes like NHS Direct [431] and Patient.UK [432], opinions remain resistant to change and continue to collide. No amount of 'education' will change opinion if the underlying assumption is that everyone derives his or her ideas from the same basic shared belief system. It is important to know that participants in this study did not agree and that they seemed at times to be operating from different paradigms. It is important because despite the volume of research and resources devoted to the problem of chronic pain, it is still in many aspects as much a puzzle as ever. Some peoples' pain responds to a biomedical approach, others' to a more psychosocial approach, and some peoples' pain seems determined to remain enigmatic in the face of all manners of intervention. It is evident that chronic pain does not follow a straightforward path and the search for the 'right' way forward may paradoxically be a significant part of the problem. As mentioned in Section 5.3, "*...If things were that simple, word would have gotten round*" Derrida in [243]. A growing voice in the literature suggests that we are seeking the wrong solutions to the wrong question. It is proposed that healthcare should focus on relationships between belief systems as opposed to 'solutions' generated within traditional positivist medical thinking, or what has been called the Paradigm of Order [433].

9.8.4 Summary

In summary, the findings from Delphi 2 are in certain ways very similar to Delphi 1 and the Stage one survey. Repeatedly, a lack of congruence between what service users and service providers believe is seen. The lack of agreement in itself is value-free; it is neither a positive nor a negative finding. Rather, the important considerations must be understanding the implication of this inevitable difference and in developing awareness of how these differences, between and within groups of service users and providers, can be influenced so as to harness the cognitive and emotional energy generated through discordant views. Discord (like musical notes) can be constructive and creative like jazz music or a cacophonous and painful event driving away supporters and participants alike. Complex adaptive systems theory has been proposed as a vehicle to achieve new insights and approaches in dealing with those currently overwhelming healthcare crises like chronic pain. This redirection is applied to the following chapter that discusses the findings of Delphi 3 within a complex adaptive systems framework.

Chapter 10

Delphi 3 findings: complex adaptive systems

10.1 Introduction

One of the purposes of the Delphi 3 questionnaire was to determine if participants validated the conclusions the researcher drew from the Delphi 2 questionnaire. Also, the Delphi 3 questionnaire introduced the concept of chronic pain within a complex adaptive systems (CAS) framework and asked participants a series of questions to determine if they agreed that the characteristics of a CAS fitted their beliefs about the chronic pain experience.

In October 2003, the Delphi questionnaire 3 was distributed to thirty-three service users (SUs) and two hundred and ten service providers (SPs). One SP questionnaire was returned – address unknown; and one SU withdrew, leaving a total of two hundred and forty-one possible responses. After three weeks reminder letters and duplicate questionnaires were mailed to SUs who had not yet responded. The final response rate (November 15, 2003) was:

- 17/32 (53.1%) service users (including 1 blank returned form)
- 81/209 (38.6%) service providers (including 4 blank returned forms)

10.1.1 Opt-in/out

It has been proposed that one of the potential advantages of a Delphi design is that it allows participants to opt in and out of rounds as their interest and time dictates [349]. A review of the Delphi methodology literature did not reveal any publications where this feature was subject to research scrutiny and unfortunately it is not possible to compare findings from the current study with other researchers' work. For this study, the assumption was made that a range of opinions was more important than consistency of participation between rounds. Also, that people who may have been unable or uninterested in participating in one round would express renewed interest after reading the reports it generated. Consequently the potential to opt in/opt out of the study at different stages was explained to participants in each round. Although this may have introduced some element of bias into the study, it was considered an acceptable risk given that the overall aim of the study was inductive and required as great a number of opinions as possible on a wide range of topics (in contrast to deductive theory testing, where tighter controls would be essential to maintain a representative sample). Table 16 shows that only fifty (20.6%) of the original participants completed all three Delphi rounds. However, the response rate (regardless of their involvement in previous rounds) across all three Delphi rounds was fairly consistent at around 40%:

- Delphi 1- 109 responses (41.1%)
- Delphi 2- 104 responses (39.2%)
- Delphi 3-98 responses (40.6%)

This 40% average response could be interpreted as offering greater validity than if analyses were based on only those individuals who participated in all three rounds. Participants' patterns of participation showed some slight variation. Service users (33.3%), physiotherapists (26.3%) and anaesthetists (23.8%) showed the greatest consistency in participating in all three rounds. Nurses showed the greatest variation in opting in and out (Table 16).

10.2 Question 1: validating Delphi 2 findings

Participants were asked to validate thirteen statements derived from responses to the Delphi 2 questionnaire and reflecting the researcher's (CB) interpretation of these responses. Box 10.i shows the response breakdown. The number of SU respondents was small and so the original four response categories (*strongly disagree, disagree, agree, strongly agree),* were recoded to *disagreed* and *agreed* to allow for statistical analysis. Overall a strong majority of SUs and SPs agreed with eleven of the statements listed in Box 10.i.

Box 10.i: validation on Delphi 2 statements*

Statement	%SU Agree	% SP Agree	Do both SUs & SPs agree with the statement?	Researcher's conclusions from Delphi 2
1	11 (68.8%)	66 (80.5%)	Yes	Service users' opinions about whether a treatment is important **are** influenced by emotions and self-image.
2**	12 (75.0%)	38 (46.9%)	No Stat Sig. *p=.044*	Service providers' opinions about whether a treatment is important **are not** influenced by emotions and self-image
3	16 (100%)	76 (93.8%)	Yes	The strongest influences on service users' opinions about treatments are service provider advice, past experience and personal beliefs.
4	13 (86.7%)	70 (87.5%)	Yes	The strongest influences on service providers' opinions about treatment are experience, consultation with the team and service user preference.
5	12 (80.0%)	51 (63.8%)	No	Service providers' have more responsibility for taking action when there is disagreement than service users
6***	16 (100%)	82 (100%)	Yes	Communication is an important concern for service users.
7	14 (87.5%)	80 (97.6%)	Yes	Communication is an important concern for service providers.
8	16 (100%)	76 (95.0%)	Yes	Open-mindedness is an important concern for service users.
9	13 (86.7%)	79 (96.3%)	Yes	Open-mindedness is an important concern for service providers.
10	15 (100%)	81 (98.8%)	Yes	Feeling respected and trusted (validated) is an important concern for service users.
11***	15 (100%)	82 (100%)	Yes	Feeling respected and trusted (validated) is an important concern for service providers.
12	14 (93.3%)	62 (78.5%)	Yes	Advocacy for change is an important concern for service users.
13	12 (80.0%)	81 (100%)	Yes	Advocacy for change is an important concern for service providers.

* Percentages are not consistent across all cells as some participants did not respond to each section in Question 1.

** Pearson's Chi-Square – SPSS V10.

*** Sections with highest rate of agreement in Question 1.

Box 10.i shows that statements 2 and 5 were not consistently endorsed. While the majority of SUs (75.0%) agreed with statement 2 (*Service providers' opinions about whether a treatment is important **are not** influenced by emotions and self-image*), only 46.9% of SPs also agreed. Furthermore, the responses to this question were contrary to what participants stated in Delphi 1 and 2. In Delphi 1 and 2, SPs stated that *affect* and *self-image* <u>were not</u> strong influences in-their decision-making and SUs stated that SPs <u>were</u> influenced by *affect* and *self-image* (Sections 9.2 & 9.3). There are several possible explanations for these findings. Firstly, service users may have modified their opinion between the 2nd and 3rd Delphi round and concluded that service providers were actually less influenced by the affective domain then they previously thought. Likewise, service providers' opinions may have altered, or more service providers who did agree that they were influenced by affect participated in the Delphi 3 round as opposed to the previous rounds. More likely is that the negative sentence construction within the context of twelve other positive statements caused participants to misread the statement and consequently offer a different response then they intended. On review, this statement is the only one of the thirteen that is worded in the negative (*...opinions about whether a treatment is important are not influenced...).* All other questions require confirmation of a positive statement. As it was not possible to determine with any certainty if one or a combination of these circumstances can explain this unexpected occurrence, the findings for this statement in Delphi 3 – Question 1 were not included in any further analysis.

10.3 Service providers and affect in decision-making

Question 2 asked participants to give their opinion in response to the following question:

'Service providers stated that emotions (how they felt about a particular treatment) and their self-image were not an influence in their decision-making. In your opinion, why did service providers say this?'

Written comments were reviewed and coded. There were no codes unique to service users and so they have not been dealt with separately here. Themes emerging from the participants' written comments were:

- *Professionalism* (with 2 sub-themes of: *because they are professional* and *they like to think they are professional*),
- *Service providers protecting themselves,*
- *Affect and experience,*
- *Lack of reflective skills,*
- *Ethos of altruism,*
- *Lack of understanding,* and
- *Model of practice*

Each of these themes will be discussed in more detail in the following sections 10.3.1-10.3.7.

10.3.1 Professionalism

The comments related to professionalism fell into two sub-themes ('*Because they are professional*' and '*they like to think they are professional*'). Comments in the first sub-theme presented an image of service providers who are shaped by society and fulfil an ascribed role. A large number of both SU and SP respondents stated that it was important for SPs to be evidence-based, objective and to meet the expectations of society and co-workers about what is considered to be working professionally.

> *'Service providers use experience and consultation to make decisions ...emotions have nothing to do with it. To use an emotive response to guide decision-making means that you may be acting in a biased manner- this is not professional' (SP 270)*

That this was an expectation held by SUs as well was stressed by many SPs. A few SPs commented on the need to be seen as strong and reliable. Some participants used 'masculine' adjectives (for example: '*macho*') that seemed to reflect that objectivity was not necessarily gender free, but rather in their minds had a relationship with behaving in what they believed to be a masculine manner.

'Perhaps we feel too macho to admit this could influence us' (SP 356)

In the second sub-theme ('*they like to think they are professional*') comments reflected that self-image and personal choice were driving forces in how SPs acted. Although the same type of comments about being evidence-based and objective were made, they were prefaced by comments such as '*they like to think they are professional*'. This suggests an additional dimension of professionalism being influenced not only by what one does but also by the image one would like to project. Many of the respondents in this category pointed out there were problems consequent to trying to maintain an image of 'objective' professional –

> *'I'm not fully convinced that they fully understand the concept. Some professionals have been trained to ignore their emotions and may respond in a 'knee jerk' reaction in this way. Some may believe that adding emotion to the consultation would de-value the 'science' or evidence-base'.(SP 263)*
>
> *'Their beliefs are shaped by past experience with treatments. Strong beliefs about a treatment can lead to strong emotions so I don't believe it' (SP 120)*

10.3.2 Service providers protect themselves

People commented on the negative affect generated in both SUs and SPs by a disagreement and stated that some SPs wanted to protect themselves by keeping 'objective' and emotionally removed.

> *'Basic tenet for self-preservation as a health professional is not to get too emotionally involved with patients as this prevents/reduces good objective treatment planning... (SP 341)*
>
> *'we believe we try our best but know we are morally doomed to failure as the problem is 99% in the users' hands. That's why we get upset when they complain! (SP 140)*

10.3.3 Affect and experience

Participants commented that experience allowed SPs to be confident and less likely to 'hide behind' the evidence-base. Some proposed that less experienced SPs used the claim of objectivity to avoid situations and emotions they were not comfortable with. Asked for comments about why service providers said that their decisions about treatment importance were not influenced by affect and self-image, one service user offered a long list of thoughts:

- *lack of experience,*
- *inability to empathise*
- *lack of confidence in own ability*

- *lack of understanding of personal projection*
- *dissatisfaction with own standing/status*
- *lack of self esteem (SU 428).*

Service provides' comments were along similar lines. For example;

> *'if unsure/unhappy with their skills* [SPs] *may stay away from certain treatment options' (SP 147).*

10.3.4 Lacking reflective skills

Some participants felt medical training did not prepare SPs to reflect on or handle their own emotions, so that they took refuge in the 'distant professional' role.

> *'The self-image of professionals is often subsumed beneath the role adopted and introspection is not encouraged. Psychological insight is not commonly fostered in professional training' (SP 345).*

10.3.5 Ethos of altruism

Some participants' comments reflected a belief that SPs put the interests of others ahead of their own.

> *'people who work with patients who have pain tend to be less self-interested than perhaps other health professionals' (SP 155).*

10.3.6 Lack of understanding

A small group of both SU and SP respondents stated that because SPs didn't have pain they didn't understand it and were unable to show genuine empathy to SUs.

> *'Because they use treatments that 'we have always done it this way'! and often are not even in touch with their own emotions and/or have not had chronic pain themselves' (SP 167).*

10.3.7 Model of practice

Lastly, several participants mentioned that some treatment programmes had models of practice and protocols that maintained the role of SP as distant and objective.

> *'...to follow the programme service providers are trying to ignore self- not sure they succeed' (SP 170).*

10.4 Chronic pain as a complex adaptive system

Question 3- Delphi 3 asked a series of twenty-three statements related to chronic pain as a complex adaptive system (Appendix 20) and participants were asked to indicate if they *strongly disagreed, disagreed, agreed* or *strongly agreed* with each statement. Due to the small sample of SU respondents, these categories were later recoded to *disagreed* and *agreed* to allow statistical analysis. The statements were based on the eight properties of complex adaptive systems presented by Plsek [239]. These eight properties are:

1. Relationships are central to understanding the system.
2. Structures, processes and patterns are varied and highly inter-related.
3. Actions are based on internalised simple rules and mental models.
4. Attractor patterns exist- irrespective of different inputs, there are certain outcomes that the system is most likely to return to.
5. The system is constantly adapting. Adaptation can either preserve the status quo against perceived threat or facilitate innovation and change.
6. Experimentation with new ideas and pruning ineffective beliefs and behaviours is necessary.
7. CAS are non-linear; the relationship between the input and the output is not proportional.
8. CAS are embedded within other systems, which can be formal or informal.

10.4.1 Co-existence of linear and complex beliefs

Table 17 shows the eight properties of complex adaptive systems in the first (left-hand side) column. The individual statements from the total group of twenty-three statements that correspond to each of the eight properties are shown in column three. The SU and SP percentage score for each response category (*Agreed/Strongly agreed* and *Disagreed/ Strongly disagreed)* for each statement are in the last four columns respectively. Where a statement relates to more than one of the eight properties, it is presented in multiple properties. For example, the first CAS property listed in Table 17 states that, *'Relationships are central to understanding the system'*. The statements that correspond to that property are listed as S1, S2, S19 & S20 (column three). However, S19 *('SU and SP must interact with a range of other services and* *people'*) is also relevant to CAS property eight – *'CAS are embedded within other systems, which can be formal or informal'*, and so the results of this statement (S19) are also listed in the last four columns of the property eight row in Table 17.

The responses to each statement (1-23) were categorised in one of three ways. The first way was if both service users' and providers' responses indicated that they held beliefs consistent with the properties of complex adaptive systems. For example, a strong majority of both SUs (81.3%) and SPs (92.0%) selected *'Agreed/strongly agreed'* in response to Statement 19 (*SU & SP must interact with a range of other services and people).* This statement is consistent with complex adaptive system - Property 1 (*Relationships are central to understanding the system).* Agreement between the statements and each of the eight properties is shown by the label '**CAS**' (Table 17- column 2). Eleven (11) of the twenty-three statements (47.8%) were labelled as consistent with the CAS properties.

Responses could also be interpreted to indicate that participants perceived that chronic pain was a more linear experience. This means that those participants made endorsements that supported a 'cause-and-effect' reductionist view of chronic pain. For example, a majority of service users (75.0%) and service providers (82.4%) agreed with Statement 8 – *(People believe more strongly in medical than psychological treatment).* This indicates a perception that most people have a biomedical model of pain as opposed to the bio-psycho-social framework commonly discussed in the literature. Statements endorsed in this manner were labelled '**Linear**' in column two-Table 17. Additionally, some endorsements showed that participants believed that services were delivered in a manner supporting a traditional biomedical approach to intervention. For example, statement 11- *(people have access to enough information to make good decisions)* was rated *Strongly disagreed/Disagreed* by SUs (75.0%) and SPs (84.0%). Because a number of the CAS properties are dependent on high information exchange (for example Property six – *Experimenting with new ideas and pruning of ineffective beliefs and behaviours is necessary*), statements (like Statement 11) indicating there are barriers to operationalizing the properties of a CAS were also labelled '**Linear**'. Nine (9) of the twenty-three statements (39.1%) were labelled '**Linear**'.

Service users and providers had similar patterns of agreement/disagreement for eighteen of the twenty statements labelled either '**CAS**' or '**Linear**'. For two **CAS** statements, (*Chronic pain is influenced by what each person believes*[12] and *Chronic pain is influenced by relationships between people – p<.000,)* the majority of both SUs and SPs *Agreed/Strongly agreed.* However, there were also significantly more service users than service providers who *Disagreed/Strongly disagreed.* Although very few service providers disagreed with these statements (1.3% and 4.0% respectively), over a third of the service users did disagree (37.5% and 33.3%). Recognising that the sample size was small and findings must be interpreted with caution, these differences between groups are still intriguing and may indicate that service users were less committed than service providers to the ideas that pain is influenced by personal beliefs and relationships as opposed to being a discrete, diagnosable entity.

Lastly, there were three statements where service users and providers were distinctly opposite in their endorsement patterns. These statements were labelled '**Mixed**' (column two-Table 17). At Statement 7 (*search for cure is the main goal for service providers)*, 60 % of service users but only 12% of the service providers selected '*Agreed/Strongly agreed'.* At Statement 22 (*SPs feel in control of how service is provided)*, service users again agreed with the statement (56.3%) while service providers did not (80.0% *Disagreed/Strongly disagreed).* This seems to indicate that service users held a more linear model where service providers are seen as actively pursuing a 'cure' for pain and as having control over the service delivery system. Service providers' responses for these two statements showed that they did not share these more traditional medical ('**Linear**') perceptions of their role and power that were held by the service users. The third statement that was labelled '**Mixed**' shows an interesting reversal. In this case, service providers endorsed the more linear Statement 9 (*guidelines, policy and funding should be decision at a central, national level)* but the majority of service users (53.3%) did not agree.

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[12] In SPSS Chi-square analysis for this statement, one cell contained insufficient numbers for the calculation and the findings were interpreted as indicating a trend only.

10.5 Certainty and agreement

Complexity theory states that linear relationships are least effective when there is **low agreement** and **low certainty**. As agreement and certainty decrease, more variation occurs and systems move into complex relationships. Participants were asked to indicate on a 10cm visual analogue scale how much '*you think people agree about which treatment for chronic pain are important*' (Question 4) and how '*certain you think people are about what treatments are important for chronic pain*' (Question 5). The scales were anchored at *'total agreement'* (0) – *'no agreement'* (12) and '*total certainty*' (0) – *'no certainty' (12).* Box 10.ii shows the descriptive statistics for the two questions. Higher scores indicated greater disagreement and uncertainty.

BOX 10. ii Delphi 3:
Questions 4 (Certainty) & 5 (Agreement) descriptive statistics

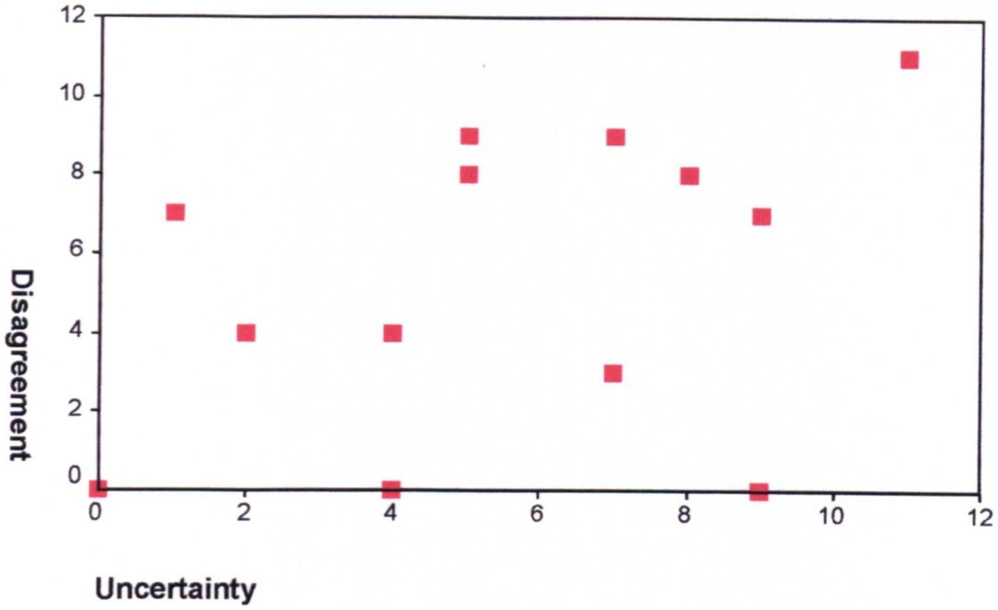
		Mean	**Trimmed mean**	**Median**	**Range (SD)**
Agreement	SU	5.56	5.57	7	0-11 (3.577)
	SP	5.86	5.88	6	0-11 (2.524)
Certainty	SU	5.94	5.99	6	0-11 (3.235)
	SP	5.50	5.49	5	1-10 (2.476)

When the mean values of service user responses to Questions 4 (X axis) and 5 (Y axis) were plotted, points in both parameters tended to be distributed across the range of both disagreement and uncertainty. The mean value fell towards the midpoint of *disagreement* and *uncertainty* (Figure 10.1) indicating that participants felt there was moderate to high disagreement and uncertainty about what constituted 'important' treatments for chronic pain. The same relationship emerged when the SPs responses were plotted (Figure 10.2). When SU and SP responses were plotted together (Figure 10.3) the trend towards higher *uncertainty* and *disagreement* became more pronounced. There was no statistically significant difference between

SU and SP ratings of these two variables when an independent samples t-test was performed (Agreement: t=-.322, df=18.062, p=.751, Certainty: t=.614, df=96, p=.541).

The participants' responses plotted in Figure 10.3 resemble the matrix termed as 'the zone of complexity' [245]. Stacey's 'Zone of Complexity' suggests that problems can be organised into one of three zones dependent on the amount of agreement and certainty people hold about the problem and course of action. Problems are labelled 'Simple' and follow a linear problem-solving path where certainty and agreement are high. Conversely, when uncertainty and disagreement are very high problems become random ('Chaotic') and it is difficult to understand what is happening and to decide on a plan of action. The third zone is that of complexity. Complex problems, like Chaotic, tend towards uncertainty and disagreement but retain enough agreement and certainty so that discernable patterns of interaction can be identified and rudimentary boundaries assumed. Figure 10.3 demonstrates that a number of responses fell in positions of moderate uncertainty/moderate disagreement (Zone of Complexity) and high uncertainty/high disagreement (chaos).

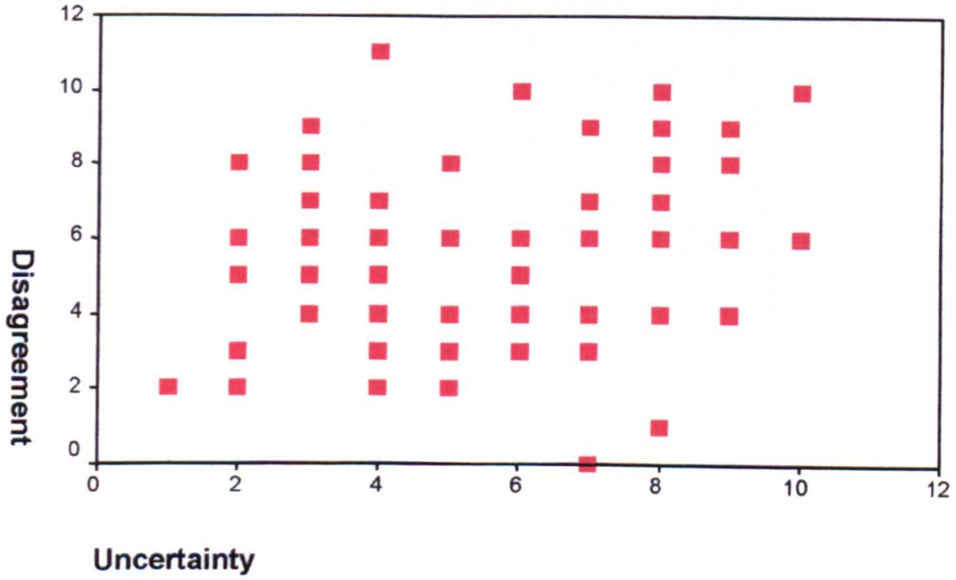
Figure 10.1: SU uncertainty & disagreement



Uncertainty x disagreement VAS scores

(0=no disagreement/uncertainty)

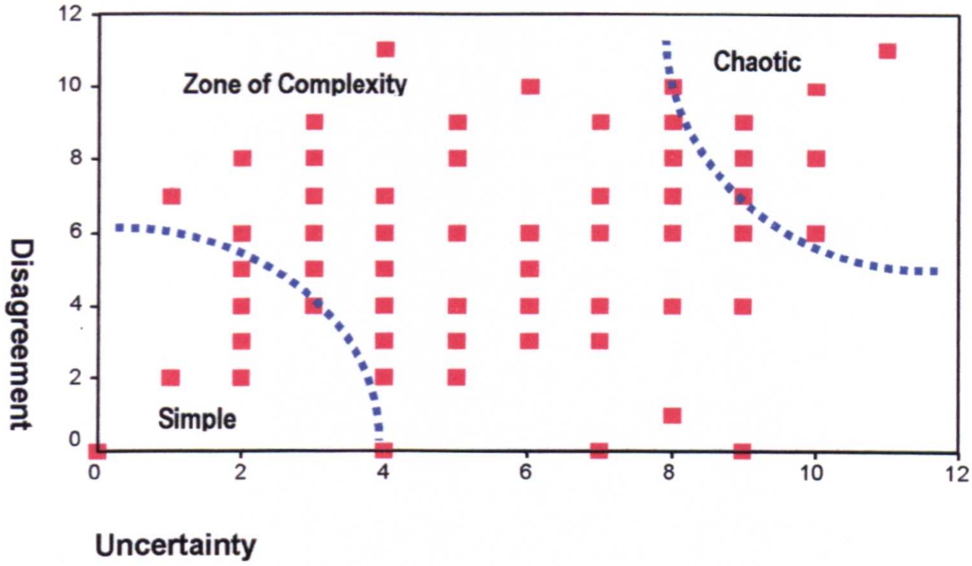
Figure 10.2: SP uncertainty & disagreement



Uncertainty x disagreement VAS scores

(0=no disagreement/uncertainty)

Figure 10.3: SU & SP uncertainty & disagreement



Uncertainty x disagreement VAS scores

(0=no disagreement/uncertainty)

10.6 Opinions about recommending SU actions

In the previous Delphi 2 round people had made suggestions about what actions should be taken as a result of disagreement between service users and providers. Most of the suggestions were requiring service providers to take action; there were very few suggestions about what service users could do. Question 6 in the Delphi 3 questionnaire offered participants an opportunity to state why they thought this was the case. A total of eighty-nine written comments were made by SPs and nineteen comments by SUs. When the written comments were analysed fourteen themes emerged (six unique to the SP responses, five shared, and three unique to the service users' responses) (Table 18). The themes unique to SPs were:

- *medical model is socially dominant*
- *action depends on who has power*
- *SUs take no responsibility and blame SPs*
- *New legislation will change this ('expert patient')*
- *SPs cannot imagine what SUs role could be*
- *SPs have a role as advocate*

Themes unique to SUs were as follows:

- *SPs are not interested in sharing knowledge*
- *Opportunity for SU participation needs more structure*
- *SPs are not interested in SUs opinions*

The five themes shared by SUs and SPs were:

- *SUs have limited knowledge and tools*
- *SUs feel defeated and disempowered*
- *SPs control resources/access*
- *SUs are individuals and cannot be expected or have the resources to act collectively*
- *SUs pain prevents them taking action*

The most frequent comments amongst service providers related to the themes of; *medical model dominance, limited service user knowledge, service user disempowerment* and *action depends on who has power.* Service users' comments most frequently related to the theme of *SUs feel defeated and disempowered.* Examples of comments from each of these themes are presented in Box 10.iii.

Box 10.iii: examples of comments related to themes in Delphi 3- Question 6

(service users' comments are in Arial **text** and service providers' in italic text.)

Themes	
Medical model is socially dominant	*'people still feel they should provide treatment for patients. They have not reached the conclusion that a lot of what has to happened in chronic pain is that the patient has to change lifestyle and has to 'own' their chronic pain' (SP-343).* *'medical model assumes users are treated/cured by providers' (SP - 2).*
SUs have limited knowledge and tools	*'most service users look to the medical/healthcare system to provide answers and may feel they lack the knowledge/experience to suggest treatment alternatives (SP- 22)* 'in my experience service users have not been informed enough on the information for self-help so they think that the medical profession should make the decisions' (SU - 442).
SUs feel defeated and disempowered	*'SUs often feel very demoralised and helpless' (SP-179).* ' ...the sufferer feels 'cast aside' and therefore doesn't bother anymore as they feel like a 'lost cause'(SU - 433)
Action depends on who has power	*'the perceived power in the relationship is with the service provider' (SP-263)* *'power to achieve change in within healthcare systems is perceived as residing with those who work in them' (SP-336).*

10.7 Participants' evaluation of the process

This study asked a high level of input from participants over an eighteen-month period regardless of whether they read all of the reports and completed all three of the Delphi rounds or not. As part of the ethical considerations addressed by the study and to support the researcher's reflective learning process, it was important to gather feedback about the research process from participants. Consequently, Question 7 solicited participants' evaluation about whether the study was interesting, clear, relevant and informative for their own needs (Table 19).

The overall content of the feedback was positive and comments were supportive. A quarter of the service users stated the questions were not very clearly written and this comment was echoed by 10% of service providers. Just over two-thirds of all participants felt they learned something about the other participants and themselves as a result of the study.

Most people stated that they were willing to take part in Delphi studies in the future (Question 7-part 8), which seems to support Delphi methodology as a valid tool for gathering and sharing opinions from a large group of participants. However, the next question (part 9) showed that the majority of service users (73.3%), and slightly more than one-quarter of the service providers, would have preferred interviews and focus groups as opposed to Delphi methodology.

10.8 Preliminary discussion Delphi 3

The purpose of the Delphi 3 questionnaire was to seek participants' validation of the researcher's findings from the Delphi 2 questionnaire. It also asked participants a series of questions about chronic pain treatments that were then organised against the properties of a complex adaptive system [239], and lastly, participants were invited to provide feedback on the study process itself.

10.8.1 Expectations of responsibility

Question 1 highlighted two very interesting findings. Firstly, SUs and SPs differed in the level of their agreement with the view that the service provider has more responsibility for taking action when there is disagreement between SUs and SPs (Box 10.1-statement 5). Service users strongly supported this statement (80.0%) but only 63.8% of the service providers agreed. This seems to indicate that though service users see a less active role for themselves in conflict resolution, a number of service providers rejected the idea that they are more responsible for dealing with disagreement. These service providers' beliefs reflect the growing focus on self-management and shared responsibility seen in national healthcare initiatives of many industrialised countries [434]. However, participants who supported the sharing of responsibility were in the minority. Assuming that these findings reflect (at least to some extent) the reality of the clinical encounter for people with pain, this suggests that interactions where a service user is expected to take a more responsible role or the service provider expected to facilitate shared responsibility, may occur more as an exception than the role. Unanticipated expectations, coupled with the anxious hurried context of most clinical appointments, may contribute to the range of negative consequences and subsequent behaviours discussed in detail in Section 4.5.

10.8.2 'Important concerns'

The second interesting finding from Question 1 involved the responses for statements 6 (*communication is an important concern for service **users***) and 11 (*feeling respected and trusted (validated) is an important concern for service **providers***). These two statements were agreed with by 100% of the service users and providers. Surprisingly, their companion statements, 7 (*communication is an important consideration for service **providers***) and 10 (*feeling respected and trusted (validated) is an important concern for service **users***), were not agreed with by all participants. Some service users (12.5%) and service providers (2.4%) did not agree that communication was an important concern for service providers. Also, one of the service providers who agreed that feeling respected and validated is an important concern for service providers did not think it was important for service users. The samples are very small and the percentages in themselves may mean little. Rather, it is the emerging relationships and patterns that offer more insight as to the importance of communication and affect, and the distinctions between service providers and service users' roles and expectations within these two domains.

10.8.3 The conflict between 'should' and affect

Question 2 asked participants to reflect on why service providers stated that decision-making was not influenced by affect and self-image. Seven themes emerged from the responses:

- *Professionalism* (with 2 sub-themes of: *because they are professional* and *they like to think they are professional*),
- *Service providers protecting themselves,*
- *Affect and experience,*
- *Lack of reflective skills,*
- *Ethos of altruism,*

- *Lack of understanding,* and
- *Model of practice.*

Participants' comments in each of these themes repeatedly reflected a conflict between internalised social messages about who and what a service provider should be and the affective experience of working with people who have pain. Both 'should' messages and comments with emotive context were clearly expressed throughout the responses to Question 2. What was lacking were links between the two. Service providers are inundated with expectations; service users, employers, co-workers, regulatory bodies, professional organisations, friends, relatives and the family dog all have a personal construct of what 'should' be expected from a service provider. Additionally, service providers have their own personal constructs of what they 'should' be able to provide. Very few of the participants' comments reflected awareness of how the two elements of expectation and emotion are inextricably linked. There were comments that showed some participants clearly felt service providers were socialised to deny affect in their professional roles (*'The self-image of professionals is often subsumed beneath the role adopted and introspection is not encouraged. Psychological insight is not commonly fostered in professional training' –SP 345*). However, no one specifically identified negative affect consequent to the conflicting/high demand expectations of the service providers' role. The impact of unmet expectations on service users trust and satisfaction with the clinical encounter [220, 435-437], and service providers' treatment behaviours [421, 438], has been widely discussed in the literature. Less evident is research exploring the relationship between expectations of service providers and their emotions. This is perhaps unsurprising given that to discuss emotion and health service provision together is contrary to the prevalent biomedical ethos of 'objectivity'. Objectivity however, appears often to be used synonymously, although incorrectly, with 'unemotional'. This creates a paradox because one of the strongest social norms in many cultures is that emotion is the cornerstone of humanity. In the movie 'Invasion of the Body Snatcher' [439] this sentiment is clearly expressed by one of the only two people left after the emotionless aliens ('pod people') have taken over the town. The comments are particularly germane as the speaker is the town physician, Dr. Miles Bennel.

> *'In my practice I've seen how people have allowed their humanity to drain away. Only it happens slowly instead of all at once. I didn't seem to mind...All of us, a little bit. We harden our hearts. Grow callous. Only when we have to fight to stay human do we realize how precious it is to us, how dear'.*
> (Bennel talking to Becky while hiding in his office from the aliens).

While the findings in Delphi 3 do not suggest that service providers have become akin to 'pod people', the images evoked by this illustration are echoed in more mainstream and contemporary voices concerned with the increasing focus on technological innovation in healthcare to the potential detriment of the human aspects of care [279, 280, 3403, 390, 391]. James Willis's work (Paradox of Progress [428]; Friends in Low Places [369]) returns repeatedly to the issue of society's increasing expectation of both risk-free and technological advanced healthcare and the conflict these expectations present to those charged with delivering the service. He comments, in relation to the regulatory and practice expectations placed on general practitioners, that efforts in the NHS to pursue 'codified perfection' (in concert with the highly sensation-selective bias of the mass media) are actually harmful because they undermine the trust needed for an effective therapeutic relationship between patient and GP. He goes on to propose that, "...the effect on human motivation when doing the best you can is never good enough is incalculable" [369:146].

Seen in the context of the preceding discussion, the Delphi 3- Question 2 findings should be interpreted as a series of warning flags. The first flag (consistent with findings from the previous Delphi rounds) identifies that there are differences that may interfere with communication between SUs and SPs. The second flag warns that most SUs and SPs hold expectations based in a traditional doctor/patient biomedical model. The final flag, most critical and yet least attended to, points towards the negative consequences of persevering in the pursuit of service delivery divorced from service providers' reflections and attention to their own affective domain.

10.8.4 Discord and paradox

The findings of Delphi 3-Question 3, where participants indicated agreement or disagreement with statements derived from the properties of complex adaptive systems [239] (Section 10.4, Table 17), demonstrated that SUs and SPs hold a mixture of beliefs about chronic pain treatments and service delivery. Some reflect the multidimensional and dynamic nature of the chronic pain experience. This would be expected from people supporting the position that chronic pain is best understood within a complex adaptive systems framework. However, at the same time as participants' endorsement of some statements demonstrated beliefs consistent with the properties of CAS, their endorsement patterns for certain other statements paradoxically indicated support for a linear (cause-and-effect) model of chronic pain. Additionally there were instances where one group's endorsements could be interpreted as more linear than the other group. This again highlights a degree of discord and paradox across some of the beliefs held by study participants. The statements that most clearly illustrate this discord and paradox are presented below[13] firstly as individual items and then organised against the corresponding CAS category to determine if particular patterns emerge.

Statement 1: ***Chronic pain is influenced by what each person believes (S1).***
While nearly all service providers (98.7%) agreed with this statement, 37.5% of service users did not . Although there were an insufficient number of participants in the SU group for reliable statistical analysis, a chi-square test showed a strong trend towards the service providers believing more strongly in this statement than did the service users.

Statement 2: ***Chronic pain is influenced by relationships between people (for example: between people with pain and employers, family members, GP, therapist) (S2).***

Most (96.0%) of the SPs agreed with this statement, however only 66.7% of the SUs stated they agreed (statistically significant difference between SPs' and SUs' endorsement, *p value* <0.000). The considerable number of service users who did not agree with statements 1 and 2 may reflect a continued SU belief that chronic pain is predominately a biomedical entity with an underlying cause.

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[13] Responses to statements that are consistent with CAS theory and where both SUs and SPs are in agreement are not discussed individually (S3,4,8,10,11,13-21, 23). Collectively they are interpreted as indictors of non- linear beliefs about chronic pain amongst participants.

Statement 5: ***Chronic pain is treated mainly within the medical system (S5).***
While the majority of service users (66.7%) and providers (60.0%) agreed that chronic pain is treated within the medical system, there was also a large minority of SUs (33.3%) and SPs (40.0%) who disagreed. This suggests that, for this considerable group, the biomedical model is recognised as insufficient to address the multidimensional nature of chronic pain.

Statement 6: ***Searching for cure is the main goal of service users (S6).***
Service users' (75.0%) and providers' (82.4%) agreement with this statement could indicate a belief system more grounded in a medical model than a bio-psycho-social framework. The statement was not constructed in a way that allowed the researcher to determine if respondents were agreeing that it is a desirable characteristic. As participants were most likely commenting on what they perceive to be the current reality, too much speculation is not warranted. However, participants' perceptions of others' beliefs and actions is also an important consideration as it influences (overtly and covertly) communication and behaviours between individuals. The outcomes of these interactions subsequently feed back into the meaning construction process (Section 9.8.1) and serve, in turn, to influence the next sequence of actions and so on throughout the cycle.

