Promoting a Lay Led Self-Care Approach to Managing Persistent Pain

by

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Statement of Originality

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RESEARCH

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Abstract

This research project explored the impact of introducing a lay led self-management approach known as the Expert Patient Programme (EPP) at patients’ initial referral stage to a pain management clinic in a secondary care setting. It involved a randomised controlled trial and employed a mixed method approach permitting triangulation of data with a longitudinal design. Sixty-three patients (Control group n=33, Intervention group n=30) with persistent non-malignant musculo-skeletal pain conditions referred to a District General Hospital (DGH) Pain Clinic, agreed to take part and provided data for the research. The intervention was usual care and an invitation to attend a lay led self-management programme known as the Expert Patients Programme (EPP). This consisted of six 2 hour per week programmes led by lay tutors. The Control group received only usual care, data being collected at baseline, 3-6 months and 10-14 months.

The primary hypothesis was to determine if the early introduction of a self-management approach alongside medical treatments could influence and encourage participants to adopt self-management approaches to managing their persistent pain. The primary outcome, readiness to take action to self-manage persistent pain symptoms was measured by the Pain Stages of Change Questionnaire (PSOCQ). Secondary outcomes of Acceptance, Pain and Interference were measured by applying the Chronic Pain Acceptance Questionnaire (CPAQ), and Brief Pain Inventory (BPI). The Qualitative data was gathered using focus groups.

The results identified significant promotion through the Stages of Change process accompanied by improvements in Pain and Interference levels for the Intervention groups’ data at 10-14 months; no significant changes were found in the Control group. Improvements in the Intervention group were related to a synergistic effect of offering a self-management approach in parallel with a medical model approach and participants taking actions to relinquish their Sick Role.

This study is the first to suggest an association between the Stages of Change process and the Sick Role. Results provide evidence that improvements seen in the Intervention group were associated with progress through the Stages of Change and linked with participants adopting self-management approaches and relinquishing their Sick Role; this allowed them to take on a more appropriate role described as the Persistent Condition Role (PCR).
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1 Introduction

1.1 Aim of the research

The management of persistent pain is an important area to research because of the misery it causes to individuals and because long-term conditions have become the greatest cost to the National Health Service (NHS) (Chronic Pain Policy Coalition, 2007; Department of Health, 2005d; DH Long-term Conditions NSF Team, 2005). Studies fail to explain why outpatient appointments and sick leave for some persistent pain problems such as back pain, have risen disproportionately to the rise in prevalence of the condition (Evans et al., 2004; Palmer, Walsh, Bendall, Cooper, & Coggon, 2000). There is uncertainty surrounding the solution to the economic burden of persistent pain, and it may be that the solution sits with modifying peoples’ attitudes and behaviours rather than how it is treated (Palmer et al., 2000).

Pain is one of the most common and obvious consequences of accidents and ill health (Clinical Standards Advisory Group, 2000) and is described as an ‘unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage’ (IASP, 1994). Persistent pain is often referred to as chronic or long lasting pain (Goucke, 2003), and the term persistent pain will be used as it is considered to foster a more positive attitude by patients and professionals (Ingham & Kramer, 2002).
Patients referred for treatment of their persistent pain symptoms as with other long term conditions can experience care that is biased towards the acute biomedical model (Engel, 1980; Holman & Lorig, 2000; Hunter, 2000). The biomedical model reasons that pain is simply a sensory physical experience where diagnosis of the cause will lead to treatment and cure (Bell, 2002). Generally the medical model expects the healthcare professional to diagnose, prescribe and cure, while the role for the patient is for the most part one of compliance (Lorig & Holman, 2000). While these learnt behaviours are effective and adaptive for the management of acute pain, they may aggravate a persistent pain condition (Richardson, 2001).

Despite treatment, sometimes pain will not go away (The British Pain Society, 2004). A study of individuals who had attended a pain management centre thirteen years previously, found 68% continued to have worse than average or abnormal levels of bodily pain associated with greater morbidity in their physical functioning. However, mortality during the follow up period was similar to the general population for the United States of America (USA) (Maruta, Malinchoc, Offord, & Colligan, 1998).

The failure of many conventional treatments to provide the technologic fix envisaged by the patient may inadvertently reinforce passivity, considered a poor prognostic sign (Frazier, 1992), and can result in unhelpful psychological and emotional responses (Gill, 1997; Janssen, Spinhoven, & Arntz, 2004). Nevertheless, many people encouraged by beliefs and values persevere with trying to find a solution for their pain. However, often there is no cause that
can be cured and no treatment that is entirely effective (Hester, 2007), and the pain symptoms may remain unresolved (The British Pain Society, 2004). The current and dominant focus within the NHS is to apply an acute model of care, but this is not always appropriate for long-term conditions, as these conditions tend to benefit from patients taking greater control of their own treatment (NHS Modernisation Agency, 2004). Effective management of these conditions can be further hindered by what has been described as the charity culture of the NHS, implying the patient is a passive recipient of a fixed product (Foote & Plsek, 2001).

It is suggested that it is only when the biomedical approach fails that an approach recognising the biomedical, psychological and social aspects of pain is considered. The psychosocial model addresses psychological and social issues that may all be contributing to the pain and disability an individual is experiencing. Delaying referral to address the psychosocial aspects may inadvertently give a message to the patient that this approach is only of value once everything else has failed. Providing effective pain management can be complex, and will often need the expertise of more than one profession.

Optimising different approaches that might provide improved pain control are not consistently and reliably offered and the following have been suggested as reasons for this failure:

- Lack of knowledge
- Values and beliefs that affect judgements
- Differences in how decisions are made and use of evidence concerning the management of pain
- Failure to prioritise pain and its management at an individual and institutional level (Seers, Watt-Watson, & Bucknall, 2006).

A fundamental part of managing long term conditions is now considered to include self-care approaches (Department of Health, 2001a, 2001b; Department of Health/National Health Service, 2005), and for some patients this may offer opportunities for improvement (Chronic Pain Policy Coalition, 2007; Hanson & Gerber, 1990). This approach requires shifting patients’ beliefs towards a greater commitment to self-management, and developing a culture within the NHS that will support self-management. This is possibly a huge challenge and unlikely to happen without professionals endorsing and reinforcing the approach with their patients (Chappie & Rogers, 1999; Lewis & Dixon, 2004; Redman, 2005).

This study aimed to introduce a collaborative management approach to managing persistent pain by exposing patients at the initial stage of their referral to a pain clinic to the concept of developing a self-care approach. The self-care approach was delivered alongside ‘usual care’ provided in the pain clinic with its initial focus on a biomedical approach. The study explored whether the early introduction of self-care approaches impacted on longer term benefits from attending a pain clinic.
1.2 The problem statement and background

Persistent pain of moderate to severe intensity has been reported in 19% of adult Europeans (Breivik, Collett, Ventafridda, Cohen, & Gallacher, 2006), and suggests persistent pain is now a considerable health problem that needs serious attention. Breivik et al (2006) findings reflect the increased prevalence of all self reported long standing illness in the United Kingdom with National Statistics showing an increase from 21% in 1972 to 35% in 2002 (National Statistics, 2002b).

The occurrence of long term conditions is unlikely to diminish as the population experiences greater longevity and accompanying this is a rising incidence of chronic conditions (Department of Health, 2005d) of which persistent pain is one of the contributing conditions. Anecdotal evidence from the researcher’s work in a District General Hospital’s (DGH) chronic pain management service suggests that despite more sophisticated treatments and medications the number of new referrals to the pain service does not diminish nor do episodes of treatment appear to shorten. Put more strongly perhaps it is that ‘physically and psychologically we have become dependent on medical treatment, and the quest for a “quick-fix” cure has left us unable or unwilling to do something to help ourselves (Boseley, 2006:7).

Patients suffering from persistent pain make great demands on resources and time available in the National Health Service (NHS) (Clinical Standards Advisory Group, 2000) and there is scepticism that NHS money may be spent on ‘things’ that don’t cure an illness or in an attempt to keep ever demanding
patients quiet (Pemberton, 2006). A previous study by the researcher exploring the impact of treatments for persistent low back pain suggested that improvements in patients perceptions of control and improved coping strategies may not be due to the efficacy of the invasive treatments but rather the influence of other mediating factors associated with attending a pain clinic (Hawksley, 2001).

It has been observed that the more seriously we take some commonly occurring persistent pain problems such as back pain, the worse the problem has become (Hadler, 1986). Adding strength to these conjectures are figures showing notable rises in the cost of sickness and invalidity benefit for back pain between 1955 and 1995 (Clinical Standards Advisory Group, 1994). This has led to a growing realisation that current approaches to caring for people with any long-term condition needs to change to improve outcomes (Department of Health, 2001a, 2005b; Von Korff, Gruman, Schaefer, Curry, & Wagner, 1997). This change in approach may be beginning to be reflected in a recent review and analysis of incapacity for work and social security benefit claims. The rising trend for claims has begun to turn with a 42% decrease in yearly new awards for back pain, although it is acknowledged that different Government approaches to capturing such data may influence outcomes. The suggestion nevertheless, is that this may symbolise recent changes in medical practice alongside cultural attitudes towards back pain (Waddell, Aylward, & Sawney, 2002).
A fundamental part of the coping and managing of many long term conditions is encouraging the patient to develop a self-care (self-management) approach to managing their condition (Department of Health, 2001a, 2005b; Rothman & Wagner, 2003; Ruecroft, 2004). This aspect of care is associated with behaviour changes and skill maintenance and encompasses psychosocial approaches to managing pain (Strong, 1996; The British Pain Society, 1997).

1.3 Rationale for the research

Self-care approaches are attracting considerable interest from Government policy makers as it emerges as a central factor in the planning of care in the NHS for those with long term conditions (Department of Health, 2001a, 2005a, 2005b, 2005d; NHS Modernisation Agency, 2004; Tattersall, 2002). Management of long term illness is not a new problem but it is one that resists solutions, while the cost of care involved is the greatest expenditure to the NHS (Department of Health, 2005c; House of Commons Debates, 2005; Smith & Elliott, 2005).

Funding the mounting demand from long term illness is a constant struggle (Bradshaw, 2000) and it has been predicted that many NHS services funded through a tax system may be unsustainable by 2020 (Bradshaw, 2003). For the first time since records were kept more of the population is over sixty than children, potentially resulting in a declining number of taxpayers available to support the increasing number of older people (National Statistics, 2002a, 2002b). Outside Europe it is estimated that over 45% of
the population in the USA suffers from one or more chronic condition accounting for 75% of their health care costs (Hoffman, Rice, & Sung, 1996).

Promoting the benefit of self-care approaches is considered significant in how future long term conditions are managed (Department of Health, 2004b, 2005c; Kennedy, Rogers, & Bower, 2007) and health care professionals will need to take greater responsibility for making patients aware of the options available to them (Blyth, March, Nicholas, & Cousins, 2005; Department of Health, 2005c, 2005d). To successfully achieve this patients and healthcare professionals need to work in partnership and develop a culture within the NHS that will support self-management, and this is possibly a huge challenge (Lewis & Dixon, 2004). Some of the issues and challenges associated with integrating lay led self-management approaches have been explored in greater detail in the Policy Review (See Part Two). In summary these issues are associated with the complexity of political and organisational settings, often making it difficult work to implement policy successfully and to improve health (Hunter & Killoran, 2004). They also relate to making time and the provision of adequate funding available for self-management approaches. Some of these issues and challenges require the power and influence of both the voluntary sector and the medical profession to be harnessed in order to provide balance to the Government’s approach to healthcare for patients with long term illnesses.

Alongside policy makers moves towards self-management approaches in delivering healthcare, has been a change in people’s attitudes to healthcare.
People are now less accepting of the traditional model of medical care as they begin to question its benefit in some areas of care (Department of Health, 2004a, 2005a; R. Johnson, 1999; Martin, Advant, Bowman, & et al, 2004). This questioning is supported by the increasing influence of the voluntary sector who see one of their roles as influencing the Government in providing quality lay led self-management programmes (Cooper, 2001; Department of Health, 2001a).

Shifts in attitude may also be about society developing its understanding of how best to manage some long term conditions and setting reasonable expectations for the outcomes of treatment along with achieving a change in outlook. This may particularly relate to managing conditions such as work related low back pain, by teaching more effective self-management strategies (Blyth, GJ, & Nicholas, 2007). These issues link with aspects discussed in the Service Development Project (SDP) (See Part Two), where variations in human behaviour and cultural norms can occur when an individual is faced with illness. The influence of culture on illness and the Sick Role has also been briefly identified in the SDP. In the SDP the Sick Role and its requirements have been acknowledged as a role individuals may associate with when they seek medical care, though it is recognised individuals may now be less accepting of aspects of the Sick Role which are connected with the traditional medical model (R. Johnson, 1999; Martin et al., 2004).

When poorly managed, persistent pain has considerable impact on health issues, including, pain severity, depression and levels of activity (Glenn &
Burns, 2003). While it is acknowledged that self-care approaches do not suit all patients, those who are receptive can be helped with appropriate support and encouragement to actively engage in taking responsibility. Individuals may find such an approach offers opportunities to regain self respect, meaning, dignity, purpose and a sense of well being that an approach dominated by a biomedical model may well inhibit (Hanson & Gerber, 1990).
2 Literature Review

2.1 Introduction

The purpose of this review is to critically evaluate and synthesise the strengths and weaknesses of literature connected with self-management care for persistent pain, and provide a summary of the state of existing knowledge (Blaxter, Hughes, & Tight, 1996; Polit, Beck, & Hungler, 2001). It also provides a critical assessment of how adequate and reliable the studies are, highlighting any limitations or gaps in the literature specifically related to self-management approaches.

The main aims of the review are to:

1. Establish the need for further research to be undertaken in patients suffering from persistent pain.
2. Determine what is currently known about self-management approaches. Self-management for the purpose of this review will refer to professional and lay self-management/self-care approaches.
3. Determine what is currently known about the relationship between self-management approaches in the overall management of persistent pain.
4. Analyse possible methodological strengths and weaknesses of previous studies.
5. Establish the appropriate methodology and design for the current study.
Sources for the literature review were Ovid MEDLINE 1950-2007, Ovid OLDMEDLINE 1950-1965, CINAHL – Cumulative Index to Nursing & Allied Health Literature 1982- 2007, British Nursing Index and Archive 1985-2007, Health and Psychosocial Instruments 1985-2007, Cochrane Database, Bandolier and search engine’ Google’. Recent journals were also manually scanned for articles relating to the research topics and articles over the last 40 years were the main focus of the literature search. Only studies published in English and involving humans were included and two unpublished PhD thesis and a dissertation presented for Master Degree from colleagues included along with information from poster presentations presented at three British Pain Society conferences.

2.2 Epidemiology of persistent pain

Establishing how extensive the problems of persistent pain are is necessary to put the issue into perspective and lend support for further research of the subject. Epidemiology is concerned with the study of the distribution and determinants of health related conditions or events in definite populations. Prevalence studies of chronic pain contribute to this information, although it is acknowledged they only deal with part of the epidemiology of pain (Crombie, Davies, & Macrae, 1994).

Until recently national statistics in Europe provided little information on the incidence of pain while information on the incidence of other conditions such as diabetes and cancer have been collected for several decades. This is because pain was seen as a symptom or consequence of a disease/illness or
injury, and therefore not usually recorded. With an industrial injury it may well be pain that prevents the person returning to work, but the nature of the injury is what will be recorded and enter statistical records and not the pain symptoms (Fricker, 2003).