Statement 7:***Searching for cure is the main goal for service providers (S7).***
Service providers strongly disagreed (88.0%) with this statement, however, the majority of service users (60.0%) agreed with it. The difference between the 2 groups was statistically significant (*p value <0.000*). As discussed in relation to Statement 6, beliefs and behaviours influence interactions and meaning construction. As indicated by this statement, service users hold a belief that service providers have 'cure' as a main goal. This conflicts with what service providers believe and the possibilities for misunderstanding based on an assumption that the search for cure is a shared goal are therefore high.

Statement 9: ***Guidelines, policies and funding should be decided at a national level (S9)***

A moderate majority of service providers agree with this statement (68.9%). Service users were more evenly divided with 46.7% agreeing and 53.3% disagreeing. Central control is seen as problematic in CAS because it hinders timely and flexible responses at a local level [392]. Service providers' belief that central control is appropriate for chronic pain issues is an example of the paradoxical situation that can be created when people attempt to hold beliefs about national standardisation and universal principles, while at the same time agreeing with the need for increased information (S11 and S20) and flexibility of service delivery and content (S12 and S13).

Statement 12: ***New ideas about treatment are easy to try out (12)***

Although the majority of SUs and SPs disagreed with this statement (68.8% and 89.3 % respectively) analysis revealed that there was also a statistically significant difference in the percentage of SUs and SPs who did agree (*p=.033*). This indicates that a number of SUs may have unrealistically high expectations of the current healthcare system's ability to change.

Statement 22: ***People who work in pain management feel in control of how services are provided (C22)***

Only 20.0% of the service providers agreed with this statement. However, more than one half (56.3%) of the service users agreed. The difference between the two groups was statistically significant (*stat sig. p<.000*). As with Statement 12 these expectations may prove unrealistic and potentially lead to conflict and frustration.

The findings for the preceding statements indicate that varying degrees of conflict exist between beliefs grounded in the traditional biomedical/ linear model and those supporting the more flexible/ systems framework represented by CAS.

10.8.4.1 Statements in relation to the 8 properties of CAS

Of the eight properties of complex adaptive systems examined through these twenty-three statements[14], there were three properties that seemed to generate little disagreement. These were:

- Property 2 – *Structures, processes and patterns are varied and highly-inter-related.*
- Property 7 – *CAS are non-linear; the relationship between input and output is not proportional.*
- Property 8- *CAS are embedded within other systems, which can be either formal or informal.*

Although all of the statements related to Property 1 (*Relationships are central to understanding the system)* were labelled **CAS**, the strong minority of SUs who did not agree that beliefs and relationships were influences on chronic pain (Statements 1 and 2) suggests that this property is not as widely endorsed as those mentioned above.

Responses to statements related to the remaining four properties showed that linear practices and perceptions influence these participants' beliefs about chronic pain. Statements related to Property 3 (*Actions are based on internalized simple rules and mental models)* endorsed beliefs and models consistent with the biomedical model. Statements grouped under Property 4 (*Attractor patterns exist- Irrespective of different inputs there are certain outcomes that the system is most likely to return to)* show that the search for a cure to chronic pain and the primacy of medical treatments continue to dominate the system, despite the amount of attention expended in the NHS and the scientific literature to promoting evidence-based self-management and bio-psycho-social interventions. Property 5 (*the system is constantly adapting)* contains the most diverse combination of statements and perhaps reflects the reality of current healthcare where organisational and practice change is occurring at an unprecedented, and often unwelcome, pace [428]. Lastly, and perhaps most tellingly, all of the statements related to Property 6 (*Experimentation with new ideas*

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[14] The number of statements was not evenly distributed across the 8 properties and the discussion should not be interpreted as conclusive.

and pruning of ineffective beliefs and behaviours is necessary) indicate that linear beliefs and practices influenced responses. Participants perceived that there is a shortage of information (S11,17,18), new treatment is hard to try out (S12), out-dated treatment are hard to abandon (S13) and neither SUs nor SPs felt they could control or influence how services are provided (S22 and 23). Again, a paradoxical situation seems to emerge from these findings. At a time when awareness that traditional biomedical approaches and practices are insufficient for the multidimensional problems of chronic conditions like pain [265] the barriers to creating new ways forward are perceived as very strong.

In summary, participants agreed that many of the statements in Question 3, based on characteristics of complex adaptive systems, were applicable to chronic pain. However, a strong thread throughout the findings was consistent with a more traditional medical and linear approach to intervention. Paradoxes were apparent in certain disagreements and conflicting beliefs. These paradoxes will be more fully discussed in Chapter 11: Findings.

10.9 Chapter 10 conclusion

Participants' responses to Delphi 3 showed the existence of a range of beliefs, some more linear than others. As with all of the previous rounds, the idiosyncratic nature of many responses was also evident. In general, many of the responses supported applying a complex adaptive system framework to the chronic pain experience. Participants selected responses indicating that relationships and context are important, that they believed services are delivered across a varied range of structures and processes, and that actions related to pain treatment can be linked to persisting practices and mental models. Additionally, the chronic pain experience was seen as dynamic and requiring high amounts of information exchange. Participants believe that there is little certainty and agreement regarding treatments for chronic pain. A graphic representation of their responses clearly illustrates a system in the zone of complexity [245].

Several key aspects of paradox and discord exist within the beliefs and behaviours of participants. The inherent conflict between SPs' and SUs' expectations and SPs' failure to recognise, or attend to, the impact of affect on decision-making was flagged up. Additionally, dissonance was identified in the responses indicating that the mental model people hold for dealing with chronic pain continues to focus on 'search for cure' and belief in the biomedical system as the primary source of assistance for chronic pain. Although many participants endorse a multidimensional bio-psycho-social analysis of chronic pain, they also endorsed attempting to find solutions within a linear, reductionist biomedical model.

Complex adaptive systems theory proposes that paradox and discord are not the barriers to effective problem-solving and service delivery [236, 250, 264]. Rather, the problem lies with how paradox and discord are treated. In more linear systems, which rely on central command-and-control, they are seen as problems that need to be resolved. Resources and efforts are channelled into remediation of differences, often to the detriment of creative problem-solving which addresses the issue that generated the disagreement in the first place. Complex adaptive systems theory stresses that variation and tension always generate energy that, properly channelled towards exploring the real issue, will lead to unanticipated and creative ways of addressing problems and self-organising for maximum effectiveness.

> ***The Sheep's Second Institutional Law of the Universe***
>
> *Simple, clear purpose and principles give rise to complex, intelligent behaviour. Complex rules and regulations give rise to simple, stupid organisational behaviour'* (Dee Hocks [15] cited in [292]).

The preceding chapters have presented preliminary discussions of the study findings and laid the groundwork for a more detailed examination of current healthcare practices for chronic pain within a complex adaptive system's paradigm. Exploring this concept in detail and offering recommendations for reframing the approach to service delivery will be the focus of the following chapters.

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[15] Dee Hocks was the CEO credited with turning the VISA credit-card company from a traditionally structured but failing entity into one of the world's largest businesses by applying complexity theory principles promoting grass-roots self-organisation.

Chapter 11

Discussion: Moving from *either/or* towards *this/as well as that*

11.1 Introduction

When a person first seeks assistance for pain he or she enters into a number of highly inter-related systems that place a significant demand on his/her ability to interact and assimilate new information and behaviours. The person carries a range of socially acquired and personally interpreted expectations and beliefs about these systems. The systems, in turn, hold expectations and beliefs about the person with pain. The progress of the individual's pain can therefore be strongly influenced by the subsequent interactions between person and system.

Some theorists propose that these interactions can be iatrogenic in nature, resulting in decreased wellbeing and so contradicting their overt purpose of improving health. Illich's seminal work explored the concept of over-medicalisation of society (what Illich calls 'expropriation of health'), in which he contends that, 'so-called health professionals have an even deeper, culturally health-denying effect in so far as they destroy the potential of people to deal with their human weaknesses, vulnerability, and uniqueness in a personal and autonomous way' [443: 42]. Illich stated that 'cultural iatrogenesis' occurs when people accept health management, designed within a linear, engineering model, with the defined output commodity labelled 'better health'. Over the twenty-five years since the publication of Illich's Limits to Medicine a growing number of researchers have supported this claim, proposing that interactions between service user and healthcare system are so important as to have a strong iatrogenic potential, whereby the presenting health problem is compounded or perpetuated by the experience of having contact with the healthcare system itself [213, 294].

Previous sections presented arguments regarding the need to see long-term, life-style affecting health issues (like chronic pain) from a different perspective than the prevalent positivist biomedical model (Sections 5.3-.5, 6.1, 7.5.1). A complex adaptive system (CAS) model is ideally suited for understanding current health care issues from a wider viewpoint. CAS theory provides a meta-framework recognising that complex problems require a flexible and diverse range of strategies dependent on the presenting contextual and interactive demands [444, 445]. It redirects the viewer away from counter-productive conflicts focused on establishing the hierarchical superiority of a given theoretical model (for example cognitive-behavioural as opposed to psychoanalytical interventions for adolescents with eating disorders). Complex adaptive system theory focuses on understanding relationships and emerging patterns of behaviours so that problem-solving can occur in a timely fashion, within the most appropriate model for the situation and context. For example, there is high agreement and certainty about the outcome of removing a ruptured appendix. There is less agreement and certainty about the outcome of insulin use by people with diabetes (how much, when, how, what about diet, exercise, stress, pregnancy, and so on), and even less about socio-cultural problems like substance misuse and violence. Attempting to treat substance misuse with tools more appropriate to a biomedical model of appendicitis will not be effective. The same is true of chronic pain.

The complexity of chronic pain renders it irreducible. In other words, chronic pain is more than the sum of its parts and demonstrates what CAS theorists have termed 'emergent' behaviour. Emergent behaviours are the new, unexpected behaviours, patterns and processes that arise as complex systems attempt to adapt to changes of input. From a linear perspective, these unexpected outcomes are problematic and appear to be random and out of control. Efforts to understand emergent behaviour using linear tools (randomised control trials for example) are counterproductive. Applying more control to a complex system serves to obscure patterns of behaviour that are evident when viewed from a wider perspective. The Genome project has been suggested as an example of valuing causal scientific methodologies to the exclusion of other forms of knowledge[446]. Williams et al [447] state that although, 'the gene is the dominant biological motif at the start of the new millennium', the construct of everything beyond the molecule being subsidiary to the gene is flawed. This position suggests that culture is a consequence of genetic evolution, and fails to recognise that human culture exerts a reciprocal influence on genetics. 'Structure, lifestyle, and environmental influences account for much larger proportions of disease than genetic differences…the genetic mantle now clouding medicine will prove to be like the emperor's new clothing' [448].

From a complexity theory perspective, emergent behaviours can be examined and understood as system responses to the diversity of influences (inputs) with which they interact. In chronic pain, the emergent behaviour that eludes understanding is chronicity itself. The question 'why is chronic pain so resistant to change?' remains, despite the ever growing volume of research 'evidence', largely unanswered. This chapter will use complexity theory to illustrate how three key findings from the preceding research, when framed in a CAS approach, can be understood to contribute to the intractability of chronic pain. A discussion of the limitations of the study will also be presented. Finally, the principles for affecting change within complex adaptive systems will be introduced to establish a basis for the recommendations and conclusions to be presented in Chapter 12.

11.2 Attractor patterns

In Chapter 5, (section 5.4.4) the principle of attractor patterns was introduced. The term 'attractor pattern' is used to describe the underlying forces that attract behaviours towards a consistent outcome regardless of the type of input exerted. "An attractor is the area that a system moves towards and where it will tend to stay" [295]. Goldstein uses the analogy of human development to describe attractors [449]. A system (like a human life) moves through different stages. At each stage certain behaviours are characteristic and although some variation may occur, behaviour usually falls within the parameters of the stage. A system's attractors set these constraining parameters. For example, using Goldstein's analogy of human development, a three-year old child is not usually able to carry out the same repertoire of fine motor skills as her mother. The child's neurological and cognitive development (the system's attractors) are at a different stage than that of an adult female. Changes to the internal and external environment of a system (as the child ages and has new experiences) act to modify attractor patterns and different behaviours can then be expected.

There are different categories of attractors. When a very limited range of possible behaviours occurs this is termed a 'fixed point' attractor. An example of a fixed-point attractor in healthcare would be the near certainty that, regardless of the social and environmental context, renal failure is life threatening. New attractors (allowing changes in behaviour) occur in complex systems when they reach a critical level and are no longer contained by existing parameters. Until this critical incident occurs however, a complex system will continue to adapt so as to accommodate changes in such a way that maintains the status quo. Consistent with the principles of complex adaptive systems, the critical incident is not necessarily proportional to the resultant change. What are perceived to be very small events can result in large system changes and the emergence of new attractor patterns and subsequent behaviours. Conversely, large system input can have little effect and very poor outcomes in terms of changed behaviour. This was discussed previously in the example of wide-scale public health initiatives targeting unsafe sex practices (Section 5.4.7). It is proposed that this poor return on efforts directed at changing complex systems is a consequence of attempting to apply linear problem-solving in complex systems. Attempting to reduce a problem to its discrete components is ineffective to address issues embedded in connectivity and relationships between multiple elements [449, 450], and is similar to saying that a game of chess can be understood by examining the physical composition of the playing pieces and game-board.

The concept of attractors is very important to understanding change management in complex systems. Complexity theorists propose that it is ineffective to carry on with the traditional style of command- and-control management that focuses energy on changing a system through manipulating the input. Rather, efforts should be redirected to understanding the attractors. The question thus becomes, 'what is keeping the system as it is?' rather than 'what will make the system change?' [235, 238, 244, 251, 264]. From a range of perspectives this approach seems ideally suited to the complex system that is chronic pain. Conceptually, a plethora of theoretical schools of thought have been applied to the question of reducing the consequences of chronic pain and, from a socio-cultural perspective, 'search for cure' remains a dominant theme. Pragmatically, however, chronic pain remains resistant to change. An example illustrating this can be extracted from the results presented in Chapter 7 (Table 3), which shows that twenty-five of the possible sixty-two (40.3%) treatment components had been tried by over half of the service users. Interestingly, these twenty-five frequently tried treatment components were not necessarily endorsed as '*important*'. It seems that people felt they were able to access a number of options and seeking to increase the number of options available may therefore be a misdirected effort to address the wrong question. The problem may rest more with what is preventing people deriving benefit from this range of options- specifically, what are the attractors that promote the pattern of chronicity in people's pain experience?

11.3 Key attractors in maintaining chronicity

Two key features re-emerged across the preliminary findings as detailed in the preceding chapters. Firstly, participants in this research experienced a high degree of non-congruence of beliefs and expectations. Secondly, although they shared a perception that information was important, the types of information service users and providers had access to appeared to differ. A third key feature was identified when analysis highlighted that a number of paradoxical beliefs, (for example, trying to apply bio-psycho-social interventions within a biomedical acute-care model), were held by participants in the Delphi 3 questionnaire. The following sections will present the proposal that these three features serve as attractors for the system outcome of chronicity.

11.3.1 Incongruent beliefs

One way in which differences of belief arise is through the perceived legitimacy and value of information. There are two forms of beliefs; those that are safe to be made public and those that are perceived as more at risk of society's censor and consequently needing to be kept private [451, 452]. Cornwall states that by expressing public beliefs, '...the person doing the talking can be sure that whatever they say will be acceptable to other people' [452:15]. Private beliefs on the other hand are more risky because they emerge from personal experience and feelings. At the beginning of the twenty-first century the healthcare beliefs valued in western industrialised societies are scientific rationality and technology [238]. Historically, healthcare has been reductionist, with healthcare workers inculcated to value knowledge that is predictable and replicable in the face of tests designed to grade probability through scientific rigour [301]. "The recent history of the species is one of bringing the physical environment under control, or at least creating the illusion that it is under control"

[453:158]. Beliefs based on non-biomedical systems of health (for example osteopathy and acupuncture) have come to be labelled 'alternative' and treated with, for the most part, a high degree of scepticism in the popular press and by the predominant biomedical practitioners. Although medical pluralism is commonplace, patients are inhibited from disclosing prior self-treatment. A strong deterrent to disclosure are SUs' perceptions that SPs will question the legitimacy of self-treatment [454]. Differences of opinion are unlikely to be expressed and discussed openly. Service users employ a range of 'safe', indirect strategies (for example hesitation and lingering during the clinical encounter) to express their disagreement. In reality, these strategies can cause further communication breakdown and false assumptions [208]. Service providers, similarly, employ indirect strategies to convey their beliefs, (for example changing the topic, decreased eye contact, writing while the service user is talking). Again, miscommunication and assumptions are common and a high level of frustration in the clinical encounter can be experienced [398, 435]. When disagreements and alternative beliefs are not made overt it is possible for both parties to assume that agreement has been reached and behave accordingly. In other words, disagreement between service users and providers sometimes exists simply because it has not been raised to an explicit level, but rather remains unspoken and active in what complexity science terms the 'Shadow System' [244, 245]. The shadow system is the antithesis of the formal processes within an organisation. The formal system consists of rules and communication structures that modify and contain the flow of information; the shadow system lies behind the scenes, is reactive, unstructured and often a very powerful influence on beliefs and behaviours.

There are a myriad of other factors at play in the issue of service users and providers holding non-congruent beliefs. Service users may employ the strategy of selective disclosure/discussion based on their evaluation of the risk of disbelief in an interaction [455], and service providers have reported feeling pressure to collude with other stakeholders' continued operationalisation of the biomedical model for pain [456]. Also, (as discussed previously in section 3.8.1) public expectations of service providers to be more 'consumer-oriented' are growing [237, 252], as is public scepticism about the traditionally held belief in the superiority of scientific knowledge [311]. Some researchers propose that, perversely, the health care system's efforts to foster shared decision-making by creating more knowledgeable service users [316], has actually triggered a crisis where service providers feel uncertainty and that their authority and role are threatened. The response to this threat has been labelled by some as an 'evidence-based backlash' [457, 458], with service providers exerting more effort to decrease the unexpected ('surprise') in clinical encounters [459] through increasing their demand for central guidelines and standardisation [250, 460]. In addition, other researchers have stressed that insufficient attention has been given to the role of workplace subcultures [408, 445] as effective mechanisms to preserve the perception of organisational agreement by relegating disagreement to the status of heresy [253].

Consistent with CAS theory, there is no one, 'most-correct', reason why incongruence exists; rather incongruence of belief is an irreducible feature of human interaction. Complexity theory proposes that focusing on the patterns of interactions between incongruent belief systems (as opposed to strategising about how to educate service users to agree with service providers) will effect creative problem-solving and positive outcomes. The Medicines Partnership: From Compliance to Concordance [16] is a clear example of this shift in perspective. Researchers have concluded that up to 50% of service users do not take their prescribed drugs correctly and that the patient education initiatives undertaken to improve compliance (predominately focused on the mechanics of presenting the information) have proven ineffective [27, 461]. It is proposed that interventions to improve medication taking are ineffective because they focus on 'compliance', (strategies to achieve patient agreement with the service provider). The Concordance Co-ordinating Group of the Royal Pharmaceutical Society of Great Britain is actively working to promote the alternative concept of concordance. Concordance recognises that taking medication is actually a decision-making process embedded in a complex socio-cultural context. Rather than taking a reductionist approach, where the superiority of a biomedical approach is assumed, to achieve concordance it is paramount to actively and explicitly seek out and discuss differences of opinion and belief.

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[16] The Concordance initiative is supported by the Department of Health, the Royal Pharmaceutical Society of Great Britain, and Merck, Sharpe and Dohme. (www.concordance.org)

> *'Concordance is a new approach to the prescribing and taking of medicines. It is an agreement between patient and healthcare worker professional that respects the beliefs and wishes of the patient in determining whether, when and how medicines should be taken Although reciprocal, this is an alliance in which the health care professionals recognise the primacy of the patient's decisions about taking the recommended medication ...Concordance recognises that the health beliefs of the patient, although different from those of the doctor, nurse or pharmacist, are no less cogent, and no less important in deciding the best approach to the treatment of the individual'* [462].

In summary, it is known that differences of beliefs and ideas can have serious negative outcomes. CAS theory suggests that these differences are not the exception. Rather, they are to be expected between service user and provider. Problem-solving should focus on exploring the divergent beliefs and not on persisting in ineffective attempts to eradicate them. These efforts to eliminate divergent beliefs and move towards a single way of understanding pain are consistent with linear thinking and serve to perpetuate the chronic pain experience. It is not the lack of congruence that is the system attractor for chronicity but rather the ways in which the non-congruence is conceptualised and addressed.

11.3.2 Differential access to information

A complex system's ability to adapt is contingent on the information it has available and its ability to disseminate and communicate that information across the multiple layers of the system. Adaptive organisations that use information to create flexible, responsive structures and foster continuous reflexivity in their human resources are known as learning organisations [463]. Management theorists propose that learning organisations are able to survive and prosper because they encourage dynamic problem solving that is responsive to the context of the presenting problem ('good-enough solutions'). This allows for rapid modification as circumstances change [464]. Department of Health policy makers have stated that the modernised NHS is dedicated to becoming a learning organisation with the ability to use past experiences and unexpected events as vital learning opportunities to continuously improve service delivery [465, 466]. However, current evidence suggests that this goal may be far from recognised. For example, a key skill in learning organisations is that of reflectivity and as early as 1993 the General Medical Council (GMC) stated in its recommendations for undergraduate education (Tomorrow's Doctors[467]) that students should be taught the reflective and critical skills to become self-directed learners. The GMC also stated that graduates should, '...be able to gain, access, apply and integrate new knowledge and have the ability to adapt to changing circumstances throughout their professional life.' Ten years on from these GMC recommendations research shows that the 'hidden curriculum'[17] for medical students still includes adoption of a 'ritualised' professional identity, emotional neutralisation, and the acceptance of hierarchy. These features do not support the critical and flexible attitudes needed to participate in reflective learning. The authors concluded that the hidden curriculum needs to be addressed if fundamental changes are to occur in the culture of medical education [468].

Traditionally and socially physicians have held a strong leadership role in healthcare. For the NHS to achieve a learning organisation culture, physicians must hold values congruent with the open exchange of information and continuous inquiry needed in a learning organisation. Additionally, to achieve the goal of being a learning organisation, the NHS needs to move beyond its current emphasis on a 'single-loop' learning style that focuses on codified individual and group knowledge (for example National Service Frameworks), towards what is known as 'double-loop' learning [469] where organisations practice reflexivity to achieve change in basic rules, norms and attractors. Single-loop learning adds new information to an organisation whereas double-loop learning actually facilitates core changes in organisational culture and values. To sustain and strengthen this type of growth management theorists propose that a third type of learning (meta-learning) is also required. Organisations that engage in meta-learning are recursive, and able to reflect on and improve their ability to learn [464].

A range of information is required for complex systems to successfully engage in the different forms of learning. Single-loop learning is predominantly concerned with skills, procedures and refinements to existing practices and beliefs. This type of learning typically depends on more linear forms of information (how much, how

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[17] 'Hidden curriculum: the set of influences that function at the level of organisational structure and culture including, for example, implicit rules to survive the institution such as customs, rituals, and taken for granted aspects.'[459:770-3].

often, in what order and under what conditions). Double-loop and meta-learning, on the other hand, target underlying beliefs and values, and require information with a potentially much higher emotive content. However, because of its value-laden content, this type of information can also be perceived as more risky and increasingly difficult to access and communicate across the system. Timpson proposes that, as a consequence of its historically hierarchical, gendered and quasi-militaristic structure, the NHS will remain particularly resistant to double-loop and meta-learning unless its management practices are fundamentally changed. 'People have to feel free to ask questions. They must not feel threatened by their own ignorance' [470]. Gaining new forms of information is contingent upon being able to ask questions about a range of issues, including those with a more emotive context, which have typically been neglected or suppressed under the guise of scientific objectivity.

This study's findings (as detailed in Sections 8.4 and 9.8) showed that service providers may have limited and potentially decreasing access to the affective domain of decision-making. This limited access creates barriers for leadership and performance within the NHS's vision of a healthcare system as a learning organisation. Indeed, organisational theorists propose that organisational learning, contrary to the popular conception of intellect and emotion as valued at opposite ends of the continuum, is permeated at all levels with 'emotion, passion and fantasy' [471]. Effective learning organisations harness the energy generated by emotions and creatively channel it towards problem-solving. Conversely, organisations that suppress exploration and discussion of the emotive context of service provision create negative forces that serve as barriers to change and innovation. This paradox for healthcare service providers of being inculcated with the professional norm of 'objectivity' while attempting to work and effect change within a highly emotive context is seen as a key challenge to moving the NHS's modernisation agenda from rhetoric to reality [239, 404, 470-472]. The present, strongly entrenched sanctions against accessing and reflecting on information with an emotive context serve to act as a counter-force to change within interventions for people with chronic pain. Service providers' lack of access to affective information creates an attractor for the current state of 'chronicity' within many peoples' experience of pain.

There are other barriers to accessing information that can also serve as attractors, increasing the probability that chronic pain will remain 'chronic'. For example, it has been proposed that the current hierarchy of evidence valued within the healthcare system presents an additional barrier to stakeholders' ability to access the scope of information required within complex systems [331, 419, 446]. 'Orthodox views about health and the correct ways to conduct health research are maintained by traditions that are developed in support of dominant beliefs and by power relationships' [446]. Randomised control trials, seen by many as the 'gold-standard' in healthcare research, are by definition linear in methodology. They assume that controlling for as many variables as possible will yield a bias-free representation of probability and causality. Complex adaptive systems require information from a range of interactive and contextually varied agents, and this type of information is for the most part inaccessible through the methodology of randomised control trials.

Another example is that although service users appear to have increasing access to 'scientific' information, its content varies in acceptability to service providers. Although there is a concerted effort within the healthcare system to increase the amount of information available to service users [266], there is also criticism that the type and amount of information can potentially be manipulated by service providers in such a way as to co-opt patients' thinking into support for the status quo [473-476]. The growing expression of concern in the literature and popular press that access to unmonitored information (for example on the internet) will create additional health problems [477, 478] is one possible mechanism to justify the continued information gate-keeping role held by service providers. This literature serves as an alert that the reality of increased access to scientific information is embedded within the context of control, values and beliefs. The continued increase in public access to scientific information is inevitable. The manner in which the growing issues of trust, power and legitimacy of information are addressed can foster new attractors that move the chronic pain experience away from chronicity. To do that requires a paradigm shift away from the biomedical model and traditional doctor/patient relationships. To continue with the prevalent viewpoint that there should be a hierarchy of access to information (from 'layperson to expert') will strengthen the current system attractor for chronicity. In the preceding section

(11.3.1) it was proposed that, ' it is not the lack of congruence that is the system attractor for chronicity but rather the ways in which the non-congruence is conceptualised and dealt with'. Similarly, in the issue of differential access to information, it maybe that how the discrepancy is dealt with is a stronger influence on the attractor of chronicity than is the discrepancy itself.

11.3.3 Paradoxical beliefs

> Paradox: '*A seemingly contradictory statement that may nonetheless be true; an assertion that is essentially self-contradictory, though based on a valid deduction from acceptable premises.*' American Heritage Dictionary[479]

There were numerous examples of paradoxical beliefs across the stages of the study. For example, in the Stage one survey, service users felt that decision-making should occur jointly between themselves and service providers (Section 7.2.1). However, in the Stage two Delphi 2 questionnaire, both service users and service providers only identified actions that providers should take to address the difference of beliefs about treatment components that existed between the two groups. There were very few suggestions about what actions the service users could take. These two sets of beliefs seem paradoxical: on one hand service users believe they should share responsibility for decision-making with service providers; on the other hand, they seem to abdicate responsibility for actions that would facilitate that decision-making. Service users thus seem to contradict themselves about whether they are partners in a consumer-focused model of service delivery, or if they occupy the more traditional role of patient, leaving responsibility in the hands of service providers. For service users to believe that they should have shared decision-making with service providers (a consumerist paradigm) while at the same time holding the view that responsibility for actions to resolve disagreement rests predominately with service providers, illustrates a paradoxical situation. Service users are inculcated with the bio-medical model but at the same time embrace the consumerist paradigm with regards to their rights and expectations of control within service provision.

The most obvious example of this inconsistency was discussed in Section 10.8.4 where the responses to Delphi 3 Question 3 illustrated that service users and providers held a range of paradoxical and seemingly contradictory beliefs about services for chronic pain. Despite the prevalence of support for the bio-psycho-social model that acknowledges the complexity of pain, people also expressed linear, reductionist beliefs and values. For example, there was high agreement with the statement that, '*Treatment must consider social, cultural and environmental aspects in addition to medical*' (100% of the service users and 97.3% of the service providers agreed). Agreement with this statement indicates a belief that chronic pain is not responsive to simple linear interventions. However, participants also strongly agreed with the statement that, '*Search for cure is the main goal for service users*' (75% of the service users and 82.4% of the service providers agreed). This latter statement reflects a linear system, focused on isolating cause-and-effect to achieve 'cure'. Other examples of contradictory beliefs expressed in Delphi 3 Question 3 emerged in Statement 11 where, although information is easier to access then ever before, and the philosophy of consumer rights in healthcare is well entrenched, people felt they had insufficient information and control to affect change. Statement 9 (*Guidelines, policy and funding should be decided at a central, national level)* and Statement 10 (*Guidelines, policy and funding should be decided at a community, local level)* offered another interesting example of some service providers' paradoxical thinking. When asked about central control, 68.9% of service providers agreed or strongly agreed with Statement 9. One would expect that only 31.1% of the service providers should then have agreed or strongly agreed with Statement 10, expressing support for local control. Interestingly, this was not the case and in actuality 51.4% of service providers agreed/strongly agreed with local control. This means that 20.1% of the service providers contradicted themselves by agreeing that both local and central control should decide guidelines, policy and funding. Of course this is a somewhat spurious analysis and there are a number of reasons that people may have responded in this apparently contradictory manner. Some participants may have been trying to indicate that there should be a process allowing for both national and local decision-making, some participants may have mis-read the question, and some may have believed only one element (e.g. funding) should be controlled centrally and that other elements (like guidelines and policy) should be local. Questionnaire data will be limited because the researcher cannot seek clarification at the time the response is made. Also the problem with asking about three discrete elements (guidelines, policy and funding) within one question was not recognised at the questionnaire design stage. Determining which of the responses indicated paradox was dependent on the researcher's perspective and interpretation and it is probable that if paradox was identified in error it was equally likely to be overlooked in some instances. However, the paradoxes identified here are of value for their illustrative purposes.

11.4 Reframing incongruence, information imbalance and paradox

The preceding sections have highlighted that disagreement, differential access to information, and paradox are three key features of the chronic pain experience. These three features are not unique to chronic pain and have been perceived as problems across the scope of healthcare organisation and service delivery. They are perceived as problems because the linear paradigm of medicine contends that there is a hierarchy of legitimate information, values and beliefs that people need to work towards sharing.

Applying complexity theory, it is proposed that these three features in themselves are not the problem. Rather, the problem is in how these inherent features of the system are dealt with. From a linear perspective efforts are targeted on reducing the occurrence of these features. Harmonisation of beliefs is seen as a priority (for example, more education to convince service users and co-workers about the 'right' way forward, and providing more information in response to peoples' perception they do not have enough). Ironically, paradoxical beliefs are actually increased as ineffective linear efforts are applied to complex problems in futile efforts to encourage homogeneity of beliefs and practices [456, 464]. Applying a CAS perspective, it is proposed that the consequence of approaching disagreement, differential access to information, and paradoxical beliefs as problems actually serves to facilitate the attractor 'chronicity'. Linear problem-solving focused on these three features generates a positive feed-back loop that serves to amplify components of the system's input and output; in this case increased expenditure of resources (input) and chronicity (output) of the pain event. The following sections will present an example of how each of these 'problems' can be reframed within a complexity perspective that will offer a novel approach to resolution.

11.4.1 Incongruence

There is no shortage of examples of difference of opinion in this study and throughout healthcare service provision in general. For instance, there are many beliefs about why someone gets influenza (living in a damp house, getting wet feet in the rain, a lack of 'fresh' air, excessive activity/too little activity, too much bacteria – 'so wash your hands'/too little bacteria – 'so drink bioactive yogurt') but regardless of the range of beliefs, government and health service efforts are channelled towards sharing a belief system with a virology basis. Service users who do not ascribe to this belief system are seen as problematic and resistant to change. They are treated as needing further education to move them towards the outcome desired by legitimised medicine. The case-study in Box 11.i illustrates the spiral nature of this feedback process.

Box 11.i

A mother brings here eight year-old son in to the surgery concerned that he is tired all the time. This is the third time in six months she has seen the GP with the same concern. The GP tells her that the son is overweight and needs to take more exercise. The mother explains that she believes the son is frail, 'just like his cousin was, and the doctors missed that until it was too late' and that too much activity will damage his heart. The doctor attempts to make a little joke to reassure her that it is only his weight that is at issue. The mother is offended and becomes uncommunicative. The GP now redoubles his efforts to explain why he is concerned about inactivity and tries to convince the mother to 'get the boy going'. The mother is thinking, ' little Jimmy's GP didn't believe there was a problem either and now he's not fit for anything'. The GP, still sensing resistance offers the mother a pamphlet about the importance of exercise. The mother concluded not only does the GP not believe her but he doesn't know what else to do so he is passing her off with some paperwork instead of examining her son more thoroughly. The mother leaves, angry to have 'wasted' 2 hours off work and having her son out of school just to get a piece of paper. The GP is frustrated and expects to see mother and son back again soon.

This is an example of a positive feedback loop[18] where the mother's actions to try and change the GP's beliefs serve to increase the GP's efforts to change the mother's beliefs and a counter-productive and energy consuming cycle is established. Neither is happy with the situation. Applying a CAS framework the GP would listen to the context of the mother's story before deciding on an action plan. The mother's understanding of her son's health is embedded in the larger story of her family and what happened to the boy's cousin, and what the doctors missed until it was 'too late'. In a CAS framework the GP would look for patterns in the mother's experience that led her to limiting her son's activity and repeatedly seeking medical attention. The linear approach (inactive child + protective mother = advice to get more exercise) leads to the behaviours and misunderstandings illustrated in the case-study above.

11.4.2 Perceived lack of information

Similarly, examples can be constructed to illustrate the positive feedback loops that occur when a linear approach is taken to peoples' perception that they do not have sufficient information. No one will ever have all the information. We are living in a knowledge driven society where the amount of new information produced increases at a rate of 800MG (the equivalent of two floppy disks) per day for every being on the planet [480] and the amount of information stored through a variety of media is predicted to continue to double every three years [481]. The NHS has invested heavily in information dissemination (for example NHS-Direct for the public, and the provision of e-mail accounts and access to on-line information portals for all staff) and yet both service providers and users state they do not have enough information. The quantity 'enough' is a linear concept. CAS theory proposes that it is the *type* of information that is lacking (as opposed to the volume) and that a battle for control and legitimisation of what is available is currently gaining momentum [252, 470]. 'Science is perpetually tentative' [252] and truth changes over time and circumstance. For example, as recently as the early 1900's syphilis was treated with mercury and a depressed woman was given a hysterectomy to prevent her womb from 'shifting' in response to the lunar cycle [482]. It is problematic to foster the belief that everything on a topic can be known, because everything has not yet been asked. Again, from a

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[18] A positive feedback system creates feedback that acts to increase the precipitating behaviour.

complexity perspective the problem it is not whether there is or isn't enough information available. Seeking and exploring information generates energy that, similar to differences of beliefs, can establish a positive feedback loop (the more information that is available the more uninformed people feel and the more information they demand). It is with this positive feedback loop, cyclically increasing both demand and production of a narrow type of information, that the problem lies. A reductionist response to a perceived lack of information is to provide more (a quantitative feature). A CAS approach would be to focus first on '*why?, what questions are not being answered?*' and '*why are people rejecting the information available?*'

11.4.3 Paradox

Recently Fraser and Greenhalgh [263] challenged British Medical Journal (BMJ) readers to accept that uncertainly and paradox are inherent in the healthcare system. Indeed uncertainty and paradox are highlighted extensively throughout the literature as integral components of complex adaptive systems across a range of disciplines and applications [235, 236, 239, 244, 317, 457]. Dissent and the idiosyncratic nature of agents are also seen as properties of CAS. Disagreement in CAS is to be expected, as opposed to being viewed as a warning signal triggering corrective action [253, 483].

Traditionally strategies for harmonisation of beliefs have assumed that there is one correct belief to be supported and the rest require discrediting. However, complex adaptive systems theory suggests that incongruence and paradox should be made overt, actively sought out and examined as tools for change. For example, an area fraught with paradox, disagreement and dissent is that of resource allocation [484, 485]. From many stakeholders' perspective the reality of resource allocation conflicts with the ethos of care. Service users want better service but lower taxation. Service providers want to give better care but are also charged with the duty of fiscal responsibility and rationalisation. The awareness that being patient-centred with Mrs 'X' (10 extra minutes to discuss her concerns) will mean being reductionist with Mrs 'Y' (trying to save time by keeping her focused on the 'real problem') places many service providers in a perpetual state of cognitive dissonance. The two goals are perceived as equally important but it is impossible to fulfil both within the current healthcare system. The

Health Complexity Group at the University of Exeter has identified four characteristic influences of decision-making in the NHS that serve to perpetuate conflict and irresolution:

- The system's goals conflict (for example equity and efficiency)
- The relationship between cause and effect is uncertain
- There are many different stakeholders with different agendas, perspectives and knowledge
- Healthcare has an emotive overlay particularly around the issue of rationalisation [484].

Typically, paradoxical questions in healthcare are viewed as dichotomous, demanding an *either/or* choice. For linear problems, such as whether to have surgery for a ruptured appendix or not, dichotomous decision-making is sufficient. These are the types of problems best suited to positivist science. But, in the current post-modern context of health and illness, paradox must be viewed through a different lens. Applying Stacey's definition of paradox, (' the presence together at the same time of self-contradictory, essentially conflicting ideas, none of which can ever be resolved or eliminated' [36]), provides some perspective regarding where problem-solving energies should be focused. If the opposing ideas/forces cannot be resolved nor eliminated then focusing efforts on attempting to do this will be futile. CAS theory proposes that efforts should instead be exerted to make the opposition explicit, developing an understanding of the patterns of interactions in play and using this understanding for decision-making.

That paradox exists is unavoidable and it is futile to see it as the problem. Attempting to achieve agreement about what should determine resource allocation (age, potential, entitlement, ability to pay, cost/benefit ratio, dependence, culpability) is attempting to resolve the irresolvable. Wyatt [486] used the Brazilian government's response to the country's emerging HIV/AIDs crisis as an example of how linear thinking can be challenged, thus allowing for creative problem solving of complex issues. Instead of engaging in the impossible task of rationalising scarce resources to purchase drugs from profit-driven corporations (*who should get treatment*?), the government posed a different sort of question starting with the assumption that everyone should get treatment (*how can we make this possible*?). This reframing resulted in Brazil leading the way for developing countries to import generic copies of patented medicines. In a linear paradigm this would equal a loss for manufacturers. However, the chief executive of Merck Pharmaceuticals, Raymond Gilmartin, was quoted as saying '...I think that as we've gotten into markets that are much less developed and the countries have a lot less wealth...pricing according to the ability of a country to actually afford the drug and make use of it was a way to maximise social good, but also contributes to the possibility of doing more research. In the case of HIV we've done something extreme, we're offering drugs at a price in which we make no profit' [487]. Drug companies cite the high cost of research to justify the high cost of medication. Brazil, by reframing the question to focus on '*how can we make this possible for everyone to be treated*', forced the pharmaceutical industry to rethink its' practice. Departing from the linear path allowed Merck to remain involved in the supply of medication to Brazil (as opposed to Brazil importing non-regulated medications or producing its own generic, low cost drugs), to claim humanistic motivations and to have ready access to huge number of research subjects. At the same time, Brazil can come close to achieving its goal of free antiretroviral drugs for all.

CAS theory proposes that fostering the perspective that paradoxes (for example, *everyone deserves treatment/we cannot afford to treat everyone)* can never be resolved but that they can be lived with, will lead to an understanding of the way organisational dynamics result in patterns of behaviour. It is these patterns of behaviour that generate tension/energy which can enhance double-loop and meta-learning [36] and facilitate the emergence of new attractors in the system.

11.4.4 Summary

The preceding sections have discussed three key features of chronic pain that emerged across the study; incongruence, information imbalance and paradox. Each of these features has been discussed within a CAS framework highlighting that positivist and reductionist approaches to problems of this nature generate single-loop feedback that contributes to and strengthens the attractors for the current system state of chronicity. Reframing the question away from '*what is the best thing to do?*' towards '*What interactions and dynamics are keeping the system in its current state of chronicity?*' has been introduced as the way forward. Complexity theory offers a number of strategies for effecting change within complex systems and many of these strategies are evident in the current NHS Modernisation Agency's policy statements. Chapter 12 (Recommendations and conclusions) will present an overview of these strategies and generate specific recommendations within the context of chronic pain service delivery.

11.5 Limitations, and limitations reframed

> *"Research is formalized curiosity. It is poking and prying with a purpose."*
>
> Nora Neale Hurston (1891-1960) in [488]

This research started because of a curiosity about whether service users and service providers agreed on which treatments are important for chronic pain. It poked and pried and, in the end, almost certainly raised more questions for the researcher than it answered. The study employed a complex process, highly contextualised and dependent on the goodwill and open communication of others. It ranged from linear to complex and at times swerved into the chaotic. The following evaluation and discussion of the process will follow that path; first presenting the perceived limitations from a scientific positivist paradigm and concluding with a more personal reflection on the learning opportunities afforded by the 'surprises' that emerged from the act of conducting the research itself.

11.5.1 Design and structure

Several design flaws became evident during the analysis stages of this research. There were problems with the wording of some of the questions. For example, Delphi 3 Question 2 asked participants to respond to a series of statements all worded in the affirmative except for one that asked if the participants refuted the statement. This unnecessarily confusing phrasing was not picked up in piloting and only recognised during the analysis stage. Similarly, the sentence structure in Delphi 2 Question 2 was complicated and may have contributed to peoples' misunderstanding. This conclusion is reflected in the participants' feedback about taking part in the study (Section 10.7) where 25.0% of the SUs and 10.5% of the SPs felt that the questions were not very clearly written. Efforts to keep the reading level for all questionnaires and reports at grade 8 or lower on the Flesh-Kincaid scale were not always successful and the reading levels varied from 6.2 to 10.9 with an average score of 8.7 across all of the materials sent out to participants (Sections 6.6.1, 6.6.3, 6.7.1, 6.7.3, 6.8.1, 6.8.3). The style of reports and questionnaires (bullet points and questions) makes achieving low scores problematic and more extensive pilot work may have assisted with this goal.

It is possible that the Delphi process presented a limitation for some participants. It can appear complicated and time consuming and some participants may have dropped out or given less than comprehensive responses as a result. Delphi method is relatively new within health care research and both the researcher's and participants' unfamiliarity with the process may also have limited some responses. The participants' evaluations (Table 19) showed that 73.3% of SUs and 29% of the SPs would have preferred to participate in a focus group. However, it is also important to note that a strong majority of participants (SU= 80% and SP= 86.6%) stated they would be willing to participate in a Delphi study in the future. It is possible that a combination of the two approaches, that allowed participants to select the data collection method they preferred, would have resulted in a higher number of participants and wider range of comments. However, this would introduced additional bias, possibly decreasing the comparability of the findings.

11.5.2 Participants

As mentioned earlier, the participants should be considered an expert group because they were recruited based on membership in a variety of groups/organisations specifically concerned with chronic pain. This would introduce an element of bias and the findings cannot be generalised to all service providers or people with pain. The Stage one postal survey resulted in three hundred and eighty-six responses (27.0%) from service providers. Of these, two hundred and sixty-five (68.5%) volunteered to participate in Stage two. [19] Thirty-three of the fifty-nine service users (55.9%) who responded to the Stage one survey volunteered for Stage two. For both SUs and SPs participation in Stage two was fairly consistent across all three Delphi rounds (41.1%, 39.2%, 40.6%). A review published in 1978, found service provider

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[19] It was not possible to determine exactly how many service users received the stage one survey and the discussion is based on the assumption that the total number printed (110) were distributed.

response rates of between 56%-99% across the nineteen samples considered [489]. Influences on response rates were identified as; the type of professional (consultants and nurses responded 58-83% and 78-86% of the time respectively), length of the questionnaire, interview versus postal survey, sponsoring body and the subject of the study. A more recent review [490] of healthcare providers' participation in postal surveys cited examples as low as 32% and indicated overall lower response rates than Cartwright found in 1978. Reasons given by non-respondents in the McAvoy study included; being 'swamped' by too many surveys, resenting researcher's unsolicited interference, questionnaires were too long, took too much time, were not confidential enough, were boring and were perceived as having little direct return for the time taken to complete. Some authors suggest a minimum of two follow-up letters to non-respondents [489, 491]. Because resource restrictions allowed for only one reminder to the service users and no reminder to the service providers, it is probable that a less then optimal response rate was achieved in the present study. However, in view of what appears to be a growing resistance to questionnaire participation, the limitations on reminder letters, and the time span of the entire project, a 40% response rate can perhaps more reasonably be interpreted as showing participants' commitment to the question, rather than as a study limitation. A telling example of questionnaire fatigue was demonstrated by the one thousand and forty-seven (1047) professionals attending the Pain Society's Annual Scientific Meeting in Manchester 2004. Only one hundred and thirty-four delegates (12.8%) completed and returned the evaluation forms despite the offer of an opportunity to win £100 worth of book tokens [492]. Admittedly this is less than scientific evidence, but it does offer some additional support for the researcher's conclusion that a 40% response rate showed participant interest and was acceptable for this type of theory building research.

11.5.3 Researcher bias

Qualitative research is not value nor bias-free. The researcher brings past experiences, knowledge and beliefs to the process. This does not give the researcher freedom however to decide what they like, as they like. Unlike positivist research, assumptions that certain terms and concepts are universally understood cannot be made. For example, a scientist can assume that a gram is the same unit of measure in any test lab, however a qualitative researcher cannot make that same assumption about the concept of social support. This awareness adds an additional dimension to qualitative studies where by the researcher must engage in a reflective process, examining and making explicit underlying values and beliefs that influence the study design and process. The rigour of qualitative research depends on the ability of the researcher to make his/her decision-making process transparent to others [347]. In this study the researcher attempted to make decision-making an overt process through providing ongoing reports after each round of the Delphi study and by seeking participants' comments and agreement with the conclusions drawn. Additionally efforts to increase the reliability of the study were carried out through piloting of questionnaires and coding validation exercises as discussed in Chapter 6.

11.5.4 Limitations reframed

The researcher's background and training (service provider trained in the prevalent biomedical model of the 70s, department manager in a large, traditionally structured teaching hospital in the 80s, and academic in the 'evidence-based' 90s) served as a strongly positivist starting point for this study. Attempting to reconcile and understand emerging ideas and new types of information were significant challenges and at times the researcher's own reflective struggles will have impacted the clarity of ideas and questions posed to study participants. Grbich proposes that, 'through feedback loops and emergent patterns we interact, react, incorporate and shift in a never-ending process' [366:60]. The researcher is not outside of the process, but rather changes, and is changed by, the interactions that occur within the study itself. If this study attempted to answer questions of a positivist nature (how tall are most eight year old boys in Manchester) the researcher's ongoing change would have presented a major limitation and invalidated any conclusions. However, complex, contextually driven questions are recursive by nature and the demand on the researcher shifts from mechanistic objectivity to reflexivity and transparency. The demands of employing a multi-stage, multi-method design with certain time constraints, created a high demand on the researcher's ability to shift between paradigms, determining what questions to ask, how to ask them and then to apply the right analytical perspective for the different types of raw data returned. However, within a CAS perspective, the paradoxes and conflicts that emerged throughout the study generated must not be seen as limitations but rather as facilitating the creative energy necessary to move forward. The researcher's process actually mirrors that conclusion arrived at in the preceding section (11.4) reframing incongruence, information imbalance and paradox. These issues can all be understood as either facilitators or limitations, dependent on the perspective and problem-solving strategies employed.

11.6 Principles for affecting change in CAS

The Department of Health in the UK has recognised that traditional strategies are no longer effective in many situations and has charged the NHS Modernisation Agency with the task to, 'work as a catalyst for change in the NHS...to discover, develop and disseminate new ways of doing things' [266]. However, complexity scientists propose that the healthcare services remain resistant to change mainly because the wrong tools are being applied to a flawed construct of the problem [238, 463, 472, 493]. Management styles that were effective in addressing previous, more linear, problems in health care are now perceived to be a major barrier to dealing with the emergent health needs of the twenty-first century [264]. Zimmerman et al [244] propose there are nine leadership principles for influencing complex systems in such a way as to facilitate adaptive and positive change (Box 11.ii). The concluding chapter will examine each principle within the context of service delivery for people with chronic pain to identify what factors are present that facilitate or impede the system's movement away from the current attractor of chronicity.

Box 11.ii: Nine leadership principles for CAS

1. Apply a complexity framework
2. Provide minimum specifications, rather than exhaustive criteria and protocols.
3. Balance planning and acting, risk and safety.
4. Foster the right degree of information flow, volume, and exchange.
5. Expect and employ surprise as opposed to suppressing paradox and tension.
6. Recognise that action is necessary for a recursive system.
7. Recognise the importance of 'informal' systems.
8. Allow complex systems to emerge from the inter-relationship of simple, independent systems
9. Mix cooperation with competition

[244]

Chapter 12

Conclusions and recommendations

12.1 Introduction

> *'Pattern and creativity are the two poles of action...It is precisely this ability to discern and manipulate patterns unknown to the ordinary person that makes the followers of Tao so formidable. When unpredictable things happen, those who follow Tao are also skilled at improvisation...To avoid confusion they still discern the patterns of the situation and create new ones, much like a chess player at the board'*
>
> Deng Ming-Dao [494:47]

> *'Miss Marple is able to solve difficult crimes not only because of her shrewd intelligence, but because St. Mary Meade, over her lifetime, has put on a pageant of human depravity rivalled only by that of Sodom and Gomorrah. No crime can arise without reminding Miss Marple of some parallel incident in the history of her time'.*
>
> The Free Dictionary [495]

At first glance, there seems little commonality between one of Agatha Christie's popular fictional characters, a contemporary Taoist philosopher and this chapter's aim of applying CAS theory to chronic pain intervention. But in actuality they share a fundamental characteristic. Miss Marple, Taoist philosophy and complexity theory all propose that the key to solving new problems is in looking for patterns. Identifying patterns allows one to employ an element of past learning and experience. Anxiety and fear are reduced when recognisable patterns emerge and this, in turn, frees up energy for creative problem-solving, as opposed to taking a protective stance towards the perceived threat of the unknown. Complexity theory reiterates that many contemporary problems are a consequence of highly interactive contexts and agents and cannot be reduced to a single cause-and-effect analysis. Complex problems can only be successfully addressed through strategies focused on understanding patterns and inter-relationships. Chapter 11 (section 11.6 and Box 11.ii) introduced nine principles to guide problem-solving efforts for complex adaptive systems like health care and chronic pain. The following sections will discuss each principle in turn, identifying existing opportunities and barriers to implementing problem-solving, and for changing the system attractor away from chronicity.

12.2 Principle 1: Apply a complexity framework

Current healthcare services are a product of a historically positivist paradigm. Healthcare is also described in predominantly militaristic and mechanical metaphors, (the 'war' on cancer, 'fighting' to his last breath, the 'invasion' of bacteria, the heart is a 'pump' in the circulatory 'system', food 'fuels' the body). This perspective is deeply entrenched and many stakeholders (for example, managers [483] and high-status service providers[446]) may have a clear interest in maintaining the status quo. Some theorists have proposed that the current drive for evidence-based medicine runs a significant risk of being subverted into a tool to maintain the existing power structure and devalue alternative perspectives [457]. It has also been suggested that the existing healthcare system has a depersonalised culture that does not allow for reflexivity and experimenting with new manners of relating and behaving [496, 497]. Rather, it deals with the inherent conflict generated by its increasing inability to 'manage' through the imposition of yet more structure and specialisation in the guise of 'professionalism' [318]. A recent hospital based study in the United States found that over 60% of the managers in the study supported the concept that healthcare is a complex system. However, at the same time, half of the participants felt that successful leadership needs to 'control the parts of the machine', and one-third thought that successful leadership required 'strong direction and control'. The researchers concluded that, although many participants recognised that healthcare had the features of a complex system, ' the same leader who is frustrated when trying to control the chaotic, complex healthcare environment is also uncomfortable giving up control and allowing the complex adaptive system to adapt and evolve toward an unpredictable outcome' [251].

A movement, contrary to this strong and well-established force of applying a reductionist lens to healthcare, is growing. Authoritative voices, which cannot be marginalised or discounted as heretical, have emerged from within respected establishments of the medical profession. The British Medical Journal (BMJ) ran a four-article series focusing on complexity science; what is complexity science, why is it relevant to healthcare, how to educate practitioners about it, and how to manage within complex systems [242, 250, 263, 264]. A book about the complex world of the general practitioner (Friends in Low Places [20]) was written, with the support of a sabbatical approved by the NHS Executive [369:2], by the provost of the Wessex Faculty of the Royal College of General Practitioners. Other examples exist that complexity science is growing in acceptance and value within the healthcare system. Highly regarded universities and scholars have established complexity organisations and networks[21], and have taken the initiative to disseminate information about health care and complexity through a range of publications (for example, Complexity and Healthcare: an Introduction [236]), newsletters and conferences.

Perhaps most important in establishing that healthcare exists within a complex system are the concerted efforts of the NHS Modernisation Agency. David Fillingham (Director, NHS Modernisation Agency) has stated, 'we are working...to discover, develop and disseminate new ways of doing things [266].' The NHS Modernisation Agency has identified that it had three key principles of modernisation (renewal, redesign and respect), and that these three principles will be achieved by applying five basic rules. Setting broad goals and rules that can be flexible to local context is consistent with complex systems management theory. It is interesting that the Modernisation Agency does not actually label its new approach 'Complexity Science' but rather uses the terminology 'Anatomical' ('...the hard project management approach to change') and 'Physiological' (the softer, people side of change') [498:10]. The characteristics identified for each of the

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[20] "Focusing on the inadequacy of models to reflect or predict the infinite subtlety of human behaviour, and the false promises of the Evidence-Based Medicine movement, Willis encourages us to have faith in our own intuitions as doctors, teachers, managers, or in whatever roles we play in relating to other human beings". Review by Douglas Jeffries, GP, on the Amazon.UK website (http://www.amazon.co.uk/exec/obidos/ASIN/1857754042/qid=1093000452/sr=1-6/ref=sr_1_8_6/026-6750948-5058031).

[21] Centre for Complexity Research - http://www.liv.ac.uk/ccr/
The Complexity Society - http://www.complexity-society.com/
Plexus Institute - http://www.plexusinstitute.org/services/Fractal_Networks.cfm
Complexity in Primary Care- http://www.complexityprimarycare.org
Health Complexity Group- http://www.healthcomplexity.net

Box: 12.i Modernisation Agency – Two approaches to improvement [498]

'Anatomical approach to improvement'	'Physiological approach to improvement'	In practice- both approaches of improvement are necessary
change is a step by step process	outcome cannot be predetermined	you need aplan to set direction but need to be flexible
it is typically initiated top down	change comes typically 'bottom up'	top down support is needed for bottom up change
objectives set in advance (and set in stone!)	there is no end point	objectives need to be set and the team should be congratulated when each objective is achieved but improvement never ends
it goes wrong because of poor planning and project control	it goes wrong because of people issues	correct use of improvement tools and techniques should be planned and monitored but gaining the commitment of people is vital

two approaches are very similar to those comparing linear to CAS (see Box 12.i).

The Modernisation Agency has a particular focus on helping 'Improvement Leaders' understand and facilitate change and the supporting documentation is extensive. This documentation does not use the label of complex systems. It is possible that the authors felt that complex adaptive systems theory was too jargon laidened and would distract the reader, putting them off the important message the agency is attempting to convey. On the other hand, a more cynical perspective would be that the Modernisation Agency is attempting to develop and control a highbred approach to change where the NHS continues to control access to information and the concepts it has identified as being the 'correct' position. For example, the Improvement Leaders' series booklet Managing the Human Dimensions of Change states that, '*…much has been written about improvement and change. So much that it is very easy to get overwhelmed by all the material. So we have gathered together the* *things that we think you will find most useful'* [498]. The reader is then referred to 'useful readings' at the Modernisation Agency website, (www.modern.nhs.uk/improvementguides/reading). However, on entering that website the reader is told, '*Below is a list of further reading we think is useful in addition to the guides that are available in the list to the left. Please refer back over time as this list will be updated as new resources become available*'. The list in Box 12.ii is then presented. None of these are linked directly to a reading list and all are directly dependent on government funding. While it is sound educational principle to present the initial pamphlet information in simple, easy to consider 'chunks', it is less easy to understand why more detailed and scholarly substantiating background literature is not offered as an additional resource. The NHS appears to have neglected to share the evidence-base for its own change agenda.

Box 12.ii Resources referenced by the Modernisation Agency

Institute of Healthcare Improvement
www.ihi.org

National Primary Care Research & Development Centre
www.npcrdc.man.ac.uk

National Institute for Clinical Excellence (NICE)
www.nice.org.uk

The Commission for Health Improvement (CHI)
www.chi.nhs.uk

Cardiff Business School
www.cf.ac.uk/carbs/

In summary, there are many barriers to the healthcare system adopting a CAS perspective. Equally, there are very important and credible forces serving to influence the system's attractors away from an exclusively biomedical paradigm towards a framework incorporating the legitimacy of a range of contextually responsive paradigms. It is unlikely that there is any one reason for the Modernisation Agency's decisions about what information it wishes to disseminate. Indeed, the Agency itself should be understood as a CAS with a myriad of different stakeholders and stakeholder agendas. Teasing out 'the reason' is counterproductive. The reality is that the Modernisation Agenda has publicly announced a framework for healthcare reform that supports complexity theory. Whether this proves to be simply rhetoric or not will depend on the use to which it is put in the general health care community and specifically, chronic pain service providers' ability to recognise and apply examples and patterns from within the framework that are relevant to chronic pain.

12.3 Principle 2: Provide minimum specifications

> *Even in traditional 3-by-3 tic-tac-toe, the number of distinct legal configurations exceeds 50,000 and the ways of winning are not immediately obvious.* [499:23]

Simple rules serve to favour adaptation and survival of a complex system. A common example in the complexity literature is that of the flock of migrating geese. Geese on migration have three simple rules; fly at the same speed, stay as close to the centre as possible and avoid collisions. When all members of the system follow these simple rules very complex behaviours are able to emerge. It is easy to see why a more linear style of migration (where there is a CEO goose, a head catering goose and a security goose charged with watching out for hunters) would not work, particularly if any of the geese with specialist roles were unsuccessful in avoiding the hunters in their flight path. Healthcare has also been criticised of having become overspecialised, lacking in the ability to understand the relationship between the parts and to respond flexibly to emerging and unanticipated events. There is a difference between systems requiring 'clock-work' organisation (for example, a car assembly line) and complex adaptive systems that are most successful when 'swarm-work' principles are in place. For complex systems, central control and micro-management impede responsiveness and adaptation to change. Theorists propose that three types of simple rules exist within CAS; those that set direction ('pointing'), those that set boundaries ('prohibition') and those having to do with required resources ('permission') [239, 464]. Kernick offers examples of simple rules that can be applied to developing more responsive heathcare services:

- *Accept that death, sickness and pain are part of life.*
- *Medicine has limited power, particularly to solve social problems, and is risky.*
- *Doctors don't know everything- they need decision-making and psychological support.*
- *We are all in this together.*
- *Patients can't leave problems to doctors.*
- *Doctors should be open about their limitations.*
- *Politicians should refrain from extravagant promises and concentrate on reality.* [464:102]

These is some evidence that these types of rules are gaining credibility and emphasis within the current healthcare system. The World Health Organisation has clearly stated that medicine is limited in its power to address social and lifestyle problems which are fast becoming the major health concerns of the 21st century [265] and the WHO is actively structuring programmes around this philosophy. The rise of public health initiatives (like anti-smoking campaigns) echoes many of the sentiments in Kernick's rules; as does the NHS's efforts to develop a culture of shared responsibility between service users and providers (for example, the Expert Patient [500] and Concordance [462] programmes). Additionally, service providers are receiving much more extensive training in communication skills and reflective practice, both of which can contribute to the acceptability of (and willingness for) abandoning the 'all knowing-all powerful' professional image. Of particular importance to the area of chronic pain, the International Association for the Study of Pain (IASP) [5] has written communication skills into its recommended curriculum for service providers [5] and is currently involved in updating and expanding these recommendations.

The IASP and the British Pain Society [278] have also published guidelines for good practice in the delivery of services for people with chronic pain. The Pain Society good practice guidelines outline nine objectives (Box 12.iii) for chronic pain services.

BOX 12.iii: Pain Society Good Practice Guidelines

The objectives of a chronic pain service include:

a Alleviation of pain. This is not always possible because any pain that is described as chronic has already proved resistant to treatment.

b Alleviation of psychological and behavioural dysfunction and distress.

c Reduction of disability and restoration of function.

d Rationalisation of medication.

e Reduction of utilisation of healthcare services including consultations in primary and secondary care, surgical operations and treatments such as physiotherapy.

f Attention to social, family and occupational issues.

g Education for nursing, medical staff and other allied health care professionals.

h Continuing audit and evaluation of the service and the needs of patients. Outcome measures for patients with chronic pain should include assessment of physical functioning, psychological status, medication consumption, utilisation of healthcare resources and work record in addition to measurement of pain intensity.

i Research into the epidemiology, causes and management of chronic pain. [269:10]

At first reading the nine objectives appear quite complicated (for example item e: *Reduction of utilisation of healthcare services including consultations in primary and secondary care, surgical operations and treatments such as physiotherapy*). Also, they are predominately focused on process (for example item h: *continued audit and evaluation of the service and the needs of patients*). The direction pointing and setting of boundaries/prohibition that characterize simple rules is not easily apparent. However, as Plsek points out healthcare is already a complex system and all complex adaptive systems follow simple rules. The challenge is to identify what those rules are [37]. Just because the system's rules are not overt does not mean they are not present, but rather simply that they are unknown.

The study reported in this dissertation proposes that the attractor for chronic pain is 'chronicity' and therefore the simple rules guiding the system are those that would establish direction (pointing), boundaries (prohibition) and resources (permission) that attract the outcome of chronic (versus resolved) pain. Kernick proposes that a system's simple rules can be discovered through the use of narrative, observation and similar qualitative methodologies [464]. A plethora of this type of research exists illustrating that the simple rules governing the healthcare system arise from the biomedical, reductionist paradigm prevalent in western, industrialized society. Some examples of simple rules, that allow this system to adapt to change and maintain its current ideology and practices regardless of alternative input, as evidenced in the literature previously discussed in this study, include:

- Keep information exchange to a minimum
- Maintain hierarchy of agents
- Seek causation by breaking down the parts to find the flawed component

These are only suggestions of the simple rules at play in the healthcare system, and are offered as illustrative, not comprehensive. Uncovering the simple rules operating in healthcare in the UK, and particularly of chronic pain service delivery as a subsystem embedded within the context of the main system, is a large research project in its own right that can only be flagged up as a need within the discussion of this study.

To summarize, the existing IASP and British Pain Society objectives for chronic pain currently reflect the prevalent biomedical framework whose simple rules promote, as opposed to preclude, 'chronicity'. The IASP and British Pain Society guidelines do however, make some important departures from the biomedical paradigm. For example, item 'f' in Box 12.iii flags up that there is a social and occupational context to the chronic pain experience. A re-examination, from a complex adaptive systems perspective, could serve as a catalyst in changing the system rules and attractors away from chronicity towards resolution.

12.4 Principles 3,4 and 6: Planning and acting, information and the iterative process

Three of the leadership principles for CAS are inherently interdependent (principle 3- *Balance planning and acting, risk and safety,* principle 4- *Foster the right degree of information flow, volume, and exchange*, and principle 6- *Recognise that action is necessary for a recursive system.*) Consequently, this section will deal with these three principles together.

As discussed previously (Section 11.3.2) successful modification of complex adaptive systems depend on an iterative cycle of action, feedback, modification, new action. The Department of Health policy makers have stated that the modernised NHS is dedicated to becoming a learning organisation with the ability to use past experiences and unexpected events as vital learning opportunities to continuously improve service delivery [465, 466]. As Kernick points out this requires a shift in values away from the prevalent model of highly prescriptive healthcare planning that attempts to control for every contingency. Instead, services should be provided within a 'good enough' vision. Good enough to address basic safety and risk concerns (setting basic parameters) while at the same time allowing timely action and flexibility to modify actions as new information becomes available [465]. When the participants in this study were asked if they thought new ideas about treatment were easy to try out, 68.8% of the service users did not agree. Even more strikingly, despite their greater control over what is available and access to information about the range of options, 89.3% of the service providers disagreed with the statement that '*New ideas about treatment are easy to try out'*. Similarly, when asked if outdated ideas are difficult to eliminate, nearly 100% of both service users and service providers agreed (100% and 96.0% respectively).

Successfully balancing planning and doing, within a 'good enough' vision, can only be possible when feedback information is available. Without action the system lacks feedback. Without feedback the system cannot modify action. The participants in this study felt that new actions were hard to implement and that old practices were hard to abandon. Additionally, as discussed in depth in section 11.3.2, participants experience differential access to the type and amount of information they hold about chronic pain.

There are a number of developments within healthcare service delivery that can facilitate a shift in vision, allowing for more rapid cycles of planning, acting and modifying. As previously discussed, public access to information is growing and the Department of Health directives for healthcare providers to work in consultation with service users and to acquire the skills to more readily access information from the affective domain are strong. Additionally, the idea that there are different types of evidence required for different types of questions (as opposed to the positivist positioning of the randomized control trial at the top of the 'hierarchy of evidence') has become an overt and legitimate debate taking place within mainstream research publications [416, 419, 446, 501]. Some researchers have proposed that standardization of trials to prevent any contextually influenced fluctuations in process (a key design feature of RCTs) can actually result in the treatment erroneously appearing to be ineffective. Because the study design is uniform across sites, it serves as a deterrent to the usual, and necessary, local-level adaptation within complex systems and therefore could actually be one of the reasons for an intervention's failure [501]. The Medical Research Council (MRC) has responded to this concern by developing guidelines for designing RCTs for complex health interventions [262]. These types of initiatives not only provide guidance for those wishing to engage in research but also serve to alert funding bodies about the need for more inclusive definitions of high quality research.

Perhaps most importantly, the policy and mechanisms for applying these new types of information are being put in place. In National Standards, Local Action: Health and Social Care Standards and Planning Framework the Department of Health has stated that:

> *'National initiatives, through the work of the NHS Modernisation Agency, National Programme for IT (NPfIT) and new workforce contracts, provide a major platform for modernization. The Care Service Improvement Partnership has been established to harness and co-ordinate service improvement support in social care. PCTs and LAs now need to ensure that these national programmes are used as levers for change locally'*[502:17].

The editor of the British Pain Society's newsletter demonstrated how this type of challenge can be taken up; applying national resources at a local level in response to a local need. He tells the readers that, ' At a meeting last week, our pain management services came under threat for the first time….together with varicose vein surgery, breast reduction surgery and a 'dizziness clinic' run by the ENT surgeons, we have been asked to establish our worth' [503]. Ward then goes on to discuss that there are excellent national reports clearly identifying the high cost of chronic pain to both the individual and the public [69, 298] but, ' …we can publish all the documents we like about how important our service is and how wonderful we are but if the commissioners don't even understand what we do on a day to day basis then we are sunk'. Instead of calling for a study of why the commissioners don't understand, and asking the membership of the British Pain Society to strike a committee to plan a survey of who doesn't understand what, and how best to tell them (and a committee to fundraise for this survey and planning), Ward suggests several simple, local activities that each member can participate in with the least amount of time and financial burden:

- Send copies of important national reports to the local PCTs
- Ask service users to write to the PCTs about the benefits of the service
- Invite the PCT service development officer to attend a clinic
- Request that MPs write the Secretary of State asking why action has not been taken on these reports.

Because chronic pain and health care are complex adaptive systems, there is no one correct action within this list and different activities will have different effects given the local context and relationships between the agents. Different members of the British Pain Society can select from a range of simple options based on what they know about their own local context. They can balance the need for action against the degree of risk, identifying local agents of change, and knowing who are the people to target within both formal and informal local systems. CAS theory maintains that predictions about the outcome of these interventions can be made with some accuracy based on an understanding of the patterns within the inter-related systems. In this case, for example, one can predict that issues brought forward by constituents to their MPs will receive attention because retaining political position depends on public votes. Likewise, the PCT chairperson will be influenced by what local service users are asking for. Ward's use of his position as editor of a national, multidisciplinary newsletter to reach a wide constituency is itself an example of applying a complex adaptive systems approach to change. The multidimensional nature of the membership precludes a linear approach to the problem of poor understanding of pain services. Rather than the British Pain Society issuing a directive to its members specifying who to contact (dependent on your profession and rank in the organization), what form the communication should take (dependent on whether you have access to e-mail or a day-time phone number), and when the action should occur (dependent on your shift rotation, sittings of the House of Parliament or annual leave), Ward has provided a simple goal – *'...we need to do some thing about our profile and make them understand'*. The action is left to the local level to strategize, who, where, how and when.

In summary, this section has discussed that complex adaptive systems need to be able to take action within a local context and have the flexibility to modify behavior based on feedback consequent to those actions. The Modernisation Agency of the NHS has provided a framework for this type of initiative and an example of CAS applied to change within the area of chronic pain services was presented.

12.5 Principles 5 and 9: Paradox and tension

'Needless to say, surprise and complexity are the norm and not the exception' Crabtree[504]

Principle 5 *–Expect and employ surprise as opposed to suppressing paradox and tension* and principle 9- *Mix cooperation with competition* are presented by many complexity theorists as key tools to effect change. Kernick states that when paradox and disagreement are suppressed people will become self-protective and not engage in the types of risk-taking and information sharing necessary for creative problem solving and recursive organizational learning to occur [464]. He goes on to propose that increased attention to the process and interaction of health services delivery can facilitate the organizational trust and learning needed to adapt to complex events. Other theorists stress the importance of making dissent and conflict overt [253, 483] and that this attitude to conflict does not come easily to many current health service provider and will interfere with their ability to take on new policies and behaviors [505]. For example, a study of interprofessional working across three practices in the same health authority concluded that an interprofessional culture was lacking currently and that 'it seems probable that it will take a new generation of health professionals to bring about an interprofessional culture in the NHS' [407].

The area of pain management itself presents some interesting paradoxes. Situations exist that can be used either to attempt reconciliation of service providers' beliefs and values or to facilitate the creative process that can emerge from a non-prejudiced sharing of ideas. For example, the British Pain Society has an interdisciplinary membership and has stated that pain management programmes need to be multi-disciplinary in nature. Depending on the level of trust and respect within these groups, ideas can either be exchanged or normed towards a 'party-line'. However, as service providers in the area of chronic pain are members of the larger healthcare community it is not surprising to find, in this study, that they share much of the communication problems, culture, and ethos of that predominantly reductionist system.

A second paradox is that despite numerous educational strategies used to implement the evidence base in pain management, authors have concluded that there is little evidence that clinical practice has actually been much enhanced [506]. Gordon and Dahl [506] speculate that this failure to see change proportionate to the effort exerted is because the wrong questions are being asked. They propose that it is not the technical aspects of pain management that require attention but rather the system itself. 'Quality pain management depends on a host of complex relationships and processes...little is known about the relationships among these processes and how they impact patient outcomes'. They propose that continuing to examine systems' problems with clinical tools is a kin to trying to break the sound barrier by tinkering with a model T Ford. The important role of issues that arise within the delivery system, as opposed to clinical pathology, have also been identified in the chronic pain literature as 'black and blue flags'[112]. The flag system (red-biomedical, yellow-psychological, blue- socio-economic and black- occupational) models the complex nature of chronic pain and can help service users and providers move away from a linear understanding of the chronic pain experience.

In summary, paradox and disagreement exist within chronic pain. Traditionally, efforts have mirrored the values of the wider healthcare systems and focused on reducing disagreement and suppressing the expression of open dissent. Dealing constructively with disagreement can generate positive and creative changes but these inter-relational skills are not typically part of the service provider's preparation. The 'warning flag' model can be employed to help facilitate a more open appreciation of the complexity of chronic pain.

12.6 Principle 7: The importance of ‘informal’ systems

名 通讯;传达

(Communication [22])

Movement, objects, speech, and words:
We communicate through gross symbols.
We call them " objective,"
But we cannot escape our point of view.[494]

Healthcare and chronic pain are complex systems. Complexity theorists stress that the human and organizational agents that inter-relate within these systems are complex adaptive systems in themselves. In other words, complex systems are embedded and have overlapping boundaries with other systems. Complexity scientists stress that this highly interactive nature must be properly understood and managed to effect positive change [36, 244]. Shaw proposes that one of the key opportunities for managing change exists in the informal, ‘shadow’ system. The ‘shadow’ system is created through unofficial communication networks (lunch break conversations, waiting in line for the photocopier) and expresses the felt beliefs of agents in the system as opposed to the authorized, official position that is communicated through more legitimized channels such as staff meetings and policy statements. The shadow system and the formal organization may actually hold divergent beliefs, sending conflicting and destructive messages. These messages in turn are subject to the idiosyncratic interpretation of individual agents within the contexts of their own social, political and psycho-dynamic processes [507]. To ignore the shadow system is potentially destructive to all change efforts. Traditionally healthcare has attempted to deal with the informal system through increased command and control efforts, taking a position of attempting to control behaviors and drown out dissenting voices with the volume of scientific evidence [419]. However, the shadow system can also be a creative force, allowing novel ideas to emerge from the dynamic interplay of multiple interpretations and perspectives made possible by the system’s inherent lack of formalized rules and structure. Zimmerman et al [244] state that the coexistence of both systems create

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[22] source of translation- http://www.tigernet.com/ Sept 2004)

diversity, tension and paradox, which in turn, generate ideal circumstances for change within complex adaptive system. To achieve positive adaptation, both systems' energy needs to be focused on listening to, and working with, as opposed to battling against, each other.

The NHS has taken a number of initiatives that have the potential to increase the communication between the informal and the formal systems, thus allowing creative and novel ideas to emerge from untraditional sources. The Consumers in NHS Research Support Unit[26], the recently announced Commission for Patient and Public Involvement in Health and the Patient and Public Involvement Forums [508], the Modernisation Agency's Improvement Leaders' Guide to Redesigning Roles [509]and Managing the Human Dimension of Change [498] are examples of efforts to widen communication and the range of perspectives within service planning. The NHS website (itself an innovation to promote wider access and communication) offers public and service providers information about a range of opportunities to become involved or express their opinions about the NHS [508].

The framework seems to exist to facilitate communication across the multitude of players within the healthcare system. However, the increasing attention the NHS is putting into the structure of these types of initiatives is potentially paradoxical in nature. More structured initiatives will result in formalized processes that will no longer represent the shadow system. Formalization and structure hinder the dynamic nature of informal systems and may result in decreased communication, the opposite effect to their stated goal. The NHS website is perhaps an example of the potential negative impact of perceiving a need to try and reduce complex events (like communication) to a linear process. The author logged onto the site (http://www.nhs.uk) to find out how one went about accessing the newly created Patient and Public Involvement Forums (PPIF). Clicking on Getting involved with how the NHS runs lead to a general information page about Patient and Public Involvement initiatives. Clicking on Patient and Public Involvement Forums (PPIF) lead to more general information about the purpose. Then clicking on Commission for Patient and Public Involvement (CPPIH) the reader was informed that the Commission has the power to appoint members, that membership is set in legislation and to follow the link to the CPPIH website (www.cppih.org/) for membership process information. At the CPPIH website the role and process of getting involved is explained (Box 12.iv) and application forms offered in a variety of formats.

Tracing the information required computer skills, approximately 20 minutes of time to read each page of information and follow the instructions for links and, ultimately, resulted in the reader needing to engage in a formal application process. Additionally, a sample of the text on the CPPIH website (Box 12:iv) tested as grade 12 on the Flesh-Kincaid scales (Microsoft Word software) which is above the recommended reading level of grade 6-8 for health related information for the general public.

Box 12.iv
PPI Forum member involvement

'PPI Forums members include individual patients and members of the public who are interested in influencing health and health care from the point of view of patients and potential patients.

There is no typical PPI Forum Member. Different PPI Forums will need to involve different types of people, based on the locality and the health issues that people experience.

A framework outlining the membership of PPI Forums is set in legislation, and the Commission will provide guidance on different types of involvement and how to carry out the work. PPI Forum members will have flexibility to work out their own priorities, based on their knowledge, skills and interests.

PPI Forums are provided with support from local voluntary organisations, known as Forum Support Organisations (FSO), and from the staff at the Regional Centres of the Commission. Forum members will also be provided with training and development to help them undertake their role.
(www.cppih.org)'

Overall, attempts by the NHS to provide structure and process for communication with all constituents may have been over-engineered and serve as a disincentive to participate as opposed to their stated goal of widening the dialogue. Greenhalgh's open letter in BMJ to the then Secretary of Health, Allan Dobson, echoes these concerns. As part of the process of marking the 50th anniversary of the

NHS, all service providers received a personal letter inviting them to offer their ideas for improving the NHS. Greenhalgh comments that, as the NHS is the third largest employer in the world, 'you must have licked a lot of stamps', and then reflects on how much civil servant time and effort it will take to keep the commitment of opening and providing a personalized reply to each response. She then discusses how many kilograms and meters of 'essential papers' she has received as a result of work for the health authority. Greenhalgh states that:

> ' *By that time I had formed the opinion that the machinery of the health authority was so single-mindedly geared to the production and reproduction of its own internal reports and memorandums (and reduplication of similar material from central office) that it was exceedingly difficult to focus its well meaning and hard working members on any task that did not involve the multiple handling of bullet pointed jargon'* [368].

These types of concern are often voiced from the shadow system (for example, the coffee break conversations) and can be very influential. Although some stakeholders accept the challenge of trying to communicate their concerns overtly (such as Greenhalgh and Willis [369, 428] there is quite possibly an equal or greater number of members of the covert shadow system whose inaccessible comments can have strong negative consequences.