The Pain in Europe Report (Breivik et al., 2006; Fricker, 2003) suggest persistent pain is a devastating and widespread problem in Europe with 19% of adults affected. They interviewed over 46,000 people and it is the largest and most detailed pain survey ever conducted in Europe, with data collected from 16 countries. Norway had the highest prevalence (30% n=2,018) and Spain the lowest (11% n=3,801). The United Kingdom (UK) prevalence was 13% (n=3,800).

Studies conducted solely in the UK suggest the prevalence of chronic pain ranges between 11.5% and 66.2% (Aggarwal, McBeth, Zakrzeswka, Lunt, & Macfarlane, 2006; Bowsher, Rigge, & Sopp, 1991; Elliott, Smith, Penny, Smith, & Chambers, 1999; Smith et al., 2001; Thomas, Peat, Harris, Wilkie, & Croft, 2004). One of the problems with studies is the variation in their estimations of prevalence (Crombie et al., 1994). This may in part be due to different data collection methods, individuals’ interpretation of questions, variations across geographical locations and time. Differences in the definition of persistent pain is also thought to contribute to the variability of incidence (Harstall & Ospina, 2003). The UK studies involve large sample numbers (n=1,037 – 3,605) gathering data using self report postal questionnaires and telephone interviews. The lowest prevalence (11.5%) came from data
gathered from telephone interviews (Bowsher et al., 1991), and this figure is surprising as telephone interviews are thought less likely to underestimate patients health problems (Bowling, 1997; Doll, McPherson, Davies, & Flood, 1991).

The highest prevalence of pain (66.2%) is found in one of the more recent studies (Thomas et al., 2004) and may be explained by the study including older individuals aged over fifty years and from one specific region of England, North Staffordshire. The survey asks only about pain in the four weeks prior to the data collection. However, a follow up survey three years later showed that for 86% of individuals in pain in the baseline data, their pain had persisted (Thomas, Mottram, Peat, Wilkie, & Croft, 2007).

Aggarwal et al. (2006) most recent study on the epidemiology of chronic syndromes is interesting for its focus on syndromes for which no physical or pathological changes have been found. They include four chronic syndromes; chronic widespread pain (CWP), chronic oro-facial pain (OFP), irritable bowel (IBS) syndrome and chronic fatigue. The highest prevalence was CWP (15%) and overall 27% of participants reported one or more syndromes. Chronic widespread pain was clearly related to increasing age, while OFP and IBS generally reduced with age while chronic fatigue remained relatively stable between ages of 40 and 75 years. Findings have to be measured against the studies cross sectional design lacking the ability to distinguish cause from effect and its focus on one general medical practice in outer Manchester, complicating generalisations. Nevertheless, this study has important clinical
implications as it suggests that the focus of care for unexplained syndromes is primarily on finding an organic cause for them. This may leave co-existing syndromes neglected. It also raises issues of why help is sought for some syndromes but perhaps not for a coexisting syndrome raising questions for associated factors such as illness behaviour (Aggarwal et al., 2006).

Studies conducted in Denmark, Sweden and Norway estimate a similar range of prevalence of chronic pain between 19% and 53.7% (Eriksen, Jensen, Sjøgren, Ekholm, & Rasmussen, 2003; Gerdle, Bjork, Henriksson, & Bengtsson, 2004; Rustøen et al., 2004b). Postal self-report questionnaires are used in all studies and again sample numbers are large (n=2,000 – 9,000). National registers provide the sample frameworks in all three studies and as data collection methods are similar, this fails to explain the diversity in incidences. Different questionnaire formats and interpretation of questions are offered as possible explanations as well as the various geographical locations.

Studies that collected data on the prevalence of long term pain following various surgical procedures suggests 30% and 43% of patients will be left with some form of persistent pain (Bruce et al., 2003; Bruce, Poobalan, Smith, & Chambers, 2004). A further area explored has been the existence of thalamic pain following a stroke. This has been estimated at 29% of persistent pains experienced by this group (Kong, Woon, & Yang, 2004).
In summary, persistent pain regardless of its cause is clearly a health issue and epidemiological studies support data on long term conditions issued by the Government indicating long term conditions have become the greatest area of cost to the NHS (Department of Health, 2005c; DH Long-term Conditions NSF Team, 2005; NHS Modernisation Agency, 2004). But all these studies and data fail to explain why the requirement for outpatient appointments and sick leave for some persistent pain conditions, for example back pain have risen out of all proportion to the rise in prevalence of that condition (Evans et al., 2004; Evans & Richards, 1996; Palmer et al., 2000). While epidemiological studies increase our knowledge for the causes for some persistent pains such as back pain this understanding has not resulted necessarily in better outcomes for patients (Macfarlane, Jones, & Hannaford, 2006).

Links may exist with the way our culture is becoming more and more competitive and achievement orientated (Hayes, Strosahl, & Wilson, 2003). This was once considered a positive cultural change but can become harmful to individuals as it may lead to a behavioural system that is out of control and no longer evolving positively (Hayes et al., 2003). The development of new treatments for persistent pain may no longer be what is needed but instead greater understanding of the mechanisms that act to maintain pain (Nurmikko, Nash, & Wiles, 1998), and approaches that improve outcomes (Von Korff et al., 1997).
2.3 Treatments for pain

There is increasing evidence that conventional treatments offered for some persistent pain conditions by the medical model may fail to provide effective reductions of pain symptoms (Bendix, Bendix, Busch, & Jordan, 1996; Brox et al., 2006; Fairbank et al., 2005; Linton, 1994; Moore, Edwards, Barden, & McQuay, 2003; Wynne, 2002). It has even been suggested treatments for pain could be adding to associated symptoms and disability (Indahl, Velund, & Reikeraas, 1995; Loser & Sullivan, 1995). Further indication of the limitations of the medical model are found in a study suggesting patients referred to pain clinics who received more invasive pain treatments, appeared to have poorer outcomes than those managed more simply by their General Practitioner (Crook, Wier, & Tunks, 1989).

However, benefit from some invasive treatments cannot be denied and two recent systematic reviews suggest there is a range of limited to moderate evidence for epidurals and facet joint injections giving short or medium periods of pain relief (Boswell, Colson, Sehgal, Dunbar, & Epter, 2007; Salahadini et al., 2007). Nevertheless, the evidence can be inconsistent (Davies, Crombie, Brown, & Martin, 1997; Koes, Scholten, Mens, & Bouter, 1995) and has to be balanced with possible complications which although rare can nevertheless occur (Alcock, Regaard, & Browne, 2003; Weingarten, Hooten, & Huntoon, 2006). It is also noted in the literature that studies tend to concentrate on treatment approaches in isolation, and there are different levels of evidence for treatments for chronic pain (Blyth et al., 2007).
In addition healthcare professionals admit there can be reluctance on their part to acknowledge that invasive treatments may not always be the appropriate management for some patients (Stannard, 2000). This failure of pain technological treatments to provide improved long term outcomes in some patients can inadvertently reinforce passivity (Frazier, 1992). As individuals look to the medical model to cure or reduce their pain, they can become passive recipients of something done to them through injections, operations, medications, or manipulation, (Moore 2004a).

Explorations of physical therapy treatments has found some professionals continue to treat individuals with persistent back pain for over three months despite them showing no improvement because discharging them meant sending them into a possible therapeutic void (Pincus, Vogel, Breen, Foster, & Underwood, 2006). This was a large study (N=354) with postal questionnaire data gathered from osteopaths, chiropractors and physiotherapist and uses a mixed method design. Thirty nine respondents said they had treated one or more patients long term without improvement, and seventy-eight had treated one patient in this way. A smaller number of clinicians were also interviewed (n=44) and interestingly only 53% of physiotherapists in National Health Trusts who reported treating a patient more than eight times without evidence of improvement, agreed to be interviewed. However, all the chiropractors and osteopaths agreed to interview. It is suggested there may be pressure to provide what are considered socially desirable responses to research questions, and failure is linked with aspects of a blame culture. This may limit the accuracy of data collected and implies the problem of treatment
without improvement may be underestimated. It also draws attention to clinicians sometimes feeling caught between research based evidence and their clinical expertise, and what their patients’ desire from treatment (Pincus et al., 2006).

The failure of external approaches to sometimes control persistent pain is suggested as resulting in the exacerbation of unhelpful internal physiological and emotional responses (Janssen et al., 2004), and in today’s society there is an inference that with enough persistence there will be a medical solution for solving most pain problems (www.painrecoveryline.com, www.overcomingpain.com). This can lead to exclusive but failed searches (Aldrich, Eccleston, & Crombez, 2000) that may result in greater suffering and lower quality of life (Frazier, 1992; Rankin, 2001), as individuals encouraged by strong cultural views will often persevere with trying to find a medical solution for their pain. Giving up trying to control pain and just accepting it may be seen as failure (Janssen et al 2004), and yet, there are authorities that advocate that giving up control of pain is just what could enhance a patient’s perception of control. This is because no longer is the reduction of pain their primary goal by which they measure success or failure by (Janssen 2004, McCracken 1998). To achieve this may require a change of cultural practice and resistance from applying accustomed approaches and efforts to solve a pain problem, that may be the very source of those problems (Hayes et al., 2003).
Much of the literature exploring treatments for persistent pain tends to explore either the benefits of medical treatments or the benefits of cognitive behavioural self-management approaches (Becker, Olsen, Sjøgren, Bech, & Erickson, 2000; Brox et al., 2006; Davies et al., 1997; Fairbank et al., 2005; Haugil, Steen E, Laerum E, Nygard R, & Finset A, 2001). One meta-analytic review involving sixty-five studies attempts to explore which treatment approaches seem to be most effective by comparing the benefit of multidisciplinary pain clinics with no treatment, waiting list or single-discipline treatments for persistent pain such as medical or physiotherapy treatments. They found a multidisciplinary approach most effective but advise caution with interpreting the result as the quality of studies varied (Flor, Fydrich, & Turk, 1992).

Only recently is there evidence emerging of interest in outcomes associated with combining approaches and outcomes appear promising (Mead, Theadom, Byron, & Dupont, 2007). Mead et al (2007) study involved a four week pain coping strategies programme based on a traditional pain management programme. They found evidence that such an approach offered at an earlier stage may be an effective intervention for promoting self-management, and teaching coping in individuals with persistent pain. Individuals experienced improvement in mood, physical ability and perceived functional ability. However, participants were selected for inclusion by healthcare professionals and the selection criteria were not clear. Regrettably their study is weakened by failing to involve a control group and use of tools that do not measure the study’s principle outcome of coping.
There is also interest in the impact psychosocial factors can have on medical treatment outcomes. One study exploring psychological predictors of the effectiveness of radiofrequency lesioning of cervical spinal dorsal ganglion (Samwel, Slappendel, Crula, & Voermand, 2000), found higher levels of pre-treatment catastrophising were associated with relatively low levels of pain reduction. Weaknesses of this study are its cross-sectional design, use of postal questionnaires and relativity small sample number (N=54). It also employs a less familiar Dutch instrument; the Pain Cognition Instrument to measure catastrophising rather than the more frequently used Pain Catastrophising Scale, making comparisons difficult. However, Samwel et al (2000) suggest that if the psychosocial factors related to pain are not addressed then treatments for persistent pain will have little chance of benefiting the patient. They advise treatment should not solely focus on a medical solution but that this approach should be combined with a multidisciplinary pain management programme in order to optimise benefits.

Achieving equal recognition for medical and psychosocial treatment approaches may be difficult while the medical model dominates medicine (Engel, 1980) and this difficulty is illustrated in a large study (N=1208) investigating quality of life in patients with persistent pain (Lamé, Peters, Vlaeyen, & Kleef, 2005). Their study found patients were only more willing to consider psychosocial factors when medical treatments were failing. This suggests treatments for psychosocial factors have less value attached to them by society, but by concentrating on psychosocial factors first, outcomes for medical treatments could improve (Lamé et al., 2005). The importance of
addressing the psychological variables involved in some persistent pains is seen elsewhere in literature (Peters, Vlaeyen, & Weber, 2005). Peter et al (2005) study suggests that targeting maladaptive pain cognitions and affective responses by involving cognitive behavioural interventions this can impact on pain and functional limitations. This study involving an acceptable sized sample (N=100) and self-report questionnaires lends additional support to the importance of addressing the psychosocial aspects of pain in any treatment approach.

Despite the lack of medical model interventions with clear proven efficacy, patients suffering from persistent pain still need help. Providing 'help' is quite often the aspect of pain care which makes patients feel better, and this can be lost in focusing exclusively on the efficacy of interventional treatments (McQuay, Moore, Eccleston, Morley, & C de C Williams, 1997).

2.4 Self-care/self-management approaches

The key to self care approaches is enabling patients to take greater control of their treatments and affect a shift from reliance on external health professionals to the adoption of active internal approaches to illness (NHS Modernisation Agency, 2004; Smith & Elliott, 2004).

Self-support, self-care and self-management are terms used interchangeably in the literature and there appears no clear agreement on a definition for them. Lorig and Holman (2000) indicate self-management is a term used widely to describe patient education, patient behaviours and health
promotion programmes, while Von Korff et al (1997) offer the following description of self-care:

- Patients and families engaging in activities that promote health, functioning and prevent adverse disease complications
- Interaction with healthcare providers and adherence to recommended protocols
- Monitoring of physical and emotional positions and making appropriate management decisions on the basis of the outcomes of this monitoring
- Managing the consequences of illness on the patient's ability to function in important roles and on emotions, self-esteem and relationships with others.

Lorig & Holman (2003) propose self-management approaches should be founded on problems perceived by the patient and that there are five core self-management skills. These are based on Lorig & Holman's experience and reviews of the literature and are: 'problem solving, decision making, resource utilization, forming of a patient/healthcare provider partnership and taking action' (Lorig & Holman, 2003:2).

Self-management is a key policy agenda and the Government has proposed that by 2007 the NHS will have established a user self-management approach to dealing with issues associated with chronic illness (Tattersall, 2002). A number of studies suggest self-care approaches may be appropriate in the management of persistent pain and its symptoms (Bury, Newbould, & Taylor,
2005; Buszewicz et al., 2006; Kemper, Lorig, & Mettler, 1993; Kralik, Koch, Price, & Howard, 2004; Lorig, Sobel, Ritter, D, & Hobbs, 2001). Buszewicz et al (2006) recently conducted randomised controlled trial (RCT) involved a large number of individuals (N=812) recruited from the UK with osteoarthritis. Participants attending the self-management programme showed improved ability to manage their symptoms associated with reduced anxiety although there was no significant impact on visits to the GP, pain and physical functioning.

Not all studies are as convinced by the benefits of self-management approaches (Griffiths et al., 2005; Haas et al., 2005). Griffiths et al RCT study exploring a lay led self-management programme, the Expert Patient Programme (EPP) for Bangladeshi patients found limited improvements in health status at four months and further benefits reduced by a reluctance to take part and attend. They recruited from primary care practices and this study is noted for directly approaching potential participants rather than leaving them to respond to adverts or written requests. The tutors who led the EPP were accredited lay tutors who themselves had a chronic disease. However, they were paid to provide their services, altering the concept of EPP tutors who are usually unpaid volunteers.

Haas et al (2005) RCT study involving older American individuals with low back pain (N=109), found no advantage at six months for participants attending the Chronic Disease Management Programme over a wait list control group. They measured pain, general health, self efficacy and self-care
attitudes, although there were suggestions that emotional well being, fatigue and functional disability improved. There also appeared to be a ceiling effect for participants taking responsibility for their low back pain which is an important aspect to recognise when promoting self-care approaches.

Shifting patients beliefs towards a greater commitment to self-manage their symptoms may lead to greater adherence to skills and routines recommended, resulting in improved pain management (Jensen, Nielson, Turner, Romano, & Hill, 2004a; Lorig, Seleznick et al., 1989; Lorig et al., 2001; Lorig et al., 1999). However, combining self-care approaches with the familiar biomedical model may prove a challenge, as the medical model can inhibit self-management (Hanson & Gerber, 1990), and the ‘crippling flaw’ of this model is that it does not involve the patient and their individual and personal characteristics (Engel, 1980); the role of the patient is simply to comply with the healthcare professionals diagnosis and instruction (Lorig & Holman, 2000). Self-care approaches require partnerships to be formed (Lorig & Holman, 2003), and doctors may not be comfortable when the balance of power does not favour them (Wileman, May, & Chew-Graham, 2002). Equally, individuals wanting to participate in health-care decisions may show a preference for a more passive role when they are actually sick that is devoid of normal role behaviour and responsibility (Stiggelbout & Kiebert, 1997).

The findings in Stiggelbout & Kiebert’s (1997) study are treated with some caution as the study has a number of weaknesses. Firstly they explore self-
care issues involving two quite different groups of patients, one with cancer and the other following surgery for a non-malignant condition. Secondly, they study responses to vignettes rather than actual behaviours. The vignettes are criticised for dealing with conditions (cancer, tinea and gallstones) with very different implications for the individuals’ long term health.

Nevertheless, what Stiggelbout & Kiebert’s (1997) paper does highlight is that greater patient involvement may not be appropriate or welcomed by all individuals and at all times. It is suggested different conditions may be more or less amenable to a self-management style of care (Stiggelbout & Kiebert, 1997), and healthcare professionals should be obliged to raise individuals awareness that opting for more passive roles could prevent them from achieving optimum care (Laine, 1997).

A number of studies exploring self-management in pain as well as other long term conditions focus on issues associated with improved patients’ health status and changing the way patients use services (Barlow, Turner, & Wright, 2000; Lorig, Mazonson, & Holman, 1993; Lorig, Ritter, & González, 2003; Lorig et al., 2001; Lorig et al., 1999). Use of healthcare services is important when little information is available on costs and benefits of services such as pain clinics (McQuay et al., 1997). However, only limited benefit may be achieved despite enormous effort put into clinical trials if there is a failure to address the ‘human importance’ of the result (Lorig & Holman, 2000; Moore et al., 2003).
Barlow et al (2000) have conducted one of the larger randomised controlled studies in the UK exploring the benefits of the Arthritis Self-Management Programme (ASMP) pioneered by Professor Kate Lorig of Stanford University United States of America (USA). Arthritis Care utilised and delivered the ASMP in the UK (NHS Expert Patients Programme, 2002), and the Expert Patient Programme (EPP) was adapted from Lorig’s ASMP and Chronic Disease Management Programme (CDMP). The process of teaching on these programmes is based on Self-Efficacy Theory, and integrates approaches suggested by Albert Bandura (Lorig et al., 1999).

Lorig and colleagues were involved in supporting the NHS EPP in England (NHS Expert Patients Programme, 2002) considered a key self-management initiative (Wilson & Mayor, 2006). Barlow et al (2000) study makes an important contribution to the development of lay led self-management programmes. It suggests ASMP provides a number of important benefits to individuals with arthritis and could be a useful ‘adjunct’ to medical care. Despite its size (N= 544), there are concerns with distortion of the randomisation technique as regions recruiting fewer than twenty participants randomly assigned ten to the intervention group in order to recruit sufficient participants to allow the ASMP course to run. The Intervention group was followed up for twelve months and the Control group for four months making it impossible to formulate longer term comparisons of the possible benefits of ASMP.
A review commissioned by the Health Development Agency, now transferred to the National Institute for Clinical Excellence involved 17 studies exploring lay led self-management programmes in the management of chronic illness (Bury et al., 2005). Five of these studies are conducted in the UK, eleven in the USA, one in China and one country is unknown. They conclude lay led self-management programmes ‘represent one potentially useful approach’ (Bury et al., 2005:20), but warn that there may be weaknesses in the evidence base and the potential for such approaches to cause harm cannot be ignored.

The style of Bury et al (2005) review appears to reinforce how self-care approaches can often be viewed as competing with the medical model rather than complementing it. Competition between the two approaches has previously been observed by Von Korff et al (1997), when what is needed is the provision of care that focuses on the patient and more closely matches their needs (Hobro, Weinman, & Hankins, 2004; Keefe et al., 2000). Self-management is considered a necessary part of that care (Lorig & Holman, 2000) and to provide effective self-management, professionals as well as patients need training. There may be aspects of self-management that are important to patients but not fully acknowledged by professionals with specialist nurses identified as possibly the best placed healthcare professionals to promote this approach (Kennedy, Gask, & Rogers, 2005).

A further study evaluating the CDSMP in a Chinese population in Hong Kong found cultural differences did not reduce benefits experienced from attending
this programme, and outcomes were similar to those found in studies involving Western cultures (Siu, Chan, Poon, Chui, & Chan, 2007). A quasi-experimental design was used with the comparison group attending Tai-Chi classes. The researchers chose to conduct the CDSMP using professional and lay leaders. Although some studies involving CDSMP have involved a mix of professional and lay leaders in general it is lay led using a well structured manual (Lorig et al., 2001) so comparisons cannot be made with many studies exploring CDSMP, ASMP and EPP conducted in the West.

Siu et al (2007) used the outcome measurement questionnaire devised by Kate Lorig. In addition participants attending the CDSMP completed a logbook aimed at collecting data associated with self-management strategies. Logbook data was not collected from the comparison group so the qualitative data lacks what could have been revealing comparisons.

A study that might be considered to take a hybrid approach to self-care, involved professionals delivering a ‘less demanding’ version of a traditional pain management programme with intention of fostering the development of community based self-help groups (Arthur & Hamling, 2003) (See Table 1). This programme was offered to individuals considered unsuitable for a traditional pain management programme. Despite concerns that participants were not ready to adopt a self-management approach to managing their pain, significant progress through the Pain Stages of Changes (PSOCQ) occurred. All groups involved in the study went on to establish their own self-
help groups and individuals described important changes to purpose and satisfaction with life.

Arthur & Hamling’s (2003) study is weakened by failing to involve a control group but they were able to compare outcomes with a traditionally led pain management programme. Results were not as powerful for the shortened version of a pain management programme, but as they point out, the participants involved were experiencing a number of complex problems. It is also significant to note that the participants involved were all considered unsuitable for inclusion in a traditional pain management programme, because they took a medical view of their symptoms, and were dependent on medical services for inappropriate psycho-social support.

Individuals in Arthur & Hamling’s (2003) study appeared reluctant to make the commitment required for a traditional pain management programme, but what the authors crucially overlook in their data is the fact that participants scores suggest the majority were in the Contemplation Stages of Change at entry to the study. This would suggest they were amenable to considering adopting self-care approaches, and may have some implications for how professionals make judgments. It also relates to the considerable influence and control professionals have on deciding which approaches to managing pain are offered to individuals, perhaps inadvertently closing some avenues of care that could be helpful.
Systematic approach

The value of self-support approaches is recognised in recent Government policies (Department of Health, 2001a, 2005d; NHS Modernisation Agency, 2004), where there are aims to identify local populations by applying a systematic approach to care for people with long-term conditions (See Figure 1).

The systematic approach to care for people with long term conditions is a NHS and social care model aimed at supporting and sustaining local innovation and integration, by providing a framework for improving the care of patients. It groups the population affected into three categories according to their different levels of need (Department of Health, 2004b);

Level 1: those requiring more support with self-management and self-care so they can take an active role in managing their conditions. This group makes up 70-80% of the population suffering from a long-term condition.

Level 2: those needing better disease management from multi disciplinary teams providing high quality, evidenced based care.

Level 3: those patients with complex, often multiple conditions who need case management approaches (Department of Health, 2005d).
Stratifying patients by need is a critical factor of this model (NHS Modernisation Agency, 2004) and essential components for good long term disease management are identified in, ‘10 High Impact Changes for Service Improvement and Delivery’ (NHS Modernisation Agency, 2004). However, there is a failure to provide further guidance on how to identify patients ‘needs’, and additional tools may be required to stratify patients safely. The Pain Stage of Change Questionnaire (PSOCQ) is a tool, which may provide assistance, as its purpose is to identify patients’ readiness to take on a self-management approach. Before reviewing the Pain Stage of Change it is important to appraise this theory in the context of others associated with the development self-management approaches.

2.5 Theoretical models and their relevance to self-management

Self-managing a health condition can involve complex behaviours and refers to actions an individual might take to manage that particular condition.
Interventions aimed at education to promote self-management behaviours have been inconsistent in their success and measured by their failure to improve outcomes. This has led many self-management interventions to incorporate concepts derived from both psychological and social theories. (Mulligan & Newman, 2007).

Theories can be seen as the drivers of research (Noar & Zimmerman, 2005) and provide understanding to the process through which interventions achieve their outcomes. Clinicians are then able to make decisions about the applicability of the theory’s process to a clinical situation (J. Johnson, 1999). Theories are also needed if knowledge gained through research is to be generalised beyond the specific intervention and situations used in a study, providing a framework for exploring and understanding the complex character of health behaviour change (J. Johnson, 1999; Noar & Zimmerman, 2005).

Several theoretical models considered to have particular connections with self-management have been identified in this review and are: The Transtheoretical Model (TTM) (Prochaska & DiClemente, 1982), Pain Stages of Change (PSOC) (Kerns, Rosenberg, Jamison, Caudill, & Haythornthwaite, 1997), Health Belief Model (HBM) (Becker, 1974), Self-Efficacy Model (SE) (Bandura, 1994), Self-Regulatory Model (SRM) (Leventhal, Nerenz, & Steele, 1984) and the Stress-Coping Model (SCM) (Lazarus, 1992). In addition the Sick Role has also been included as it is a theory that examines influences on
health and illness behaviours and is closely associated with the HBM (Becker, 1974).

The TTM is a particularly useful theory for exploring behaviour change and decision making processes individuals may experience where promotion of health behaviours are involved (Velicer, Prochaska, Fava, Norman, & Redding, 1998). The TTM is a staged based approach to change and research has shown approaches based on this theory are effective for altering a variety of health related behaviours (Ewles & Simnett, 1999). Stages of Change theories represent measures of time that can help healthcare professionals to understand when shifts in an individual’s intentions and behaviours might occur (Prochaska, DiClemente, & Norcross, 1992).

The TTM consists of five stages, Precontemplation, Contemplation, Preparation, Action and Maintenance. It has been widely applied in studies measuring readiness to adopt a self-management approach for managing persistent pain through application of the Pain Stage of Change Questionnaire derived from the TTM (Arthur & Hamling, 2003; Jensen, Nielson, Romano, Hill, & Turner, 2000; Keefe et al., 2000; Kerns & Rosenberg, 2000; Kerns et al., 1997).

However, Stage of Change models have been accused of over simplifying processes associated with change. While the TTM identifies a number of stages an individual might progress through during the process of change, it is suggested the key to applying this model to complex behaviours is to
regard it as involving both a linear and cyclical process. Individuals may go round and back through the different stages more than once before entering an enduring stage of change (Ewles & Simnett, 1999; Prochaska et al., 1992).

Another model widely used to help explain health related behaviours is the Health Belief Model (HBM) (Becker, 1974; Rosenstock, 1974). This model conjectures that individuals will not make decisions to take on behaviours associated with improved health until they are ready to take this action (Galvin, 1992). The HBM proposes perceived benefits minus perceived barriers are most likely to influence behaviour change (Strecher & Rosenstock, 1997).

A limitation of the HBM is that it assumes that all benefits are considered equally good and all barriers as equally bad (Oliver & Berger, 1979). A further criticism is its inability to hypothesise when an individual is likely to take the recommended health action. However, Noor and Zimmerman’s (2005) review of health behaviour theories identifies a considerable volume of research applying the HBM and involves cross sectional studies or the various components of the HBM, severity, susceptibility, benefit and barriers are explored as separate constructs (Strecher & Rosenstock, 1997). This may in part be responsible for weakening the theory’s capacity and difficulty in accounting for behaviours that involve complex relationships with health such as exercise or regimes of behaviours (Sharpe & Curran, 2006; Strecher & Rosenstock, 1997).
The HBM has been connected with the Sick Role (Becker, 1974), and the Sick Role will be considered because adopting it can be influential in the management of long-term conditions (Wade & Halligan, 2007). The strength of influence on health and illness is recognised in Kasl & Cobb’s (1966b) conceptual model that integrates certain behaviours related to illness and health. The Sick Role is a role individuals adopt when they believe they are unwell (Wade & Halligan, 2007) and was identified in the Service Development Project (See Part Two) as possibly shaping behaviours associated with managing persistent pain. It can be regarded as activities taken by individuals who consider themselves sick for the purpose of getting well (Kasl, Cobb, & Arbor, 1966b).

Fundamental to the Sick Role is the idea that being sick represents a deviant role compared to the rest of the ‘well’ population and the presence of illness requires sanctioning by the medical profession (Parsons, 1951). There are firm expectations associated with this role and these define what are considered the norms and acceptable behaviours for this role. By entering the Sick Role the individual is given a legitimate role and regarded as not responsible for their illness. In return the individual is expected to be motivated to get well because it is an undesirable state and is obliged to seek professional help to achieve this. During this period they are exempt from certain usual responsibilities and can indulge in dependent behaviours within strictly defined boundaries (Kassebaum & Baumann, 1965; Parsons, 1951).
On occasions the Sick Role may be inappropriate or even unhelpful (Wade & Halligan, 2007), and the HBM is considered an suitable model for predicating and explaining Sick Role behaviours (Becker, 1974). However, the Sick Role has its critics. The main concerns are that different levels of society will hold different norms in relation to the Sick Role. The intensity of these norms will alter and different aspects of the Sick Role may be viewed with varying proportions and perspectives by individuals (Kassebaum & Baumann, 1965). Also illness does not always have clear boundaries of onset and end and for many individuals who experience long term conditions, they may be considered as 'partially sick' (Wade & Halligan, 2007).

Another key theory to emerge in the area of self-management has been Self Efficacy (SE) (Bandura, 1994). Bandura defines SE as the individual’s belief about his/her capabilities to perform a given behaviour. Lorig and colleagues’ research involving lay led self-management programmes has been based on the concept of SE (Bandura, 2005; Lorig, Chastain, Ung, Shoor, & Holman, 1989). Bandura (2005) proposed self-management approaches could be enhanced if the level and nature of the intervention was tailored to the individual’s self-efficacy beliefs, self-management abilities and motivation in order to achieve the desired change. Bandura suggests the individual’s baseline level of self-efficacy together with the self-efficacy instilled by a self-management approach will predict the health outcomes.

SE has been compared with the TTM/Pain Stage of Change and found to be a better predictor of outcome on a multidisciplinary pain programme that
emphasises a self-management approach. However, the PSOC has shown that individuals who progress through the stages of change scale 'develop beliefs more consistent with a self-management approach as a function of treatment' (Strong, Westbury, Smith, McKenzie, & Ryan, 2002:71). This provides support for the Pain Stages of Change as a process measure while self-efficacy may prove more reliable as predictor of outcome.