In summary, many resources are now in place for expanding communication links and accessing the informal sources of information that exist within healthcare. Within the area of chronic pain there is evidence of the move towards providing a platform for service user voices. For example, the Annual Scientific Meeting of the British Pain Society has, for the last several years, included presentations from representatives of the Expert Patient programme and the supporting documentation for the IASP/WHO sponsored Global Day Against Pain on-line web conference [510] provided a range of service user perspectives about their chronic pain experiences. However, attention must be paid to prevent these mechanisms from becoming over-engineered to the point where the process becomes another formalized barrier to the free flow of information required for creative problem-solving.

12.7 Principle 8: Allow complex systems to emerge

Complexity theorists use the internet as an example of a successful complex adaptive system. The internet is an emergent system, evolved from many components that combine and interact in an iterative manner. What works is integrated into the system, what doesn't work is abandoned and the system moves on. The internet, like other complex systems, wasn't 'designed', it evolved as linkages were made between the smaller components. The smaller components in themselves (for example the telephone line and the video display screen) were designed for entirely separate purposes but, when combined in new ways, resulted in unanticipated results. The successful ('good enough') combination of components are retained in the system, the obsolete are abandoned (for example the 51/2 inch floppy disc). It is proposed that the most successful approach to building, and refining, complex systems requires the bottom-up application of a series of small 'chunks' (simple, independent systems) with careful attention to the patterns of interaction that emerge.

Looking at chronic pain as a complex adaptive system, a number of chunks are evident. The pharmaceutical industry, the National Health Service, the British Pain Society, local PCTs, the treatment team, the person with pain, the public transport system that takes people to and from appointments and the malfunctioning automatic coffee machine that leaves service users in the overcrowded waiting room without refreshment, are all 'chunks' in the system. Zimmerman et al [244] propose that adopting this perspective helps the system's stakeholders think in new and creative ways and move from an immobilizing (and futile) search for 'the problem and its solution' towards taking small actions that provide relatively rapid feedback and opportunity for re-evaluation and refinement. Freyer uses the imagery of the Trojan horse to illustrate the difference between a linear, large-scale, command and control approach to complex problems and Trojan mice, small, well-focused and easily maneuverable initiatives focused on building creative relationships between existing chunks [23]. Trojan mice reflect the complex adaptive system's principle that change is not incremental; small inputs can have unexpectedly large return.

Many of the initiatives previously discussed (for example the NHS Modernisation Agency, the multidisciplinary nature of the British Pain Society and the IASP, the 'legitimization' of complexity thinking in highly regarded journals like the BMJ, and peoples' ever-growing access to information available through the electronic media) can be used to facilitate an examination of the relationship between the chunks and to empower people to take action, regardless of how small. 'You cannot reflect on anything until you do something. So start small, but do start' [244:41].

12.8 Summary

The preceding review has highlighted that a number of opportunities exist that can be used to move the chronic pain system away from the attractor of chronicity and to allow creative and adaptive responses to emerge. As discussed in section 5.3, the need for new approaches to the emerging healthcare problems of the 21st century is strongly articulated by respected stakeholders like the Medical Research Council [262], the British Medical Journal [242, 264] and the World Health Organisation [265]. The opportunities afforded by this cannot be over-emphasized, as stakeholders' responses can either legitimize or undermine and block the acceptance of new ideas (as detailed in section 12.2). Capitalizing on this forward momentum for reframing healthcare within a complex adaptive system is critical for the following reasons:

- Health service delivery is no longer following a linear path with increased resource equating to increased outcomes;
- Social forces no longer support a hierarchical service provider/service user structure for decision-making and access to information;
- Many 21st century health issues are not responsive to a reductionist paradigm,

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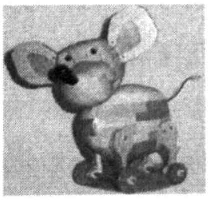
[23] 

'Much change is of the 'Trojan horse' variety. At the top of the organisation a decision is taken to introduce a strategic change programme and consultants or an internal team are commissioned to plan it down to the very last detail. The planned changes are then presented at a grand event (the Trojan Horse) amid much loud music, bright lights and dry ice. More often than not, however, a few weeks later the organisation will have settled back into its usual ways and rejected much of the change. This is usually because the change was too great to be properly understood and owned by the workforce.

Trojanmice, on the other hand, are small, well focused changes, which are introduced on an ongoing basis in an inconspicuous way. They are small enough to be understood and owned by all concerned but their effects can be far-reaching. Collectively a few trojanmice will change more than one Trojan horse ever could.

Peter Freyer http://www.mice.com (Sept 10,2004) resulting, as they do, from high interactivity between social-political, environmental and biological aspects.

In other words, the entrenched biomedical model can no longer exclusively deal with the challenges of health and well-being. As highlighted throughout preceding sections of the report, the complex adaptive systems model has much to offer in reframing healthcare and service delivery. Perhaps most importantly, it does not discount existing frameworks, pitting biomedicine against psycho-social or constructivist paradigms. Instead, as discussed in detail in sections 5.4 and 11.1, CAS theory offers a meta-framework [268] that acts to integrate and unify, recognizing that complex systems require a range of epistemologies dependent on the contextual and temporal nature of the many questions they raise. This is a key feature in a healthcare system that has been characterized as quasi-militaristic [470], where fear of giving up control and prestige can serve as a significant barrier to change and innovative practice (Section 11.3.2). A CAS framework clearly has advantages that mitigate for its acceptance by the healthcare establishment. The NHS has attempted, through the Modernisation Agency and related initiatives, to foster this acceptance since without it any other conceptual reframing of service delivery would be an impossible task.

However, non-threatening and inclusive perspectives are in themselves of insufficient value to justify the radical paradigm shift that CAS theory holds for healthcare. '*Why is a shift of paradigm needed?*' has been a recurrent theme across this thesis and each sequence of the study has highlighted that the current way of thinking about chronic pain is less than adequate to address its elusive and multifaceted nature. The first survey showed that people, both within and between service user/service provider groups, are idiosyncratic; and the assumption of uniformity present in linear systems is, in the case of chronic pain, flawed. Subsequent Delphi rounds repeatedly highlighted idiosyncratic beliefs and the potential for significant problems generated by attempting to deal in a traditional biomedical manner with these differences. Much exists in the research literature about why communication problems occur and their significant consequences, and yet recommendations for dealing with them remain set within a traditional framework of providing more information in order to persuade the service user as to the 'correctness' of the service provider's message. As discussed in more detail across the chapters of this thesis (section 5.5, 11.4.3, 12.10.2) complexity theory reframes dissent as a tool that can be harnessed to allow creative and innovative behaviors to emerge. At first look this seems radically different from how disagreement is traditionally dealt with in the healthcare system and yet, paradoxically, using the energy generated by dissent to improve communication and exchange of ideas seems tacitly logical within the postmodern context of 21st century western society.

In summary, a paradigm shift is essential because the existing perspective no longer works for many dominant issues. A CAS paradigm, while presenting a radical challenge to the prevalent biomedical model, also affords a non-threatening approach through conceptualization of a meta-framework, grounded in the assumption that a range of theoretical models are required. The NHS, because of the legitimization offered by key stakeholders, is uniquely poised to affect this shift in perspective. The critical skill in maintaining forward momentum will be in preserving the energy stimulated by these new ideas and preventing the well-laid groundwork of bodies such as the Modernisation Agency from dwindling into rhetoric. The competing agendas of the diverse agents within branches of the NHS are highlighted in this thesis; central control versus local flexibility (sections 5.4.5, 10.8.4, 11.3.3, 12.3), time-frames dictated by political expediency (5.2, 5.5, 9.8.1, 12.10.3) and a culture focused on preventing harm at the same time as innovating for change (10.8.3) are all significant areas to be addressed. Trojan Mice (section 12.7) become critical to the equation – small changes, made frequently, over time will effect more lasting benefit then efforts to exert a strong push on a deeply embedded and bulky mass like the NHS. The NHS is uniquely poised to assume a strong leadership role for other national healthcare systems as they too grapple with the changing healthcare demands of the 21st century. How the NHS deals with these challenges will in itself serve as an illustration to other service providers in their examination of patterns and metaphors that can be applied to developing a deeper understanding of locally emergent issues.

The three key issues that emerged from this research, (incongruence of pain treatment beliefs, the perceived need for more information and the paradoxes inherent in service delivery within a transitional system like the NHS and within post-modern western society), can be addressed with the tools currently available. However, the challenges to broadening the vision of health service delivery, so that both linear and complex approaches can be employed as the situation indicates, are very high. The political agenda that pervades healthcare planning creates unrealistic expectations of the pace at which change can occur [235], the traditionally hierarchical organization of service delivery is resistant to perceived challenges to power and control, and pragmatically, the cognitive dissonance, consequent to equally important but contradictory demands, experienced by many healthcare workers are several examples of potentially overwhelming barriers. Also, the tools for understanding the patterns of systems and how to change them are found not only in Cochrane reviews and the labyrinth-like government web-pages but, with reassuring accessibility, in the stories about Miss Marple, movies about humanity, teachings of eastern religions and the migration of flocks of geese. Because nature is a complex adaptive system in itself, the opportunities to understand patterns and interrelationships are commonplace. Kernick suggests that a starting point is to change the metaphor we apply to health services. Instead of the modernist view of a machine that can be engineered, we should view the NHS as an ecosystem. 'Each agent cannot be understood in isolation. All parts adapt by learning to survive in a topography that is provided by coexisting and changing parts. Ecosystems cannot be engineered, ...However, they can be nurtured' [464]. The final section of this chapter will present recommendations for how this 'nurturing' of change can be facilitated in particular reference to the area of chronic pain.

12.9 Research questions revisited

The original aims of the study were to address the following four questions:

1. What do people with pain believe are important treatment components? Why?
2. What do service providers believe are important treatment components? Why?

3. How much agreement is there between Service Providers and Service Users?
4. Do service users and providers think it matters if there is disagreement and, if so, what should be done?

Many aspects of these questions were addressed through quantitative data collection techniques consistent with traditional scientific research methodologies. On a basic level the questions outlined at the start of this study (Section 1.2) have been answered. What treatments participants think are important were identified. Areas of agreement and, more commonly, intra and inter-group disagreement were highlighted. The study also revealed that most participants felt it that it mattered whether service users and providers agreed and a number of recommendations were generated. This information was invaluable in pointing out the issues that needed following-up with more theoretical questions intended to examine 'why' and 'how'. Pursuing 'why' and 'how' proved to be a very dynamic process and the Delphi method, because of its iterative nature with on-going opportunities for two-way feedback, was well suited to this exploration. In looking at 'why' and 'how' new questions arose requiring the researcher to make decisions about what direction to follow next. The strength of following a CAS theoretical perspective is that the opportunity exists to refine and revisit methodologies, thus making choices based on the presenting context as opposed to dogmatically following a predetermined path. The principles of rigorous research are fundamentally consistent from one methodology to another and following these principles provided the boundaries within which the researcher was able to change her own behaviour and beliefs, contingent on new information and feedback coming into the study.

12.10 Recommendations

This study concluded that service users and providers were idiosyncratic in their beliefs about chronic pain treatments, that they perceived a need for more information (although not necessarily of the same type), and that they held what appeared to be paradoxical beliefs in some instances. The role played by these three broad categories as facilitators for the attractor of 'chronicity' was then presented. The following recommendations will identify strategies for affecting change, in relation to these three conclusions, based within complex adaptive systems theory.

12.10.1 Identify existing patterns

> *'...all clinicians, whatever their degree of subspecialisation, have to manage an irreducible uncertainty. It is not the consequence of ignorance of fact or failure of logic. It is rather the inevitable consequence of all those givens addressed by 'complexity' – the multiplicity, the multi-level, diverse, interconnectedness and dynamism, of events'*
>
> Marinker [511]

To manage uncertainty we need to seek patterns and learn lessons from what is already known about how complex agents interact within embedded systems. There is a growing body of healthcare literature that people concerned with chronic pain can turn to for examples of how CAS principles have been successfully applied. Patterns and examples of good practice in creative strategies for intervention are not condition specific and can be drawn from across a range of other chronic illness. For example, lessons from research with people who have irritable bowel syndrome have been highlighted throughout this thesis as useful (e.g. the consequences of prolonged search for diagnosis and the conflicting beliefs of service providers and users) for understanding the experience of people with chronic pain (sections 4.5.2-.4). Recent publications contain examples from clinical areas as diverse as community regeneration, public health, acute-care hospital bed control [512], diabetes, cardiac care and mental health service delivery [513]. Exploring these examples will help chronic pain service providers identify patterns within their own area of expertise. Likewise, the lessons from this research can be applied in developing a deeper understanding of issues across a range of chronic healthcare conditions sharing similar features with chronic pain.

Primary research offers another route for identifying patterns that serve to maintain chronicity as an attractor in the pain experience. Research that utilizes the spectrum of methods needs to be supported and legitimized. As evidenced by the range of scientific approaches presented at the British Pain Society Annual Scientific Conferences and the content of the IASP publication Pain) this shift has already begun. But attention is still needed to withstand the counter-forces that tie research funding and professional credentials to more linear types of inquiry. The pharmaceutical industry is a major source of funding into pain research and allocates funding based on a commercial agenda. In academia, research expertise is recognized through audit driven initiatives such as the Research Assessment Evaluation (RAE). The RAE is funded by the government's Higher Education Funding Council for England (HEFCE) and uses a researcher's publication in high rated scientific journals as an indicator of quality. Journals with the high citation ratings desired by the HEFCE predominately reflect a positivist research agenda. This systemic valuation of positivist research over other approaches makes it difficult for questions of a more complex nature to be addressed.

Identifying existing patterns allows the simple rules, currently operating to maintain chronicity, to become overt. An example from this study is that a pattern seems to exist regarding peoples' inherently idiosyncratic nature. Participants held different beliefs about many of the questions posed in all 3 Delphi rounds- *what are important treatments, who should take action about disagreement, what influences decision-making,* and so on. The research concerning differences of opinion between and within groups of service users and providers also demonstrates a pattern in that efforts to shift peoples' beliefs towards that held by the most powerful in the hierarchy are often disproportionately low in relation to the effort exerted (Section 11.3.1). Research also shows that people in a range of health care situations are selective in what they disclose and often do not deal with conflicting opinions in an overt way [208, 396, 435]. A linear perspective applied to these three examples would pose the question, '*How can we get people to agree more?*' Using complex adaptive systems theory however, the question is posed as '*how do we make it possible for people to express their beliefs so we can communicate and collaboratively develop a way forward*?' The simple rule that emerges when linear problem solving is applied to complex issues is that: *there is a 'right' way that everyone must follow*. In the CAS perspective the rule is: *open communication facilitates problem-solving*. An illustration of this point would be a chronic pain programme, operating with rules consequent to linear problem-solving efforts, where service users are informed that attendance is mandatory for all sessions, regardless of the service user's belief in the value of each individual component. Research has shown that operant behavioral approaches may be effective in the short term but that the behavior is extinguished once outside of the treatment environment and its reinforcement system (Sections 3.3.1-2). For example, if a person does not value relaxation therapy, forced participation is more likely to have negative consequences (hostility, frustration, disruptive behavior) and to provide fuel for counter-productive positioning in the 'shadow system'. The simple rule *(everyone must agree)* generated by applying linear thinking to complex problems serves to reinforce chronicity.

12.10.2 Encourage the expression of dissent

To understand the true patterns and simple rules at play in a system people must freely express their beliefs. Much has been written about the need for more collaborative communication within health services delivery and, as discussed in previous chapters, a number of initiatives exist to teach people the skills required. Dissent and expression of alternative views to the status quo generate energy that can either be used destructively or to facilitate creative change. This is a difficult culture to change and requires skilled leaders [36, 37, 235, 238]. It has been proposed that the biggest barrier to achieving new ways of relating in the current healthcare system are the incumbent leaders who achieved their current positions of power and status through success within a system based on command and control based hierarchy [264]. That being the case, initiatives like the NHS Modernisation Agency's Improvement Leaders' Guidebook series [498] are an important tool because they offer both practical information and, perhaps most importantly, they legitimize the current efforts to increase information flow and flatten decision-making structures. Similarly strategies developed by the Expert Patient Programme and Involve [160, 321], can be employed to facilitate open exchange of ideas and opinions, by involving service users in the actual design and evaluation aspects of programming.

12.10.3 Create new simple rules

New rules to move chronic pain away from chronicity need to be developed. Identifying existing patterns and encouraging new forms of communication and information flow are important parts of that process. Equally, the process of creating new simple rules is key. The NHS Modernisation Agency has set out five simple rules for health services that can guide service delivery in the area of chronic pain.

Modernisation Agency 5 Simple Rules:

1. See things through the patient's eyes.
2. Find a better way of doing things.
3. Look at the whole picture.
4. Give frontline staff the time and tools to tackle the problems.
5. Take small steps as well as big leaps[266].

However, these simple rules also need a mechanism by which to make them meaningful at a local level and within the context of chronic pain. Without additional tools they easily become rhetorical, lacking enough specificity to fulfill their purpose of setting direction, prohibitions and providing permission [37]. Plsek proposes that there are key questions to ask when designing simple rules and that taking a questioning approach will facilitate the adoption of 'good-enough' strategies and the openness required to evaluate, modify and nurture the system's evolution.

There are a number of mechanisms in place for service users and providers to ask and discuss questions specific to chronic pain within a complexity framework. The Pain Society Annual Scientific Meeting provides an excellent venue for multidisciplinary sharing of ideas and the opportunity to identify patterns of practice common to all programmes and participate in facilitated application of complex adaptive systems principles to emerging issues. Management schools within UK universities that teach complexity theory could be approached to offer facilitation resources of this nature. This would have the added benefits of widening awareness of issues across disciplines and reducing the burden for expert input that is currently carried by the Modernisation Agency. Involving other disciplines holds the potential to stimulate new ways of thinking and would also validate the types of principles the Modernisation Agency is attempting to disseminate. Local chronic pain programmes that incorporate user feedback sessions (similar to the Patient and Public Involvement Forums of the Department of Health) are another potential source of ideas exchange but again, would perhaps require facilitation from outside the sponsoring agency to create a 'safe' environment for honest exchange of ideas.

It is beyond the scope of this research to suggest what the simple rules should be for people with pain. However, questions that can guide that process should include attention to all three of the features identified by Plsek (direction, prohibition and permission).

For example:

- What are the rules currently preventing people from accepting 'increased function' as a goal?
- What are the rules keeping people focused on searching for a 'cure'?
- What can be done to make it possible for people to express their opinions openly?
- What are the linear components of the system that need to be managed in a traditional way (for example, determining the dosage of analgesics) and what are the more complex components that would benefit from less control and more flexibility to respond (for example, which components of a chronic pain management program can the service user opt to participate in)?
- What do service users and providers stand to lose by taking on new ways of communicating and interacting (for example, time, status, self-protection, control)?
- How can service users and providers avoid a 'culture of blame' and promote willingness to try new ideas and abandon out-dated ideas?
- What are some achievable, 'good enough' steps to start the change happening?

This list is by no means inclusive and, given the iterative nature of working in complex systems, it will likely change with each reading. Its usefulness lies in being a prompt to think about chronic pain in a different perspective and hopefully to facilitate the action/feedback/action loop required for dealing with complex, ever-changing systems.

12.11 Summary

The research project presented in this thesis has followed an evolving course, originally grounded in a predominately reductionist paradigm, through to a reframing of chronic pain as a complex adaptive system unable to move forward because of the strength of 'chronicity' as a system attractor. Three key findings from the research were explored in relation to their role in maintaining the attractor of chronicity and opportunities and challenges to system change were identified. The NHS Modernisation Agency and the rapidly growing dissemination of complexity science theory in the healthcare literature emerged repeatedly as strengths and opportunities within the current service delivery system. The dominant challenge appears to be one of moving these types of resources from rhetoric into practice and examples of questions to facilitate the process of developing new simple rules, focusing on function as opposed to chronicity, were presented.

This research project and the writing have raised many questions, stimulated great debates and allowed the writer to understand that a range of paradigms can fit complementarily into the heath care service delivery tool-box. Every problem is not a nail and the choice of hammer or spanner needs to be made selectively. A friend quoted a Nike athletic shoe commercial ('Just Do It') to get the author's research process started and so it seems appropriate to use information forwarded from the same friend to close. The e-mail explained how some Japanese programmers felt that the typical error messages programmed into Microsoft Word were too harsh and so had designed alternatives in the form of haiku poetry. The one that seems to sum up this research process goes as follows:

Chaos reigns within.
Reflect, repent, and reboot.
Order shall return.

Tables

Table 1 Postal survey: Service user demographics (%)

Variable	**Frequency (Central Tendency)**	**Range**	
Total respondents = 59 Spoiled surveys = 4 Final respondent group = 55			
Gender	30 (54.5%) female 25 (45.5) male		
Age (mean years)	57 (male) 51(female) 53.6 (Overall)	27-80 years	
Current pain intensity (VAS anchored with 0= no pain, 10=worst ever)	Median = 7 Mean= 5.8	1-9	
Who should choose treatment (VAS anchored with 0=Doctor is best, 10= my choice is best)	Median = 5 Mean=4.9	0-9	
Duration of Pain	10.7 years	1-30 years	
Frequency of treatment components endorsed as 'Important' (total possible =62)	Mean =24.75 Median =34.3	0-62 treatments	
Duration of Support Group Membership	2.2 years	0-10 years	
Occupation:			
i. Employed outside the home	3 (5.5%)		
ii. Homemaker	2 (3.6)		
iii. Retired	7 (12.7)		
iv. Retired because of pain	21 (38.2)		
v. Unemployed because of pain	12 (21.8)		
vi. Other	2 (3.6)		
vii. No response	8 (14.5)		
Learned about the support group through:			
i. Health care worker	37(67.3%)		
ii. Media	3 (5.9)		
iii. Personal friend/family	11 (20)		
Mean BPCQ Scores –(Skevington 1990)*	**Mean**	**Range**	**Weighted Mean**
IS (Internal Control)	11.37	5-23 (SD 4.95)	3.75
PD (Powerful Doctors)	10.80	4-24 (SD 4.25)	4.53
CH (Chance Happening)	13.83	4-23 (SD 4.42)	5.73

*low scores indicate lower endorsement of this belief

Table 2 Postal survey: Service users' treatment component endorsement pattern

	Important	*Not Important*
100% agreement		
80-99% agreement		Capsaicin ointment (96.3) Post discharge support group (96.3) Biofeedback (96.3) Anticonvulsants (94.4) Pilates (94.4) Social worker (90.7) Creative therapies (88.9) Internet chatrooms (87.0) Corticosteroids (85.2) Homeopathy (81.5)
50-79% agreement	Education about pain (68.5) Posture/body mechanics (64.8) Medication review (63.0) Physiotherapist (61.1) Relaxation (60.4) Graded return to ADL (59.3) Support group (59.3) Humour (57.4) Modality specific clinic (57.4) Pacing (57.4) Stretching (55.6) Self-management training (55.6) Hydrotherapy (53.7) Education about anatomy (53.7) Lifestyle counselling (53.7) Psychological assessment (50.0) Massage (50.0) Access to research (50.0) Print materials (50.0)	Spirituality (79.6) Inpatient programme (77.8) Chiropractor (77.8) Family advice (77.8) Vocational advice (77.8) Yoga (77.8) Pharmacist (75.9) Meditation (74.1) Nurse (72.2) Ergonomics (72.2) Antidepressants (70.4) Aromatherapy (70.4) Recreation therapist (68.5) Financial advice (68.5) Anger management (68.5) Dietician (66.7) Equipment (66.7) Nutritional advice (66.7) Communication skills (66.7) Acupuncture (64.8) Sources of information (64.8) Assertiveness training (63.0) Thermal modalities (61.1) TENS (59.3) Occupational therapist (57.4) Outpatient programme (57.4) Multidisciplinary (57.4) Psychologist (53.7) Tai Chi (53.7) Physician (51.9) Condition specific clinic (51.9) Topical issues discussion (51.9)
Treatment component agreement:	Mean – 24.75, Median – 21, Range 0-62 (0-100%)	
Treatment components where 20% or greater participants offered no response	Reconditioning (66.7%- no response)	

Table 3 Postal survey: Treatment components identified as 'Tried' by service users

Total SUs 'Tried'	% (N=54)	Treatment component
47	87.0	Tai Chi
46	85.2	Physician TENS Physiotherapist
44	81.5	Outpatient Stretching Education about pain
42	77.7	Relaxation Posture/body mechanics Print materials
39	72.2	Thermal modalities Support group
37	68.5	Pacing
36	66.7	Antidepressants Lifestyle counselling Graded return to ADL Self-management
34	62.9	Massage
32	59.2	Psychologist Acupuncture
31	57.4	Hydrotherapy Education about anatomy
30	55.5	Psychological assessment Humour
29	53.7	Creative therapies
27	50.0	Occupational therapist
26	48.1	Topical issues discussion
25	46.3	Medication review
24	44.4	Assertiveness training Access to research Multidisciplinary programme
20	37.0	Condition specific clinic
18	33.3	Nurse Recreation therapist Yoga
16	23.4	Meditation
15	27.7	Anger management Modality specific clinic Corticosteroids Chiropractor
14	25.9	Homeopathy Chemist Inpatient
13	24.0	Equipment Information sources
12	22.2	Dietician Communication training
10	18.5	Pilates Vocational advice
9	16.6	Spiritual support
8	14.8	Ergonomics
7	12.9	Hydrotherapy
6	9.3	Anticonvulsants Family advice
3	5.5	Social work Capsaicin ointment
2	3.7	Biofeedback
total 1602		

Table 4 Postal survey: Service provider demographics

Total distributed	Disposition	Final sample size	Composition		Treatments selected as 'important' (mean)
1426	A. Returned 447 (31.3%)	386 service providers	Anaesthetist	122(31.6)	43.3
			Nurse	103 (26.7)	50.2
	B. Spoiled, retired, refused & returned 61 (4.2%)		OT	52 (14.1)	43.8
			PT	35 (9.0)	43.8
			GP	32 (8.3)	39.0
			Psychologist	24 (6.2)	45.9
			Pharmacist	3 (<1%)	24.5
			'Other'	15 (3.9)	34.0
					Across group mean = **44.33**
			Total	100%	

	Age -Mean of years	Female (%)	Male (%)	Undergraduate Training-mean hours (median)	% CPD over 30 hours	Years of Experience in profession	Type of pain worked with (%)	
							Specific	Multiple
Anaesthetist	45.4	32 (26.4)	89 (73.6)	16.8 (2)	84	19.15		73
Nurse	41.5	96 (95)	5 (5)	4.18 (1)	74.8	17.15		52.4
Occupational Therapist	41.1	48 (92.3)	4 (7.7)	2.60 (0)	69.2	14.3		69.2
Physical Therapist	44.1	23 (71.9)	9 (28.1)	3.14 (0)	91.4	19.51	65.7	
General Practitioner	49	10 (35.7)	18 (64.3)	6.28 (0)	75	22.77		59.4
Psychologist	43.7	13 (61.9)	8 (38.1)	6.16 (3)	75	17.95		58.3
Pharmacist	47.3	2 (66.7)	1 (33.3)	0 (0)	66.7	20	66.7	
Other	48.5	8 (37.1)	6 (42.9)	7.11 (0)	missing	16	66.7	
Unreported	5 cases	14						
SAMPLE TOTAL	Mean = 43.8	232 (62.3)	140 (37.6)	Mean =8.34 Trimmed mean=**3.47**	Mean % with CPD over 30 hours = 77.5%	Mean years of experience = 18.20		

- surveys needed to have either complete BPCQ scores and completed information for 'important/not important', or both to be included.
- Most common reasons for returned, incomplete surveys: 'moved', 'retired', 'not working in chronic pain'. 4 returned, non-completed stated the survey was 'too long'.

Table 5 Postal survey: BPCQ weighted scores for service users and providers

	Occupational Therapist	Physiotherapist	General Practitioner	Psychologist	Anaesthetist	Nurse	Total Service Providers	Service Users
IS	5.64	5.94	5.01	5.17	6.03	5.01	5.52	3.75
PD	3.08	2.73	3.25	2.73	3.45	3.30	3.21	4.53
CH	4.07	4.80	4.80	4.51	4.99	4.24	4.48	5.73

Table 6a Postal survey: Endorsement profile by professional group

	Occupational Therapist (OT)	Physiotherapist (PT)	General Practitioner	Psychologist	Anaesthetist	Nurse
100% agreement within group AGREEMENT > > > > > > > > >	Psychologist OT PT Multidisciplinary Posture/body mechanics Relaxation Education about pain Education about anatomy Medication review Psychological assessment	Psychologist PT Outpatient Multidisciplinary Reconditioning Relaxation Education about pain Medication review Psychological assessment Graded return to ADL Family advice Vocational advice Self-management Print material	Psychologist Outpatient Multidisciplinary	Physician Psychologist Nurse PT Outpatient Multidisciplinary Reconditioning Posture/body mechanics Education about pain Medication review Psychological assessment Graded return to ADL Family advice Ergonomics Pacing Stretching Print materials		Nurse Multidisciplinary Relaxation Psychological assessment

Table 6a (Con't)		OT	PT	GP	Psychologist	Anaesthetist	Nurse
80-99% agreement that treatment component is *'important'*	**AGREEMENT > > > > > > >**	Pacing (98.1) Graded return to ADL (98.0) Stretching (96.2) Vocational advice (96.1) Self-management (96.1) Reconditioning (95.7) Print materials (94.1) Communications training (94.0) Ergonomics (94) Outpatient (93.6) Family advice (90.4) Assertiveness training (90.0) Lifestyle counselling (89.8) Humour (89.8) Support group (88.5) Physician (88.2) Nurse (84.3) topical issues discussion (84.0) Post-discharge support group (82.7) Information sources (82.0) Access to research (82.0)	Pacing (96.9) Physician (96.8) Ergonomics (96.8) Posture/body mechanics (96.7) Stretching (93.5) Nurse (93.3) OT (93.3) TENS (89.7) Lifestyle advice (86.7) Communication skills (86.2) Information sources (84.4) Anger management (80.6)	PT (96.3) Physician (96.2) Nurse (92.3)	OT (95.0) Antidepressants (95.0) Relaxation (95.0) TENS (90.0) communication training (90.0) Self-management (90.0) topical issues (90.0) Assertiveness training (85.0) Inpatient (80.0) Access to research (80.0)	Psychologist (99.1) Psychological assessment (99.1) PT (98.2) Medication review (98.2) Graded return to ADL (98.2) Antidepressants (98.2) Outpatient (98.1) Nurse (97.4) Multidisciplinary (97.2) Anticonvulsants (96.4) Relaxation (96.3) Print materials (95.5) Education about pain (95.4) Physician (94.7) Pacing (94.3) Reconditioning (93.4) Posture/body mechanics (93.4) TENS (91.8) Family advice (91.4) Inpatient (91.2) Capsaicin (89.9) Vocational advice (89.7) OT (87.3) Self-management (84.0) Acupuncture (83.5) Support group (83.2) Post-treatment support groups (81.4) Corticosteroids (81.3)	Psychologist (99.0) PT (99.0) Medication review (99.0) Outpatient (98.9) Graded return to ADL (97.9) Acupuncture (79.8) Antidepressants (96.9) TENS (96.9) Physician (96.9) Education about pain (96.7) Print materials (95.8) Family advice (94.7) Anticonvulsants (94.9) Posture/body mechanics (94.6) Support group (94.6) Pacing (93.7) Capsaicin (92.6) Self-management (90.6) Reconditioning (90.0) Equipment (89.4) Education about anatomy (89.2) OT (88.5) Lifestyle advice (88.3) Post-discharge support groups (88.0) Vocational advice (87.2) Inpatient (86.4) Hydrotherapy (86.0) Access to research (85.9) Corticosteroids (85.7) Spirituality (85.6) Information sources (85.3) Thermal modalities (85.2) Financial advice (82.4) Massage (82.3)

Table 6a (Con't)		OT	PT	GP	Psychologist	Anaesthetist	Nurse
51-79% agreement that treatment is '*important*'	AGREEMENT>>>>>>>	Financial counselling (76.5) Anger management (77.1) Nutritional counselling (67.3) Equipment (66.0) Spirituality (60.0) Hydrotherapy (56.0) Meditation (55.6) Internet chatrooms (53.3)	Assertiveness training (73.3) Acupuncture (73.3) Equipment (71.9) support group (69.0) Nutritional counselling (61.3) Biofeedback (54.8)	Inpatient (76.9)	Nutritional counselling (66.7) Hydrotherapy (65.0) Pharmacist (57.1) Biofeedback (57.1) Social worker (55.0) Dietician (55.0)	Lifestyle advice (78.8) Information sources (77.1) Equipment (76.7) Stretching (75.2) Anger management (70.9) Biofeedback (70.7) Financial advice (69.3) Hydrotherapy (68.3) Access to research (66.0) Ergonomics (63.6) Spirituality (57.1) Pharmacist (55.6) Social worker (53.3) Thermal modalities (53.1)	Pharmacist (79.8) Stretching (79.3) Ergonomics (78.5) Topical issues (78.4) Anger management (78.0) Communication skills (77.7) Aromatherapy (76.7) Humour (73.3) Nutritional counselling (71.1) Condition specific clinic (69.4) Biofeedback (67.0) Assertiveness training (61.5) Yoga (59.1) Social Worker (57.3) Chiropractor (54.8) Internet chatrooms (54.4) Dietician (52.9) Creative therapies (51.2)

Table 6a (Con't)		OT	PT	GP	Psychologist	Anaesthetist	Nurse
50-79% agreement that treatment is *'not important'*	AGREEMENT >>> >>>	Yoga (50.0) TENS (50.0) Antidepressants (50.0) Acupuncture (53.1) Biofeedback (55.3) Creative therapies (56.0) Corticosteroids (57.1) Thermal modalities (57.1) Tai Chi (58.3) Pilates (63.0) Aromatherapy (66.7) Massage (69.4) Homeopathy (77.6)	Pharmacist (54.8) Social Worker (55.2) Dietician (63.3) Thermal modalities (69.0) Homeopathy (73.3) Massage (75.9)		Massage (65.0) Aromatherapy (65.0) Chiropractor (70.0)	Humour (50.0) Yoga (51.0) Tai Chi (52.0) Assertiveness training (52.0) Nutritional counselling (52.4) Massage (54.9) Condition specific clinic (55.0) Communication training (56.3) Chiropractor (56.4) Recreation therapist (67.3) Aromatherapy (67.6) Chatrooms (73.5) Dietician (76.7) Homeopathy (79.2)	Homeoparthy (54.2) Tai Chi (51.2) Pilates (54.2) Recreation therapist (51.7)

80-100% agreement that treatment is '*not important*'	**AGREEMENT >>> >**	Chiropractors (81.6) Recreation therapist (87.2)	Chiropractor (89.7)

Contents: When a treatment component was responded to by 80% or more of the participants the 'Valid %' (from the SPSS frequency tables) was entered. When 20% or mare of the participants offered no response, the treatment component was not displayed in Table 6a. These treatments components are displayed in Table 6b.

Highlight indicates: Treatment components where more than 80% of members of all the service provider groups agree.