Bandura’s social learning theory of Self-Efficacy is associated with coping, and this is a key concept in another theory relevant to self-management, the Self-Regulatory Model (Leventhal et al., 1984). The key theme to the SRM is that individuals are motivated to regulate or lessen their health-related risks and to work at reducing ‘these health threats in ways consistent with their perceptions of them’ (Leventhal et al., 1984:219). The SRM proposes that teaching individuals coping and self-care activities will increase feelings of Self-Efficacy. The SRM theory suggests that individuals will opt to cope in ways that are consistent with their understanding of the experience (J. Johnson, 1999). The impact of instruction in coping and self-care approaches are increased when combined with ‘concrete–objective information’ suggesting the process of coping is more complex than just increased feelings of self-efficacy (J. Johnson, 1999:446).

The SRM has been suggested as a model that may offer direction for the development of interventions that facilitate adherence to preventative regimes (Horne & Weinman, 2002). The focus though is away from exploring what may impact on behaviour change in chronic conditions and Self-
regulatory models are criticised for focusing on predicting health behaviour while offering minimal functional guidance on how to change and maintain it (Bandura, 2005).

Another theory to influence the growth of self-management approaches is the Stress-Coping Model (Lazarus, 1992). The SCM suggests active coping approaches are generally more helpful than passive approaches on health outcomes and psychological well being. However, similar to the TTM, there is uncertainty as to whether there are distinct stages or instead an underlying continuum that individuals employ to cope with a stressor such as persistent pain (Lazarus, 1992).

The theories that have been evaluated here are summarised in Table 1. Two models are considered to have particular relevance to self-management and persistent pain. These are the TTM and HBM and have been chosen for further evaluation.
<table>
<thead>
<tr>
<th>Theory</th>
<th>Features</th>
<th>Limitations</th>
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<tr>
<td><strong>Self-efficacy</strong> <em>(Bandura, 1994)</em></td>
<td>Perceived self efficacy is defined as an individual’s belief in their ability to produce designated levels of performance that put into effect influence over events that shape their lives. SE beliefs determine how individuals, think, motivate themselves and behave <em>(Bandura, 1994)</em></td>
<td>May be effective predicting outcomes of a multidisciplinary pain programme but less able to measure changes in beliefs consistent with a self-management approach as a function of treatment. The SE may fail to benefit from theoretical advances because there can be a lack of creative translation and social diffusion models <em>(Bandura, 2005)</em></td>
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<tr>
<td><strong>Health Belief Model</strong> <em>(Becker, 1974; Rosenstock, 1974)</em></td>
<td>Popular model for explaining health behaviour. It attempts to explain actions an individual might take when faced with choices about health behaviours. HBM contends an individual will take health action dependant on, susceptibility, severity, benefits and barriers perceived by the individual.</td>
<td>Core of HBM involves individuals’ subjective rational assessment of the consequences of potential actions. Different belief levels towards a given condition effect perceived severity and susceptibility, beliefs in benefits. Applying the HBM in some areas of care, the variance in use of some services is low</td>
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<tr>
<td><strong>Pain Stages of Change</strong> <em>(Kerns et al., 1997)</em></td>
<td>Developed from TTM to assess individuals’ readiness to adopt a self-management approach to managing pain</td>
<td>Readiness to adopt self-management approaches to managing pain may be better conceptualised as a continuum rather than discreet stages</td>
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<td><strong>Stress-Coping Model</strong> <em>(Lazarus, 1992)</em></td>
<td>Focuses on strategies individuals use to cope with a stressor such as persistent pain. Active coping approaches are generally more beneficial while passive strategies tend to be less helpful on health outcomes and psychological well being</td>
<td>Focus is strategies used by individuals rather than what might influence an individual to consider adopting self-management behaviours</td>
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<td><strong>Self-regulatory Model (SRM)</strong> <em>(Leventhal et al., 1984)</em></td>
<td>Approaches based on SRM focus on changing individuals views of their condition and its treatments. These are seen as key in both coping and health related behaviours. The SRM provides a convincing explanation of coping that may be useful for clinical practice</td>
<td>Offers direction for the development of interventions that facilitate adherence to preventative regimes, rather than exploring what may impact on behaviour change in chronic conditions</td>
</tr>
<tr>
<td><strong>Transtheoretical Model</strong> <em>(Prochaska, 1979; Prochaska &amp; DiClemente, 1982)</em></td>
<td>Explores behaviour change and decision making processes involved in promotion of health</td>
<td>Research does not identify whether distinct stages truly exist or whether there is instead an underlying continuum</td>
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<tr>
<td><strong>Sick Role</strong> <em>(Parsons, 1951)</em></td>
<td>Influential model associated with health and illness behaviours. Being sick represents a deviant role compared to the rest of the ‘well’ population. The presence of illness requires sanctioning by the medical profession</td>
<td>Norms and aspects of role are viewed differently by individuals. Does not take in to account differences in human behaviour and cultural norms or between acute and chronic illness</td>
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**Table 1:** Overview of theoretical models and their relevance to self-management
The TTM and HBM have been chosen for further review for the following reasons:

- The TTM is widely linked with influencing self-management
- The TTM is associated with persistent pain through the development of PSOCQ
- The PSOCQ is in the unusual position of having a measurement scale developed to specifically to test it. Other theories rely on appropriate measurement items to be selected when testing them.
- TTM and HBM involve decision making concepts related to choice and decision making. Influencing decision making processes may be important in influencing outcomes in self-management for persistent pain in clinical practice.

Despite the value attached to the TTM as a theory for explaining health behaviour change, its usefulness as a model of change for individuals with persistent pain has been questioned (Jensen et al., 2000). This is because few differences between concepts associated with change have been found when the Pain Stages of Change Questionnaire (PSOCQ) has been applied, regardless of the individual's different stage categorisation. In addition the use of self-management as the concept on which to categorise an individual’s readiness to change may be an unsuitable measurement because it involves a wide range of behaviours and attitudes. Also because self-management is complex, it may be that individuals can be situated concurrently in more than one stage at one time (Jensen et al., 2000), and time alone may not be the only factor attributed to stage differences (Lippke & Ziegelmann, 2006). For
these reasons it has been proposed that readiness to adopt a self-
management approach to pain management may be better thought of as a
continuum rather than discreet stages (Jensen et al., 2000).

These concerns are reflected in other areas of the literature where it is
suggested stages of change constructs may not be appropriate to apply to
complex health behaviours (Brug et al., 2005). Complex behaviours are
identified as involving more than one single behaviour; for that reason
individuals may be at different stages of change for various particular
behaviours. While limitations of the TTM need acknowledging it is also
important to recognise that much of the research exploring the TTM has like
the HBM involved cross-sectional studies. This research design does not
demonstrate the predictive power of variables such as decision making and
self-efficacy. Neither does it identify ‘whether distinct stages truly exist or
whether there is instead an underlying continuum’ (Brug et al., 2005:252).

Perhaps it is that the TTM should be viewed as involving both a linear and a
cyclical perspective in order to explain how people progress through the
different stages of change and described by Prochaska et al (1992) (see
Figure 2). Its value as a measure of time enabling clinicians to understand
when shifts in individuals’ attitudes, behaviours and intentions may occur in a
complex health condition could then be better recognised.

The HBM also a popular model for explaining health behaviour and has the
potential to explain and predict behaviours that are associated both with
preventative health behaviour and diagnosed illness. However, it is a model that fails to take into account changes in an individual’s beliefs and behaviours that may occur as a consequence of natural events, for example age and different approaches offered by healthcare professionals. Its focus on individual factors when exploring health interventions omits to consider social and environmental factors (Roden, 2004), failing to acknowledge the influences of a family setting and in the main has been tested against external interventions (Davidhizar, 1983).

It is also suggested that concepts of the HBM may be more suited to middle class rather than lower class individuals and there has been concern whether it can be applied with equal confidence to acute and chronic conditions (Davidhizar, 1983). Further criticism suggests the HBM does not define what an optimal level of readiness is (Davidhizar, 1983). However, it cannot be overlooked that over the last forty years the HBM has become one of the most widely employed theories to help explain health related behaviours (Strecher & Rosenstock, 1997). It has been fully evaluated and ‘has received empirical support and is considered one of the most influential models in health promotion’ (Roden, 2004:2).

In common with the TTM, decision making is an important aspect of the HBM and links between the HBM’s and TTM’s decision making concept and motivation have previously been identified (Jensen, Nielson, & Kerns, 2003; Strecher, Wang, Derry, Wildenhaus, & Johnson, 2002). These associations
are further explored in Chapter 4 where the theoretical framework for this study is discussed.

### 2.6 Pain Stages of Change

The Pain Stages of Change Questionnaire (PSOCQ) was developed by Kerns and colleagues (Kerns et al., 1997). This followed observations that numerous variables identified in previous studies such as disability and depression had limited reliability predicting successful participation in pain management programmes (Kerns & Rosenberg, 2000). As already mentioned, the development of the PSOCQ was influenced by the Transtheoretical model (TTM) of behaviour change (Prochaska & DiClemente, 1982, 1983) that proposed that the degree to which an individual is prepared to change behaviour would vary depending on their Stage of Change. In other health promotion areas such as smoking, Stages of Change was a greater predictor of successfully giving up smoking and was strongly dependent on the Stage of Change the person was at, at the time (DiClemente et al., 1991).

The Pain Stages of Change model suggests that individuals with persistent pain may vary in their readiness to take on a self-management approach to managing it. It proposes that individuals will have different views on how management of their pain should be approached. Some will view it as a medical problem that requires professional help and may have links with resistance to adopt self-management approaches as they are seen as inappropriate. Other individuals may acknowledge the medical model has
limitations and a self-management approach may have some benefit. Another group may consider they are already taking steps to actively self-manage their pain while still others may perceive themselves as having accommodated certain self-management strategies into their everyday life (Kerns & Rosenberg, 2000). The PSOCQ has been further evaluated (Jensen et al., 2000), and four scales describe differing stages of readiness to take on a self-management approach to managing pain; Precontemplation, Contemplation, Action and Maintenance.

The PSOCQ has been used as a measure of readiness for adopting a self-management approach to persistent pain in numerous studies (Biller, Arnstein, Caudill, Federman, & Guberman, 2000; Burns, Glenn, Lofland, Bruehl, & Harden, 2005; Carr, Klaber Moffett, Sharp, & Haines, 2006; Glenn & Burns, 2003; Jensen, Nielson, Turner, Romano, & Hill, 2004b; Jensen, Nielson, Turner, Romano, & Hill, 2003; Strand et al., 2006). All these study have in common findings that suggest individuals in the precontemplation stage of change are less likely to benefit as completely from self-management interventions as those with higher action and maintenance scores.

The validity of the PSOCQ for predicting participation in a self-management programme has been explored by Carr et al (2006) using a mixed method approach. The sample is drawn from a pain clinic in the United Kingdom. The qualitative approach involved a survey of interest in self-management and while the questions, all on 5-point likert type scale are described the method
of analysing the data obtained is not explained. This study found considerable support for the structure of the PSOCQ except for the two subscales, Action and Maintenance, which appeared to be measuring a single dimension. Patients in the Contemplation Stage where more open to exploring alternative ways to manage their pain, but as this study identifies patients involved in studies using the PSOCQ tend to be more educated. Carr (2006) draws on a previous paper to suggest the reason for this is because the idea of self-management is more acceptable to the middle class or better educated individual (Carr & Moffett, 2005).

Not all studies support PSOCQ as an effective measure of readiness to self-manage pain. It has been considered a less effective predictor of outcomes following completion of a pain rehabilitation programme than self-efficacy (Strong et al., 2002). Strong et al (2002) found the Pain Self-efficacy Questionnaire (Nicholas, 1994) was a better predictor of treatment outcome. Self-efficacy contributed significantly to pain severity at discharge, but progress through the Stages of Change was found to suggest greater commitment to adopt a self-management approach following attendance of a two week (5 days per week) intensive programme for individuals with neck and back pain. Strong et al (2002) advise further refinement of the PSOCQ if it is going to be reliable in contributing towards cost effective treatments through stage-matched interventions.

However, there are a number of factors in Strong et al (2002) that make comparisons with other studies difficult. Participants’ duration of pain was
lower with the mean duration between six and twelve months, and the sample (N=107) were recruited from a private rehabilitation centre. There were no drop outs despite 20.4% of the participants being employed full or part-time, and as with other studies (Biller et al., 2000), the recruitment technique may have self-selected out many participants with high precontemplation scores.

However, as the authors note self-efficacy and the stage of engagement on the PSOCQ significantly correlated in their study. Although independent constructs, they may measure strongly associated constructs that cannot be effectively separated. A summary of these studies, their outcomes and strengths and weaknesses are given in Table 2.

Kerns et al (2005) further explores readiness to change by exploring if it is possible to identify cluster groups based on the PSOCQ. They identify five clusters, precontemplation, contemplation, non contemplation action, participation and ambivalent. The greater number of participants’ profiles fitted with the ambivalent cluster (33.6%) and the researchers suggest profiles may be useful in predicting outcomes of treatment and is an important step in translating the transtheoretical model to the management of persistent pain.

In summary these studies indicate that individuals with high Precontemplation scales are less likely to benefit from self-management interventions as they are tending to focus on a medical solution for their
symptoms. Individuals in the Contemplation stage will tend to be ambivalent to adopting a self-management approach to managing their pain but may be receptive to engaging in a self-management approach if offered. Those already with high Action and Maintenance scores are likely to experience more complete benefit from self-care approaches providing reinforcement of this stage occurs during intervention.

Individuals with persistent pain may need support to help shift beliefs from Precontemplation and Contemplation Stages of Change to an Action and Maintenance stage. This attitude appears to support the Governments systematic approach to managing long-term conditions, where it has been suggested that patients with appropriate long term conditions who may be amendable to self-care approaches, could be better helped by developing their own self-support skills rather than being offered treatments that rely on healthcare professionals.

A principal feature of managing chronic pain is accepting a change in life is needed (Risdon, Eccleston, Crombez, & McCracken, 2003), and acceptance of pain and its possible link with adopting a self-management approach to managing pain will be explored in the literature.
<table>
<thead>
<tr>
<th>Study</th>
<th>Concept explored</th>
<th>Sample number</th>
<th>Intervention</th>
<th>Measures</th>
<th>Primary outcome</th>
<th>Limitations</th>
</tr>
</thead>
<tbody>
<tr>
<td>(Arthur &amp; Hamling, 2003)</td>
<td>Self-support groups</td>
<td>N=70 N=26 attended 3 month follow up review. 78% female Mean age 56.39 std.14.79</td>
<td>Less demanding version of traditional pain management programme. 2 hour/10 week programme</td>
<td>Pain stages of Change Questionnaire (PSOCQ), Roland Morris disability questionnaire (RMDQ), Hospital Anxiety Depression Scale (HADS)</td>
<td>Significant progress through the PSOCQ with Contemplation, Action &amp; Maintenance scores. All groups went on to establish self-help community groups</td>
<td>No control group. Self report questionnaires. Influence of Stage of Change point at entry to study overlooked in analysis and discussion.</td>
</tr>
<tr>
<td>(Biller et al., 2000)</td>
<td>Completion of pain management programme</td>
<td>N=300 Multi-centre</td>
<td>10 session cognitive behavioural programme</td>
<td>PSOCQ</td>
<td>Precontemplation best single predictor of who would or would not complete the programme. Older participants and those with higher pain, disability and depression more likely complete.</td>
<td>Self report, participants self selecting by returning PSOCQ.</td>
</tr>
<tr>
<td>(Burns et al., 2005)</td>
<td>Determine pre-treatment stage interacts with early treatment stage progression to predict late treatment outcomes</td>
<td>N = 65</td>
<td>4 week pain management programme</td>
<td>PSOCQ Multidimensional Pain Inventory (MPI) Beck depression Inventory (BDI)</td>
<td>Patients with bias toward a precontemplation view at pre-treatment did not report significant early treatment attitude shift did not benefit as completely. Predominantly patients in the action stance who showed further shift towards solidifying this stance showed greatest late treatment improvements in pain, interference and activity.</td>
<td>No control group. Risk of bias as participant scored mid treatment. PSOCQ simplified and focus on precontemplation and action stages only may neglect transition stages. Focus on one direction of movement of changes. Predominantly Caucasian (72.3%)</td>
</tr>
<tr>
<td>(Carr et al., 2006)</td>
<td>Self-management course</td>
<td>N=96 68% female</td>
<td>None</td>
<td>PSOCQ Chronic Pain Acceptance Questionnaire (CPAQ) Survey of interest in self-management programmes</td>
<td>Examine process of change to a self-management approach. Hypotheses focused around criterion and validity of PSOCQ</td>
<td>Sample size. Response rate low - sample may not be representative of clinic population. Qualitative analysis approach not described</td>
</tr>
<tr>
<td>(Glenn &amp; Burns, 2003)</td>
<td>Whether changes in stage represented a therapeutic process factor</td>
<td>N=65</td>
<td>4 week multi-disciplinary PMP</td>
<td>PSOCQ MPI BDI</td>
<td>Individuals’ attitudes towards self-management at the start of treatment may influence degree of improvement. High precontemplation associated with poorer outcomes. Pain, depression &amp; activity levels improved as attitude increased toward a self-management approach</td>
<td>Relatively small sample number. Majority male 63.5%. No control group. Short data collection time (4 weeks).</td>
</tr>
</tbody>
</table>

Table 2: Comparison of Studies involving PSOCQ
<table>
<thead>
<tr>
<th>Study</th>
<th>Concept explored</th>
<th>Sample number</th>
<th>Interventions</th>
<th>Measures</th>
<th>Primary outcome</th>
<th>Limitations</th>
</tr>
</thead>
<tbody>
<tr>
<td>(Jensen, Nielson, Turner et al., 2003)</td>
<td>PSOCQ associated with coping, disability &amp; depression</td>
<td>N=243 Persistent pain n=144 Fibromyalgia n=99</td>
<td>3 week (5.5 days/week) pain management programme</td>
<td>PSOCQ Coping Strategies Questionnaire (CSQ). Centre of epidemiological studies-depression scale (CES-D). Fibromyalgia impact questionnaire (FIQ-PI). VAS pain. Pain group data - telephone interviews pre, post treatment &amp; 6/12. Fibromyalgia group data pre &amp; post treatment via programme &amp; follow-up 1/12</td>
<td>PSOCQ scales associated with coping. Higher precontemplation scores associated with maladaptive coping strategies. No PSOCQ scale consistently associated with measures for disability &amp; depression</td>
<td>Self report, correlational analysis. Different disability tools used in groups and different follow up data collection time. Small sample in view of number of variables used in regression analysis</td>
</tr>
<tr>
<td>(Jensen et al., 2004a)</td>
<td>Readiness to self manage pain increases following attending pain management programme (PMP)</td>
<td>N=422 Pain clinic group n=110 Fibromyalgia group 312</td>
<td>3 week (5.5 days/week) pain management programme</td>
<td>PSOCQ Coping Strategies Questionnaire (CSQ). CES-D RMDQ West Haven-Yale Multidimensional Pain Inventory (WHYMPI)</td>
<td>Readiness to self-manage pain increased attendance at PMP. Some return to pre programme scores at 6 months. Contemplation score thought to represent ambivalence.</td>
<td>Pain clinic sample subset from previous study. Self report questionnaire. 69% completed assessments. Predominantly Caucasian 92%</td>
</tr>
<tr>
<td>(Kerns &amp; Rosenberg, 2000)</td>
<td>Predicting responses to self-management treatments</td>
<td>N=109</td>
<td>Participation in self-management programme</td>
<td>PSOCQ Pain rating index (McGill) WHYMPI (multi-dimensional pain inventory SOPA (survey of pain attitudes BDI (Beck Depression Inventory) Behavioural goal achievements</td>
<td>Changes in PSOCQ were associated with improved outcomes. Supports predictive validity and utility of PSOCQ</td>
<td>41 patients refused treatment or failed to attend. Further 9 dropped out. n=59 completed</td>
</tr>
<tr>
<td>(Strand et al., 2006)</td>
<td>Explore relationship between pain readiness to change &amp; weekly measures of positive &amp; negative affect over 8 weeks</td>
<td>N=163 Rheumatoid group n=40 Rheumatic diagnosis n=40 Chronic pain syndrome n=83</td>
<td>RA outpatient RD inpatient rehab unit CPS inpatient pain management programme</td>
<td>PSOCQ Numerical rating scale (NRS) Positive &amp; negative affect schedule (PANAS)</td>
<td>Action/maintenance scale associated with positive affect. No association between PSOCQ &amp; weekly pain levels.</td>
<td>Correlational Short data collection period. Only sub sample RA included in weekly pain &amp; affect scores</td>
</tr>
<tr>
<td>(Strong et al., 2002)</td>
<td>Comparison of PSOCQ and self-efficacy</td>
<td>N=107 75% male Mean age 36.2 std.10.6</td>
<td>Pre and post rehabilitation programme</td>
<td>PSOCQ PSEQ (Pain self-efficacy WHYMPI)</td>
<td>Comparison between PSOCQ and PSEQ in predicting treatment outcome. PSEQ was a better predictor</td>
<td>No drop outs raises questions about recruitment Younger group, higher proportion of males</td>
</tr>
</tbody>
</table>

Table 2 contd.: Comparison of Studies involving PSOCQ
2.7 Acceptance

The significance of acceptance as a concept in relation to managing persistent pain is increasingly considered a useful solution for behaviour problems where efforts to control pain have failed (Crombez, Morley, McCracken, Sensky, & Pincus, 2003). Acceptance of pain has been defined as living with pain without reacting to it, disapproving of it or attempting to reduce or avoid it (McCracken, 1998; McCracken, Spertus, Janeck, Sinclair, & Wetzelb, 1999). This definition is focused on behavioural aspects of acceptance and other clinicians have suggested that another important aspect of acceptance are the psychological and social aspects of it related to loss, such as features of physical functioning and the ability to act spontaneously (Rankin, 2001). Acceptance of disability is another facet of acceptance that has been researched and found to be negatively associated with adjustment to disability in individuals suffering from persistent pain though the process of disability adjustment is complex (Li & Moore, 1998).

McCracken, Vowles, & Eccleston (2004) component analysis and revised assessment method for acceptance of chronic pain the Chronic Pain Acceptance Questionnaire (CPAQ) is criticised for failing to control for other cognitive variables that have been shown to impact on adjustment to persistent pain and may impact on acceptance (Nicholas & Asghari, 2006). McCracken, Vowles & Eccleston (2004) focus only on the role of acceptance and its relationship with measures of function and distress However, studies focusing on the behavioural aspects of acceptance have consistently shown its association with less emotional distress and better physical and social
functioning (McCracken, 1998, 2007; McCracken & Eccleston, 2005; McCracken, Vowles, & Eccleston, 2005). Greater acceptance of pain is also associated with lower pain, anxiety and depression levels and higher daily uptime (McCracken, 1998; McCracken & Eccleston, 2003; McCracken et al., 1999), as well as more variance in measures of functioning than coping (McCracken & Eccleston, 2003, 2006).

The findings in McCracken & Eccleston (2006) study, it should be noted, are an extension of findings from their study in 2003, but certainly outcomes of McCracken’s studies show consistently that acceptance has an important and complex role in individuals with persistent pain; patients may be ‘better off’ if they relinquish attempts to eliminate pain (McCracken, 1998).

McCracken & Eccleston (2005) argue for a directional relationship between acceptance and functioning, and while their study widely explore concepts associated with acceptance and pain they are limited by using convenience samples from two pain centres, one in South West England and one in USA. The studies involve good sample numbers (N= 108/230) but cross sectional designs and correlational analysis limit indications for causality.

Another study has found evidence for summarising acceptance of persistent pain as the ‘engagement in normal life activities despite pain’ (Viane, 2003). Again a cross sectional design study involving a convenience sample and correlational analysis is used. While this study states the sample is recruited from a university hospital it is not clear if this not the same site as one used
in McCracken studies, tending to limit generalisation of studies exploring acceptance to wider populations.

Acceptance and its relationship with coping have been explored in other long term conditions. In individuals with insulin dependent diabetes acceptance appeared to correlate with fewer complications and a higher sense of coherence and metabolic control. This linked with higher education and employment (Richardson, Adner, & Nordström, 2001), and the study is strengthened by using a random sample (N=150 56% female). Outcomes advise individualising care so that levels of acceptance can be taken into account, as it is considered an important aspect of providing appropriate care for this group.

Carr et al (2006) is the only study found that examines the relationship between CPAQ and PSOCQ. They found a negative association between Precontemplation and Contemplation and Acceptance. This is consistent with ideas that individuals in the Precontemplation and Contemplation Stages of Change are likely to be looking for a cure for their pain and therefore less accepting of it. Positive correlations were found between Acceptance and individuals in the Action or Maintenance Stage of Change. This supports the idea that individuals in these stages are more likely to be getting on with life despite their pain and not ‘trapped in a vicious cycle of pain and disability. However, outcomes in this study are constrained by sample size and representativeness of a pain clinic population.
Two studies exploring the role of acceptance and the experience of pain involve experimental designs conducted in laboratory settings (Keogh, Bond, Hanmer, & Tilston, 2005; Masedo & Esteve, 2007). Masedo & Esteve (2007) involve a RCT while Keogh et al (2005) uses a cross over design but gives minimal recovery time between the approaches. Both studies showed that individuals employing acceptance based strategies while experiencing pain reported lower sensory pain ratings although not necessarily greater tolerance of pain, and Masedo & Esteve's (2007) results also showed lower distress rating. Although these two experimental studies are conducted in healthy younger volunteers (mean age 21.1 yrs std 3.7), they do add further support to acceptance based approaches in managing pain.

While it is suggested the management of pain may need to focus more on acceptance rather than coping and trying to change ways people cope (Schmitz et al 1996), healthcare professionals frequently endeavour to change pain through treatment. This may connect with healthcare professionals difficulty in accepting their own limitations in curing some long-term conditions (Baszanger, 1989). Patients' expectations may inadvertently be influenced by health care professionals' expectations about treatment (Galer et al 1997), and increased understanding and awareness of these expectations may be associated with the growing significance being placed on acceptance, and its association with self-management for chronic conditions (Crombez et al., 2003; Department of Health, 1999, 2000, 2001b; McCracken, 1998; McCracken & Eccleston, 2003; McCracken et al., 1999;
Risdon et al., 2003; Viane, 2003). A summary of a number of these studies, their outcomes and strengths and weaknesses are given in Table 3.
<table>
<thead>
<tr>
<th>Study</th>
<th>Concept explored</th>
<th>Sample number</th>
<th>Intervention</th>
<th>Measure</th>
<th>Primary Outcomes</th>
<th>Limitations</th>
</tr>
</thead>
<tbody>
<tr>
<td>(Li &amp; Moore, 1998)</td>
<td>Acceptance of disability and its correlates</td>
<td>n=1,266 random sample drawn from state provided vocational rehabilitation services 53% female</td>
<td>No intervention</td>
<td>Acceptance of disability scale (ADM) Self rating form</td>
<td>Acceptance of disability is directly associated with success of rehabilitation Presence of multiple disabilities or chronic pain negatively related to successful adjustment</td>
<td>Sample selected from rehab services Correlational</td>
</tr>
<tr>
<td>(McCracken, 1998)</td>
<td>Acceptance of pain</td>
<td>n=160 convenience sample data completed during initial evaluation in PMC 66.3% female</td>
<td>Data completed during initial evaluation in PMC</td>
<td>VAS CPAQ BDI PASS SIP Demographic information</td>
<td>Greater acceptance of pain associated with lower pain intensity, depression, less pain anxiety, disability</td>
<td>Data collection at one point Self report Correlational CPAQ possibly needs refinement</td>
</tr>
<tr>
<td>(McCracken et al., 1999)</td>
<td>Examine role of pain-related anxiety &amp; acceptance pain in differentiating patients classified as adaptive copers, dysfunctional, interpersonally distressed</td>
<td>n=190 convenience sample</td>
<td>Data completed during initial evaluation in pain management centre (PMC) 66.3% female</td>
<td>VAS CPAQ BDI MPI Pain Anxiety Symptoms Scale (PASS) Demographic information</td>
<td>Adaptive copers reported greater acceptance Pain related anxiety strong predictor of adjustment to pain Shaping an accepting attitude &amp; decreasing anxiety will improve functioning in persons with pain</td>
<td>Data collection at one point Self report Correlational CPAQ may need refinement</td>
</tr>
<tr>
<td>(McCracken &amp; Eccleston, 2003)</td>
<td>Compares acceptance of chronic pain and coping as predictors of adjustment to pain</td>
<td>n=230 convenience sample</td>
<td>Data completed during initial evaluation in PMC 66.5% female</td>
<td>VAS CPAQ CSQ BDI Sickness Impact profile (SIP) PASS</td>
<td>Greater acceptance of CP associated with less pain, disability, depression, pain related anxiety, higher daily uptime, better work status</td>
<td>Data collection at one point Self report Correlational Regression analysis</td>
</tr>
</tbody>
</table>

**Table 3:** Comparisons of Studies exploring concept of Acceptance
<table>
<thead>
<tr>
<th>Study</th>
<th>Concept explored</th>
<th>Sample number</th>
<th>Intervention</th>
<th>Measure</th>
<th>Primary Outcomes</th>
<th>Limitations</th>
</tr>
</thead>
<tbody>
<tr>
<td>(McCracken, Vowles, &amp; Eccleston, 2004)</td>
<td>Investigated item content, internal consistency &amp; factor structure of CPAQ. Examines relations of subcomponents of acceptance with other aspects of chronic pain</td>
<td>n= 235</td>
<td>Data completed during initial evaluation in PMC 61.8% female</td>
<td>VAS BDI PASS SIP Demographic information</td>
<td>Further refinement of CPAQ Acceptance is a potentially valuable concept in our understanding of the process &amp; treatment of pain</td>
<td>Data collection at one point Correlational Convenience sample</td>
</tr>
<tr>
<td>(Richardson et al., 2001) Diabetes</td>
<td>Describe how persons with IDDM accept their disease, &amp; determine if acceptance of disease is related to coping,</td>
<td>n = 150 random sample patients attending out patient clinic 56% female</td>
<td>No intervention</td>
<td>ADM Sense of Coherence Scale (SOC) Medical nursing documentation studied.</td>
<td>Higher education, working related with greater acceptance. More than one complication lowers ADM. High acceptance correlated with sense of coherence and metabolic control</td>
<td>Self-report questionnaire Correlational</td>
</tr>
<tr>
<td>(Risdon et al., 2003)</td>
<td>Studying what it might mean to accept CP, &amp; studying the accounts of what it is to be a person who achieves acceptance of pain</td>
<td>n=30</td>
<td>No intervention</td>
<td>Q-factor analysis Interviewed clinicians, researchers. Searched encyclopaedias historical texts etc</td>
<td>8 separate accounts that reflect ways in which sense can be made of idea of accepting chronic pain. Primary feature of acceptance of CP is that change in life is required.</td>
<td>Postal pack of materials No detail on sample selection unclear how sample selected 60 people originally contacted Only 5 had chronic pain majority female</td>
</tr>
<tr>
<td>Viane et al 2003</td>
<td>Acceptance of pain as independent predictor of mental well-being</td>
<td>n=120</td>
<td>No intervention</td>
<td>CPAQ MPI MOS-36 PCL pain cognition list</td>
<td>Greater acceptance of pain associated with better mental health. Lack of association between acceptance and physical health</td>
<td>Cross sectional Regression analysis</td>
</tr>
</tbody>
</table>

Table 3 (continued) Comparisons of studies exploring concept of Acceptance
2.8 Summary of key findings and gaps in the literature

Three key issues and gaps have been identified in this review. These are:

- Further exploration is required to identify when lay led self-management approaches may be indicated in an individual’s management of his/her persistent pain.
- A lack of evidence exploring the value of lay led self-management in secondary care locations.
- Pain Stage of Change (PSOC) may be a valuable model for identifying when individuals are most likely to engage in self-management approaches. However, further exploration is required to confirm its appropriateness in different clinical locations and at different points along patients’ care pathways. These in particular relate to primary and secondary care settings and to initial referral stages of patients’ care in pain clinics and multidisciplinary pain management programmes.