Table 6b Postal survey: Treatment components with 20%+ non-response (% non-response)

OT	PT	GP	Psychologist	Anaesthetist	Nurse
Condition specific clinic (21.2) Modality specific clinic (32.7) Antoconvulsants (25.0) Capsaicin (36.5)	Recreation therapist (22.9) Inpatient (31.4) Condition specific clinic (25.7) Modality specific clinic (20.0) Education about anatomy (20.0) Corticosteroids (20.0) Antidepressants (22.9) Anticonvulsants (25.7) Capsaicin (34.3) Financial advice (20.0) Creative therapies (20.0) Yoga (22.9) Tai Chi (22.9) Hydrotherapy (20.0) Humour (22.9) Pilates (20.0) Aroma therapy (20.0) Access to research (20.0) Meditation (20.0) Topical issues (20.0) Post-discharge support group (20.0) Internet chatroom (20.0) Spirituality (20.0)	OT (25.0) Social work (28.1) Pharmacist (21.9) Dietician (34.4) Recreation therapist (43.8) Condition specific clinic (31.3) Modality specific clinic (37.5) Reconditioning (28.1) Posture (28.1) Relaxation (34.4) Education about pain (28.1) Education about anatomy (28.1) Medication review (21.9) Psychological assessment (21.9) Graded return to ADL (21.9) Family advice (28.1) TENS (21.9) Corticosteroids (37.5) Antidepressants (25.0) Anticonvulsants (25.0) Capsaicin (25.0) Vocational advice (28.1) Financial advice (31.3) Assertiveness training (31.3) Massage (21.9) Communication (34.4) Lifestyle advice (31.3) Support group (28.1) Information sources (31.3) Creative therapies (43.8) Anger management (31.3) Nutritional counselling (34.4) Ergonomics (43.8) Pacing (28.1) Stretching (31.3) Yoga (37.5) Tai Chi (43.8) Thermal modalities (37.5) Hydrotherapy (34.4) Humour (43.8) Acupuncture	Reconditioning (20.8) Condition specific clinic (29.2) Modality specific clinic (25.0) Education about anatomy (25.0) Corticosteroids (33.3) Anticonvulsants (25.0) Capsaicin (33.3) Vocational advice (25.0) Financial advice (25.0) Lifestyle advice (20.8) support groups (20.8) Information sources (25.0) Creative therapies (25.0) Anger management (20.8) Yoga (20.8) Tai Chi (29.2) Thermal modalities (29.2) Humour (29.2) Acupuncture (20.8) Pilates (25.0) Homeopathy (20.8) Equipment (20.8) Meditation (29.2) Post-discharge support groups (20.8) Internet chatrooms (29.2) Spirituality (33.3)	Modality specific clinic (22.1) Education about anatomy (21.3) Creative therapies (20.5) Pilates (26.2) Meditation (28.7) Topical issues (20.5)	Modality specific clinics (23.3) Meditation (32.0)

		(21.9) Biofeedback (40.6) Chiropractor (40.6) Pilates (46.9) Homeopathy (43.8) Aromatherapy (40.6) Equipment (34.4) Access to research (31.3) Print materials (21.9) Meditation (50.0) Topical issues (31.3) Post-discharge support group (37.5) Internet chatroom (34.4) Spirituality (40.6)			

OT	**PT**	**GP**	**Psychologist**	**Anaesthetist**	**Nurse**
Range of % non-response for all 62 treatment components					
21.2-36.5%	20.0-34.3%	21.9-50.0%	20.8-33.3%	20.5-28.7	
Number of treatment components where 20% + did not respond					
4	23	54	27	6	2

Table 7 Postal survey: Service provider treatment component endorsement

Treatment Component	Over-endorse	Under-endorse	Pearson chi-square Asymp. Sig. (2-sided)
▪ Pharmacist	Nurses		.001
▪ Dietician	Nurses	Anaesthetists	<.001
▪ Recreation Therapist		OT	.001
▪ Condition Specific Clinic	Nurses	OT, Anaesthetists	.005
▪ Modality Specific Clinic	Nurses	OT	.001
▪ Assertiveness Training	OT	Anaesthetists	<.001
▪ Massage	Nurses	OT, PT, Psychologists, Anaesthetists	<.001
▪ Communication Training	OT	Anaesthetists	<.001
▪ Thermal Modalities	Nurses	OT, PT, Psychologists	<.001
▪ Hydrotherapy	Nurses	OT	<.001
▪ Humour as therapy	OT	Anaesthetists	.012
▪ Biofeedback		OT	.002
▪ Chiropractic Therapy	Nurses, Anaesthetist	OT, PT	<.001
▪ Homeopathy	Nurses	Anaesthetists	.010
▪ Aromatherapy	Nurses	OT, PT, Anaesthetists	<.001
▪ Spirituality	Nurses	Anaesthetists	.003

Table 8 Postal survey: Comparison of service user and provider endorsements

	Service Provider= 386		Service User=55	
15 most frequent selected treatments	Physician	94.9	Education about pain	67.2
	Psychologist	93.2	Posture/body mechanics	65.4
	Psychological assessment	92.6	Physiotherapy	58.1
	Medication review	92.6	Pacing	58.1
	Physical Therapist	92.3	Graded return to ADL	58.1
	Graded return to ADL	89.9	Support group referral	56.3
	Multidisciplinary Team	89.3	Humour as therapy	56.3
	Education about pain	88.8	Modality specific clinic	54.5
	Relaxation	88.4	Print materials	54.5
	Print materials	88.4	Relaxation training	54.5
	Outpatient programme	86.6	Stretching exercise	54.5
	Posture/body mechanics	84.8	Lifestyle advice	52.7
	Family counselling	84.2	Access to research	52.7
	Reconditioning	82.1	Education about anatomy	50.9
	Vocational advice	81.8	Hydrotherapy	50.9
10 least frequently selected	Social Worker	44	Homeopathy	16.3
	Condition Specific Clinic	43.5	Corticosteroids	14.5
	Tai Chi	39.6	Internet chatroom	12.7
	Aromatherapy	38.4	Family advice	9.3
	Nutritionist	33.3	Social worker	9
	Internet Chatroom	32.7	Hypnotherapy	7.2
	Chiropractor	32.1	Pilates	5.4
	Recreation therapist	27.7	Anticonvulsants	5.4
	Homeopathy	26.2	Biofeedback	5.4
	Art Therapy	24.7	Capsaicin cream	1.8

Highlight indicates SP and SU shared treatment component endorsements for most frequent and least frequent

Table 9 Postal survey: Service users' endorsements in comparison to service providers'

Treatment components with no statistically significant difference in endorsement

Psychologist
Education about pain
Humour as therapy
Posture/body mechanics
Graded return to ADL
Recreation therapist
Physiotherapist
Homeopathy
Psychological assessment
Aromatherapy
Relaxation
Tai Chi
Dietician
Massage
Reconditioning
Medication review
Creative therapies

Treatment components with statistically significant difference in endorsement

Treatment	Pearson Chi-Square	Treatment	Pearson Chi-Square
Physician	p=<.000	Nurse	p=<.000
Occupational Therapist	p=<.000	Social Worker	p=<.000
Pharmacist	p=<.000	Inpatient programme	p=<.000
Outpatient programme	p=<.000	Multidisciplinary team	p=<.000
Education about anatomy	p=<.000	Thermal modalities	p=<.000
TENS	p=<.000	Corticosteroids	p=<.000
Antidepressants	p=<.000	Anticonvulsants	p=<.000
Support group	p=<.000	Capsaicin Cream	p=<.000
Financial advice	p=<.000	Pacing	p=<.000
Assertiveness training	p=<.000	Communication training	p=<.000
Information sources	p=<.000	Biofeedback	p=<.000
Vocational advice	p=<.000	Anger management training	p=<.000
Diet advice	p=<.000	Ergonomics	p=<.000
Stretching	p=<.000	Yoga	p=<.000
Acupuncture	p=<.000	Hydrotherapy	p=.024
Internet chat-rooms	p=<.000	Spirituality	p=<.000
Topical issues discussion	p=<.000	Post discharge support group	p=<.000
Assess to research	p=<.000	Chiropractor	p=.025
Pilates	p=<.000	Equipment	p=<.000
Print materials	p=<.000	Family advice	p=<.000
Lifestyle counselling	p=<.000	Self-management	p=<.000
Condition specific clinic	p=<.000	Modality specific clinic	p=<.000
Meditation	p=<.000		

Table 10 Delphi 1: Service users' & providers' responses to 'why important' by theme

'Feature of Consciousness' Themes	Service user Sub-themes	% of overall comments related to theme	Service provider Sub-themes	% of overall comments related to theme
Coherence	▪ Being informed ▪ Doing it right	18.6%	• What others expect • How the team/programmes is organised • Specialised knowledge • What SP believes works	28.7%
Purposiveness	• Keeping pain free • Keeping fit • Keeping emotional strong • Keeping able	34.8%	• Providing treatment • Providing diagnosis • Giving reassurance • Giving Education • Protecting resources • Measuring outcome • Normalising SU experience • Changing the SU	64.4%
Self-image	• Pain is legitimate • In control • Normal • Social	30.2%	(SPs made no comments in this category)	0%
Affect	• Fear of pain • Fear of isolation) • Anxiety & Loss	16.4%	• Protecting SP • Supporting SP • Reinforce each others' work • Share power with other SP	6.9%

* Comments are cumulative across all 10 treatment components discussed in Question 1

Table 11 Delphi 1: Service users' and providers' response to 'why not important' by theme

'Feature of Consciousness' Themes	Service user sub-themes	% of overall comments related to theme	Service provider Sub-themes	% of overall comments related to theme
Coherence	• They have no training in pain • What role do these SP's play?	SU 23%	• They have no role • Role poorly understood • Conflicts with Self-management approach • Not traditionally part of team • disbelief in effectiveness • Treatment does not match condition • Not recognised by 'mainstream' medicine • Not SP role to make referral • Contraindicated with regular treatment •	SP 35%
Purposiveness	Useful but not available	SU 30.8%	• Would work but unavailable (cost, resources, time etc)	SP 22%
Self-image	• Loss of privacy • Prefer direct communication • Avoids coping	SU 23%	• Not someone SP usually works with • (Speaking on behalf of SU) • Not part of SU role • SP cannot protect SU through control of access or information	SP 16%
Affect	• Far of more pain • Distrust	SU 23%	• Distrust • Creates 'challenging' SUs • Commercial interests are distasteful • Ethnocentrism/nationalism • Uncomfortable with unknown	SP 27%

* Comments are cumulative across all 3 treatment components discussed in question 3

Table 12 Delphi 1: Service user and service provider 'impact of disagreement' responses by category

Category	Rank (median)	SU (%)	SP (%)	Stat sig (T-test)
Financial	0-No effect	7 (31.8)	5 (6.6)	t (93)= -2.862; p=*.008*
	1-Some	2 (9.0)	1 (1.3)	
	2-Moderate	6 (27.3)	24 (32)	
	3-Marked	4 (18.2)	26 (34.6)	
	4-Very marked	3 (13.6)	19 (25.3)	
Emotional	0	2 (9.0)	6 (7.8)	no stat.sig.
	1	2 (9.0)	11 (14.3)	
	2	9 (40.9)	20 (25.8)	
	3	4 (18.2)	23 (29.9)	
	4	5 (22.7)	17 (22.1)	
Treatment Outcome	0	4 (18.2)	2 (2.6)	t (95) = -3.314; p=*.001*
	1	5 (22.7)	9 (11.7)	
	2	7 (31.8)	14 (18.2)	
	3	2 (9.0)	32 (41.5)	
	4	4 (18.2)	20 (25.8)	
Relationship between SP & SU	0	3 (14.3)	3 (3.8)	t (95) = -3.114; p=*.002*
	1	3 (14.3)	5 (6.4)	
	2	9 (42.8)	16 (20.1)	
	3	3 (14.3)	32 (41.0)	
	4	3 (14.3)	22 (28.2)	
What the public believes	0	4 (18.2)	1 (1.3)	no stat sig.
	1	1 (4.5)	5 (6.3)	
	2	4 (18.3)	17 (21.5)	
	3	7 (31.8)	33 (41.8)	
	4	6 (27.2)	23 (29.1)	
Range of treatment options	0	2 (9.0)	1 (1.3)	no stat sig.
	1	2 (9.0)	6 (8.0)	
	2	9 (42.8)	20 (26.7)	
	3	3 (14.3)	27 (36.0)	
	4	6 (27.3)	21 (28.0)	
Relationship with co-workers	0	SUs not asked this question	1 (1.4)	
	1		2 (2.7)	
	2		21 (28.4)	
	3		32 (43.2)	
	4		18 (24.3)	

Highlight indicates median score for SU & SP groups in each category

Table 13 Delphi 2: Validating SP/SU statements from Delphi 1 findings

	Validated by SU (median)	Validated by SP (median)	Comments
▪ *Service providers are more concerned than service users about costs to the NHS	Yes (4)	Yes (4)	Valid
▪ *Service users are concerned about being seen as individuals	Yes(3)	Yes (4)	Valid
▪ *All service providers in a team should agree on what treatments they feel are important	Yes (4)	Yes (3)	Valid
▪ *Service users can get more resources by lobbying together	Yes (4)	Yes (3)	Valid
▪ *Service users benefit most from treatments selected individually by themselves and their service provider	Yes (4)	Yes (3)	Valid *
▪ **Service providers feel it is important to be consistent in the information provided by the team	No (2)	No (2)	Not valid
▪ **If service providers are given too many options it will confuse them	No (2)	No (2)	Not valid
▪ **If there are too many options there will not be enough resources to cover the basics	No (2)	No (2)	Not valid
▪ **Service users benefit most from a standard treatment prescribed by a team of service providers	No (2)	No (2)	Not valid
▪ ***People who do not have pain will have no opinion about what services should be provided	Yes (3)	No (1)	Valid for SU only p=.001
▪ ***Disagreement about treatments will result in lost credibility to the public	Yes (3)	No (2)	Valid for SU only p=.015
▪ ***Service users are not strongly influenced by the opinions of other service users	Yes (3)	No (2)	Valid for SU only

* Agreed by both SUs & SPs
**Disagreed by both SUs & SPs
***Agreed by SUs only

Table 14: Delphi 2 (Part 6)- Recommended actions -frequency of participants making the statement ( )

Type of action	**Both SUs & SPs said:**	**SUs only said that SPs should;**	**SPs only said that SPs should;**
1. SP action to support professional decision (SP control)	*SP should provide more information (9) ,SP should justify options offered (8)*	*present a 'united front' to SU (5), provide more aftercare (1), make more SPs available (2)*	*discuss differences openly with other SPs (5), educate the SU (16) control misinformation (3), take more time to explain (3), Increase public awareness (3), lobby for more resources (2)*
2. SP action to gain more information (SP Control)		*ask SUs what they believe (1)*	*do more research (5), educate other SPs (5),* *listen to SUs to gain understanding (14), be evidence-based (7)*
3. SP action to negotiate plan (SP sharing control with SU)	*provide more individualised treatment (4), be more client-centred (2), be willing to get a 2nd opinion (5), be less biomedical & more holistic (2), improve communication/negotiation skills (12)*	*use arbitration/ mediation skills (1),* *use questionnaires to get more information from SUs (2)*	*build trust (11), jointly develop treatment plans (13), have community & SU input to planning (2), increase awareness of limited resources & need to negotiate (4), have large group discussions (6), develop SU defined outcome measures (1)*
4. Shared action (flexible control)	*promote more SU responsibility & ownership (5)*	*act on SU comments(1), keep SU's family involved (1)*	*determine if SUs are ready for change/treatment (5)*

Table 15 Delphi 2: Statements of actions needed between and within groups

S U comments to SPs	S P comments to other SPs	SU comments to other SUs	SP comments to SUs
Communication issues: e.g. listen to what SU are saying, be honest about what is possible, don't give 'false hope', do not make assumptions about what SU understands, work on building a healthy rapport	**Communication issues:** e.g. **Listen to SU (most frequent comment)**, do not make assumptions about what SU need, build rapport with SU, be honest with SU, don't give false hope, be aware of SU expectations.	**Communication issues:** e.g. learn to be assertive, ask for referrals and information, speak up, give more information- don't wait to be asked.	**Communication issues**: e.g. speak up and be assertive, ask for a referral if not happy, learn communication skills, ask more questions, give more information, listen to the information you are given, don't accept everything- listen critically
Validate the service user: e.g. recognise pain is real, understand that pain changes my whole life, see me as an individual, understand that SU's need control over their lives	**Validation issues:** see each SU as unique, understand separate needs/wants, accept SU opinions as real, accept pain as 'real', appreciate SU needs control because of life disruption, realize pain changes a SU's whole life.	**Validation issues:** e.g. don't be afraid to look foolish by disagreeing or asking questions.	
Treatment issues: e.g. make more options available for SU to chose , be more accepting of alternative therapies, facilitate more support groups, follow protocols	**Treatment issues:** e.g. make more options available, give SU more choice, follow protocols, take direction from experts, develop a National Service Framework, be more accepting of alternative therapies (not just evidence-based), use only evidence-based treatments, increase community based treatment options, do more education for SUs, audit outcomes,	**Treatment issues:** e.g. act on the advice given by SP, access more education about pain	**Treatment issues**: e.g. get more education, take advantage of education sessions, attend treatment sessions, take advice about what is 'good' information, learn strategies to live with pain,
	Professionalism issues: e.g. increased education for SP, defend professional expertise, use other team members to validate message to SU, foster interdisciplinary learning and understanding. stop 'empire building' , accept specialist .		
	Advocacy/lobbying issues: e.g. SP should lobby for resources, work to obtain more resources, increase profile with managers, public, decision makers,	**Advocacy/lobbying issues:** e.g. learn to lobby	**Advocacy/lobbying issues:** e.g. lobby for resources, increased staff, more research, public awareness, form lobby groups, participate in public forums, form support groups
	Paradigm shift issues: e.g. treatment planning with SU, include SU in research and programme planning, accept the reality SP cannot cure pain, 'evidence' is not just RCT's, use a biopsychosocial or holistic model, accept professional limitations, stop seeing pain as 'specialist' and see it as normal part of life	**Paradigm shift issues:** e.g. take more responsibility for own health, don't worry about disapproval of the GP, keep an open mind to new ideas	**Paradigm shift issues**: e.g. accept that medicine has limitations, stop hunting for a miracle cure, be realistic, stop fighting, keep an open mind to new ideas, stop seeing pain as unique, take responsibility for self-management

Table 16 Delphi 3: Pattern of participation across all three Delphi rounds

Background	Volunteered for interview	Completed Delphi 1	Completed Delphi 2	Completed both Delphi 1&2	Completed Delphi 3	Stage 1 volunteers completing all 3 rounds
Occupational Therapist	43	14 (32.5%)	10 (23.3)	7 (16.3)	7 (16.3)	3 (6.9%)
Physiotherapist	19	10 (52.6)	8 (42.1)	7 (31.6)	7 (16.3)	5 (26.3%)
General Practitioner	19	4 (21.0)	8 (42.1)	3 (15.8)	5 (26.3)	1 (5.2%)
Psychologist	17	4 (23.5)	6 (35.3)	3 (17.6)	3 (17.6)	2 (11.8%)
Anaesthetist	63	28 (44.4)	27 (42.8)	18 (28.6)	27 (42.8)	15 (23.8%)
Nurse	65	25 (38.4)	27 (41.5)	16 (24.6)	30 (46.1)	12 (18.5%)
Other	6	2 (33.3)	2 (33.3)	2 (33.3)	2 (33.3)	1 (1.6%)
Service User	33	22 (66.6)	16 (48.5)	16 (48.5)	17 (51.5)	11 (33.3%)
Total	265 (241)*	109 (41.1)	104 (39.2)	71 (26.8)	98 (40.6)	50 (20.6%)*

*By completion of Delphi 3 twenty-four participants had withdrawn, moved with no forward address or were deceased.

Table 17 Delphi 3: Key properties of complex adaptive systems and corresponding statements

Complex adaptive system property	Response indicates support for CAS/Linear or Mixed	Question 3 (page 5 – Delphi 3 questionnaire). Corresponding statements (S)	Strongly agreed or Agreed (%)		Disagreed or Strongly disagreed (%)	
			SU	SP	SU	SP
1. Relationships are central to understanding the system	CAS	S1- Chronic pain (CP) is influenced by what each person believes	62.5%	98.7%	37.5%	1.3%
	CAS*	S2- CP is influenced by relationships between people	66.7%	96.0%	33.3%	4.0%
	CAS	S19- SU & SP must interact with a range of other services and people	81.3%	92.0%	18.8%	8.0%
	CAS	S20- information and services need to be available to families and employers	93.8%	95.9%	6.3%	4.1%
2. Structures, processes and patterns are varied and highly inter-related	CAS	S3- services are delivered in a wide variety of ways	68.8%	86.7%	31.3%	13.3%
	CAS	S4- the process to access services varies across the UK	93.8%	98.7%	6.3%	1.3%
3. Actions are based on internalized simple rules and mental models	Linear	S5- CP is treated mainly within the medical system	66.7%	60.0%	33.3%	40.0%
	Linear	S6- Search for cure is the main goal for service users	75.0%	82.4%	25.0%	17.6%
	Mixed**	S7- Search for cure is the main goal for service providers	60.0%	12.0%	40.0%	88.0%
	Linear	S8- People believe more strongly in medical than psychological treatment	75.0%	82.4%	25.0%	17.6%

Table 17 (continued): Key properties of complex adaptive systems

4. Attractor patterns exists -Irrespective of different inputs, there are certain outcomes that the system is most likely to return to.	**Linear**	S5- CP is treated mainly within the medical system	66.7%	60.0%	33.3%	40.0%
	Linear	S6- Search for cure is the main goal for service users	75.0%	82.4%	25.0%	17.6%
	Mixed**	S7- Search for cure is the main goal for service providers	60.0%	12.0%	40.0%	88.0%
	Linear	S8- People believe more strongly in medical than psychological treatment	75.0%	82.4%	25.0%	17.6%
	CAS	S21 – people are anxious about the availability of resources for pain management	93.8%	86.7%	6.3%	13.3%
5. The system is constantly adapting. Adaptation can either preserve the status quo against perceived threat or facilitate innovation and change.	**Mixed**	S9- Guidelines, policy and funding should be decided at a central, national level	46.7%	68.9%	53.3%	31.1
	CAS	S10- Guidelines, policy and funding should be decided at a community, local level	68.8%	51.4%	31.3%	48.6%
	CAS	S15- the effect of treatment can change over time for the same person	100%	98.7%		
	Mixed ***	S22- SP feel in control of how services are provided	56.3%	20.0%	43.8%	80.0%
	Linear	S23- SU are able to influence how service is provided	20.0%	33.8%	80.0%	66.2%

Table 17 (continued): Key properties of complex adaptive systems

Complex adaptive systems property		**Question 3 (page 5 – Delphi 3 questionnaire).**	**Strongly agreed or Agreed**		**Disagreed or Strongly disagreed**	
			SU	**SP**	**SU**	**SP**
6. Experimentation with new ideas and pruning of ineffective beliefs and behaviours is necessary	**Linear**	S11- People have access to enough information to make good decisions	25.0%	16.0%	75.0%	84.0%
	Linear	S12- New ideas about treatment are easy to try out	31.3%	10.7%	68.8%	89.3%
	Linear	S13- Outdated ideas about treatment are difficult to eliminate	100%	96.0%	0.0	
	Linear	S17- information about pain is readily available	31.3%	30.1%	68.8%	69.9%
	Linear	S18- New ideas about treatment spread quickly through the healthcare system	18.8%	14.7%	81.3%	85.3%
	Linear	S22- SP feel in control of how services are provided	56.3%	20.0%	43.8%	80.0%
	Linear	S23- SU are able to influence how service is provided	20.0%	33.8%	80.0%	66.2%
7. CAS are non-linear; the relationship between input and output is not proportional.	**CAS**	S14 – Treatment follows a logical, step-by-step process	50.0%	32.0%	50.0%	68.0%
8. CAS are embedded within other systems, which can be either formal or informal.	**CAS**	S16- Treatment must consider social, cultural and environmental aspects in addition to medical	100%	97.3%		
	CAS	S19- SU & SP must interact with a range of other services and people	81.3%	92.0%	18.8%	8%
	CAS	S20- information and services need to be available to families and employers	93.8%	95.9%		

Statistically significant difference between SU and SP responses:
*S2 - *p<.000*
***S7-p<.000*
****S22 - p<.000*

Table 18 Delphi 3: Why are few SU actions recommended? (Delphi 3 – Question 6)

Theme	Service provider (frequency)	Service user (frequency)
▪ Medical model is socially dominant	**21 (23.6%)**	
▪ SUs have limited knowledge and tools	16 (17.9%)	2 (10.5%)
▪ SUs feel defeated and disempowered	13 (14.6%)	**6 (31.6%)**
▪ Action depends on who has power	13 (14.6%)	
▪ SUs take no responsibility & blame SPs	10 (11.2%)	
▪ SUs are individuals and can not be expected or have the resources to act collectively	4 (4.5%)	2 (10.5%)
▪ SPs control resources/access	5 (5.6%)	3 (15.8%)
▪ This will change with new legislation ('expert patient')	2 (2.2%)	
▪ SP cannot imagine what SUs role could be	2 (2.2%)	
▪ SPs have a role as advocate	2 (2.2%)	
▪ SUs' pain prevents them taking action	1 (1.1%)	1 (5.3%)
▪ SPs are not interested in sharing responsibility		3 (15.8%)
▪ Opportunities for SU participation needs more structure		2 (10.5%)
▪ SPs are not interested in SUs' opinions		3 (15.8%)
Total Comments	89	19

Table 19 Delphi 3: Evaluation of the Delphi process

	Yes, very		Yes, mostly		No, not very		No, not at all	
	SU	SP	SU	SP	SU	SP	SU	SP
The reports after each questionnaire were interesting.	50%	20%	50%	53%		2.7%		
The questions were clearly written.	18.8%	25.0%	56.3%	64.5%	25.0%	10.5%		
The questions were interesting.	37.5%	26.3%	50.0%	67.1%	12.5%	6.6%		
This study was relevant to my work.	20.0%	40.5%	26.7%	47.3%	26.7%	9.5%	26.7%	2.7%
I learned something about service users through this study.	26.7%	17.3%	53.3%	56.0%	20.0%	22.7%		4%
I learned something about service providers through this study.	31.3%	8.0%	37.5%	61.3%	31.3%	26.7%		4.0%
I learned something about myself through this study.	25.0%	8.2%	43.8%	52.1%	31.3%	34.2%		5.5%
Based on this experience I am willing to participate in a Delhi study in the future.	40.0%	29.3%	40.0%	57.3%	13.3%	9.3%	6.7%	4.0%
Would you have preferred focus groups and interviews as opposed to this type of Delphi research?	33.3%	11.6%	40.0%	17.4%	13.3%	43.5%		

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Appendices

Appendix 1: Sample letter to support group organisers

Ms. xxxxx
SMILE representative
address xxxxx

January 5, 2001

Dear Ms. xxxx,
I am writing to ask your assistance in conveying my request to the organising committee of SMILE. Your name was given to me as someone I should contact but if this is incorrect can you please let me know who to redirect this letter to?

I am an occupational therapy lecturer at the University of Liverpool and am currently working on my PhD. I have worked for people with chronic pain in a number of different types of health settings and have learned a great deal from their stories, coping strategies and persistence in a sometimes-frustrating health care system. For my current research I plan to survey service providers (OT, Physio, Psychology etc) from different chronic pain programmes about what they believe are important treatment components. I would also like to get the service users' opinions to see what treatments they think are important. I believe the information will be of interest to both service users and health care workers. Hopefully, it will help to reinforce the need for programme planning that clearly states the expectations and components of treatment that are valued by service users. I have attached an information sheet that gives more background on the study.

To this end, I am writing to ask if I can access the SMILE mailing list. I would like to mail an invitation to participate in the research to each member. Can you please tell me how I can make a formal application to access the membership mailing list? I would be happy to meet with your group to explain further and I would certainly like to share the findings of the study afterwards. I am also writing to other support-groups and your members' responses would be combined with theirs' so that everyone remains anonymous.

My research is being supervised by Professor Ann Jacoby, Department of Primary Care at the University of Liverpool and Dr. Gus Baker who some of your members may know from the Walton Centre.

You can contact me how ever is most convenient. My e-mail is: cabrown@liv.ac.uk, phone: 794-5723, and I've enclosed a stamped envelop if you wish to write back.

Thank you very much for your consideration of my request. I look forward to hearing from you in the near future. All the best for the New Year.
Sincerely,
Cary A. Brown, Lecturer
Division of Occupational Therapy
University of Liverpool
Johnston Building, Brownlow Hill
Liverpool, L69 3GB

Appendix 2:Sample letter to service provider organisation administration

Pain Association Scotland
Cramond House
Cramond Glebe Road
Edinburgh, Scotland
EH4 6NS

June 20, 2001

Dear xxx;

I am writing to ask your assistance in contacting your membership to see if they would be interesting in participating a research study I am carrying out. I am an occupational therapy lecturer at the University of Liverpool, currently working on my PhD. I have worked for people with chronic pain in a number of different types of health settings and have learned a great deal from their stories, coping strategies and persistence in a sometimes-frustrating health care system. For my current research I am surveying both service providers (OT, Physio, Psychology etc) from different chronic pain programmes and people who have pain about what they believe are important treatment components.

I believe it is essential to seek service users' opinions about what treatments they think are important. Too often the range of options is not clearly outlined, people with pain are not aware of the choices open to them and the service provider selects options based on his or her own values, rather than the client's. This information will be of interest to both service users and health care workers and, hopefully, will help to reinforce the need for programme planning that clearly states the expectations and components of treatment that are valued by service users. I have attached an information sheet that gives more background on the study for your review.

To insure that the research includes as many service users as possible, I am writing to ask if I can access the Pain Association mailing list. I would like to mail an invitation to participate in the research to each member. Where it has not been possible to let me have a mailing list, other groups have agreed to put mailing labels onto the stamped envelops I send them. I would of course pay a fee for the service and the cost of any labels. Would either of these options be a possibility for your group? Your members' responses would be combined with those of other support groups so that everyone remains anonymous.

My research is being supervised by Professor Ann Jacoby, Department of Primary Care at the University of Liverpool and Dr. Gus Baker who some of your members may know from the Walton Centre in Liverpool.

You can contact me how ever is most convenient. My e-mail is: cabrown@liv.ac.uk, phone: 0151-794-5723, and I've enclosed a stamped envelop if you wish to write back.

Thank you very much for your consideration of my request. The opinions of the people who actually use chronic pain services is under-represented in the research and I hope your Pain Association groups will be able to assist in correcting this imbalance. I look forward to hearing from you in the near future, and all the best for a pleasant summer.

Sincerely,

Cary A. Brown, Lecturer
Division of Occupational Therapy
University of Liverpool
Johnston Building, Brownlow Hill
Liverpool, L69 3GB

Appendix 3: Sample letter to pilot group

xxx
Arthritis Care
18 Stephenson Way
London, NW1 2HD

July 31, 2001

Dear xxx,

Thank you for being willing to help with my research by giving me your evaluation of the survey form. I know that it is very frustrating to receive a survey that is unorganised and confusing and comments on this pilot form will go a long way to helping avoid this. Please be as critical as possible about the form and any questions that are confusing. If you have any suggestions about what would make problem areas better please jot them down as well.

After I've made revisions based on your and other peoples' feedback, the survey will be going to members of chronic pain support groups in the Midwest of England. Their ages, education, occupations and duration of pain are quite wide and the study includes both men and women. Their survey results will be compared with a similar survey sent out to healthcare workers. I want to see if people with pain and service providers agree or disagree on which treatments are important for pain.

What I am asking you to do:

- ☐ First, try filling out the form.
- ☐ Second, make note of any questions or instructions that need clarifying.
- ☐ Next, add any comments you have on the blank sheet of paper attached at the end of the form.
- ☐ Lastly, return the form and your comments in the enclosed stamped envelop.

Thank you again for your help with this. I look forward to hearing your comments and making the needed changes. I will be forwarding a donation to Arthritis Care as a token of my appreciation and also including an acknowledgement of Arthritis Care in any publications forthcoming from the final research.

All the best wishes for a pleasant summer.

Sincerely,

Cary A. Brown, Lecturer
University of Liverpool, School of Health Sciences
Division of Occupational Therapy
Johnston Building, Brownlow Hill
Email: cabrown@liv.ac.uk

Appendix 4:Service user consent and information letter

Date

Dear SMILE member-

The SMILE organisers have kindly sent this letter to you on my behalf. I am asking for your help with the research study described in this letter. The results will be used to educate health care providers about the treatments you want for chronic pain. This research is a chance for YOU to make your opinions known about what treatments are needed.

I am also surveying health care providers (like doctors and nurses) about what treatments they think are important. Once I have everyone's feedback, I'll see where there is agreement and where people have different opinions. Then I'll talk to those people who volunteered to get more detail about their opinions. After that I will report back to both service users and providers and so all the information is shared. The SMILE organisers have already asked me to come and talk to your group.

One reason I am doing this study is to help health care providers learn more about what service users (like you) want as treatment for chronic pain. We know very little about what people think of the treatment they receive. The NHS has made a promise to listen more carefully to what the public has to say and health care workers are eager to learn from you. This study is part of that process and will give people with chronic pain a chance to tell their opinions to health care workers.

I would like to invite you to participate in this research. The first section of the survey is about your opinion on different types of treatment offered to people with chronic pain. It will take about 15-20 minutes to fill out. There are also a few questions about your age and so on. Lastly, there is a short questionnaire about your general beliefs regarding pain. In total, the whole package will take around 1/2 hour to complete, but can be completed in segments to fit into your schedule.

I hope you can find the time to complete the survey and return it before the end of next week. I have provided a stamped envelope for you to return the survey. You do not need to put any postage on the envelope.

Professor Ann Jacoby, Department of Primary Care, University of Liverpool and Dr. Gus Baker (who you might know from the Walton Neurological Centre) are supervising my study. The Head of the Department of Allied Health Professions, School of Health Sciences, University of Liverpool, has also given approval for this study.

The survey results will be presented to groups of service users (like SMILE) and published in appropriate professional journals. None of the information will be used in such a way that you can be identified and it will be stored in a locked file drawer for my use only. Whether you choose to participate or not will have no bearing on any treatment you are currently receiving for your pain.

If you complete and return the survey it will mean that you have consented to participate. You can change your mind at any time later and I will withdraw your comments from the study. You just need to phone me to do that. If you have any other questions or comments I can be reached at the following address/e-mail.

Your views are very important and can help improve the quality of health care for people with chronic pain. Thank you for your help with my study.

Sincerely,

Cary A. Brown, Lecturer
Division of Occupational Therapy
University of Liverpool
Johnston Building
Brownlow Hill, Liverpool
L69 3GB
E-mail: cabrown@liv.ac.uk
Phone: 0151-794-5723

Appendix 5: Service user Stage one survey

Services for People with Chronic Pain Survey

Introduction

Thank you for agreeing to take part in this survey. Your response is confidential and
will not be used in any way that will identify you personally. **Please answer the questions based on your own opinion and including any treatments- not just the ones provided by the NHS.** If you have any questions please call me. My phone number is 0151-794-5723, and my e-mail is: cabrown@liv.ac.uk

Your answers and opinions are important and I appreciate the time you are taking to fill this out.
Cary Brown, Lecturer- University of Liverpool

Section One

The following is a list of services and treatments available to people with chronic pain. Put a ' √ ' in the box beside each item that you have received. You should also put a ' √ ' in the **"Would try if offered** column" for any items you haven't tried but think would be useful.

For example - if you have tried yoga, put a √ in the 'I have tried' box. If you think yoga **was not** an important treatment for your pain, leave the 'Important for pain' box empty. If you had never tried exercises, but wanted to and believed they are an important treatment for your pain, you would put a ' √ ' in the 'I would try if offered' and also in the 'I believe this is important for pain' box.

Example

Services/ Treatments	'I have tried'	'I would try if offered'	' I think this is important for pain'
Yoga	√		
Exercise		√	√

Part A: Service providers	I have tried treatment from a....	I would try Treatment from this professional if offered	I think the services of this professional are important for treatment of chronic pain
Doctor			
Psychologist			
Nurse			
Occupational Therapist			
Physiotherapist			
Social worker			
Chemist			
Nutritionist			
Sports/leisure counsellor			
Other? (please write in any other workers)			

Part B: Ways services are provided:	I have tried services ...	I would like to try services ...	I think this type of service is important for pain
As an Inpatient			
As an Outpatient			
From a team of different professionals			
From someone who specialises in one condition (e.g. migraine specialist)			
From a clinic that specialises in one type of treatment (e.g. nerve block clinic)			

Part C: Medication treatments	I have tried	I would like to try	I think this is an important treatment
Corticosteroids			
Anti-inflammatories			
Antidepressants			
Pain reduction ointments			
Capsaicin ointment			
Analgesics			
Anticonvulsants			
Nutritional supplements (eg. Vitamins)			
Any others? Please write in			

Part D: Physical Techniques to reduce pain	I have tried	I would like to try	I think this is an important treatment
Relaxation training			
Electrical stimulation/TENS machine			
Massage			
Stretching exercise			
Yoga			
Tai chi			
Heat or ice for pain			
Hydrotherapy			
Hypnosis			
Acupuncture			
Biofeedback			
Pilates			
Chiropractic Adjustment			
Reflexology			
Alexander technique			

Part E: General Services	I have tried	I would like to try	I think this is an important treatment
Psychology & counselling			
Advice about healthy lifestyle and pain			
Family counselling			
Diet information			
Job related advice			
Welfare/financial advice			
Referral to other agencies for help			
An assessment of workplace demands that may affect your pain			
Information about preventing pain during sexual activity			
Group discussions about issues and pain (e.g. using cannabis to reduce pain, welfare rights, etc)			
Meditation			
Spiritual support			

Part F: Information & Education	I have tried	I would like to try	I think this type of education is an important treatment
Education about posture & how to lift			
Education about what causes pain			
Education about the body's anatomy			
Education on how to do activities of daily living			
Classes about how to be assertive			
Classes for communication skills			
Classes on how to express myself through Artwork			
Referral to a support group			
Education about where to			

get more information (e.g. the internet)			
Referral to a self-management course led by other people with pain			
Classes for dealing with anger			
Classes on how to pace myself			
Information on self-care equipment (e.g. reachers, bathlifts)			
Information about current research in pain			
Part G: other types of assistance with pain	I have tried	I would like to try	I think this is an important treatment
Booklets and tapes about pain			
Advice about how to reduce medication			
Information about how humour can help reduce pain			
Homeopathy			
Aromatherapy			
Information about internet chat-rooms for people with pain			
Please list any other treatments or services that have not been mentioned. Please identify if you though it was important for your pain or not.			

How much pain are you having now as you complete the survey? Place an 'X' on the line below to show your pain if 0 = no pain and 10= the worst pain ever.

'NO PAIN'
'WORST PAIN EVER'
0---10

1. Date survey completed:_______________

2. Your age:__________ Please circle: Male Female

3. Which of the following best describes your current job status? (please tick)

   - ☐ Employed outside the home
   - ☐ Homemaker
   - ☐ Retired
     - ☐ Because of pain
     - ☐ For reasons other than pain
   - ☐ Unemployed
     - ☐ Because of pain
     - ☐ For reasons other than pain
   - ☐ Other (please specify)

4. How long have you had chronic pain? (number of months)

5. How long have you belonged to a Chronic-pain support group? (number of months)

6. How did you hear about the Support Group you belong to?

7. Some people prefer to have a health care professional decide what treatment is best, other people prefer to have more choice about what treatment to use. Place an 'X' on the line at the spot that matches how you feel. 0 = 'the doctor's choice is best' and 10 = 'I want to make my own choice'.

   0____10

   Doctor's choice best — I want to make my own choice

Any comments about having choices in treatment(s)?

8. **Please complete the attached Pain Beliefs Questionnaire on the following page.**

9. **Would you be willing to be interviewed to give more specific details about your opinions on pain treatments?** The interview would be approximately an hour long and could occur when and wherever is convenient for you. If you would be interested in knowing more about this, please give your name and phone number in the box below.

Name:
Address:

Phone:

E-mail:

Thank you for your time and interest in this research. Your opinions are important and I appreciate your willingness to take part. If you would like me to send you a summary of the final report, or a list of internet sites where you can get more information about the types of chronic pain resources that are available to you, please fill in the box below.

Name:

Address:

Yes, I'd like a final report ______. Yes, please send me inter-net information ____

Please return this survey in the enclosed envelope. You do not need to put a stamp on it. Remember, if any of the questions are unclear, give me a call.
Many Thanks!

Cary Brown, Lecturer
School of Health Sciences
University of Liverpool
Phone: 0151-794-5723

Appendix 6: Service provider consent and information letter

October 15,2001

Dear Colleague-

I received your name from The Pain Society Council after they approved my application to contact members. Most health care professionals will work at some time in their career with people who have pain. I believe this is a very significant area for our professions and have made this the focus of my PhD research. Specifically, I am examining what service providers (Occupational and physical therapists, physicians, psychologists, etc) and service users believe to be important components of treatment. Because of your own expertise in the area, I would like to invite you to participate in the first phase of this research that is related to the beliefs service providers' hold regarding pain. Your comments will be combined with those of other service providers to obtain a composite picture of professionals working with people who have pain in the United Kingdom.

The first part of the survey consists of a few brief questions about you and the second part is a short questionnaire designed by Skevington (1990) on Pain Beliefs. The third, and last, section concerns your opinion about different types of treatments for chronic pain. It should take about 15 minutes to fill out. In total, the whole package will take less than 1/2 hour to complete, but can be completed in segments to fit into your schedule.

What physiotherapists, occupational therapists, nurses and other service providers believe about pain is currently very under-represented in the literature. I believe it is important to address this imbalance and hope that you will be able to find the time to complete the enclosed survey and return it **before October 31st, 2001**. I have provided a stamped envelope for you to return the survey.

My research is supervised by Professor Ann Jacoby, Department of Primary Care, University of Liverpool and Dr. Gus Baker, Walton Neurological Centre. It has been approved by the Head of the Department of Allied Health Professions, School of Health Sciences, University of Liverpool.

These survey results, along with others, will be used for presentation and publication in appropriate professional journals. None of the information will be used in such a way that individuals can be identified. Whether you choose to participate or not will have no bearing on any other relationship you have with the University and you can ask to withdraw your participation at any time.

Your returned survey will be taken as consent to participate. However, if at a later date you wish your information to be withdrawn, you need only contact me.

If you have any questions or comments I can be reached at the following address/e-mail.

I know you're a very busy person (any one who works in health care cannot help but be!), and I want to reassure you that I take your willingness to help with this study very seriously. Thanks in advance for taking a short coffee break to complete what I believe you will find an interesting survey.

Sincerely,

Cary A. Brown, Lecturer
Division of Occupational Therapy
University of Liverpool
Johnston Building
Brownlow Hill, Liverpool
L69 3GB
E-mail: cabrown@liv.ac.uk
Phone: 0151-794-5723

Note: Please disregard this copy of the survey if you have previously completed one because of your membership in a different Special Interest Group.