The literature suggests there is awareness that aspects of persistent pain and other long term conditions could also be addressed by involving self-management approaches; this may reduce both the resulting health impact and financial cost for the NHS. However, it has not been established at what point in an individual’s care pathway a lay-led self management approach could provide most benefit. Is it that lay led self management has greater impact if introduced at the initial stage of care or once care has been established or when conventional care has been completed?
While the debate surrounding point of access to professionally led programmes has largely been resolved, this debate has not occurred with lay led self-management approaches. This disparity exists despite our understanding that professionally-led pain management programmes should be offered when indicated. Previous practice of referring patients to these programmes only when other treatments have failed is now seen as historically illogical (British Pain Society, 2007). Healthcare professionals may be doing patients a disservice if they do not have evidence to inform their clinical practice when a lay led self management approach could be best integrated into an individual’s management plan for their persistent pain.

It is also evident that studies in the UK exploring lay led self-management have focused on primary care to provide the context for studies (Barlow et al., 2000; Buszewicz et al., 2006; Griffiths et al., 2005). No studies have explored the possible value of lay led self-management in secondary care locations. This imbalance has the potential to reinforce lay led self-management as an approach that should be resorted to once other treatment approaches have failed. It may not be new treatments that are needed but new approaches that have the ability to modify individuals’ attitudes and behaviours (Palmer et al., 2000), and understanding the value lay led self-management approaches may have in secondary care settings is important. It could have the potential to contribute to current treatment approaches and improve patients’ abilities to cope with their pain.
Further gaps identified in the literature link with healthcare professionals’ limited understanding of the mechanisms involved in achieving improvement when lay led self-management approaches are involved. Lorig & Holman (1989) suggest it is not possible to identify these exact mechanisms. The Pain Stages of Change Questionnaire (PSOCQ) may be a tool able to identify aspects of patients’ needs associated with self care. However, no study has explored how this might link with current approaches of care if applied to the NHS systematic approach to care for people with long term conditions. The relationship between self-management approaches and an individual’s readiness to engage in this approach may provide important understanding to develop new and different approaches. These could be included in the formal and informal resources offered in pain management services’ located in a secondary care settings supporting care provided in primary care and linking into the NHS’s systematic approach.

Undoubtedly there is a need to provide further research that will increase understanding of lay led self-management approaches for managing persistent pain in secondary settings. There is also a need to understand when this approach has the greatest impact and the PSOCQ derived from the Transtheoretical Model (TTM) may be a tool that can contribute. The following research project describes a study informed by the key issues and gaps identified in the literature and attempts to:

• Determine the impact of introducing a lay led self-management approach at patients’ initial referral stage to a Pain Management Service
• Determine the impact of introducing a lay led self-management approach in secondary care.

• Establish the potential of the PSOCQ to contribute to understanding the stage when lay led self management has greatest impact in managing persistent pain in a secondary care location.

3 Aims and Hypothesis/Research Questions

The aim of this study was to determine if the early introduction of a self-management approach in the treatment of individuals with persistent pain, referred to a District General Hospital's Pain Clinic, could influence their readiness to adopt a self-management approach to managing their persistent pain symptoms and subsequently influence Pain, Interference and Acceptance levels.

The Service Development Project (SDP)\(^1\) suggested the majority of patients referred to the DGH pain management service were in the Precontemplation or Contemplation Stage of Change. It was proposed conscious raising, catharsis and self re-evaluation processes considered most important in the first two stages of change (Precontemplation and Contemplation) would be experienced by participants in the Intervention group through exposure to self-care approaches. Participants in the Control group would not be exposed to this experience, and therefore would experience no accelerated promotion through the Stages of Change. Once in the Contemplation stage of change participants would experience weighing up the pros and cons (benefits and

\(^{1}\) See Service Development Project Portfolio Part Two
barriers) interrelated to susceptibility and severity of symptoms. It is suggested progress through the Stages of Change occurs before progress in behaviour changes can occur and a self-care approach can be incorporated into the management of the patient’s pain.

3.1 Hypothesis

The hypothesis was that the promotion of self-management approaches at the start of treatment referrals to a Pain Clinic would increase individuals’ readiness to take on self-management approaches when offered in parallel with conventional support and treatments for persistent pain.

A two tailed null hypothesis was tested. This examined the impact of the early introduction of a self-management approach in both directions (improved or regressed patients readiness to take on self-management approaches) compared with conventional treatment. A null hypothesis was tested as attempting to assess exactly how much readiness individuals may gain in taking on a self-management approach and listing all the possible variables that would impact on this would be impossible to test for. Previous studies exploring related concepts have been set in different environments and countries and measure a number of different outcomes (Burns et al., 2005; Dannecker, Gagnon, Jump, Brown, & Robinson, 2004; Griffiths et al., 2005; Lorig & Holman, 1989; Strong et al., 2002). It was therefore not possible to predict a clear percentage of increase in readiness to adopt a self-management approach and a null hypothesis negated this difficulty as the
assumption was there was no relationship between the variables (Devane, Begley, CM, & Clarke, 2004).

The null hypotheses were:

1. There will be no difference between the Intervention and Control groups’ Stages of Change scales following early exposure to a self-management approach, the Expert Patient Programme (EPP) as measured by the Pain Stages of Change Questionnaire (PSOCQ).
2. There will be no difference between the Intervention and Control groups’ level of Pain following early exposure to a self-management approach (EPP) as measured by the Brief Pain Inventory (BPI).
3. There will be no difference between the Intervention and Control groups’ level of Interference following early exposure to a self-management approach (EPP) as measured by the Brief Pain Inventory (BPI).
4. There will be no difference between the Intervention and Control groups’ level of Acceptance of their pain following early exposure to a self-management approaches (EPP) as measured by the Chronic Pain Acceptance Questionnaire (CPAQ).

Decisions relating to the null hypothesis and sample size were all arrived at following discussion and advice from a University statistician.
4 Method

4.1 Rationale for Methodology

Methodology refers to the strategy or overall approach chosen to answer a research question (Holloway & Walker, 2000; Potter, 1996). A mixed method approach permitting triangulation of data was the chosen methodology for this study. A mixed method approach can provide greater completeness and development of outcomes that may offer a broader and more detailed picture of the population studied. Quantitative data collected from questionnaires was combined with qualitative data collected from focus groups, with the attention on how people with persistent pain made sense of self-management approaches, and come to behave in socially acceptable ways associated with their diagnosis.

Quantitative data, is often described as providing information on what happens (Young, 2004), while qualitative data can provide answers for why it might happen. Qualitative data is widely used to assist our understanding of complex behaviours, needs and cultures (Ritchie & Spencer, 1994). By combining these two approaches, it was hoped voice would be given to both validated clinical measures and the shared views and values of participants’ own experiences, and avoid the shortcomings of singular methodologies (Young, 2004). Had questionnaires only been employed, the information collected might have been limited by the very questions asked, but by gathering data from focus groups this allowed information on how the participants themselves talked about the subject of persistent pain and self-care, to be collected and its content analysed (Morgan, 1996).
Combining different methods of data collection and analysis within one research study is not a new approach (Maggs-Rapport, 2000), though much of the literature exploring the impact of self-management programmes has employed only quantitative approaches to investigate its impact (Barlow et al., 2000; Keogh, McCracken, & Eccleston, 2005; LeFort, Gray-Donald, Rowat, & Jeans, 1998; Lorig, Hurwicz, Sobel, Hobbs, & Ritter, 2005; Lorig et al., 2001; Lorig et al., 1999). Studies involving a qualitative approach are less available (Jerant, von Friederichs-Fitzwater, & Moore, 2005; Lorig, González, Laurent, Morgan, & Laris, 1998), and few studies were found that employed a mixed method approach (Barlow, Williams, & Wright, 1999; Lorig et al., 1998; Ruecroft, 2004).

When researching a complex population and concept such as self-management, the choice of a mixed method approach and involvement of methods which are very different from each other can have advantages. Instead of focusing on a specific research question mixed methods can be used to involve different but complementary research questions. This may give a better assessment of the outcomes and enhance interpretability (Robson, 2002). In this study the interpretation of the quantitative data collected from questionnaires was enhanced by qualitative narrative accounts collected from focus groups.

However using a mixed method approach has led to considerable debate in the literature regarding its appropriate use (Annells, 2006; Dootson, 1995; Freshwater, 2006; Sale, Lohfield, & Brazil, 2002; Thurmond 2001). Dootson
(1995) has particular concerns that nurse researchers may forget that the origins of research will come from one of two paradigms, either rationalistic or naturalistic and that these cannot be combined. However, providing this is understood then the uniting of various quantitative and qualitative methods in one study can complement each other, and provide a greater sense of balance, richer data and more complete analysis that contributes to the understanding of the phenomenon (Cowman, 1993; Creswell, Fetters, & Ivankova, 2004; Maggs-Rapport, 2000; McEvoy & Richards, 2006; Thurmond 2001).

Further concerns exist that researchers using mixed method research may apply the terms integration, combination and mixing of methods interchangeably. These have different practical relationships depending on the reason for incorporating the approach (Moran-Ellis, Alexander, Cronin, Fielding, & Thomas, 2006). Integration requires the different methods to be given equal weight whereas the combining and mixing of methods is seen to support or explain the findings of the other, with the intention of giving added depth or quality to the findings (Moran-Ellis et al., 2006).

This study has used a quantitative method (questionnaire) in combination with a qualitative approach (focus groups) and the two approaches have not been placed with the intention that each will make equal contributions to understanding the phenomenon being researched (Greene, Caracelli, & Graham, 1989; Moran-Ellis et al., 2006). However, their data will hold equal value and the reasons for this are that:
• There will be a greater volume of quantitative data as all participants will contribute to this information.
• The qualitative data will be collected from a smaller number of participants because of practical aspects of gathering data from participants involved in contributing to the qualitative data.
• The qualitative data may hold a richness of information and beliefs that cannot be attained from quantitative approach involving a questionnaire.
• Both the quantitative and qualitative data has been collected from randomised participants. While potential variations in the traits of those participants choosing to take part in the study may vary from those choosing not to get involved, participants contributing information through the focus groups may hold further variations in traits and this factor may require reflection at the analysis stage.

Outcomes generated from mixed method approaches are sometimes referred to as the triangulation of data (Moran-Ellis et al., 2006). Forceful views exist suggesting quantitative and qualitative methods cannot be combined for purposes of triangulation as they do not study the same phenomenon (Sale et al., 2002). Their mechanisms will by their design support theories with different logical structures and no single theory can be supported by both a quantitative and qualitative approach (Annells, 2006; Cowman, 1993; Risjord, Dunbar, & Moloney, 2002). While the ability of two different research designs to support a single theory is argued, there appears some degree of agreement on one of the commonly referred to purposes of triangulation, that of confirmation of outcomes (Rees & Bath, 2001; Tobin & Begley, 2004).
However, confirmation is not sought in this study on the basis that the two approaches involved are studying different facets related to self-management. The combining of qualitative and quantitative approaches have been used to complement each approach and contribute to the understanding of the phenomenon, also recognised as a use of triangulation (Sale et al., 2002; Thurmond 2001). In this study the relationship between quantitative and qualitative methods and data has been blended and integrated to provide different perspectives on the same phenomenon of lay led self-management. While the focus always remained on self-management, the quantitative methods sought reliability and gathered information from questionnaires. This provided data on possible progress made through the PSOCQ, changes in Acceptance, Pain and Interference.

In order to add to the quantitative data, the qualitative data sought understanding of the meaning of lay led self-management by gathering data from focus groups involving semi structured questions. Data gathered from these groups concerned individuals' perspectives on issues associated with self-management and persistent pain. Overall triangulation in this study permitted quantitative data on behaviour change, acceptance and pain to be complemented by individual perceptions and interactions. This stimulated better definition and analysis of issues associated with self-management, contributing to a more complete understanding of the possible impact of a self-management approach for persistent pain.
Combining method approaches permitted methodological triangulation and this was viewed as a practical relationship between the different methods, collection of data and analyses of findings (Moran-Ellis et al., 2006). Two types of triangulation have been used in this study and are:

1. Across method triangulation (between method) design: Combining of quantitative and qualitative approaches in one study.

2. Data triangulation: Data will be gathered using quantitative and qualitative methods. Quantitative will consist of patient self-report questionnaires; Qualitative data will consist of information generated from focus groups. The two sets of data will be combined to aid interpretation of findings.

In summary, methodological triangulation has been used to confirm completeness of data and illuminate aspects that might otherwise have been missed if only one method had been used. The concept for this study is now described using a theoretical framework to assist understanding.

4.2 Theoretical framework

A theoretical framework provides a supporting structure that can offer ways to evaluate or explain problems, provide meaning and understanding while facilitating the interpretation of the data. It can also help to inform us why something occurs, rather than merely what occurs (Klein & Zedeck, 2004), and a number of health behaviour frameworks have been developed to predict health behaviour (Galvin, 1992). Two models were chosen from the
literature and integrated into a theoretical framework to assist understanding of the concept of self-care in managing persistent pain.

The first model was the Pain Stages of Change (Kerns et al., 1997) developed from Prochaska and DiClemente’s Transtheoretical Model of Behaviour Change (Prochaska, 1979; Prochaska & DiClemente, 1982, 1983, 1992). It was developed to assess an individual’s readiness to adopt a self-management approach to managing their pain, and was most likely the first attempt to integrate the Transtheoretical Model (TTM) of behaviour change with cognitive-behavioural theories in the management of persistent pain (Kerns et al., 1997).

The second model chosen was the Health Belief Model (HBM), and was considered helpful in understanding some of the complex behaviours involved in managing pain. The HBM takes into consideration the involvement of personal factors (Galvin, 1992), and has previously been used to help explain why people fail to adopt behaviours that could promote health (Poss, 2001). The two models have been integrated in an over-arching framework to support the research.

4.2.1 The Transtheoretical Model and Pain Stages of Change

The Transtheoretical model (TTM) offers a particularly useful framework for exploring behaviour change and decision-making processes that individuals may experience in the promotion of health behaviours (Velicer et al., 1998). It endeavours to integrate a number of key concepts from the theories of
several respected psychotherapist such as Freud, Skinner, and Roger in order to develop a more complete understanding of health related behaviours (McCormack Brown, 1999).

TTM describes a model of intentional change and does not make conjectures about how ready an individual may be to change, but helps to identify what Stage of Change the individual might be at; it can be used to develop treatments that are better matched to a persons particular stage or needs (Keefe et al., 2000; Velicer et al., 1998). Fundamental to it are five stages of change central to the organising construct of phases that people go through when changing behaviour. These stages are precontemplation, contemplation, preparation, action and maintenance:

1. **Pre Contemplation**: This stage relates to the individual having no intention to change their behaviour in the near future (certainly not within the next 6 months).

2. **Contemplation**: This stage relates to the individual having awareness that a problem exists, and is seriously considering changing behaviour in the future but has not made a commitment to take action.

3. **Preparation**: This stage is defined as the time when a person who has seriously considered changing a behaviour over the past year will seriously try to change the behaviour in the next month.

4. **Action**: This stage relates to the individual carrying out concrete activities that will lead to the desired change.
5. **Maintenance:** This stage relates to the individual making active efforts to sustain the change, prevent relapses and consolidate gains of the action stage. This stage may be long term or for the rest of the patient's life (Prochaska et al., 1994).

The five stages of change are best understood by considering them as involving both a linear and a cyclical perspective in order to explain how people progress through the different stages of change (Prochaska & DiClemente, 1992; Prochaska et al., 1992) (See Figure 2).

![Figure 2: A Spiral Model of the Stages of Change (Prochaska et al., 1992)](image)

The Stages of Change model symbolises a measure of time that enables us to understand when shifts in a person’s attitudes, intentions and behaviours might occur (Prochaska et al., 1992). The verbal processes of change involving consciousness raising and catharsis, where often the raising and correcting of an emotional experience, enables people to commit to changing a pattern of behaviour, and links contemplation, preparation and determination. These are most important in the first two stages of change (Prochaska & DiClemente, 1982) (see Figure 3 and Appendix 12.1).
The TTM proposes that the degree to which an individual is prepared or motivated to change behaviour will depend on which stage of change they are at and whether they might be expected to engage in self-management approaches (Jensen, Nielsen, & Kerns, 2003). Studies suggest that patients with high Precontemplation scores are less likely to take on self-management behaviours and the least likely to improve (Glenn & Burns, 2003).

Contemplation appears to be the stage when the majority of individuals weigh up the pros and cons of a problem and its solution, and experience crossover between the pros and cons (Prochaska et al., 1992; Prochaska et al., 1994). Kerns et al (1997) found in developing the PSOCQ the Contemplation and Preparation scales were closely linked, so combined these into one stage called Contemplation.

Forward stage movement appears to depend on reducing scores on Precontemplation and increasing scores in Action and Maintenance before a greater commitment to taking on a self-management approach occurs and the patient experiences improved outcomes (Glenn & Burns, 2003). Making changes to behaviour requires weighing up the pros and cons of making
these changes and the TTM has links with behaviour change constructs in the Health Belief Model (HBM), a model that emerged in the 1950’s to help explain health behaviours.

4.2.2 Health Belief Model

The HBM has over the last forty years become one of the most widely used psychosocial approaches to help explain health-related behaviours, use of health care resources and compliance with medical advice (Polit & Hungler, 1993; Strecher & Rosenstock, 1997). It was originally developed to help explain preventative health behaviours and the limited success some health related programmes were having (Becker, 1974; Poss, 2001; Rosenstock, 1974; Strecher & Rosenstock, 1997). Its potential to explain and predict behaviours was then extended to help understand behaviours taken in response to diagnosed illness (Becker, 1974).

The HBM has also been applied in health promotion studies (Galvin, 1992), where it conjectures that an individual’s decision to take on behaviours associated with improved health will not be made unless they are ready to take this action. The HBM also proposes that individuals will weigh up the benefits of taking a particular action against the barriers and providing the benefits outweigh the disadvantages, then the more likely the person is to take on the advised health behaviour (Cummings, Jette, & Rosenstock, 1978; Strecher & Rosenstock, 1997) (See Figure 4).
The HBM has also been used to explore tailoring approaches to an individual's needs through the exploration of people's perceived benefits of making behaviour changes, their perceived obstacles, self-efficacy and cues to action (Cummings et al., 1978; Glenn & Burns, 2003; Jensen, Nielson, & Kerns, 2003; Strecher & Rosenstock, 1997). In common with the TTM, decision making is an important aspect in HBM and the links between the HBM's and TTM's motivation and decision making concepts have previously been identified (Jensen, Nielson, & Kerns, 2003; Strecher et al., 2002).

4.2.3 Integrated Theoretical Framework

Both TTM and HBM models suggest that to make a decision the individual needs to become aware of choice and this only becomes possible with the
development of raised consciousness (Prochaska & DiClemente, 1982). With choice comes responsibility and Prochaska & DiClemente (1982) propose that the therapeutic process of being freer to choose how to respond is the result of using verbal communication.

While decision making can be seen as complex with as many as eight categories on which individuals rely on to make decisions (Janis & Mann, 1977), the TTM proposes it to be much simpler with just two major categories influencing decisions to change behaviour, that of pros and cons (Prochaska et al., 1994). The pros and cons of decision making and process of change are the dimensions chosen from the TTM and HBM for particular focus and integration in this study’s framework (See Figure 5).
Figure 5: Theoretical Framework: Influence of early self-care approaches on stage of change to adopt a self-management approach to managing persistent pain.

Control Group
- Maintenance 21%
- Action 16%
- Contemplation 37%
- Pre contemplation 26%

Intervention Group
- Conventional treatment & self-care programme

No behaviour changes

PROS
CONS
Stage of Change

Behaviour

No accelerated promotion through Stage of change process

Promotion through Stage of change process

Improved pain management

Classification of patients' Stages of Change (Service Development Project)

Intervention

TTM & HBM Readiness to change

Relationship established in the literature
5 Research Design

The study design can be considered the structural framework for implementing a research project and is concerned with converting research questions into projects (Robson, 2002). This study uses a prospective longitudinal research design involving a randomised controlled trial (RCT) as the structural framework allows investigation of the following research questions:

1. Does exposure to a self-management approach in the early stages of referral to a pain clinic, promote progress through the Stages of Change Scale and assist participants to take on a self-management approach to managing their pain?

2. What differences occur between the Intervention and Control groups’ level of Pain, Interference and level of Acceptance following early exposure to a self-management approach?

5.1 Rationale for a longitudinal design

A longitudinal design was considered essential as data collected in this way can measure changes linked to social happenings, providing opportunity to collect fuller information about individuals’ behaviours. It also allows changes in participants’ behaviour to be measured over time and by involving an RCT the best evidence for measuring the effectiveness of the intervention was available (Ruspini, 2000).

Data was collected and analysed on repeated measures of the same variables from a random sample of the same participant groups over a 14 month
period. The data collected was considered 'panel data' as the same patients completed questionnaires allowing the study to trace individuals in order to detect and determine features of individual change (Ruspini, 2000).

The use of a longitudinal design had the potential to provide richer information but this benefit had to be balanced with a greater possibility of theoretical and methodological problems as well as the requirement for more resources and researcher's time (Ruspini, 2000). Nevertheless, the strengths of a longitudinal study were considered to outweigh the more practical but weaker cross-sectional design that could seriously mislead outcomes (Polit & Hungler, 1993).

5.2 Randomised Controlled Trial Design

The Medical Research Council (MRC) advocate using a RCT to minimise bias and achieve the most accurate estimate of the benefits of a complex intervention (Medical Research Council, 2000). Defining precisely the active ingredients of this study's intervention and how they might relate to each other was difficult, and fitted with the MRC's (Medical Research Council, 2000) description of a complex intervention. Thus an RCT design was implemented with the overall development of this project guided by the MRC's framework for trials of complex interventions (See Figure 6).
Randomised controlled trial designs have many interrelated facets involving choice of sample, sample size, interventions and assessments. All these factors influence the statistical power or the sensitivity of the design to detect significant effects (Faithfull, 1999; Kemper et al., 1993).

5.3 Sample and sampling method

This study was aimed at all patients with a diagnosis of non-malignant musculoskeletal pain referred to a NHS District General Hospital’s Pain Management Service and provided the sampling framework. Sampling methods are important for their link with external validity or generalisability of findings (Robson, 2002), and these patients were considered a sub-
population of all patients referred to NHS pain clinics with musculoskeletal pain. Other persistent pain conditions were excluded in order to lessen the number of variables that could reduce the sensitivity of the intervention making it more difficult to detect changes, but still allowed for a heterogeneous population to be included with respect to key variables. This reduced the risk of sampling bias (Polit & Hungler, 1993).

5.4 Sample size and statistical power

One of the major concerns when conducting research into self-management is attaining sufficient statistical power. The power of a given test is the probability that a test will produce a significant difference at an agreed significance level, and this will depend on the size of the sample, the significance level chosen and the size of change between the populations compared (Bland, 2000; Cohen, 1977). The difficulty in many self-management studies is that the degree of change between the control and intervention groups can be relatively small. Furthermore, studies exploring use of health care resources will often involve a large heterogeneous population resulting in a large standard deviation. As a result of these two factors, self-management studies can require bigger samples to acquire statistical power (Kemper et al., 1993).

Advice from a statistician was sought in order to calculate the sample size and power of the study and involved the following areas: Effect size, significance level, power calculations and sample size.
5.4.1 Effect size

The effect size or degree of change between the control and intervention group relates to what is considered to be a clinically important outcome and will vary extensively between studies (Faithfull, 1996). It can be seen as the smallest difference that can be considered as having clinical meaning and importance (Devane et al., 2004). However, the smaller the effect size the harder it is to detect changes requiring a larger sample size in order to distinguish possible changes in the samples scores (Clegg, 1990; Kemper et al., 1993). An effect size of 0.10 is suggested as small, 0.50 as a medium while 0.70 is considered a large effect size (Cohen, 1977).

Effect size will also be dependent on aspects such as easiness of the intervention, the severity of the condition and measurement of the outcome (Devane et al., 2004). One of the few studies to discuss issues associated with effect size and self-care interventions suggest the size of change is relatively small in self-care studies, generally in the range of 0.08 -0.20 (Kemper et al., 1993). Further studies exploring self-management calculated an effect size of 0.40 (Ersek, Turner, Cain, & Ker, 2004), and 0.35 (Siu et al., 2007). Based on the literature and advice from a statistician a conservative effect size for this study of 0.20 was proposed.

Effect size relates to this study's hypothesis and it is proposed there will be a 0.20 difference in patients' readiness to take on self-management approaches as measured by promotion through the Stages of Change phases. The study's hypothesis suggests this will occur in the Intervention group as a result of exposure to early self-care approaches as discussed in Chapter 3.
5.4.2 **Significance level**

Use of a two-tailed hypothesis was important and contributed to determining the level of probability associated with the studies outcomes. It was agreed with the statistician to set a significance level or the probability of a Type 1 error at alpha = 0.05. This is often considered a conventional level although perhaps arbitrary choice, but it is more likely that a significant difference will be obtained when the P value chosen is larger (0.05) rather than smaller (0.01) (Bland, 2000; High, 2000).

A significance level of 0.05 was considered appropriate for this study taking into consideration the resources and time limit for the research. The researcher was aware that by choosing a significance level of 0.05 there was a 5% probability of making a Type 1 error and falsely rejecting the null hypothesis when in fact there may be no difference between the control and interventional groups.

5.4.3 **Power calculations**

A minimum of 80% statistical power is often chosen in clinical trials (Ersek, Turner, Cain, & Kemp, 2004; Griffiths *et al*., 2005) and while commonly used it does not represent a specific choice (High, 2000). Ersek *et al* (2004) calculate a power of 84% with an effect size of 0.40 for their sample of 218, while Griffiths *et al* (2005) calculated a sample number of N=196 to power their study to detect a 40% standard deviation change with 80% power and 0.05 significance. Ersek *et al* (2004) offers only rough guidance as their participants were randomised by site rather than by individual, a factor that requires further consideration when calculating the power of a study. A
further study exploring self-care behaviours among patients with heart failure rather than persistent pain, suggests a power of 74% to detect a large 'medium effect' with a sample size of n=110 (Artinian, Magnan, Sloan, & Lange, 2002).

Using these studies as guidance and with advice from a statistician, a power of 80% was chosen. This gave the study a 20% chance of a Type 2 error occurring whereby no difference between the control and interventional group would be detected when in fact there may be one.

5.4.4 Sample number
In summary an effective sample size for this study was explored using an effect size of 0.20 and a power of 80% at the 0.05 level of significance which gave the following results:

<table>
<thead>
<tr>
<th>Effect size</th>
<th>Power %</th>
<th>Alpha</th>
<th>Sample size per group</th>
</tr>
</thead>
<tbody>
<tr>
<td>0.20</td>
<td>80</td>
<td>0.05</td>
<td>79</td>
</tr>
</tbody>
</table>

The power calculations suggested a sample number of n=158 (control n= 79 intervention group n=79) was required to distinguish possible differences in the participants scores. This was considered a feasible sample size as referral numbers to the pain clinic average 110 -130 per month with the intention to over recruit in order to allow for drop outs. A drop out rate of between 30 – 60% was considered likely based on the Service Development Study and previous audits conducted in the Pain Management Department. A similar
size sample has been calculated (N=160) by Siu et al (2007) in their study exploring self-management programmes using a quasi-experimental design and considered adequate for a clinical trial.

5.5 Subject inclusion

The principle inclusion and justification criteria were:

<table>
<thead>
<tr>
<th>Inclusion criteria</th>
<th>Justification</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male or female</td>
<td>Reduction of variables and complexities</td>
</tr>
<tr>
<td>Aged 18-75 years</td>
<td>Reduction of variables and allowed comparison with studies in the literature exploring aspects of persistent pain and self-management</td>
</tr>
<tr>
<td>Experienced continuous/intermittent non-malignant pain for 3 months or longer</td>
<td>This met the International Association for the Study of Pain’s (IASP) criteria for chronic pain (IASP, 1994)</td>
</tr>
<tr>
<td>Referred to DGH Pain Clinic</td>
<td>One site sample framework</td>
</tr>
<tr>
<td>Referred with a diagnosis of musculoskeletal pain</td>
<td>Ensure safe practice and appropriate care offered. Reduce number of variables in the study by limiting the cause of pain.</td>
</tr>
<tr>
<td>Adequate literacy to be able to complete questionnaire</td>
<td>Study will not be able to collect and analyse meaningful data if participant unable to complete questionnaires</td>
</tr>
<tr>
<td>Willing to take part in the study and sign a consent from</td>
<td>Uphold ethical principles and ensure patient has capacity to consent</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Exclusion criteria</th>
<th>Justification</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender reassignment</td>
<td>Adds additional variables and complexity to study</td>
</tr>
<tr>
<td>Urgent referral</td>
<td>Ensure safe practice and care for patients: a self-management approach may not initially be appropriate for urgent referrals</td>
</tr>
<tr>
<td>History of malignancy, HIV or diagnosis requiring the involvement of the palliative care team</td>
<td>Ensure safe practice and appropriate care offered: a self-management approach may not be appropriate for these patients.</td>
</tr>
<tr>
<td>Significant sight impairment</td>
<td>Resources not available to provide questionnaires in Braille</td>
</tr>
</tbody>
</table>

Table 4: Subject Inclusion and Exclusion Criteria

5.6 Recruitment and enrolment

From October 2005 through to November 2006 patients referred to the DGH Pain Management Department with a diagnosis of persistent non-malignant musculoskeletal pain, fitting the study’s inclusion and exclusion criteria were
invited by letter to take part in the study. The letter was accompanied by an information sheet (See Appendix 12.2 and 12.3). If they were interested they were asked to contact the researcher by returning their details on a form in a stamped addressed envelope or to contact the researcher by telephone.