Appendix 7: Service provider Stage one survey

Health Care Professions and Beliefs About Chronic Pain Treatments

Section I

1. Date survey completed:________________

2. Age:________ 3. Gender________

4. Training (check all that apply)

	achieved	pursuing
Diploma in		
Bachelor's Degree in		
Masters Degree in		
PhD in		
Other		

5. Professional Title:____

6. Years in Practice: ___________

7. Please list the medical diagnosis/condition causing the pain that your patients have had and how much experience you have working in that area. (e.g. Arthritis -18 months). **If you have never worked with people who have pain, proceed to question 8. Please add to the list, if necessary, on the back of this page.**

Condition	Duration of experience

8. Approximately how much time was spent in your undergraduate/pre-registration training on the subject of pain? ______________________hours

9. Please list any additional training you've taken in the subject of pain and how many hours each consisted of:

Training	Hours

10. What sources do you go to for information about pain?

11.Are you currently working in a pain management service?
(please circle) Yes No

**If NO, please complete ONLY columns D & E in part II.

12. Are you willing to be contacted for an interview about pain beliefs?
(please circle) Yes No

If "**Yes**" , please provide your name and contact information.

Name:
Address, phone number, e-mail:

Please proceed to sections II & III

Part II Chronic Pain Program Components Survey

Introduction

The following list of chronic pain treatment components is drawn from the scientific literature, guidelines of the International Society for the Study of Pain and the Pain Society (UK), and a review of treatment issues covered on the Web-sites of pain organisations and support groups. **Feel free to add additional treatment components or append your comments on the ones listed**. I recognise that for some treatment components you may feel that there should be a '**don't know**' column but please try to select what is closest to your own feelings. It is important not to leave sections blank - if you would like clarification about a question please call.

Instructions

In the following list, please tick (√) the appropriate column for the chronic pain services you provide. Please note: each row should have at least two ticks and some as many as three. For example if your service provided a physician and you thought it was important, you would tick **both** 'have' and 'important' boxes. If you had no physician, and would have one if there were enough resources, but personally thought it was not important, you would tick the **three** respective boxes ('do not have', 'would have' and 'not important').

If you are not currently working, please complete **only columns D & E**.

				I believe for a chronic pain service, this is:	
	provide	do not provide	Would provide if resources	important	not important
Column	A	B	C	D	E
Staffing Physician					
Psychologist					
Nurse					
Occupational therapist					
Physical therapist					
Social worker					
Pharmacist					
Nutritionist					
Recreation therapist					
Other (please write in)					
Organisation Inpatient					
Outpatient					
Multidisciplinary Team					
Condition Specific Clinic (e.g. Migraine)					
Modality Specific Clinic (e.g. biofeedback clinic)					
Other (please write in)					

				I believe for a chronic pain service, this is:	
	provide	do not provide	Would provide if resources	important	not important
Column	A	B	C	D	E
Specific Services Physical Reconditioning					
Posture & body mechanic Training					
Relaxation Techniques					
Hypnotherapy					
Sexual activity advice					
Education about pain Etiology					
Education about anatomy					

	provide	Do not provide	Would provide	important	Not important
Medication review & advice					
Psychological Assessment &Intervention					
Graded return to Activities of Daily Living					
Family/Significant Other Counselling					
TENS (transcutaneous electrical nerve stim)					
Corticosteroid medication					
Antidepressant medication					
Anticonvulsant medication					
Topical NSAID					
Topical Capsaicin					
Vocational Advice					
Welfare/financial Advice					
Interagency Liaison					
Assertiveness Training					
Massage					
Communication Skills					
Art Therapy					
Lifestyle Counselling					
Support Group					
Education about information sources (e.g. Websites for patients)					
Self-management training					
creative therapies					
Anger management					
Nutritional Counselling					
Ergonomics					
Pacing of activity					
Stretching					
Yoga					
Tai Chi					
Thermal modalities (ice, heat)					
Hydrotherapy					
Humour as treatment					
Acupuncture					
Biofeedback					
Alexander Technique					
Chiropractor					
Pilates					
Homeopathy					
Aromatherapy					
Information about self-care equipment (eg reachers, bath lifts)					
Access to research findings					
Printed materials/ tapes					

	provide	Do not provide	Would provide	important	Not important
Meditation					
Group discussion of topical issues (e.g. use of cannabis for pain).					
Referral to post-treatment support group					
Referral to pain sufferer's chat-rooms					
Spiritual support					

What other components of service does the program you work in offer? (please list below).

What Model of Practice does your program follow? (e.g. holistic, cognitive behavioural, behavioural etc).

____

Are patients allowed to select which components of the program they will/will not participate in? (please circle)

Yes **No**

Please complete Section III (attached) – Pain Questionnaire (BPCQ)

Thank you for taking the time to complete this survey. The survey results will be used to formulate more in-depth interviews with service providers regarding their beliefs about what are important treatment components for someone with chronic pain. If you have said you'd be willing to be interviewed I may be in touch with you again when that phase of the research is ready to proceed.

Survey completed by:

name:

address:

e-mail:

You should return your completed survey in the stamped, addressed envelope attached here. Please call me if you would like more information at any point (0151-794-5723)

Thank you for your time and kind assistance.

Cary Brown, Lecturer
School of Health Sciences, University of Liverpool

Appendix 8: BPCQ form

PAIN QUESTIONNAIRE (BPCQ)

Name:..

Date:.. **Record Number:**..

Here are some opinions which people sometimes hold about pain. I would like you to read them carefully and show me how much you agree or disagree with each one by ticking one of the numbers for each question. There are no right or wrong answers; I am interested in your views.

	Strongly Disagree 1	Disagree 2	Mildly Disagree 3	Mildly Agree 4	Agree 5	Strongly Agree 6
1. If I take good care of myself, I can usually avoid pain.						
2. Whether or not I am in pain in the future depends on the skill of the doctors.						
3. Whenever I am in pain, it is usually because of something I have done or not done.						
4. Being pain-free is largely a matter of luck.						
5. No matter what I do, if I am going to be in pain, I will be in pain.						
6. Whether or not I am in pain depends on what the doctors do for me.						
7. I cannot get any help for my pain unless I go to seek medical help.						
8. When I am in pain I know that it is because I have not been taking proper exercise or eating the right food.						
9. Whether or not people are in pain is governed by accidental happenings.						
10. People's pain results from their own carelessness.						
11. I am directly responsible for my pain.						
12. Relief from pain is chiefly controlled by the doctors.						
13. People who are never in pain are just plain lucky.						
	1	2	3	4	5	6

This measure is part of *Measures in Health Psychology: A User's Portfolio*, written and compiled by Professor John Weinman, Dr Stephen Wright and Professor Marie Johnston. Once the invoice has been paid, it may be photocopied for use **within the purchasing institution only.** Published by The NFER-NELSON Publishing Company Ltd, Darville House, 2 Oxford Road East, Windsor, Berkshire SL4 1DF, UK. Code 4920 02 4

Appendix 9:Report of Stage one survey findings

(Note: although the layout has been modified to fit the page, the content is the same as the original)

Beliefs about treatment for chronic pain:
Service providers' and service users' Phase one report
September 2002

Introduction

This report briefly reviews findings from the survey you responded to last year which asked whether you thought specific treatment components were *important* or *not important*. It also included the Beliefs about Pain Control Questionnaire (BPCQ- Skevington 1990). The BPCQ identified whether people believed the solution to pain was more likely found through personal actions (IS), health care professionals (PD), or chance happening (CH).

The following tables highlight the key findings from the survey. **Table 1** shows some basic information (number, age, gender) about each group of people who responded to the survey. You can also see how different the BPCQ scores are for each group. High scores in any of the BPCQ scales indicate stronger belief. For example, Physical Therapists have a score of 17.83 in IS. Service Users have a score of 11.37 in IS. This means that physical therapists believe more strongly in personal control over pain than do service users. The highest score possible in each category is 30 for personal action (IS), 24 for health care professional (PD) and 24 for chance happening (CH).

This report is a very brief over view of some complex findings. If you would like more information please contact Cary Brown by e-mail: cabrown@liv.ac.uk

Table 1 – Participant Profile

Profile- Service Provider	Final group (%)	Mean Age	Female (%)	Male (%)	BPCQ-IS	BPCQ-PD	BPCQ-CH
Anaesthetist	122 (31.6)	45.4	32 (26.4)	89 (73.6)	16.12	8.28	11.99
Nurse	103 (26.7)	41.5	96 (95)	5 (5)	15.03	7.92	10.15
Occupational Therapist	52 (14.1)	41.1	48 (92.3)	4 (7.7)	16.94	7.33	9.77
Physical Therapist	35 (9.0)	44.1	23 (71.9)	9 (28.1)	17.83	6.57	9.68
Physician	32 (3.3)	49	10 (35.7)	18 (64.3)	15.27	7.81	11.54
Psychologist	24 (6.2)	43.7	13 (61.9)	8 (38.1)	15.52	6.57	11.00
Pharmacist	3 (<1%)	47.3	2 (66.7)	1 (33.3)			
Other service provider	15 (3.9%)	48.5	8 (37.1)	6 (42.9)			
Unreported		5 cases					
TOTAL – Service Provider	386	43.8	232 (62.3)	140 (37.6)	15.98	7.72	10.78
Profile - Service User	55	53.9	30 (54.5)	25 (45.5)	11.37	10.80	13.83

Who responded to the survey?

As a group, the Service Provider (SP) respondents tended to be in their early to mid-forties, around 60% were women and the tendency was to more strongly endorse self-management and internal control as opposed to fate or health care professionals as responsible for alleviating pain. The Service Users were older (X=53.9), fairly evenly distributed between men and women and tended to most strongly endorse professionals as able to change pain.

The following list presents all of the chronic pain treatment options you were asked to rate in the first survey as being either *important* or *not important.* The list was compiled based on a review of the treatment literature, professional guidelines and relevant websites.

Service Provider Options

Chemist
Doctor
Leisure counsellor
Nurse
Nutritionist
Occupational Therapist
Physical Therapist
Psychologist
Social Worker

Treatment Format Options

Inpatient
Outpatient
Condition specific clinic (eg migraine)
Treatment Specific clinic (eg nerve block)
From a team of professionals

Treatments Options

ADL Education
Alexander technique
Acupuncture
Anger management classes
Antidepressants
Anatomy education
Aromatherapy
Assertiveness training
Anticonvulsants
Biofeedback
Booklets about pain
Capsaicin crème
Corticosteroids
Communication skills
Current issues discussion

Treatment Options

Diet information
Diet supplements (eg vitamins)
Ergonomic assessment
Expressive art therapy
Family counselling
Heat/ice
Hydrotherapy
Homeopathy
Internet chat rooms
Internet sources of information
Job/work related advice
Lifestyle advice
Massage
Medication reduction
Meditation
Pilates
Posture education

Treatment Options

Pain etiology education
Psychological assessment
Referral to other agency
Relaxation
Research information
Selfcare equipment
Self-management programme referral
Sexual positioning advice
Spiritual support
Stretching exercise
Support group referral
Tai chi
TENS
Using humour for pain
Welfare/financial advice
Yoga

What did service providers and service users select as important treatments?

The top two lines in **Table 2** on page 4 show what type of service provider and treatment setting everyone (100%) of the participants in each group agreed on. You'll notice that most groups have a different opinion about who is needed on the treatment team and that in some groups there is no agreement at all. The next lines in the table list the **10 most endorsed** and **10 least endorsed** treatment components broken down by service users and individual professional sub-groups. The second last column shows service providers' as a combined group. The final column shows what service users thought were *important* or not *important* treatments.

Because less than 80% of the General Practitioners responded to any questions about treatments their replies are not displayed in Table 2. Also, any treatment component where less than 80% of everyone in the Service Provider group responded was deleted from the table.

Did service providers and service users agree about what treatments are important?

Service Users and Service Providers have very weak agreement about what treatment components for chronic pain they endorse as '*important*' (**Table 2**). Of the 10 highest endorsed treatment components, only 5 are found on both the service provider and the service users' lists. These five treatment components for chronic pain are:

- Education about pain
- Physiotherapist
- Graded return to ADL
- Print/tape materials
- Relaxation training

As a group, these treatment components fall within biomechanical and rehabilitation frames of reference (Hagedorn 2001). These frameworks focus on returning the individual to maximum functional potential through increasing strength and stamina while also learning compensatory and protective techniques to prevent re-injury.

> ***The surveys of Service Users' and Providers' seem to demonstrate that there is little intra or inter-group agreement about which treatments people believe are important for chronic pain. In general there was higher agreement between the service providers. However, service providers seemed to agree more on*** **'who'** ***(physician, psychologist, physiotherapist) should be providing service as opposed to*** **'what'** ***the treatment options should be. The service users were more individual in their selections, and tended to endorse a much smaller range of treatments as*** **'important'*.*** ***Service users' highest agreement appeared focused around what the interventions should be as opposed to which health care professional should deliver them.***

This report has provided a brief overview of a wide range of complex survey findings. There is a great deal more detail available from the Stage One Survey. Statistical analysis has been carried out on all of the data gathered from the survey and is currently being used as the foundation for manuscript submission to relevant journals. Anyone who would like more information is encouraged to contact the researcher (Cary Brown) directly at cabrown@liv.ac.uk.

References

Hagedorn R Foundations for Practice in Occupational Therapy 3rd ed. Churchill Livingstone, London 2001.
Skevington, SM (1990) A standardised scale to measure beliefs about pain control (BPCQ): a preliminary study. *Psychology and Health* 4:221-32.

CA Brown - Sept.2002

Table 2: Endorsement Profile by Service User and Service Provider - Professional Group

	OT	PT	Nurse	Psych	Anaesthetist	Total Group	Service Users
100% agreement for Treatment Team	Psychologist OT PT	Psychologist PT	Nurse	Physician Psychologist Nurse PT			
100% agreement for structure	Multidisciplinary.	Outpatient Multidisciplinary	Multidisciplinary	Outpatient Multidisciplinary			
10 Most endorsed Treatments (%)	-Posture/body mechanics(100) -Relaxation (100) -Pain etiology (100) -Anatomy (100) -Medication review (100) -Psychological Assessment (100) -Graded return to ADL (98.1) -Pacing (98.1) -Stretching (96.2) -Vocational Advice (96.1) -Self-management (96.1)	-Reconditioning (100) -Relaxation (100) -Pain. Etiology (100) -Medication review (100) -Psychological assessment (100) -Graded return to ADL (100) -Family Counselling (100) -Vocational advice (100) -Self-management (100) -Print/tape materials (100)	**-Psychological assessment (100)** -Medication review (99) -Acupuncture (97.8) -Graded return to ADL (97.7) -TENs (96.9) -Antidepressants (96.9) -Pain. Etiology (96.7) -Print/tape materials (95.8) -Anticonvulsants (94.9) -Family counselling (94.7)	-Relaxation (100) -Pain. Etiology (100) -Anatomy (100) -Medication review (100) -Psychological assessment (100) -Graded return to ADL (100) -Family counselling (100) -Ergonomics (100) -Pacing (100) -Stretching (100) -Print/tape materials (100)	-Psychological Assessment (99.1) -Medication review (98.2) -Graded return to ADL (98.2) -Antidepressants (98.2) -Anticonvulsants (96.4) -Print/tape materials (95.5) -Pain.Etiology (95.4) -Pacing (94.3) -Reconditioning (93.4) -Posture/body mechanics (93.4)	-Physician (94.9) -Psychologist (93.2) -Psychological assessment (92.6) -Medication review (92.6) -Physical Therapist (92.3) -Graded return to ADL (89.9) -Multidisciplinary Team (89.3) -Pain.Etiology (88.8) -Relaxation (88.4) -Print/tape materials (88.4)	-Pain Etiology (67.2) -Posture education (65.4) -Physical Therapist (65.4) -Pacing Education (58.1) -Graded return to ADL (58.1) -Support group referral (58.1) -Humour as therapy (58.1) -Modality specific clinic (56.3) -Print/tape materials (54.5) -Relaxation training (54.5)
10 Least endorsed treatments (%)	-Condition specific clinic (41.5) -Anticonvulsants (41) -Nutritionist(40.8) -Social worker(34.7) -Aromatherapy (33.3) -Massage (30.6) -Art therapy (25) -Homeopathy (22.4) -Chiropractor (18.4) -Recreation therapist (12.8)	**-Chatroom (39.3)** **-Nutritionist (36.7)** -Alexander technique (35.7) -Thermal modalities (31) -Art therapy (27.6) -Homeopathy (26.7) **-Aromatherapy (25)** **-Massage (24.1)** **-Recreation therapist (22.2)** **-Chiropractor (10.3)**	-Social Worker (57.3) -Chiropractor (54.8) -Chatroom (54.4) -Alexander Technique (53) -Homeopathy (50) -Tai Chi (48.8) -Recreation therapist (48.3) -Nutritionist (48.3) -Art therapy (38.2) -Biofeedback (33)	**-Tai Chi (52.9)** **-Biofeedback (42.9)** **-Recreation therapist (36.8)** -Aromatherapy (35) -Massage (35) -Art therapy (30) -Chiropractor (30) -Thermal modalities (29.4) -Homeoparthy (26.3) -Chatroom (17.6)	-Condition specific clinic (45) -Communication training (43.7) -Chiropractor (43.6) -Recreation therapist (32.7) -Aromatherapy (32.4) -Biofeedback (29.3) -Chatrooms (26.5) -Nutritionist (23.3) -Art therapy (21.9) -Homeopathy (20.8)	-Social work (44) -Condition specific clinic (43.5) -Tai Chi (39.6) -Aroma therapy (38.4) -Nutritionist (33.3) -Chatroom (32.7) -Chiropractor (32.1) -Recreation therapist (27.7) -Homeoparthy (26.2) -Art therapy (24.7)	-Alexander technique (18.1) -Homeopathy (16.3) -Corticosteroids (14.5) -Internet chatroom (12.7) -Social worker (9) -Hypnotherapy (7.2) -Pilates (5.4) -Anticonvulsants (5.4) -Biofeedback (5.4) -Capsacian crème (1.8)

Appendix 10:
Chronic Pain Delphi 1 Questionnaire
November 2002

Code: SU___________

Background

The report on the Stage One survey (enclosed) shows that people with chronic pain had some agreement about which treatment components are important. The following question asks why do you think people selected the 10 treatments listed below as most important.

Please note: it is not necessary for you to respond to every question if you feel that it is not of interest to you or that you have no time. **Please just answer what you can and return the form in the enclosed envelope.**

Question 1.

Under each treatment component listed, write your comments about **why you think people with chronic pain ranked this component as important**. Please add extra pages if you need more room.

Education about what causes pain (67.2% of those who replied agreed this was important)
Education about posture (65.4% of those who replied agreed this was important)
Services of a physical therapist (65.4% of those who replied agreed this was important)
Education about pacing (58.1% of those who replied agreed this was important)

Graded return to daily activities (58.1% of those who replied agreed this was important)

Referral to a support group (58.1% of those who replied agreed this was important)

Using humour as therapy (58.1% of those who replied agreed this was important)

A modality specific clinic (for example – a nerve block clinic) (56.3% agreed this was important)

Booklets and Audiotapes of pain information (54.5% of those who replied agreed this was important)

Relaxation training (54.5% of those who replied agreed this was important)

Question 2.
In each of the following boxes, write your comments about **why you think people with chronic pain ranked this treatment as Not important**. Please add extra pages if you run out of room to write on.

Services of a Social Worker (91% of those who replied agreed this was **not important** for people with pain)
Internet Chatroom (87.3% of those who replied agreed this was **not important** for people with pain)
Homeopathy (83.7% agreed this was **not important** for people with pain)

Question 3.
The survey showed that people with chronic pain **did not** agree with one another about which treatments were important. We would like to know if you think this disagreement has any effect on the areas listed below. Please ring the number that best matches your opinion. Feel free to write in comments to explain your answer in the space below each item.

i. How much would it affect a person's **finances** if people with pain do not agree with each other about what treatments are important?

0 1 2 3 4

No effect moderate very marked effect

Why?

ii. How much **negative emotion** is caused when people with pain do not agree between themselves about what treatments are important?

0 1 2 3 4

No effect moderate very marked effect

Why?

iii. How much is the **success of treatment** affected when people with pain do not agree amongst themselves about what are important treatments?

0 1 2 3 4

No effect moderate very marked effect

Why?

iv. How much is the **relationship with service providers** affected when people with pain do not agree amongst themselves?

0 1 2 3 4

No effect moderate very marked effect

Why?

v. How much effect does it have on **what the public believes about pain** when people with pain do not agree amongst themselves?

0 1 2 3 4
No effect moderate very marked effect

Why?

vi. How much effect does it have on the **range of treatments available** when people with pain do not agree amongst themselves?

0 1 2 3 4
No effect moderate very marked effect

Why?

vii. What **other** things are affected when people with pain do not agree amongst themselves about which treatments are important?
(Please write in ____)

0 1 2 3 4
No effect moderate very marked effect

Why?

viii. **Other (write in**
____)

0 1 2 3 4
No effect moderate very marked effect

Why?

Please add any additional responses on an extra sheet of paper.

Question 4.
Please select the top 3 things that can influence decisions about what treatment is important from the following list. Place a '**1**' beside what you think has the strongest influence, a '**2**' beside the 2nd strongest and a '**3**' beside the 3rd strongest influence. If any thing you believe should be in the **Top 3** influences is not on the list, please write it in the space provided.

' I decide if a treatment is important based on....':

☐ my past experience

☐ advice from a healthcare provider (doctor, nurse, physiotherapist etc)

☐ advice from a complementary therapist (chiropractor, aromatherapist, etc)

☐ what my family and friends recommend

☐ what I believe is causing my pain

☐ what I have found on an internet search

☐ what I have read in magazines and books or seen on television

☐ information provided by someone else with pain

☐ what I can afford on my budget

☐ Other (please write in ________________________________)

☐ Other (please write in ________________________________)

☐ Other (please write in ________________________________)

Thank you very much for taking part in this stage of the questionnaire. **Please mail** your form back in the enclosed, stamped and addressed envelope **within two weeks**. I will analyse the results and send you a report and the next stage of the questionnaire shortly after that.

Cary Brown
School of Health Sciences
University of Liverpool
cabrown@liv.ac.uk

Appendix 11: Service provider Delphi 1 questionnaire

Response code:______________

THE UNIVERSITY
of LIVERPOOL

Beliefs About Chronic Pain Treatments: Views of Service Providers and Service Users
Delphi
Round One

Date
CA Brown, Lecturer
School of Health Sciences
Service Provider Questionnaire

Chronic Pain Delphi Questionnaire
Round One

Code: SP__________

Background
The report on the Stage One survey (enclosed) shows that Service Providers agree strongly about the importance of certain treatment components for chronic pain. The following questions ask why, in your opinion, the Service Provider group selected a treatment as important. The 10 most highly endorsed treatment components are listed below.

Please note: it is not necessary for you to respond to every question if you feel that it is not of interest to you or that you have no time. **Please just answer what you can and return the form in the enclosed envelope.**

Question 1.
Under each treatment component listed, write your comments about **why you think service providers ranked this component as important** for people with chronic pain. Please add extra pages if you wish to expand your response. The percentage of service providers who endorsed the specific component is identified in the (%)s. (see Table 3 in the report for details).

Services of a physician (94.9%)
Services of a psychologist (93.2%)
Psychological assessment (92.6)
Medication review (92.6)

Services of a physiotherapist (92.3%)

Graded Return to Activities of Daily Living (ADL) (89.9%)

Services of a Multidisciplinary Team (89.3%)

Education about pain (88.8%)

Relaxation Training (88.4%)

Print/Tape materials (88.4%)

Question 2.

Under each treatment component listed, write your comments about **why you think service providers ranked this component as <u>not important</u>** for people with chronic pain. Please add extra pages if you wish to expand your response. The percentage of service providers who endorsed the specific component is identified in the (%)s. (see Table 3 in the report for details).

Services of a Social Worker (44%)

Internet Chatroom (32.7%)

Homeopathy (26.2%)

Question 3.

Do you believe it matters if service providers agree on what are the most important treatments? (please circle your answer)

YES- it matters NO-it doesn't matter

If you answered **NO**, go onto Question 4.

If you answered **YES**, continue with the following ...

In your opinion, how much effect does it have if service providers do not agree on which treatments are important? Please select the number that most closely matches your opinion for each of the following categories. Please use the space under each category for any comments you would like to make. Also feel free to add any other categories you feel are needed.

ix. **Financial** 0 1 2 3 4
No effect moderate effect very marked effect

x. **Emotional effect on service provider**

0 1 2 3 4
No effect moderate very marked effect

xi. **Treatment outcome**
0 1 2 3 4
No effect moderate very marked effect

xii. **Relationship with patient/client**

0 1 2 3 4
No effect moderate very marked effect

xiii. **Public perception of treatment for pain**

0 1 2 3 4
No effect moderate very
marked

effect

xiv. **Range of treatments available**

0 1 2 3 4

No effect moderate very marked effect

xv. **Relationship with co-workers**

0 1 2 3 4

No effect moderate very marked effect

xvi. **Other effect (write in specifics here______________________________)**

0 1 2 3 4

No effect moderate very marked effect

Please add any additional responses on an extra sheet of paper.

Question 4.
From the following list please select the 3 most significant influences in your decision making about what treatment is important. Place a '**1**' beside what you think has the strongest influence, a '**2**' beside the 2nd strongest and a '**3**' beside the 3rd strongest influence. If any thing you believe should be in the **Top 3** influences is not on the list, please write it in the space provided.

' I determine if a treatment is important based on....':

- ☐ my past clinical experience
- ☐ what my patient expresses as a preference
- ☐ government and NHS guidelines
- ☐ clinical protocols developed by the treatment programme I work on
- ☐ consultation with my treatment team members
- ☐ the philosophical framework of my treatment programme
- ☐ what I have found in an internet search
- ☐ what I have read in current journals
- ☐ information provided by pharmaceutical companies
- ☐ what my patient is willing to try
- ☐ other (please write in ________________________________)
- ☐ other (please write in ________________________________)
- ☐ other (please write in ________________________________)

Thank you very much for taking part in this stage of the questionnaire. **Please mail** your form back in the enclosed, stamped and addressed envelope **within two weeks**. I will analyse the results and send you a report and the next stage of the questionnaire shortly after that.
Cary Brown
School of Health Sciences
University of Liverpool
cabrown@liv.ac.uk

Appendix 12: Information letter for service user

Dear

Last year you volunteered to participate in an interview about pain treatment beliefs. I'm very pleased to tell you that a total of 441 people participated in the study, which I believe shows that people think that this is an important topic. Because of this very positive (but large) volunteer response, I shall use a Delphi method to gather further information.

Q. 'What is Delphi?'
Delphi method is a way of collecting and analysing the opinions of a group of people on a specific topic. In a Delphi study, you answer questions about your opinion on a given topic. After you return the questionnaire, I write a report based on these answers. Then a copy of this report and new questions are sent back to you. This way, you can compare your own answers with other peoples'. You also have time to think about your answers before completing the next round of questions. This Delphi study will also include a chance for service providers (like nurses and GPs) and chronic pain service users (like you) to look at and comment on each opinions.

Q. 'What were the results of the survey I answered last year?'
The survey you completed last year identified how much chronic pain service providers and service users agreed about what are important treatment components. The attached report (printed on yellow paper), shows that service providers in their professional groups (eg. Nursing, Physiotherapy, General Practitioner, etc) do not have strong agreement. When you look at the service providers' beliefs compared to the service users' beliefs there is even less agreement.

Q. 'What is the aim of this Delphi stage?'
The Delphi stage is to explore why there is so little agreement. It is also to find out what different groups believe is the effect of this disagreement. That's why the Delphi approach was selected for this phase. Delphi allows a large group of people to exchange ideas without the time or expense of meeting in person. It is flexible, you can think about the reports and answer questions at your own convenience. You can change your opinion and reflect on other people's ideas without pressures you might feel in a group setting.

This Delphi stage is about ideas, opinion and debate. You do not need to agree with everyone else. You can read more about the use of Delphi study at the **Scottish Network for Chronic Pain Research** website (www.sncpr.org.uk/delphi.htm).

Q. 'What are you asking me to do?'

- Read the report (on yellow paper) from phase one included with this letter.
- Complete the questionnaire in this pack (on blue paper) and send it back to me within 2 weeks.
- After about 8 weeks, you'll receive a second report to read and a new set of questions for you to fill out.
- There will be several rounds like this to gather all the opinions and then I will send you a final report for your own information.

Q. 'How long will it take?'
The people who piloted the questionnaire said it took between 60-90 minutes to complete in total. Most said they did it one question at a time (approximate time = 20 minutes per question) so they could think about their answers *without feeling* pressured. There is no need for you to respond to every question if you feel you have nothing to say – just send back the parts that you do want to comment on.

Q. 'How private are my responses?'
For the study purposes I have given you a code-number that will appear on all of the questionnaires I send you. However, no one else will be able to identify you. All of the study materials will be stored in a locked file drawer or on a computer that is protected by a password. No personal data that people could identify you by will be revealed at any time. You can withdraw at any time and if you request it I will return your raw data and delete it from future reports.

Q. 'Can e-mail be used to reply?'
I would be happy to send you the reports and questionnaire by e-mail. If you would like to receive information this way, please e-mail me at the following address (cabrown@liv.ac.uk).

Q. 'What happens now?'
Please read the report (on yellow paper) and then fill out the questionnaire (on blue paper) and send it back to me. If you have any questions or would like to receive the future questionnaires by e-mail, please let me know.

After the Round One questionnaires are returned and analysed I'll send you a report on what people said and the questions that arise from their comments.

Thank you again for your participation up until this point. I hope you will find the next phase interesting and thought provoking. If you want to contact me for any reason my e-mail is cabrown@liv.ac.uk or you can write me at the address below.

Sincerely,

Cary A. Brown, Lecturer
School of Health Sciences
University of Liverpool
Johnston Building, Brownlow Hill
Liverpool, L69 3GB

Appendix 13: Information letter for service providers

Dear ____________________

Last year you volunteered to participate in an interview about pain treatment beliefs. I'm very pleased to tell you that a total of 441 people participated in the study, which I believe shows that members of the Pain Society and people with pain think this is an important topic. Because of this very positive (but large) volunteer response, I decided that instead of interviews I will use a Delphi method to gather further information.

Q. 'What is Delphi?'
Delphi method is a way of systematically collecting and analysing the opinions of a group of experts on a specific topic. In a Delphi study, each participant receives a questionnaire seeking his or her opinion on the topic. The answers from the returned questionnaires are summarised into a report and new questions are generated from this information. Then a copy of the report and these new questions are sent back to each volunteer. In this way people can compare their own answers with the group's and reflect in their own time before completing the next round of questions. This process will ultimately include an opportunity for service providers and chronic pain service users to look at and comment on each others' reports.

Q. 'What were the results of the first survey?'
The aim of the first phase of the study (the survey you completed last year) was to identify the rate of congruence between what chronic pain service providers and service users believed were important treatment components. As you can see from the attached report, service providers in their professional groups (eg. Nursing, Physiotherapy, General Practitioner, etc) do not have strong agreement. When you look at the service providers beliefs compared to the service users there is even less agreement.

Q. 'What is the aim of this next stage?'
The aim now is to explore why there is so little agreement, and to find out what different groups believe is the effect of this disagreement. That's why the Delphi approach was selected for this phase. Delphi allows a large group of people to exchange ideas without the time or expense of meeting in person. It is flexible, you can think about the reports and answer questions at your own convenience. You can change your opinion and reflect on other people's ideas without time pressures or the constraints of group communications.

In the literature, this type of approach is called a 'Policy Delphi'. The policy Delphi is about ideas, opinion and debate. It is not intended to form a consensus of opinion and you do not need to finally agree with everyone else. The use of Delphi research approach has been growing in the health care literature and recently the **Scottish Network for Chronic Pain Research** placed a summary of the method on their website (www.sncpr.org.uk/delphi.htm).

Q. 'What are participants asked to do?'

- Read the report from phase one included with this letter.
- Complete the questionnaire in this pack and send it back to me within 2 weeks.
- After about 8 weeks, you'll receive a second report to read and a new questionnaire.
- There will be several rounds like this to gather all the opinions and then I will send you a final report for your own information.

Q. 'How long will it take?'

The people who piloted the questionnaire said it took between 30-60 minutes to complete at one go. Most said they did it one question at a time (approximate time = 15 minutes per question) and felt that allowed them to think about their answers without feeling pressured. There is no need for you to respond to every question if you feel you have nothing to say – just send back the parts that you do want to comment on.

Q. 'How confidential are responses?'

For the study purposes I need to give all participants a code number which will appear on all of your questionnaires. However, no one else will be able to identify you and all of the study materials will be stored in a locked file drawer or password protected for any electronic data. In the summary reports for each round, the data will be presented by profession and gender only. No identifying characteristics will be revealed at any time. You can withdraw at any time and if you request it I will return your raw data and delete it from subsequent reports.

Q. 'Can e-mail be used to reply?'

I would be happy to send you the reports and questionnaire by e-mail. If you would like to receive information this way, please e-mail me at the following address (cabrown@liv.ac.uk).

Q. 'What happens now?'

This questionnaire starts part two of the study Service Providers and Service Users Congruence in Beliefs Related to Chronic Pain Treatment Components. If you have any questions or would like to receive the future questionnaires by e-mail, please let me know.

After the Round One questionnaires are returned and analysed I'll send you a report on what people said and the questions that arise from their comments.

Thank you again for your participation up until this point. I hope you will find the next phase exciting and thought provoking. If you want to contact me for any reason my e-mail is cabrown@liv.ac.uk or you can write me at the address below.

Sincerely,

Cary A. Brown, Lecturer
School of Health Sciences
University of Liverpool
Johnston Building, Brownlow Hill
Liverpool, L69 3GB

Appendix 14: Delphi 1, Question 1 coding

14.i: Service users responses

SU1-1: Why is education about pain important?

Grouping title	**Respondent by code number**
1A learning = coping	852,488,840,808
1B Don't hurt yourself	836,832,418
1C You need accurate information	826, 843
1D To understand pain	853,847,833, 830
1E Decrease worries with right information	835,832,418,827
1F Emotional validation	846,847,802
1G Empowers/choices	839
1H gives me control	843

SU1-2: Why is education about posture important?

Grouping title	**Respondent by code number**
2A Comfort	808,852,
2B Prevent pain	835,853,836,846,847,840,832,808,830,827,843
2C fear of more pain	826,849,829
2D To know what is right	833,839

SU1-3: Why is physiotherapy important?

Grouping title	**Respondent by code number**
3A emotional support	*847,848*
3B Exercise/keep fit	846,833,*852,826,832,830*
3C Releases endorphins	846,839
3D Correct information	833,836,826,849,808, 848
3E Decrease fear of activity	835,829,839, 418, 843
3F Decrease pain	832,839

SU1-4: Why is pacing important?

Grouping title	**Respondent by code number**
4A prevent pain	835, 846,847,829,808,839,848, 418
4B builds self-confidence	826,843
4C prevent overdoing	833,829,830
4D learn patience with self	833,849,848
4E make life bearable	832
4F Control my own life	843,848

SU1-5: Why is Graded ADL important?

Grouping title	**Respondent by code number**
5A participate in normal life	847,852,826,835,849,827,839
5B Learn how to do things	846,830
5C Protect against pain and overdoing	833,808

SU1-6: Why is a support group important?

Grouping title	**Respondent by code number**
6A belonging and feeling understood	802,835,849,840,829,808,839,843
6B social support	835,826,836,846,847,832,830,827,843
6C Exercise programme	853,846,839

SU1-7: Why is humour important?

Grouping title	**Respondent by code number**
7A Seen as having a positive attitude	847,836,802,849,840,829,827,830
7B endorphins	846,839
7C Relax from anxiety	833
7D Diversion from problems	833,841,835,843
7E Accepted by others	808

SU1-8: Why is a modality specific clinic important?*
*This question has been deleted because, although selected as one of the ten (10) interventions by service users during the survey stage, very few people commented on it in the Delphi 1. It is possible that the people who supported it were not amongst the group who responded to the survey.

SU1-9: Why are books/tapes about pain important treatments?

Grouping title	**Respondent by code number**
9A to get more information	847,835,840,830,839
9B getting information is a way of coping	829,848
9C gives power over my life	843
9D flexible, I control when & where I use it	848

SU1-10: Why is relaxation training important?

Grouping title	**Respondent by code number**
10A Coping with anxiety	835,836,847,843
10B Knowing reduces pain	841,840,829,808,839,848
10C Flexible, I control where and when	836
10D Allows me to socialise	847
10E Decreases muscle tension	829,839,830

14ii: Groupings organised by sub-themes and, subsequently, themes (Consciousness model)

Groupings	**Number of groupings in sub-theme**	**Sub-themes**	**Theme**
▪ *you need accurate information (1C)* ▪ *you need to know what is right (2D)* ▪ *you need the correct information (3D)* ▪ *learn how you should do things (5B)*	4	Doing it right	**Coherence** (total groupings in theme = **8**)
▪ *learning is coping (1A)* ▪ *so you understand pain (1D)* ▪ *to get more information (9A)* ▪ *knowing reduces pain (10B)*	4	Being informed	
▪ *don't hurt yourself (1B)* ▪ *increases comfort (2A)* ▪ *prevents pain (2B) & (4A)* ▪ *releases endorphins (3C) & (7B)* ▪ *decreases pain (3F)* ▪ *prevents overdoing (4C)* ▪ *protect against pain & overdoing (5C)*	9	Keeping pain free	**Purposiveness** (total groupings in theme = **15**)
▪ *exercise and keep fit (3B)* ▪ *exercise programmes (6C)*	2	Keeping fit	

▪ *learning patience with self (4D)* ▪ *social support (6B)*	2	Keeping emotionally strong	
▪ *participate in normal life (5A)* ▪ *decrease tension & stiffness (10E)*	2	Keeping able	
▪ *emotional validation (1F)* ▪ *emotional support (3A)*	2	Pain is legitimate	**Sense of Self** (total groupings in theme = **13)**
▪ *Empowers/choices(1G)* ▪ *gives me control (1H) & (4F)* ▪ *builds self-confidence (4A)* ▪ *getting information is a way to cope (9B)* ▪ *gives me power over my life (9C)* ▪ *gives me flexibility (9D) & (10C)* ▪	8	In control	
▪ *seen as having a positive attitude (7A)* ▪ *diversion from pain to normal tasks(7D)* ▪ *accepted by others (7E)*	3	Normal	
▪ *decreases worry (1E)* ▪ *fear of more pain (2C)*	2	Fear of pain	**Affect** (total groupings in theme = **7)**
▪ *belonging and feeling supported(6A)*	1	Fear of isolation	
▪ *learn patience with myself (4D)* ▪ *makes life bearable (4E)* ▪ *relax from anxiety (7C)* ▪ *coping with anxiety (10A)* ▪	4	Anxiety & loss	

14.iii: Service provider responses

SP1-1: Why is a doctor important?

Grouping title	**Respondent by code number**
1A Controls resources	51,148,2,189,53,22,290,198,336,126,362,14 ,346,54,193, 280,318,345,123,79,56
1B Credible to others	266,20, 276,223,362,171,341,39,25,345,79,370
1C Expert knowledge	106, 298, 280,343, 332, 257
1D Reassuring to SU	148, 293,6,2,198,120,276,39, 146,343,309,262,190
1E Diagnostic skills	151,158,185,258,221,189,229,20,290,336,120, 276,223,267,29,208,41,355,362,168,171,89,101, ‘X’, 346, 42, 116, 210, 111, 289, 275, 318, 345, 44, 273, 123, 79, 56, 309, 178, 332, 138
1F Treatment skills	293, 6, 292, 263, 158, 250, 258, 221, 32, 20, 22, 336, 120, 152, 298, 168, 171, 260, 346, 210, 275, 44, 273, 123, 56, 370, 343, 178, 257, 299
1G Cultural Expectations	158, 69, 22, 290, 126, 298, 168, 327, 14, 39, 146, 25, 370, 190
1H Educate others	185, 223, 171, ‘x’, 346, 111,289, 43, 273
1I Lead others	189, 336, 106, 298, 14, 116, 111, 289, 280, 146, 275, 44, 178, 257, 299
1J Secure funding	298, 79
1K fits theoretical model	316, 256

SP1-2: Why is Psychologist Important?

Grouping title	Respondent by code number
2A Explain body/mind	346, 168, 185, 2, 6, 266, 56, 309, 123
2B Treatment skills	346, 42, 'x', 101,89, 283, 171, 168, 298, 152, 355, 267, 223, 120, 106, 22, 189, 221, 258, 185, 158, 292, 275, 43, 44, 345, 343, 178, 299, 69, 190
2C Diagnostic Skills	101, 89, 298, 41, 120, 290, 221, 258, 292, 205, 318, 44, 345, 343, 59, 79, 257
2D Explain psychology of pain	14, 327, 298, 198, 193, 111, 341, 210, 54, 275, 25, 39, 257
2E expected member of team	89, 69, 32, 250, 158, 151, 229, 56
2F Explain Emotion = pain	283, 189, 29, 126, 229, 25
2G teach coping	171, 362, 298, 208, 29, 276, 336, 22, 53, 20, 189, 258, 2, 6, 293, 151, 266, 59, 331, 309, 190, 332
2H Screen malingerers	41, 210, 289
2J support team	276, 120, 318, 79, 138
2K Train team	276, 120, 318, 146
2L Unique skills	116, 318, 39, 280, 44, 316, 138, 106

SP1-3: Why is a psychological assessment important?

Grouping title	Respondent by code number
3A assess for motivation for treatment	266, 2, 20, 53, 41, 283, 280, 25, 44, 123, 79, 138
3B how to treat	205, 151, 258, 22, 120, 276, 208, 152, 298, 246, 210, 341, 289, 280, 79, 331, 178, 257, 262, 138
3C diagnose strengths	148, 263, 189, 89, 318
3D diagnose issues	292, 158, 32, 276, 152, 316, 106, 262
3E Diagnose pathology	2, 158, 20, 120, 355, 362, 'x', 42, 273, 343, 309, 299, 332
3F validate reality of SU pain	69
3G educate team	69, 336, 39
3H Set baseline/outcomes	53, 29, 39, 25, 343, 309, 299,
3I Established team member	171, 54, 111
3J Prove there is change to SU	309

SP1-4: Why is medication review an important part of treatment?

Grouping title	Respondent by code number
4A Prevent error	42, 101, 327, 283, 171, 362, 298, 152, 355, 41, 208, 29, 233, 276, 120, 106, 336, 198, 290, 22, 53, 20, 189, 32, 258, 185, 250, 158, 2, 263, 292, 293, 151, 205, 111, 210, 54, 116, 318, 275, 25, 39, 280, 44, 345, 343, 370, 316, 59, 79, 123, 273, 331, 309, 257, 190, 262, 332, 266
4B Educate SU	'x', 298, 276, 158, 148, 205, 229, 341, 146, 43, 273, 299
4C SU's expect pills	14, 51
4D Monitor for abuse	283, 208, 233, 258, 266, 289, 79, 331
4E Monitor for compliance	152, 29, 120, 151, 341, 289
4F SUs have different attitudes to pills	41, 69, 158, 343
4G SP belief in medication	126, 22, 6, 266
4H Support for SU	20, 229, 44
4I Save NHS £ /rationing	258, 293, 210, 56
4J Biochemical base of pain	256

SP1-5: Why is a physiotherapist important for treatment?

Grouping title	Respondent by code number
5A Restore fitness	266, 205, 263, 158, 221, 32, 189, 20, 276, 223, 29, 355, 152, 362, 168, 171, 327, 89, 'x', 42, 346, 341, 256, 289, 25, 275, 318, 44, 123, 79, 331, 309, 257, 262, 138, 190
5B Increase confidence	266, 148, 69, 198, 276, 41, 341, 43, 309, 252
5C Educate about pain	205, 293, 2, 189, 20, 198, 336, 298, 56, 59, 331
5D Pain control	205, 151, 258, 189, 53, 336, 106, 298, 56, 59, 331
5E decrease fear of movement	148, 293, 2, 267, 41, 171, 14, 89, 'x', 210, 111, 289, 39, 318, 79, 309
5F Assessment	151, 32, 276, 318, 345, 56
5G improve function	6, 292, 158, 185, 221, 20, 22, 106, 120, 126, 208, 41, 355, 283, 346, 116, 54, 111, 146, 343, 331, 178, 257, 332, 262
5H Expected member of team	42, 193, 280, 39
5J Expert knowledge	123, 316

SP1-6: Why is graded return to ADL important?

Grouping title	Respondent by code number
6A Improve function	346, 42, 171, 298, 152, 41, 263, 6, 266, 318, 25, 289, 44, 343
6B What SU wants	'x', 14, 362, 298, 126, 276, 120, 336, 318
6C Prevent reinjury	101, 283, 171, 208, 267, 53, 189, 2, 205, 39, 289, 316
6D ADL is a normal part of life	89, 171, 20, 293, 151, 123, 178, 332
6E Make SU feel more confident	171, 208, 106, 198, 69, 6, 151, 193, 210, 318, 79, 331
6F ADL improves QoL	298, 152, 198, 20, 189, 258, 158, 205, 266, 39, 331, 309, 257, 299, 190
6G ADL improves independence	152, 106, 53, 20, 258, 205, 210, 79, 123, 331, 309,
6H activity decreases pain	208, 20, 2, 59, 273
6I part of program goal	29, 22, 292, 341, 54, 116, 43, 39, 280, 345, 343, 123, 257
6J decreases costs of DA	279
6K decreases family conflict	158

SP1-7: Why is the MDT important?*

Grouping title	Respondent by code number
7A Combination of skills	44, 116, 151, 293, 22, 106, 89, 56, 123, 190, 289, 25, 318, 263, 2, 283, 273, 331, 257,
7B Spreads blame & responsibility	345, 263,
7C Support against difficult SU	345, 318, 210, 20, 'x', 309
7D complex problem required complex skills	290, 275, 266, 205, 292, 22, 336, 120, 276, 126, 208, 298, 171, 101, 42, 370, 178, 262
7E Reinforce SP message	289, 39, 25, 221, 189, 336, 276, 41, 'x', 309, 299
7F Holistic	332, 43, 146, 2, 158, 258, 20, 223, 152, 298, 14, 123
7G Evidence based	210, 111, 256, 205, 290, 198, 336, 362, 327
7H SU expect this	193
7I Team work is more effective	53, 189, 20, 346
7J Team learns from each other	276, 309
7K Teams are more equal	158, 223, 29

(*Some people misunderstood and responded from a SU perspective (why would the SU choose a MDT as important). These answers were not entered in the table.)

SP1-8 : Why is education about pain important?

Grouping title	Respondent by code number
8A Increase knowledge	346, 355, 29, 267, 223, 106, 290, 69, 221, 266, 289, 59, 79, 123, 262
8B Change beliefs about pain	42, x, 171, 208, 158, 263, 266, 256, 318, 146, 345, 370, 316, 331, 332
8C Acceptance and coping	101, 89, 151, 205, 341, 25, 343, 190, 283, 41, 205, 256
8D teaches self-management	362, 298, 41, 53, 20, 32, 258, 185, 292, 341, 210, 318, 49, 56, 331, 309, 299
8E improve compliance	298, 336, 22, 189, 151, 273, 178, 299, 151, 146, 299
8F decrease fear of injury	298, 152, 276, 120, 336, 198, 20, 189, 32, 6, 293, 148, 266, 39, 44, 123, 190
8G keeps SU realistic	126
8H Helps families understand	69, 343
8I promotes more active lifestyle	189, 39, 257
8J Less angry at Dr. when no cure	193
8K decreases costs to NHS	257

SP1-9: Why is relaxation training important for treatment?

Grouping title	Respondent by code number
9A improves self management	44, 318, 266, 205, 6, 185, 20, 69, 120, 355, 152, 298, 42, 331, 309, 262
9B Increases activity level	44
9C Part of CBT treatment	345, 341
9D Decreases muscle tension	289, 205, 189, 336, 276, 171, 42, 346, 273, 370, 343
9E Part of PMP	280, 256, 22, 41
9F Evidence base	39, 210, 292
9G Decreases pain cycle	43, 293, 2, 189, 20, 53, 126, 208, 262, 283, 89, 101, x, 273, 56, 59, 178, 190, 370
9H Decreases stress	25, 318, 210, 229, 151, 293, 263, 258, 32, 53, 198, 336, 106, 276, 29, 171, 273, 257, 299
9I Improves sleep	229, 205, 148, 293, 189, 20, 198, 336, 120, 332
9J Releases endorphins	205, 257
9K low cost	

SP1- 10: Why are print/tape pain education materials important for treatment?

Grouping title	Respondent by code number
10A improve understanding	346, 101, 290, 158, 148, 116, 39, 332
10B Reinforce teaching	42, x, 89, 283, 171, 298, 152, 355, 41, 29, 126, 276, 336, 20, 292, 151, 205, 256, 318, 146, 289, 44, 343, 370, 79, 123, 331, 309, 257, 299, 190
10C Share/educate others	X, 151, 205, 289, 79, 299
10D Alternative to group tx	171
10E Save consultants time	298, 126, 22, 256, 257, 190
10F Can learn at own pace/space	298, 41, 223, 276, 106, 69, 20, 258, 158, 263, 331, 262
10G Pain interferes with memory	208, 120, 6, 293, 193, 318, 25, 345, 44
10H SU has taken action	267
10I SU feeling of control	189, 263, 266, 273
10J improve compliance	229, 146, 39

14.iv: Service provider groupings organised by sub-themes and, subsequently, themes (Consciousness model)

Groupings	**Number of groupings in sub-theme**	**Sub-themes**	**Theme**
▪ *credible to others (1A)* ▪ *expected member of the team (2E), (3I) & (5H)* ▪ *SUs expect pills (4C)* ▪ *SUs have different attitudes to pills(4F)* ▪ *What SUs want (6B) & (7H)*	8	What others expect	**Coherence** (total groupings in theme = **29**)
▪ *leadership to others (1I)* ▪ *theoretical model (1K)* ▪ *part of programme goal (6I)* ▪ *part of CBT treatment (9C)* ▪ *part of PMP (9E)*	5	How service is organised	
▪ *expert knowledge (1C) & (5J)* ▪ *unique skills(2L)* ▪ *complex skills required (7D)* ▪ *increased knowledge (8A)* ▪ *helps families understand (8H)*	6	Specialised knowledge	
▪ *SP believe in medication (4G)* ▪ *biochemical basis of pain (4J)* ▪ *ADL improves QoL (6F)* ▪ *activity decreases pain (6H)* ▪ *need combination of skills (7A)* ▪ *holistic (7F)* ▪ *evidence-based (7G) & (9F)* ▪ *team work is more effective (7I)* ▪ *team learns from each other(7J)*	10	What SPs believe works	
▪ *treatment skills (1F) & (2B)* ▪ *prevent error (4A)* ▪ *prevent reinjury (6C)* ▪ *decreases muscle tension (9D)* ▪ *alternative to group treatment (10D)* ▪ *pain interferes with memory (10G)*	7	Doing treatment	**Purposiveness** (total groupings in theme = **65**)
▪ *diagnostic skills(1E), (2C) & (3C)* ▪ *assess motivation for treatment(3A)* ▪ *how to treat (3B)* ▪ *validate reality of pain (3F)* ▪ *assessment (5F)*	7	Doing diagnosis	
▪ *reassuring to SU (1D)* ▪ *support for SU (4H)* ▪ *decreases family conflict (6K)* ▪ *acceptance and coping (8C)*	4	Giving reassurance	
▪ *educate others (1H), (4B), (5C) & (10C)* ▪ *explain psychology of pain (2D)* ▪ *explain emotion and pain (2F)* ▪ *teach coping (2G)* ▪ *train team (2K) & (3G)* ▪ *improve understanding (10A)* ▪ *paced learning (10F)*	11	Giving education	

- *control resources (1A)* - *secure funding (1J)* - *screen malingerers (2H)* - *monitor for abuse (4D)* - *monitor for compliance (4E) , (8E) & (10J)* - *save NHS£/ration(4I)* - *decrease costs of disability (6J)* - *lower cost (9K)* - *save consultants' time (10E)*	11	Protecting resources	**Purposiveness** (continued) (total groupings in theme = **65**)
- *set baseline/outcomes (3H)* - *prove there is change (3J)*	2	Measuring outcomes	
- *explain body/mind link (2A)* - *validate reality of pain (3F)* - *ADL is normal part of life (6D)*	3	Normalising	
- *restore fitness (5A)* - *increase confidence (5B), (6E)* - *control pain (5D)* - *decrease fear of movement (5E), (8F)* - *improve function (5G), (6A),(8I), (9B)* - *change pain beliefs (8B)* - *acceptance & coping (8C)* - *able to self-manage (8D), (9A)* - *decrease pain cycle (9G)* - *decrease stress (9H)* - *improve sleep (9I)* - *release endorphins (9J)* - *SU takes action (10H)* - *SU feels in control (10I)*	20	Changing the SU	
	0		**Sense of Self** (total grouping sin theme = **0**)
- *spreads blame and responsibility* - *SU less angry at GP when 'no cure'*	2	Protecting SP	**Affect** (total groupings in theme = 7)
- *support team (2J)* - *support against difficult SU (7C)*	2	Supporting SP	
- *reinforce SP message (7E)* - *reinforce teaching (10B)*	2	Reinforce each others work	
- *teams are more equal (7K)*	1	Sharing power with other SPs	

Appendix 15: Validation of Delphi 1 Coding

Coding Validator Responses for Delphi 1			
	Validator 1 % agreement	Validator 2 % agreement	Average % agreement
Question 1 (coding of Service User responses)	68.5	60.0	64.3
Question 2 (coding of service provider responses)	78.3	56.7	68.1

[24]

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[24] Validators were given 10% of the service users' and service providers' responses (selected randomly) for the first 5 treatments in question 1 and all three of the treatments identified in Question 2. Provided with a list of categories of data that emerged from the participants' statements about each treatment, they identified which (if any) of the participants' statements they would sort into each category of data. There were also the options of proposing a different category or identifying participants as not having answered the question. At the end of this process the researcher identified whether there was agreement in the category assignment between both the original coding and the validators' coding.

Appendix 16: Delphi 1 report

(Note: font size and layout slightly altered to fit page size)

Beliefs About Treatment for Chronic Pain:

How Service Users and Service Providers
Decide Which Treatments are Important
Delphi Questionnaire One Report
February 2003

THE UNIVERSITY
of LIVERPOOL

Introduction

This report summarises responses to the Delphi Round One Questionnaire sent to participants in September 2002. Replies were received from 22 (68.7%) of the service users and 98 (44.5%) of the service providers.

The Round One Questionnaire asked people to comment on why they think certain treatment components were selected as important or not important. It also asked people how much effect they believed disagreement between each other would have on certain aspects of the chronic pain experience. Lastly, people selected the **3 most important influences** on their decision-making about pain treatments.

This report is a brief over-view of some very detailed findings. If you would like more information please contact Cary Brown by e-mail: cabrown@liv.ac.uk

RESPONSES TO QUESTION 1.

' How were the comments analysed?'

This question asked service users ' W*hy do you think people with chronic pain said this treatment component was important?'*. The 10 most frequently selected treatment components from the first survey were listed. Service providers were asked the same question, *' Why do you think service providers said this treatment component was important?'*. Again, the service providers' ten most frequently selected treatment components were listed.

The comments on each of the treatment components were sorted into groups. Usually 7-12 groups appeared for each treatment component. For example, when the service users were asked about 'W*hy is education about pain important?'*, all of the answers seemed to fit into the following groups:

A. Learning more helps people cope
B. Learning helps prevent re-injury
C. Learning gives you accurate information
D. Education helps people understand
E. Education decreases worry and stress
F. Education validates how I am feeling
G. Education gives me more choices
H. Education gives me more control over life

The same process was followed with the service providers. For example in the question *'why is graded return to activities of daily living important?'* all of the answers for this question seemed to fit into the following groups:

A. It helps people function
B. This is one of the patient's goals
C. Graded activity prevents re-injury/set back
D. Activity helps people have normal lives
E. To improve people's mood and self-confidence
F. To improve people's quality of life
G. To increase independence
H. To decrease pain
I. It is a goal of pain management programmes
J. It decreases the cost of disability
K. It decreases family conflict

'What did the analysis find?'

Chapman [25], a researcher in chronic pain, suggests that how aware we are of pain depends on what we believe the purpose of the pain to be, how it effects our emotions and how it makes us feel about ourselves. Awareness also depends on whether the pain makes sense to us. These four influences are called purposiveness (P), affect (A), self identity (S), and coherence (C).

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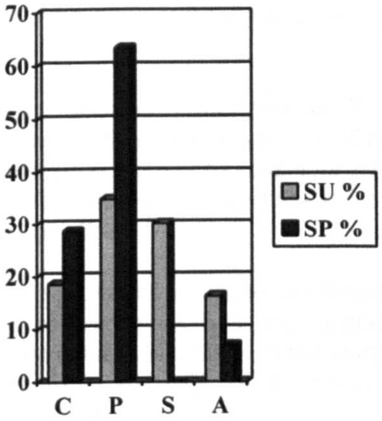
[25] Chapman et al (1999) Chronic pain and consciousness. In Psychosocial factors in pain Gatchel & Turk (ed). New York, Guilford Press.

Table 1. ***Important Treatments***



Key:
SU- Service User
SP- Service Provider
C- Coherence
P – Purposiveness
S – Self-image
A - Affect

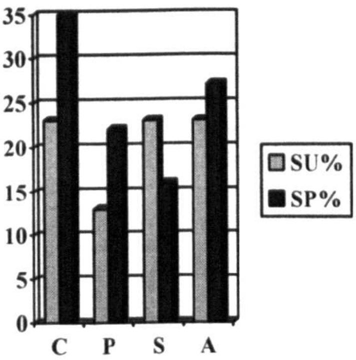
The groups of comments mentioned on page 1 were sorted into these 4 categories. Some clear differences between how many of the service user and service providers' answers fit within each category were seen (Table 1).

Generally the service users' answers were spread across all four categories. Answers that related to the purpose of a treatment and how it affected their self-identity occurred most often. The service providers' answers were mostly related to the purpose of the treatment and that the treatment is coherent (makes sense with what one believes). Service providers gave few answers that fit the affect and self-image categories.

RESPONSE TO QUESTION 2.

This question asked '*Why do you thing that people said these three treatment components were not important?*. Each treatment component was analysed in the same way as question 1. The response groups were sorted into the four categories (C, P, S, A) and the results summarised in the table at the top of the next column.

Table 2. ***Unimportant Treatments***



Like Question 1, the number of answers within each theme in Question 2 differs between service users and service providers.

Service users seemed to feel that certain treatment components were *not important* because they did not make sense as treatments for chronic pain. Also these treatment components did not fit with their image of someone coping with pain.

Service users' answers also showed some general distrust and fear that these treatment components could increase pain. Their answers reflected an overall feeling that these three treatment components had little use in treating pain. The Service user answers must be interpreted with caution given the small group size.

The types of answers service providers' gave covered a wider range within each theme. Service providers believed that these three treatment components either were not correct given current medical thinking in the area of chronic pain or were not considered common practice.

It was interesting that in the theme of self-image service providers made statements interpreting the emotion of service users. Although not conclusive, it is possible that service providers may see 'speaking on behalf of service users' as part of their role.

Lastly, there were more responses in the service providers' affect theme for Question 2 then for Question 1. Distrust was frequently expressed, as were concerns over controlling and preventing the spread of incorrect information. Several service providers said that, in their opinion, other service providers made decisions based on fear of challenges from service users. They also thought some service providers were anxious about their own lack of knowledge.

QUESTION 3.

Service users were asked to comment on how much effect they believe it would have if service users did not agree with other service users. The categories they were asked to comment on were

- *financial*
- *emotional*
- *treatment outcome*
- *relationship between service user and service provider*
- *public perception of treatments for pain*

and

- *the range of treatments available*

Service providers were asked the same question regarding the effect of disagreement between service providers. The responses were rated between 0 (no effect) to 4 (very marked effect).

Service users' most often selected ***'2-moderate effect'*** except when asked about the '*public perception of treatment for pain'*. For that the most frequent (median) score was '***3-marked effect'***.

Service providers tended to rate disagreement between themselves as having a higher impact and the most frequently selected score (median) for all categories (i-*vi)* was '***3-marked effect'***.

Analysis[26] found statistically significant relationships for the three categories of

- *financial effect*[27]
- *effect on treatment outcome*[28], and
- *the relationship between service user and service provider*[29].

For all three of the areas service providers believed there would be a higher effect if they disagreed amongst themselves. The other areas of *emotional effect, public perception of pain treatments and the range of treatments available* showed no relationship.

Summary of responses to each category

Participants gave many comments to support their opinion. They are too numerous to report here and have been summarised instead. At the end of each summary examples of participants' comments are given in *italics*.

i. The first category was the perceived **financial** effect of disagreement.
Service users and service providers' comments were different. Service users' comments were related to personal finances and did not mention anything about NHS funds for pain management. Service Providers were the opposite. They had concerns about funding for programmes but few mentioned financial cost to service users.

Service Users: *' You have a low income because of pain and cannot afford all the treatments, My work is at risk because employers do not understand pain, Allowances and benefits might not allow for expensive treatments'*

Service Providers: – 'Funders will not allocate resources to a service that cannot decide what it wants; May conflict with what the Trust is able to afford, Failure to focus on most effective treatment; Will effect results and potential for further funding, Purchasing power effects treatments available; Detrimental outcome on management and therefore wastes resources'

ii. The second category was about any **emotional** effect when there is disagreement. Service users were concerned about being individuals and not being influenced by others 'negativity'. The service providers' comments showed a concern for mutual support amongst professionals and for presenting a 'united front' and staying credible to service users and external agencies.

Service Users: ' People all have different emotions; No two people are alike in their chronic pain experience; We all have different views on most things; I don't consider it any of my business what other people think'

Service Providers: ' Frustrating at the point of patient contact; Doesn't matter to money-holders; Especially if patient sees several service providers in the same institution which give opposite advice (demoralising); Feelings of dissonance; Dysfunctional team or professional working'

iii. The third category concerned how much effect there is on the **success of treatment** when there is disagreement. Service users' comments reflected a belief that treatments are individually suited to people and that disagreement with other service users has little bearing on this. Service providers were concerned that 'mixed messages' from professionals will confuse clients and perhaps prevent acceptance of certain types of intervention.

Service Users: *'You will always find a treatment that works for one does not work for another; It is my pain and I try to use what is offered; Most people see their treatment as a personal matter; Each person has to try different treatments and hopefully find the one that suits; Many people are negative and say nothing has worked in the past'*

---

[26] (Mann-Whitney U Test)
[27] p=.003
[28] p=.004
[29] p=.007

Service Providers: 'Confidence levels of patients need to be reinforced by service providers agreeing on best treatment; Conflict between providers on what is best may not help the pain; User cannot have contradiction in treatment; If everyone is 'singing the same tune' it must have an effect on outcomes!?; Already mixed messages from medical model; Chronic pain patients will pick up the disagreement and this adds to their confusion as to what is best to do'

iv. The fourth category concerned how much the **relationship between service users and service providers** is affected when people with pain disagree amongst themselves about what treatments are important. Service users' comments showed a belief that the relationship between a patient and a service provider is individual and not strongly influenced by other service users' opinions about treatments. Service providers' comments however, seemed to indicate a belief that professionals must be consistent in their treatment endorsements to prevent confusion and frustration in service users.

Service Users: *'It is no good if service providers try to treat everyone the same; If I didn't have access to various treatments it would create a negative relationship; People tend to put too much faith in service providers and this trust can be affected by other people's beliefs'*

Service Providers: 'Relationship suffers, the patient needs consistency from the team; It makes justification of your preferred treatment difficult if others want to do something different – the patient gets confused and annoyed; Danger of push/pull between professions'

v. The fifth category was the effect on **what the public believe** about pain when service providers and service users do not agree amongst themselves about what treatments are important. Service users' comments reflect a belief that pain is not of interest to anyone who has no pain and that this lack of interest could at times translate into lack of support for certain treatments (e.g. funding reduction to programmes). Service providers' comments also indicate that they see the general public as lacking in knowledge about pain, pain treatment and that disagreement between professionals causes confusion and undermines credibility. A trend seems to be emerging of service users valuing individuality (*pain is my own experience*) and service providers being concerned for consistency and credibility (*the right answer).*

Service users: *'If you have no pain you would not understand; people see you and think you are all right even if you are in agony; If you haven't got pain you are not really bothered about it; You don't know about chronic pain unless you have it'*

Service providers: 'People are confused who to believe- but do we give them personal choice if we decrease treatment options or service; Presents an image of chaos and misunderstanding of pain problem; Would seem chaotic treatment; If we are not clear we cannot give a clear message to non-specialist clinicians or the public; People are confused who to believe- but do we give them personal choice if we decrease treatment options or services'

vi. The sixth category was how the **range of treatments** available is affected when service users and service providers do not agree about what are important treatments. Service users' comments showed that they were concerned about having individually suited treatments. They raised the issue of limited resources and the need for action coalitions to ensure resources were available for the treatments they wanted. Service providers were less concerned with the desire to 'customise' programmes for people with pain but did focus on how a lack of agreement could result in lost resources.

Service users: *' Providers should provide for individuals, not try to treat all the same; Each sufferer is an individual with her/his own problems and symptoms; The range of what one person likes might not be best for me; I need to be selfish and pick the treatments best for me; Service providers may stop trying new treatments ; Nobody listens to whingers anyway'*

Service providers:' We are often limited in chronic pain programmes in what we can offer; If we disagreed some people wouldn't know what to offer; If we only use treatments that we all agree on people will be exposed to fewer and may not encounter the one that helps them move forward.'

vi viii. The final category was for <u>service providers only</u> who commented on how **relationships with co-workers** could be affected by disagreement about which treatments are important. Comments reflect a concern for group cohesion, cooperation and consistency. There were no comments suggesting that multiple opinions were of value to allow the client selection from a range of individualised treatment. The median response was '3 (marked effect)'.

> 'Essential to ensure people receive reinforcement of pain management principles; If a team does not agree certain aspects will be under/over emphasised; to the detriment of the overall message; Arguments, discord, splitting into subgroups;
> *If you do not work as a team it will reflect on how you treat the patient'*

Other write-in comments on this question from Service Users:

- *'people can become insular; people will stop communicating and moral is effected'*
- *'family members can lose patience; you avoid discussing pain if you can help it'*
- *'Pain is your own, it is not about groups of people'*
- *' can lead to mistrust, frustration and misunderstanding'*

Other write in comments on this section from Service Providers:

- 'service provider disagreement can have an emotional effect on service user'
- 'uncoordinated approach and disagreement will give the public a message that professionals do not know what they are doing'
- ' patients can lose confidence in conventional medicine-explore unproven methods OR become depressed AND fail to keep appointments equalling a big loss of resources (for others)'
- ' if all providers have agreement then treatments are more likely to have effect and weight to obtain the best resources; peer support external to the team is also effected; disagreement can cause delays in appropriate treatment'
- ' this all depends on how large the disagreement is and how apparent to service users'

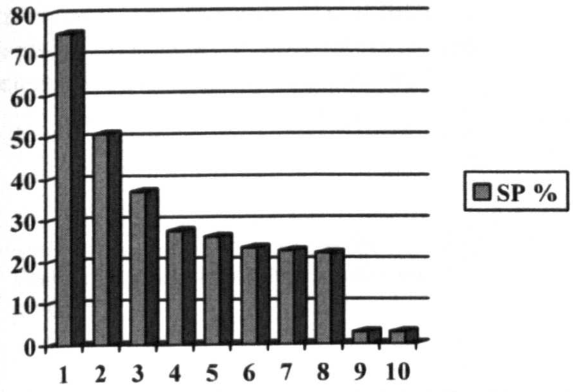
Table 3. *Summary of trends*

Service User Trends	Service Provider Trends
A. Pain is individual	A. It is important to present a consistent approach
B. If you don't have pain you cannot understand it	B. It is important to maintain service user confidence through minimizing conflicting information
C. Treatment should be individual, not the same for everyone	C. Lack of team agreement can have resource implications and make getting funding difficult
D. Treatment that works for one person does not work for everyone	D. Conflicting messages will increase service user frustration and make them search outside traditional medicine for answers
E. Negative comments from other people can have consequences and should be avoided	

RESPONSES TO QUESTION 4

This question asked service users and service providers to identify *the 3 most significant influences on decision-making* about treatments from a list of 9 (with the option of writing-in other influences if desired). The following tables summarise the order in which service users and service providers ranked influences on their decision-making.

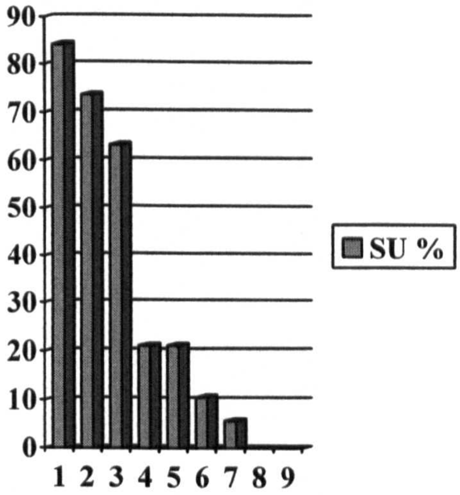
Table 4. Service Provider Frequency of Selection for Decision Making Variables



Key: Decision-making variables

1. Professional experience
2. Consultation with team members
3. Service user preference
4. Journal reports
5. Team philosophical framework
6. Clinical protocols developed by the team
7. What the service user is willing to try
8. Government & NHS guidelines
9. Pharmaceutical company information
10. Internet information

Table 5. ***Service User Frequency of Selection for Decision Making Variables***



Key: Decision Making Variables

1. Service provider advice
2. Past experience
3. What I believe
4. Advice from a Complementary therapist
5. Advice from an other service user
6. Information in a magazine
7. What I can afford
8. Internet information
9. Advice from my family

(Table 6 on the following page presents the specifics of the above graphs).

Years in Practice

The data was also reviewed to see if the number of years a service provider had been in practice had any affect on the decision making influences they selected[30].

This review found that service providers who were in practice longer tended to have their decisions influenced by '*What the service user is willing to try*[31]'.

Other Relationships

The same analysis reviewed relationships between the decision-making features themselves.

Service providers who selected '*Professional experience*' as a top influence of their decision making were more likely to also select '*What the service user prefers*'.

They were less likely to select:

- '*NHS Guidelines*'
- '*Team developed protocols*' *and,*
- '*The model of practice used by the team*[32]'

---

[30] Pearson's product moment correlation.

[31] p=.041

[32] p=.027, p=.032, p=.001 & p=<.000 respectively)

Table 6: *Service user and provider decision-making variables*

Service User (%)	Frequency selected	Service Provider (%)	Frequency selected
Service Provider Advice	16 (84.2)	Professional experience	55 (75.3)
Past experience	14 (73.7)	Consult with team	37 (50.7)
What I believe	12 (63.2)	Service user preference	27 (37.0)
Advice from a Complementary Therapist	4 (21.1)	Journals	20 (27.4)
Advice from another Service User	4 (21.1)	Team philosophical framework	19 (26.0)
Information in a magazine	2 (10.5)	Clinical protocols developed by team	17 (23.3)
What I can afford	1 (5.6)	What the service user is willing to try	16 (22.5)
Internet information	0	Government & NHS guidelines	16 (21.9)
Advice from my family	0	Pharmaceutical company information	2 (2.8)
		Information from the internet	2 (2.7)

SUMMARY

This report has attempted to summarise the large amount of information participants generously provided from the
Delphi Round 1 survey. While the report does not include all of the comments made, it does try to capture the general trend of responses. If you would like more specific detail about any of the questions please contact the researcher.

Overall, the responses seem to indicate that service users and service providers had different opinions about how important it is to agree about treatments and the effect of any disagreement. Service users rated the impact of disagreement lower and service providers felt that the impact of disagreement would be higher. Service users often stated that their pain was individual to them and others' beliefs were not that important.

Service users and providers also seemed to be influenced in different ways as to how they decided what treatments were important. Service users were guided by service providers, what they personally believed about a treatment and how it made them feel physically and emotionally.

Service providers were influenced more by past experience and the other members of the team rather than government and NHS guidelines. They also identified that what service users wanted was an important feature in reaching a decision about which treatment was important.

PLAN

Comments in this report need to be examined by the participants to see if they agree with the researcher's summary. The report will be sent to all of the service users and providers who originally volunteered, regardless if they responded to the Delphi Round 1 survey or not. This will help to ensure that as many opinions as possible are gathered and shared.

A Delphi Round 2 survey is included with this report. It is intended to gather feedback about how accurately this report reflects the opinions of the participants. It also contains questions to explore what actions participants think need to occur to improve understanding of treatment importance between service users and service providers.

CA Brown

March 2003

Appendix 17: Delphi 2 questionnaire

Response code_____________

Beliefs about Treatment for Chronic Pain
Delphi Questionnaire Two
March 2003

Instructions: First read the attached Delphi Study 1 report. The following questions will ask your opinion about what is in that report.

Part 1

In the last questionnaire you filled out, question 1 asked participants to say why they thought certain treatments for pain were important. The Delphi I report summarises what people said. The comments people made have all been sorted into 4 broad themes. The themes are:

1. Coherence (Because this treatment makes sense*)*
2. Purposiveness (Because of what this treatment does*)*
3. Self-image *(*Because it fits a person's idea of who he or she is)
4. Affect (because of the emotional feelings one has about this treatment).

Please think again about the reasons you selected some treatments as important. Now complete each of the following statements by circling the response that best matches your opinion.

' My reasons for thinking a treatment is important are guided by.....

	Not at all	A little	Some-what	Mostly	Completely
Whether the treatment makes sense to me	0	1	2	3	4
The purpose of the treatment	0	1	2	3	4
Whether someone like me would think this treatment was important	0	1	2	3	4
How this treatment makes me feel	0	1	2	3	4

Comments:

Part 2

The same four themes were also used to group the comments about why a treatment is *not important.* Please think again about the reasons you selected some treatments as not important. Now complete each of the following statements by circling the response that best matches your opinion.

' My reasons for thinking a treatment is not important are guided by.....

	Not at all	A little	Some-what	Mostly	Completely
Whether the treatment makes sense to me	0	1	2	3	4
The purpose of the treatment	0	1	2	3	4
Whether someone like me would think this treatment was important	0	1	2	3	4
How this treatment makes me feel	0	1	2	3	4

Comments:

Part 3

All of the responses from question 3 in the report have been summarised into statements. **How much do you agree** with each of following statements? **Please circle the number that best matches your opinion.**

'I agree....	not at all	a little	Some-what	mostly	completely
Service providers are more concerned than service users about costs to the NHS	0	1	2	3	4
Service users are concerned about being seen as individuals	0	1	2	3	4
Service providers feel it is important to be consistent in the information provided by the team	0	1	2	3	4
If service users are given too many options it will confuse them	0	1	2	3	4
Service users are not strongly influenced by the opinions of other service users	0	1	2	3	4
People who do not have pain will have no opinion about what services should be provided.	0	1	2	3	4
Disagreement about treatments will result in lost credibility to the public.	0	1	2	3	4
If there are too many options there will not be enough resources to cover the basics.	0	1	2	3	4
Service users can get more resources if they lobby together	0	1	2	3	4
Service users benefit most from a standard set of treatments prescribed by a team of service providers.	0	1	2	3	4

Service users benefit most from treatments selected individually by themselves and their service provider.	0	1	2	3	4
All service providers in a team should agree on what treatments they feel are important.	0	1	2	3	4

Comments:

Part 4 SERVICE USER Influences

Table 4 on page 7 of the report shows what influences service users when deciding which treatments are important. Each influence is listed below in the order that all the service users rated them in the last survey.

Please put YOUR ranking for each influence in the space provided .

(1 = most significant influence, 9= least significant influence.)

Influence on decision-making	Ranking results from Delphi 1	Your ranking
Service provider advice	1	
Past experience	2	
Personal beliefs	3	
Complementary therapist advice	4	
Other service user advice	5	
Magazine information	6	
What I can afford	7	
Internet information	8	
Family advice	9	

Comments:

Question B:

Do you have any specific concerns based on this information? If so, please list them in the following space.

Part 5 SERVICE PROVIDER Influences

Table 5 on page 7 of the report shows the influences service providers have when deciding what treatments are important. Each influence is listed below in the order that all the service providers rated them in the last survey

Please put YOUR ranking for each influence in the space provided .

(1 = most significant influence, 10= least significant influence.)

Influence on decision-making	Survey result rating	Your ranking
Professional experience	1	
Consultation with team members	2	
Service user preference	3	
Journal reports	4	
Philosophical framework of team	5	
Clinical protocols developed by the team	6	
What the service user is willing to try	7	
Government and NHS Guidelines	8	
Pharmaceutical company information	9	
Internet information	10	

Comments?

Question B:
Do you have any specific concerns based on this information? If so, please list them in the space provided:

Many respondents to the Delphi 1 questionnaire thought it could cause problems when service users and providers assumed that they agree about what treatments are important. The comments are summarised in the Delphi Survey 1 report (page 3 to 6).

Do you think any **action** should be taken if service users and providers have different views about what treatments are important? (please circle)

YES **NO**

If you circled YES, list what actions you think are needed. Do not worry about whether you think the action is possible right now. We want to gather as many of your ideas as possible at this point, so please write down all of your ideas.

Part 7

The same report from this survey goes to all participants, both service users and providers. You may have formed some opinions when reading other people's responses to the survey. This is an opportunity for you to give advice about what you think people need to be aware of in order to improve treatment for chronic pain.

You may choose to make your comments by completing the statements below. Or, you can make more specific comments. Just draw a line through the printed statement and write in your own comments instead. Please add extra pages if you wish to make a longer comment.

Statement 1

' I think service providers need to .....

Statement 2

'I think service users need to.....
(please add extra pages if you wish)

Thank you very much for taking the time to complete this part of the study. I hope you have found it interesting. Even if you decided not to complete the questionnaire this time around, please return the blank form to me. If you could return it (completed or uncompleted) to me within three weeks I would be very grateful. There is a stamped, addressed envelope in the pack for you to use.

'What happens next?'

Once I have the questionnaires back I will analyse them and send you a report as soon as it is available. This will likely be early September. The third, and final Delphi questionnaire will also be sent to you at that time.

If you would like more information on any part of the study I can be reached by e-mail at cabrown@liv.ac.uk

Again, my thanks for your participation and interest in this study.

Cary A. Brown, Lecturer
School of Health Sciences
University of Liverpool
Johnston Building, Brownlow Hill
Liverpool L69 3GB

Appendix 18: Delphi 2 covering letter

April 14, 2003

Dear study participant,

Last October you received a questionnaire for the first round in a Delphi Study seeking your opinions about why people said certain treatments for chronic pain were important and others were not. The questionnaire also asked what influenced your decisions about pain treatments. I'm very pleased to say that 120 people responded to this first round of the Delphi study. The enclosed report summarises the results of the questionnaire. I hope you will find the comments from everyone as interesting as I did.

The next stage of the Delphi study has two purposes. The first is to find out if people agree with how I have organised the responses. Questions about this are in the Delphi Round 2 questionnaire (green form) enclosed in this pack. Also, the Delphi Round 2 questionnaire asks your opinion about possible actions to take to improve chronic pain treatments.

Once the Delphi Round 2 questionnaires are all back to me I will prepare a second report so that you can see what everyone else thought as well. This way you have access to everyone else's comments throughout the study. You also have the opportunity to comment on what you have read in the reports at any stage.

Q: 'What should I do with the information in the pack?'

- Please read the enclosed Delphi Round 1 report.
- Now complete the Delphi Round 2 questionnaire (green form).
- Mail your completed form back in the enclosed envelope.
- If you decide not to complete the questionnaire, please mail it back anyway.
- Please try to return your Delphi Round 2 questionnaire form within the next 3 weeks.

Q: ' How many more rounds will there be?'

There is only one more round after this. The next questionnaire will focus on ideas for ways to make treatments for chronic pain better. Remember, you can comment as much or as little as you want at any of the rounds. Your opinions are important and I hope you will be interested in sharing them.

Q: 'Where else will the information from this study go?'

I appreciate the time people have taken to share their thoughts and ideas. I believe it is important to share the information from this study as widely as possible so others will benefit from your efforts as well. Parts of the findings to date have been published in 3 different journals and have been presented at both the national College of Occupational Therapists' conference and the World Federation of Occupational Therapists' conference in Stockholm last year. A poster about service users beliefs was presented at the Pain Society conference in Glasgow this April. I am working hard to share your ideas and opinions with as many people as possible and I would welcome any other suggestions you have about what else should be done to distribute the reports.

Thank you again for your participation up until this point. I hope you will find the next phase exciting and thought provoking. If you want to contact me for any reason my e-mail is cabrown@liv.ac.uk or you can write me at the address below.

Sincerely,

Cary A. Brown, Lecturer
School of Health Sciences
University of Liverpool
Johnston Building, Brownlow Hill
Liverpool, L69 3GB

Appendix 19: Delphi 2 report
(font and layout modified to fit page)

THE UNIVERSITY
of LIVERPOOL

Beliefs about treatment for chronic pain:
Influences on Service user and Service provider decisions about treatment importance and the actions they recommend

Delphi Questionnaire Two

September 2003

CA Brown
School of Health Sciences
University of Liverpool
cabrown@liv.ac.uk

Introduction

People made many interesting comments in the Delphi 2 questionnaire. The response rate was good for this type of in-depth questioning: 90 (40.9%) Service providers (SPs) and 16 (50%) Service Users (SUs) in total replied. Although 43 of the participants from the Delphi I questionnaire opted out this round, 35 service providers who had not participated in Delphi I opted back into the study. This is a strength of the Delphi approach- people can participate as and when hey are able or interested. This report is a very brief over view of all the information that people provided. For more detailed information please contact the researcher by e-mail: cabrown@liv.ac.uk

Summary of Findings

This report covers the key findings from the wealth of information generously provided by participants.

The Delphi 2 survey showed that for the SUs and SPs who responded:

@ SUs think purposiveness, coherence, self-image and affect influence their decision-making but SPs think **only** purposiveness and coherence influence their decision-making.

@ SUs and SPs agreed that:

1. *Service providers are more concerned than service users about costs to the NHS*
2. *Service users are concerned about being seen as individuals*
3. *Service users benefit most from treatments selected individually by themselves and their service provider*
4. *All service providers in a team should agree on what treatments they feel are important*
5. *Service users can get more resources by lobbying*

@SUs believe more strongly than SPs that:

1. *People who do not have pain will have no opinion about what services should be provided (p=.005)*
2. *Disagreement about treatments will result in lost credibility with the public (p=.012)*

@ SU & SP agreed that service users were most strongly influenced by:

- *service provider advice*
- *past experience*
- *personal beliefs*

@ SU & SP agreed that service providers were most strongly influenced by:

1. *SP experience*
2. *consultation with the team*
3. *SU preferences*

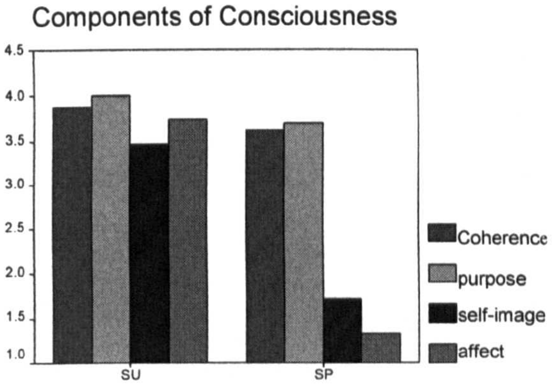
@ Most actions recommended by both groups involve service providers demonstrating to service users that they have been provided with the correct treatment.

@ SU & SP's comments to each other concern communication, validation, treatments, advocacy and being open to new ideas.

Specific findings for each part of Delphi 2

Part One
People were asked how much their decision-making about what treatments are important was influenced by the following four themes:

1. Coherence (*does the treatment make sense?)*
2. Purposiveness (*What does this treatment do?)*
3. Self-image *(is this a treatment for a person like me?)*
4. Affect *(how does this treatment make me feel?)*



Delphi 2

Service users and providers agreed that *coherence* and *purposiveness* influenced their decision-making. Service users also believed that self-image and affect were influences but service providers did not agree [33]. SP said these two items did not influence their decisions about what treatments for pain are important.

Part Two
People were also asked how much their decision-making about what treatments are **not important** was influenced by the four themes. The differences between SU & SP answers were still present but not as great. Some people commented that the question was confusing and this may have influenced the answers.

Discussion
Why were the four themes more accepted by the SU then by the SPs? Some research says that healthcare providers are taught to avoid looking at or expressing their own emotions [393]. Research also suggests that when service providers do not acknowledge emotions there can be negative results to their own health and to the health of their patients [270, 394].

Part Three
Twelve statements representing comments from the first questionnaire were presented and people said if they still agreed with them.

Both SP and SUs agreed with the following statements:

1. *Service providers are more concerned than service users about costs to the NHS*
2. *Service users are concerned about being seen as individuals*
3. *Service users benefit most from treatments selected individually by themselves and their service provider*
4. *All service providers in a team should agree on what treatments they feel are important*
5. *Service users can get more resources by lobbying*

Both SU & SPs **disagreed** with four other statements:

1. *Service providers feel it is important to be consistent with the information provided by the team.*
2. *If service users were given too many options it will confuse them.*
3. *If there are too many options there will not be enough resources to cover the basics.*
4. *Service users benefit most from a standard treatment prescribed by a team of service providers.*

There was a difference of opinion between SUs and SPs about two statements. Service users **agreed** with the following statements significantly [34] stronger than did service providers:

1. *People who do not have pain will have no opinion about what services should be provided (p=.005)*
2. *Disagreement about treatments will result in lost credibility with the public (p=.012)*

Lastly, although both SU and SPs agreed that *service users can get more resources by lobbying together*, SPs do not agree as much as Service users (p=.052).

---

[33] p=<.000

[34] Mann-Whitney U Test (independent sample of medians)

Table 1
Rankings of Influences on Decision- Making

SU Influences	**SU Original Ranking**	**SU 2nd Ranking**	**SP Ranking Delphi II**		
SP advice	1	2	1		
SU past experience	2	1	2		
SU beliefs	3	3	3		
Complementary therapist advice	4	4	5		
Other SU advice	5	5	4 △		
Magazine	6	6	7 ▽		
What SU can afford	7	5 ▲	8 ▽		
Internet Information	8	7	7		
Family advice	9	7 ▲	6 △		
SP Influences			**SP Original Ranking**	**SP 2nd Ranking**	**SU Ranking Delphi II**
Professional experience			1	1	1
Consultation with team			2	2	2
SU preference			3	3	3
Journal report			4	4	7 ▽
Philosophical framework			5	6	5
In-house clinical protocols			6	5 ▲	8 ▽
SU willing to try			7	7	6
NHS/DoH guidelines			8	8	10 ▽
Pharmaceutical company info			9	9	9
Internet information			10	10	4 △

Key : ▲▼ within group difference between Delphi I & II
△ ▽ between group difference for Delphi II

PART FOUR

In both Delphi I and Delphi 2 people rank ordered the influences on their own decision making about treatments (1= most influence though to 10 = least influence). SP and SUs also commented on what they thought were the influences on the other group's decisions.

SU & SP agreed that service users were most strongly influenced by:

- *service provider advice*
- *past experience*
- *personal beliefs*

SU & SP agreed that service providers were most strongly influenced by:

- *SP experience*
- *consultation with the team*
- *SU preferences*

SU & SPs did not agree on several influences:

- SUs thought SPs were more influenced by the *internet* then *scientific journals*. **However,** SPs put the internet as the least important influence of all.
- SPs though SUs were more influenced by *family members* and less influenced by the *cost of treatment*. ***However,*** SUs actually ranked cost as more important than family members' opinions.
- SUs thought SPs were least influenced of all by *clinical protocols* and *NHS/DofH guidelines*.

Table 1 has specifics of all of the rankings across both Delphi 1 and 2.

Part 5

People were asked if any action should be taken if SUs and SPs did not agree. All of the SUs (except 3 who did not state either yes or no) said **YES**. Twelve SPs (14.3%) said **NO**, 6 had no opinion (7.1%) and 67 (79.8%) said **YES**.

Part 6

Types of Actions Recommended

People were asked to suggest actions to be taken when there is disagreement. The responses were put into categories of who should take the action (SU, SP, joint) and what was the purpose. Five categories were identified.

The first two categories, *Service provider action to support professional decision,* and *Service provider action to gain information* contained suggestions focusing on the SP as the one who should take action with the purpose of reinforcing to the service user that the correct selection of treatment(s) had been made.

The third category (*Service provider actions to negotiate plan)* again had actions the SP should take but the purpose is to negotiate agreement with the SU. There were no suggestions of actions the SUs should take independently.

The 4th category contains the few suggestions that were made about SU & SP joint actions and shared responsibility. As shown on Table 2 very few suggestions were made about actions the SUs should take. The last category includes the suggestions that did not fit any of the main headings.

Table 2
Recommended Actions
Key

- *( ) =number of respondents commenting,*
- both SU & SP Commenting,
- SU comments only,
- *SP comments only*

1.**Service Provider Action to Support Professional Decision (SP Control)**
SP to provide more information (9)
justify the options offered (8)
Present ' united front' to SU
Provide more aftercare (1)
Have more clinicians available (2)
SP need to discuss differences openly amongst themselves) (5)
Education of the Service User (16)
Control misinformation (3)
Take more time for explaining (9)
More and better quality patient education materials (2)
Reality testing, confront unrealistic expectations (3)
Increase public awareness of pain issues and barriers to management (3)
SP should lobby for more resources (2)

2. **Service Provider Action to Gain more Information (SP Control)**
Ask SU what they believe (1)
Do more research (5)
Educate SP (5)
Understand the SU's beliefs by listening (14)
Follow evidence-based guidelines (7)

3. **Service Provider Actions to Negotiate Plan (SP sharing control)**
More individualised treatment options (4)
Be more client-centred (2)
SP should be willing to refer elsewhere and get 2nd opinion (5)
Remove medical lead and have 'holistic' focus (2)
Improve communication and negotiation of treatment (12)
use arbitration and mediation skills (1),
use a questionnaire to gather info from SP and SU (2)
Build trust (11)
Jointly develop a plan for treatment/ match tx to beliefs (13)
Have community and SU input in programme planning (2)
Increase SU and public's awareness of limited resources (4) Create forum for discussing issues in large groups (6)
Develop SU identified outcome measures (1)

4. **Shared Action (Dynamic Control)**
Develop care pathways allowing more SU responsibility and ownership (5)
Act on what SUs tell you (1), Keep family members involved (1)
Are people ready for treatment (want it, agree to it, ready for it) (5)

5. **Service User Action (SU Control) -** No recommends were made

6. **Service User Action to Gain More Information (SU Control)** -No recommendations were made

PART 7
The final section offered people a chance to comment to each other. Service users could make suggestions to both other service users and to service providers. Service providers could do the same. Comments were offered around six different issues:

- communication
- validation
- treatment
- professionalism
- advocacy/lobbying
- new ideas (paradigm shift)

Table 3 shows the comments made between and within SP and SU groups.

Conclusion

Delphi 2, like Delphi 1, has shown that there are specific things that both SUs and SPs agree on. It also shows that there are a wide range of things that they do not agree on. The agreed areas have to do with the need for information, communication and mutual respect, these are clear areas to build on. Areas where there was disagreement serves to highlight that assumptions can be dangerous, people do not all think alike.

What happen now?
It is important that people get a chance to say if they agree or disagree with the conclusions I have drawn. You will get a chance to do this in Delphi 3. Delphi 3 will be the last questionnaire you receive from me. After that questionnaire is analysed you will receive a final report on the whole study (Delphi 1-3).

Table 3 Recommendations Between and Within Groups

Service Users' Comments to Service Providers	Service Provider Comments to Other Service Providers	Service User Comments to Other Service Users	Service Provider Comments to Service Users
Communication issues: e.g. listen to what SU are saying, be honest about what is possible, don't give 'false hope', do not make assumptions about what SU understands, work on building a healthy rapport	**Communication issues:** e.g. Listen to SU (#1 comment), do not make assumptions about what SU need, build rapport with SU, be honest with SU, don't give false hope, be aware of SU expectations.	**Communication issues:** e.g. learn to be assertive, ask for referrals and information, speak up, give more information- don't wait to be asked.	**Communication issues:** e.g. speak up and be assertive, ask for a referral if not happy, learn communication skills, ask more questions, give more information, listen to what the information you are given, don't accept everything- listen critically
Validate the service user: e.g. recognise pain is real, understand that pain changes my whole life, see me as an individual, understand that SU's need control over their lives	**Validation issues:** see each SU as unique, understand separate needs/wants, accept SU opinions as real, accept pain as 'real', appreciate SU needs control because of life disruption, realize pain changes a SU's whole life.	**Validation issues:** e.g. don't be afraid to look foolish by disagreeing or asking questions.	
Treatment issues: e.g. make more options available for SU to chose , be more accepting of alternative therapies, facilitate more support groups, follow protocols	**Treatment issues:** e.g. make more options available, give SU more choice, follow protocols, take direction from experts, develop a National Service Framework, be more accepting of alternative therapies (not just evidence-based), use only evidence-based treatments, increase community based treatment options, do more education for SUs, audit outcomes,	**Treatment issues:** e.g. act on the advice given by SP, access more education about pain	**Treatment issues:** e.g. get more education, take advantage of education sessions, attend treatment sessions, take advice about what is 'good' information, learn strategies to live with pain,
	Professionalism issues: e.g. increased education for SP, defend professional expertise, use other team members to validate message to SU, foster interdisciplinary learning and understanding. stop 'empire building' , accept specialist .		
	Advocacy/lobbying issues: e.g. SP should lobby for resources, work to obtain more resources, increase profile with managers, public, decision makers,	**Advocacy/lobbying issues:** e.g. learn to lobby	**Advocacy/lobbying issues:** e.g. lobby for resources, increased staff, more research, public awareness, form lobby groups, participate in public forums, form support groups
	Paradigm shift issues: e.g. treatment planning with SU, include SU in research and programme planning, accept the reality SP cannot cure pain, 'evidence' is not just RCT's, accept professional limitations, use a biopsychosocial or holistic model, stop seeing pain as 'specialist' and see it as normal part of life	**Paradigm shift issues:** e.g. take more responsibility for own health, don't worry about disapproval of the GP, keep an open mind to new ideas	**Paradigm shift issues:** e.g. accept that medicine has limitations, stop hunting for a miracle cure, be realistic, stop fighting, keep an open mind to new ideas, stop seeing pain as unique, take responsibility for self-management

Appendix 20: Delphi 3 Questionnaire

Response code__________

THE UNIVERSITY of LIVERPOOL

Beliefs about Chronic Pain

Influences on decisions about treatment and recommendations for action

Delphi Questionnaire 3

October 2003

Instructions

You may wish to look over the enclosed Delphi 2 report before answering the questionnaire. Although the following questions are based on that report you can answer them without having read it in detail.

If you have any questions I can be contacted by e-mail at cabrown@liv.av.uk

Please return the questionnaire in the enclosed envelop. Any additional comments you wish to add will be most welcome.

Thank you for your time and attention.

Cary A. Brown, Lecturer
School of Health Sciences
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Johnston Building, Brownlow Hill
Liverpool L69 3GB

Question 1

Several conclusions were drawn from the last questionnaire (Delphi 2). I would like to know if you agree with these conclusions. Please put a tick beside the answer that best reflects your opinion about each of the following statements.

	strongly disagree	**disagree**	**agree**	**strongly agree**
Service users' opinions about whether a treatment is important are influenced by emotions and self-image.				
Service providers' opinions about whether a treatment is important are not influenced by emotions and self-image.				
The strongest influences on service users' opinions about treatments are service provider advice, past experience and personal beliefs.				
The strongest influences on service providers' opinions about treatment are experience, consultation with the team and service user preference.				
Service providers' have more responsibility for taking action *when there is disagreement than service users.*				
Communication is an important concern for service users				
Communication is an important concern for service providers				
Open-mindedness is an important concern for service users				
Open-mindedness is an important concern for-service providers				
Feeling respected and trusted (validated) is an important concern for service users				
Feeling respected and trusted (validated) is an important concern for service providers				
Advocacy for change is an important concern for service users				
Advocacy for change is an important concern for service providers				

Question 2

Service providers stated that emotions (how they felt about a particular treatment) and their self-image were not an influence in their decision-making. In your opinion, why did service providers say this? Please use the space below for your comments.

Comments about emotions:

Comments about self-image:

Question 3

One theory about chronic pain is that it has a single (perhaps undetected) cause. Another theory is that chronic pain is a complex interaction between biological, psychological and social factors. There are many other theories as well. Please check the box beside each statement below that best agrees with what you personally think about chronic pain.

	strongly disagree	disagree	agree	strongly agree
Chronic pain is influenced by what each person believes				
Chronic pain is influenced by the relationships between people (for example: between the person with pain and employers, family members, GP, therapist).				
Services for people with chronic pain are delivered in a wide variety of ways.				
The process to access treatment varies across the UK.				
Chronic pain is treated mainly within in the medical system .				
Searching for a cure to chronic pain is the main goal for service users.				
Searching for a cure to chronic pain is the main goal for service providers.				
People believe more strongly in medical treatment than psychological treatment for chronic pain.				
Guidelines, policies and funding for chronic pain management should be decided centrally, at a national level.				
Guidelines, policies and funding for chronic pain management should be decided locally, at a community level.				
People have access to enough information to make good decisions about treatments for chronic pain.				
New ideas about treatment are easy to try out.				
Out-dated ideas about treatment are difficult to eliminate				
Treatment for chronic pain follows a logical, step-by-step process.				
The effect of a treatment can change over time for the same person.				
Successful treatments for chronic pain must consider social, cultural and environmental aspects in addition to medical aspects.				
Information about pain and treatment is easily available.				
New ideas about treatment for pain spread quickly through the healthcare system.				
Managing chronic pain required each service user and service provider to interact with a range of other people and services.				
To manage chronic pain there needs to be information and services available for family and employers.				
People are anxious about the availability of resources for chronic pain management.				
People who work in the pain management programmes feel in control of how services are provided.				
People with pain are able to influence how services are provided.				

Question 4

Please place an **X** on the line below to show how much you think people agree about which treatments for chronic pain are important.

●————————————————————●

no agreement **total agreement**

Question 5

Please place an **X** on the line below to show how certain you think people are about what treatments are important for chronic pain.

●————————————————————●

no certainty **total certainty**

Question 6

In the last questionnaire people were asked to suggest what actions should be taken when service users and service providers do not agree about which treatments are important. Most of the suggestions focused on actions the service providers should take. Very few suggestions were made by anyone about what service users should or could do. Why do you think this happened? Please write any comments in the space below.

Question 7

This is the final questionnaire I will send you. Your willingness to share your time and comments with me has been much appreciated and I hope you have found the process and the reports interesting.

This last question is about what it was like being involved in the study. Your evaluation of how I carried out this type of research is important. It will help me and others make improvements for the future.

Please put a tick in the box that most closely reflects your opinion for the following questions. I would also welcome any written feedback you might like to offer.

	Yes, very	Yes, mostly	No, Not very	No, not at all
The reports after each questionnaire were interesting.	☐	☐	☐	☐
The questions were clearly written.	☐	☐	☐	☐
The questions were interesting.	☐	☐	☐	☐
This study was relevant to my work.	☐	☐	☐	☐
I learned something about service users through this study.	☐	☐	☐	☐
I learned something about service providers through this study.	☐	☐	☐	☐
I learned something about myself through this study.	☐	☐	☐	☐
Based on this experience I am willing to participate in a Delhi study in the future.	☐	☐	☐	☐
Would you have preferred focus groups and interviews to this type of Delphi research?	☐	☐	☐	☐

Comments:

What next?

Please return the questionnaire in the enclosed envelope.

Even if you decide not to complete the questionnaire please return the blank form. That way I will not bother you with a follow-up reminder. I would appreciate if you could return the questionnaire within 4 weeks.

Once all of the questionnaires are analysed I will send you a final report summarising all stages of the study.

I have been trying to disseminate the information you have shared with me as widely as possible so your efforts haven't just been for my personal gain. Some of the findings have been presented at the World Federation of Occupational Therapists Convention in Stockholm, Sweden(2002); the Pain Society annual conference in Glasgow (2003); the College of Occupational Therapists annual conference in Brighton (2002) and the Pain Management Special Interest Group of the Pain Society conference in Norwich (2003). Publications based on the findings can also be found in the following journals:

- Brown, CA (2003) **Service Users' and Occupational Therapists' Beliefs About Effective Treatments for Chronic Pain: A Meeting of the Minds or the Great Divide?** Disability & Rehabilitation 25 (19) in press.
- Brown, CA (2003) **Occupational and Physical Therapists' Beliefs Regarding Treatment Options for People with Chronic Pain** British Journal of Therapy and Rehabilitation 10 (2): 46-52.
- Brown, CA (2002) **Occupational therapists' beliefs regarding treatment options for people with chronic pain.** British Journal of Occupational Therapy 65(9):398-404.

Thanks again for all your time and effort.

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Appendix 21: Delphi 3 covering letter

October 2003

Dear study participant,

I'm very pleased to send you this last questionnaire in the Delphi study about pain treatment beliefs. There were 106 people who responded to the questionnaire in April 2003. The enclosed report and this round of the Delphi is based on those responses. I hope you'll find the ideas people shared as interesting as I did.

This last stage of the Delphi study has two purposes. The first is to find out if people agree with how I have organised the responses. Questions about this are in the Delphi Round 3 questionnaire (beige form) enclosed in this pack. Also, the Delphi Round 3 questionnaire asks your opinion about participating in this study and if the information was of use to you.

Once the Delphi Round 3 questionnaires are all back to me I will prepare a final report so that you can see what everyone else thought as well. This way you have access to everyone else's comments throughout the study.

Q: 'What should I do with the information in the pack?'

- Please read the enclosed Delphi Round 2 report.
- Now complete the Delphi Round 3 questionnaire (beige form).
- Mail your completed form back in the enclosed envelope.
- If you decide not to complete the questionnaire, please mail it back anyway.
- Please try to return your Delphi Round 3 questionnaire form within the next 3 weeks.

Thank you again for your participation up until this point. I hope you will find this last phase interesting and thought provoking. If you want to contact me for any reason my e-mail is cabrown@liv.ac.uk or you can write me at the address below.

Sincerely,

Cary A. Brown, Lecturer
School of Health Sciences
University of Liverpool
Johnston Building, Brownlow Hill
Liverpool, L69 3GB

Appendix 22: Delphi 3 report

THE UNIVERSITY
of LIVERPOOL

Beliefs about treatment for chronic pain: Chronic pain is a complex problem

Report on Delphi

Questionnaire 3

February 2004

CA Brown
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Report for Delphi 3
February 2004

INTRODUCTION

Last October the Delphi 3 Questionnaire was sent to 33 Service Users (SUs) and 210 Service Providers (SPs). 53.1% of the service users and 42.1% of the service providers replied.

One of the advantages of a Delphi design is that it allows people to opt in and out of rounds as their interest and time dictates. Service users, anaesthetists and physiotherapists were most likely to consistently participate in all three rounds. Nurses showed the greatest variation in opting in and out (see Table 1 on page 7).

The Delphi 3 questionnaire asked people if they agreed with the researcher's conclusions from the previous questionnaire (Delphi 2).
It also asked people questions about how complex an issue they think chronic pain and its management is. Also, comments were asked for about why very few suggestions were made for actions that service users should take when there is disagreement about treatment importance.

The rest of this report contains the answers and comments participants made for each question in the Delphi 3 questionnaire.

QUESTION 1

Participants were asked if they agreed or disagreed with thirteen statements the researcher derived from the Delphi 2 questionnaire. Table 2 shows the 11 (out of the 13 possible) statements that the majority of both service users and providers agreed with.

Table 2: Conclusions from Delphi 2

Statement	**Statements the majority of both SUs & SPs agreed with**
1	Service users' opinions about whether a treatment is important are influenced by emotions and self-image.
3	The strongest influences on service users' opinions about treatments are service provider advice, past experiences and personal beliefs.
4	The strongest influences on service providers' opinions about treatment are experience, consultation with the team and service user preference.
6	Communication is an important concern for service users.
7	Communication is an important concern for service providers.
8	Open-mindedness is an important concern for service users.
9	Open-mindedness is an important concern for service providers.
10	Feeling respected and trusted (validated) is an important concern for service users.
11	Feeling respected and trusted (validated) is an important concern for service providers.
12	Advocacy for change is an important concern for service users.
13	Advocacy for change is an important concern for service providers.

There was much less agreement over statements 2 and 5. These are discussed individually as follows:

- **Statement 2 – "Service providers' opinions about whether a treatment is important are not influenced by emotions and self-image".**
  The majority of SUs (75.0%) agreed with this statement that SPs are not influenced by emotion and self-image. However, less that half (only 47.3%) of SPs agreed.[35] This means that a small majority of SPs do think their decision-making is influenced by emotion.

---

[35] chi-square analysis *p=.044*

- **Statement 5 –"Service providers' have more responsibility for taking action when there is disagreement than service users."**
  The majority of SUs (80.0%) and SPs (64.4%) agreed with this statement. However there was also a large minority of SPs (35.6%) who did not agree.

QUESTION 2

Question 2 asked participants to answer the following question:

"In the Delphi 2 questionnaire most *service providers said that emotions (how they felt about a particular treatment) and their self-image did not influence their decision-making. In your opinion, why did service providers say this?"*

The following themes emerged from people's written comments:

1) **Being a professional**
These comments fell into two groups. The first group was **'Because they are professional'**. Many SUs and SPs said that it was important to be scientific, objective and to meet the expectations of society and co-workers by being professional.

The second group was **'they like to think they are professional'**. These comments reflected that self-image and personal choice might affect how SPs acted. Many of the respondents in this group pointed out it was not always easy to maintain the image of 'objective' professional. For example -

> *"I'm not fully convinced that they fully understand the concept. Some professionals have been trained to ignore their emotions and may respond in a 'knee jerk' reaction in this way. Some may believe that adding emotion to the consultation would de-value the 'science' or evidence-base".*
>
> *"Their beliefs are shaped by past experience with treatments. Strong beliefs about a treatment can lead to strong emotions so I don't believe it".*

2) **SPs Protecting Themselves**
People commented that disagreement caused negative feelings for both SUs and SPs. They also thought that some SPs tried to protect themselves by keeping 'objective' and distant. For example-

> *"...service providers are trying to ignore self and act in the patient's best interest – not sure they succeed"*

3) **Affect and Experience**
Participants commented that experience made people confident and less likely to 'hide behind' the evidence-base. Some said that less experienced SPs used objectivity to avoid things they were not comfortable with. For example -

> *"...lack of experience, inability to empathise and lack of confidence in own ability"*
> *"...if unsure/unhappy with their skills may stay away from treatment options".*

4) **Lacking Reflective Skills**
People said medical training did not prepare SPs to understand their own emotions, so that they took refuge in the 'distant professional' role.
"The self-image of professionals is often subsumed beneath the role adopted and introspection is not encouraged. Psychological insight is not commonly fostered in professional training".

5) **Ethos of altruism**
Some people said that SPs put their own ambitions and emotions aside for the good of patients and for team harmony.

> *" people who work with patients who have pain tend to be less self-interested than perhaps other health professionals".*

6) **Lack of Understanding**
A small group of both SUs & SPs said that because SPs didn't have pain they didn't understand it and were unable to show genuine empathy to SUs.

> *"Because they use treatments that 'we have always done it this way'! and often are not even in touch with their own emotions and/or have not had chronic pain themselves".*

7) Lastly, several people mentioned that programmes had models of practice and protocols that maintained the role of SP as distant and objective.

The problems with health care professionals distancing themselves from the emotional consequences of service provision are increasingly documented and many medical schools now include mandatory course in reflective practice and communication skills. The comments presented here highlight the need for more study in this area. As one service provider commented "*service providers are trying to ignore 'self'- not sure they succeed*".

QUESTION 3

Many experts say that pain is a complex problem that has no one simple cause-and-effect. People were asked if they agreed or disagreed with 23 statements related to the idea that chronic pain is complex. The statements were based on the eight characteristics of complex adaptive systems presented by Plsek (2003).

Responses demonstrate that participants in general feel that chronic pain is ever changing and has many dimensions. Also, it is affected by the context of each person's life and the type of relationships involved. Service providers said that new ideas are difficult to implement and out-dated practices difficult to abandon. There were also some statements where SUs and SPs did not agree. These are as follows:

1. ***Chronic pain is influenced by what each person believes (C1).***
    - 98.7% of service providers agreed with this statement.
    - 37.5% of service users did not.

2. **Chronic pain is influenced by relationships between people (for example: between people with pain and employers, family members, GP, therapist) (C2).**
    - 96.0% of SPs agreed with this statement.
    - Only 62.5% of SUs agreed (stat sig. *p*=<*.000*).

3. ***Chronic pain is treated mainly within the medical system (C5).***
    The majority of service users (66.7%) and providers (60.0%) agreed that chronic pain is treated within the medical system. This suggests that people believe pain is a largely biomedical problem.

4. ***Searching for cure is the main goal of service users (C6).***
    Service users (75.0%) and providers (82.4%) agree with this statement. This suggests that many SUs believe pain is for the most part a biomedical problem.

5. **Searching for cure is the main goal for service providers (C7).**
    - Only 12% of SPs agreed (which may indicate a belief in more multidimensional models of pain).
    - However, the majority (60%) of service users agreed. This suggests that SUs believe that service providers should have searching for a cure to pain as a priority goal.
    - The difference between the 2 groups was statistically significant (*p*=<*.000*).

6. ***Guidelines, policies and funding should be decided at a national level (C9)***
    - Less than half (46.7%) of SUs agreed with this statement.
    - A moderate majority (68.9%) of SPs agreed.

Complexity theory proposes that there needs to be freedom to modify solutions at the local level because national directives tend to overlook unique community contexts.

7. ***New ideas about treatment are easy to try out (C12)***
    - Very few SPs (10.7%) agreed with this statement,
    - however a significant portion of the SUs (31.3%) agree (*p=.033*).

This inconsistency may negatively influence relationships between service users and providers if SPs cannot be as flexible as SUs believe possible.

8. ***People who work in pain management feel in control of how services are provided (C22)***
    - 80.0% of service providers **disagreed** with this statement.
    - 56.3% of service users believe that SPs feel in control (*stat sig p=<.000*).

As with statement 7, negative feelings can be created if SUs have expectations SPs cannot meet.

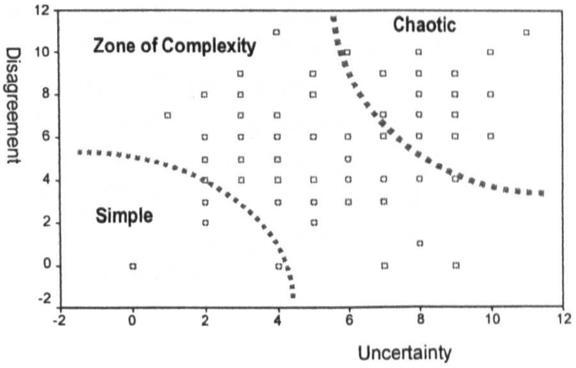
QUESTIONS 4 & 5

Theories about complex adaptive systems state *that* when there is **low agreement** and **low certainty** problems do not respond to simple, cause-and-effect solutions. As agreement and certainty decrease, the outcome of interactions become less predictable.

Question 4 & 5 asked people to indicate on a 10cm visual analogue scale ***how much disagreement and how much uncertainty you believe people have about which treatments are important for chronic pain***.

The points on the graph in figure 1 show where peoples' ranking of uncertainty and disagreement intersect. This plotting of responses to Questions 4 & 5 shows that people believe chronic pain treatments are relatively high in uncertainty and disagreement. Their responses fall mainly into what Stacey (1996) termed 'the zone of complexity'. Complexity theorists (Kernick 2002; Plsek 2003) propose that high disagreement and uncertainty can result in a system breaking down. More positively, they also see the 'zone of complexity' as a window of opportunity for creative problem-solving and letting go of outdate but firmly held practices. They also say that energy and resources are wasted in trying to apply ineffective simple solutions to complex problems.

Fig 1: SU & SP Uncertainty & Disagreement



QUESTION 6

In previous Delphi rounds people suggested what actions should be taken when service users and providers disagree. Most of the suggestions were about what the service providers should do. There were very few suggestions about what service users could do. Question 6 asked participants why they thought this happened. Their comments showed the following themes:

- SUs are individuals – they have no resources and can't be expected to act collectively
- SUs pain prevents action
- SUs have limited knowledge and tools
- SUs feel defeated and disempowered
- SPs control resources/access
- *Medical model is socially dominant*
- SUs take no responsibility & blame SPs
- This is changing with new legislation (for example- *the Expert Patient Programme*)
- SP cannot imagine what SUs role could be.

QUESTION 7

This study involved a high level of input over an eighteen-month period. I was very interested to know what people thought of the process and what they may have gained from being involved. Question 7 asks participants **whether they found the process interesting, clear, relevant and informative.**

Overall the feedback was positive and comments were supportive. A quarter of the service users stated the questions were not very clearly written and this comment was echoed by 10% of service providers.

Of particular note, is that close to 1/3 of all participants felt they learned little about the other participants and themselves as a result of the study. This is disappointing as the Delphi methodology is intended to be iterative, offering both the participants and the researcher repeated opportunity to reflect and generate new insights. One possible explanation is that the process took too much time.

Most people stated that they were willing to take part in Delphi studies in the future. This supports the Delphi technique as a valid tool for gathering and sharing opinions from a large group of participants. However 73.3% of SUs and 29.0% of SPs would have preferred interviews and focus groups as opposed to Delphi methodology.

CONCLUSION

Over the Delphi rounds participants agreed that coherence, perceived purpose, self-image and affect (Chapman's Consciousness model (Chapman and Nakamura 1999) influenced how they made decisions about what treatments are important. There was one notable exception. In earlier Delphi rounds service users felt that that affect and self-image influence everyone's decision-making. Service providers did not agree and stated that affect and self-image are features of service users' decision-making but not features of their own decision-making. SU and SP comments about why this occurs reflected that the traditional medical model and traditional patient/professional relationships are strong influences. However, in the last questionnaire this position seemed to shift slightly as more service users agreed that the providers were not influenced by emotion. Also, service providers in Delphi 3 seemed more accepting that affect and self-image influence their decision-making. This apparent reversal of opinions should be treated with caution given the small sample sizes in both groups.

Responses also support applying a complex adaptive system framework to the chronic pain experience. Relationships and context are important, structures and process are varied, actions can be linked to persisting practices and personal beliefs. Additionally, the chronic pain experience is seen as changing and requiring high amounts of giving and receiving information. Participants believe that there is little certainly and agreement regarding treatments for chronic pain. A graphic representation of their responses clearly illustrates a system in the 'zone of complexity' (Stacey 1996).

Paradox seems to exist within responses of participants to questions about certain beliefs and behaviours. For example, responses indicate that *search for cure* and *the medical system as the source of assistance* are still part of the personal belief system most people hold for dealing with chronic pain. Many participants said that chronic pain has a wide range of biological, psychological and social influences. However, they are also attempting to find solutions within a simple, cause-and-effect biomedical model. This can result in frustration and inertia as large amounts of effort continue to be put into solutions that don't work.

Once again, **my deepest thanks** to all of you who gave so generously of your time and thoughts. I have enjoyed the process and have learned a great deal from it. If you would like any more information about what you have read here please contact me. My e-mail address is cabrown@liv.ac.uk Also, if you are interested in seeing where some of the findings of this study have been published there is a list of articles on the last page of this report.

Table 1: Pattern of participation across all three Delphi rounds

Background	Volunteered for interview	Completed Delphi 1	Completed Delphi 2	Completed bot Delphi 1&2	Completed Delphi 3	Initial volunteers completing all rounds
Occupational Therapist	43	14 (32.5)	10 (23.3)	7 (16.3)	10(23.3)	3 (6.9)
Physiotherapis	19	10 (52.6)	8 (42.1)	7 (31.6)	8 (42.1)	5 (26.3)
General Practitioner	19	4 (21.0)	8 (42.1)	3 (15.8)	5 (26.3)	1 (5.2)
Psychologist	17	4 (23.5)	6 (35.3)	3 (17.6)	4 (23.5)	2 (11.8)
Anaesthetist	63	28 (44.4)	27 (42.8)	18 (28.6)	28 (44.4)	15 (23.8)
Nurse	65	25 (38.4)	27 (41.5)	16 (24.6)	30 (46.1)	12 (18.5)
Other	6	2 (33.3)	2 (33.3)	2 (33.3)	2 (33.3)	1 (1.6)
Service User	33	22 (66.6)	16 (48.5)	16 (48.5)	17 (51.5)	11 (33.3)
Total	265 (241)*	109 (41.1)	104 (39.2)	71 (26.8)	105(43.5)'	50 (20.6%)*

*By completion of Delphi III twenty-four participants had withdrawn, moved with no forward address or were decreased.

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