The researcher then contacted potential participants by telephone to discuss the study and any areas of concern. If participant gave verbal agreement to take part in the study they were randomised using a random number generator using Excel. This allowed unbiased assignment of participants to either the Control or Intervention group. They were then sent a consent form and baseline questionnaire to complete and return in a stamped addressed envelope to the researcher. A telephone ‘Helpline’ and contact numbers were made available via the Pain Management Department should further questions or concerns arise for participants during the study.

Patients who failed to respond to the first invite letter after 3-6 weeks were telephoned or sent a reminder letter. If necessary a further reminder was sent at 8-12 weeks and if there was no response, no further contact was made. This principle was also applied to participants who failed to return questionnaires at the three collection stages during the course of the study.

5.7 Intervention

This study was aimed at patients who following referral to a DGH Pain Management Service were on a waiting list for an appointment with the pain clinic. At the time of the study the Government’s target for new patient
appointments referred by their General Practitioner (GP) was 13 weeks with internal referrals often waiting longer. Participants randomly allocated to the Control group received usual care, in that they remained on the waiting list until offered an out patient appointment in the Pain Clinic. Participants allocated to the Intervention group while on the waiting list or during initial stages of treatment were invited to attend an additional intervention. This was a six week 2.5 hours a week self-care programme, also know as the Expert Patient Programme (EPP), an NHS lay led self-management programme (see Table 5).

<table>
<thead>
<tr>
<th>Week</th>
<th>Course Content</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Overview of self-management and chronic health conditions, making action plans, relaxation and cognitive symptom management, better breathing</td>
</tr>
<tr>
<td>2</td>
<td>Feedback/problem solving: making action plans, dealing with anger/fear/frustration and introduction to fitness and exercise</td>
</tr>
<tr>
<td>3</td>
<td>Feedback/problem solving: making action plans, relaxation/cognitive symptom management, fitness/exercise, dealing with fatigue</td>
</tr>
<tr>
<td>4</td>
<td>Feedback/problem solving: making action plans, relaxation/cognitive symptom management, nutrition, living wills or community resources, communication</td>
</tr>
<tr>
<td>5</td>
<td>Feedback/problem solving: making action plans, relaxation/cognitive symptom management, medications management, making treatment decisions, dealing with depression</td>
</tr>
<tr>
<td>6</td>
<td>Feedback/problem solving: making action plans, relaxation/cognitive symptom management, informing the health care team, working with your health care professional, future plans</td>
</tr>
</tbody>
</table>

Table 5:  
EPP Course Content (NHS Expert Patients Programme, 2002)

The development of EPP has been discussed in detail in the Policy Review2. However, the practicality of organising these programmes is important to understand in the context of delivery. The local EPP was led by the Health

2 See Policy Review Part Two
Promotion Specialist (HPS) based in a local Primary Care Trust (PCT). It had been one of the pilot sites for the Department of Health’s initial evaluation of EPP before being incorporated into main stream healthcare provision by the NHS (Murphy, Larsen, & Smith, 2002). The HPS was keen to help support the study providing additional costs were not incurred by the PCT.

Nine months into the study Primary Care Trusts went through a restructuring process and responsibility for leading and organising EPP was transferred to the Patients Advocate and Liaison Officer. While responsibilities within the new structure settled, the original HPS continued to oversee EPP within the local PCT, allowing the study to continue without disruption. Two neighbouring PCTs were approached in the latter part of the study to increase the choice of venue and dates of EPPs and help improve access/convenience for participants and increase attendance numbers.

To support the local EPP and HPS, the researcher agreed to assist with recruiting new EPP tutors and with the administration of running the EPPs involved in the study. The researcher was aware from the literature (Lorig et al., 1998) that as well as the challenge of recruiting participants to the study, the recruitment of tutors could be an issue alongside tutor availability due to sickness and holidays. The latter is discussed in greater detail in Chapter 9 on Clinical Implications.
5.8 Ethical considerations

Conducting research in an ethical way is always required and must be given adequate attention. The four main ethical principles are autonomy, non-maleficence, beneficence and justice (Beauchamp & Childress, 1994). Briefly summarised, autonomy refers to freedom of the individual to make independent decisions and its principle includes the following rules:

- To tell the truth
- Respect the privacy of others
- Protect confidential information
- Obtain consent for interventions with patients
- When asked, help others to make important decisions (Beauchamp & Childress, 1994).

To uphold these principles a letter and information sheet about the study (Appendix 12.2 and 12.3) was sent to potential participants and opportunity provided to discuss the study. Written consent was required and participants were identified by a study number providing a degree of anonymity. As the study was longitudinal the progress and assessment of variables were required making full anonymity impossible. All data collected was securely stored on Trust computers and within the areas of the pain management department and will be destroyed in accordance with Trust ethical policy on data protection.

The principle of non-maleficence asserts an obligation not to intentionally allow risk or harm to another person. Patients suffering from pain can often
feel quite distressed by their symptoms and needy of help which could make them feel obliged to co-operate with the study. To guard against this vulnerability, all patients were contacted after they had received correspondence confirming their referral and place on the waiting list for an appointment with the pain clinic.

Principles of beneficence require not only respect for another person's autonomy and avoidance of harming them, but also contributing to their welfare. Therefore participants were made aware that if they decided to take part they were free to withdraw at any time and without giving a reason, and that this would not affect the standard of care they received. The researcher was also aware that should information have become available which may have been relevant to their continued participation, participants would have been written to enclosing relevant details. Ethical consideration was also necessary for the lay persons recruited as tutors providing the self-management programmes. The recruitment and training of these tutors relied on existing mechanisms in place within the NHS PCTs and additional ethical issues were not envisaged, but all ethical principles described above applied.

Thought was also given to the involvement of all members of the Pain Management Department to ensure they were fully aware of the study. A presentation of the service development project was given to all team members in May 2005. This consisted of medical consultants, healthcare professional (nurse, clinical psychologists, and physiotherapists), managers
and secretaries. Agreement from the team to support the study was given with a commitment from the researcher to keep the team updated on progress.

Attention was given as to whether the study could cause harm to the participants. EPP had been offered for 4 years in the community and as already mentioned the PCT involved had been one of the Department of Health pilot sites for EPP. They experienced no adverse effects and participants benefited from a greater sense of control over their symptoms (Murphy et al., 2002). In respect of the questionnaires chosen, these are routinely used with patients suffering from persistent pain and considered well trialled and tested tools.

The focus groups were an area which had the potential to discuss sensitive or upsetting topics and where disclosures could be made by participants that might require action from the researcher. Although these possibly contentious areas were not the focus of the study, it was important to provide usual routes of referral if problems arose.

5.8.1 Ethical approval

Ethical review from the Local Research Ethics Committee and NHS Research and Development Committee and the University of Surrey Ethical Committee was sought and given (See Appendix 12.4).
5.9 Method of data collection

Selecting the data collection method was determined by the information sought and quantitative data using a postal questionnaire (See Appendix 12.5) combined with qualitative data gathered from focus groups was used.

5.9.1 Quantitative

The researcher was the only person involved in collecting the quantitative data reducing possible collection variables, and using questionnaires had a number of advantages. These included lower cost and time implications and also ensured there was no bias reflecting the participant’s reaction to the researcher, rather than to the questions themselves. Nevertheless, limitations of involving a postal questionnaire need to be acknowledged, and these include possible poor response rates, exclusion of patients who cannot not fill them out and misinterpretation of questions (Polit et al., 2001).

Missing data was a limitation exposed when the questionnaire was used in the Service Development Project, and small adjustments were made to the questionnaire, but major changes were not possible as this would have limited the depth of data collected. These potential weaknesses are reflected upon in the data analysis, but overall postal questionnaires were considered the most practical way to access the quantitative data when limited resources and time available to the researcher were taken into consideration.

The initial postal questionnaire was sent to participants as soon as they had consented to be in the study and acted as the baseline questionnaire. A
further identical questionnaire was sent three to six months later and depending on the point when the participant was recruited into the study, a third questionnaire sent between ten and fourteen months after the start of the study.

Instruments were chosen that would gather data permitting comparisons and reflecting changes in behaviour over time between the Intervention and Control group. Detecting changes in conditions is an important aspect of experimental research (Faithfull, 1999) and the quantitative instruments chosen to measure differences between the Intervention and Control groups’ readiness to take on a self-management approach and changes in levels of Acceptance, Pain and Interference were three validated questionnaires exploring:

- Pain Stages of Change Questionnaire (PSOCQ)
- Levels of Acceptance (Chronic Pain Acceptance Questionnaire) (CPAQ)
- Levels of Pain and Interference (Brief Pain Inventory) (BPI)

The questionnaire was designed to cover the following areas:

- *Descriptive data:* to elicit age, gender, length of time the participant had experienced pain, whether they had been given a diagnosis, age when they left school, whether they were in currently employed and use of health care resources.

- *Pain Stages of Change Questionnaire (PSOCQ) (Kerns et al., 1997):* The development and initial validation of the PSOCQ was designed to assess an
individual's readiness to adopt a self-management approach to their persistent pain condition. Five stages of change have been identified in studies exploring health related behaviour associated with addictive behaviour and smoking (DiClemente et al., 1991; Prochaska et al., 1992). These are Precontemplation, Contemplation, Preparation, Action and Maintenance. Kerns et al (1997) found the Contemplation and Preparation scales were closely linked, so combined these into one stage called Contemplation. Internal consistency varied with Precontemplation 0.77, Contemplation 0.64, Action 0.86, and Maintenance 0.88. These internal consistencies were largely replicated in a later study evaluating further the PSOCQ, thereby supporting its validity (Jensen et al., 2000).

- **Chronic Pain Acceptance Questionnaire (CPAQ)** (McCracken, Vowles et al., 2004): The original study developing the CPAQ consisted of four factors: activity engagement, pain willingness, thought control and chronicity (Geiser, 1992). McCracken et al (2004) recommended dropping factors related to thought control and chronicity as they proved unreliable with item inter correlation. Internal consistency and predictive validity were strongly supported in the application of two layer factors comprising of activity engagement (0.82) and pain willingness (0.78).

- **Brief Pain Inventory (BPI)** (Tan, Jensen, Thornby, & Shanti, 2004): The BPI was originally developed as a quick and simple tool to measure pain and extent of interference in the lives of those suffering from pain related to cancer intensity (Cleeland & Ryan, 1994). It has since been translated into
many languages and used in numerous countries to assess cancer pain. Tan *et al.* (2004) (*n*=440) showed good internal consistency (0.85 for the intensity items, 0.88 for the interference items) when applied to patients experiencing chronic non-malignant pain referred to a pain clinic. However, this study was limited by being a one centre study. Nevertheless, correlations with the Roland Morris Disability questionnaire (not more than 0.80) concluded that the psychometric properties of the BPI are validated, suggesting its use can be extended to those people experiencing persistent non-malignant pain.

The PSOCQ, CPAQ and Pain intensity scales are instruments that have been used in previous studies to predict responses to self-management treatments (Ersek, Turner, Cain, & Kemp, 2004; Heapy *et al.*, 2005; Kerns & Rosenberg, 2000; McCracken, Vowles *et al.*, 2004) and it is important that any information gained from this study adds to the growing understanding of self-care approaches in long-term health conditions.

### 5.9.2 Qualitative

The qualitative data was gathered using focus groups which although widely used in research studies have rarely been involved in studies exploring self-management and persistent pain. The focus groups were used to explore possible difference between the Intervention and Control groups’ data following exposure to a self-management approach.
Data was collected from five focus groups (two groups involved participants from the Control group and three involved participants from the Intervention group) exploring self-care issues. The researcher aimed for four to twelve participants to attend each group as this is considered an ideal number for a focus group (Clarke, 1999; Kitzinger, 1995; Smithson, 2000; Stevens, 1996). To reduce possible influences on participants' behaviour, focus groups were not held prior to the intervention; experience with the Expert Patients self-management Programme indicated that the effect of participants interacting with each other could influence their behaviour in both a positive or negative way. This could have impacted on the validity of findings in this study; consequently focus groups were held at four month, eight month and twelve month points in this study.

Participants who had consented to be part of a focus group were contacted by letter informing them of the date, time and venue of the focus group and travel expenses were offered. The focus groups were held in the pain management department, and the clinical health psychologist in the pain management department facilitated the sessions while the researcher took field notes. All focus groups were recorded and transcribed verbatim by the researcher.

5.9.3 Focus groups
Focus groups were chosen because they have a number of advantages over one to one interviewing. The most obvious advantage is that the researcher can collect data comparatively quickly from a larger number of research
participants and they produce a more natural setting to an interview, encouraging conversation that is more likely to occur in everyday conversation (Silverman, 2004). This can be an effective way of collecting information about participants' feelings and opinions (Clarke, 1999; Kitzinger, 1995), and the growth in its popularity as a research tool in health care is confirmed in the literature (Kitzinger, 1995; McLafferty, 2004; Morgan, 1996; NYS Teacher Centres, 2004; Sim, 1998; Webb & Kevern, 2001). Focus groups are considered a rich source of data providing insight into the origins of complex behaviours and motivations (McLafferty, 2004; Morgan & Krueger, 1993), while group interactions can be an important ingredient as the participants are both likely to question and explain themselves to each other, giving synergy to the outcomes that individual interviews cannot compete with (Morgan, 1996).

Giving thought to how the focus groups were set up and facilitated was important in order to reduce possible limitations that could occur, such as one or two participants dominating the process. There can also be a tendency for what are considered socially acceptable opinions to come out (Kitzinger, 1995; Smithson, 2000), and these issues led the researcher to ask a colleague, with experience and skills in working in group situations to facilitate the groups. This also reduced any bias the researcher may have introduced through previous contact with participants during the recruiting phase and subsequent use of the help line, and left the researcher free to make field notes.
Structure of the focus group can influence data and while recognising the less structured the focus groups the more likely issues that are relevant and important to members will emerge, it was felt that a degree of guidance using questions would keep the group discussions more purposeful and provide a consistent framework for each focus group (See Box 1).

The focus groups were arranged to take place in the pain management department in the afternoon. Participants were met by the researcher and offered refreshments to help create a relaxed and comfortable atmosphere. They were asked to wear name badges with their choice of name written on it and the facilitator and researcher wore name badges. The facilitator introduced the session by briefly explaining the purpose of the group and set ground rules for confidentiality. Written consent to record the session had previously been obtained and verbal confirmation that participants were still happy for the session to be recorded was sought.

1. What is your understanding of why you have been or were referred to the pain clinic?
2. How do you see your pain in the future?
3. What do you currently do to help yourself with your pain?
4. What would help you to manage your pain?
5. Is responsibility an issue in managing your pain?
6. What is your understanding of self-care or self-management?
7. What attitude do you take to your pain? Does acceptance play a part?
8. What are your expectations of the pain clinic?

**Box 1: Focus Group Questions**
The focus groups lasted 1 hour and if a member of the focus group arrived more than 15 minutes after the start of the group they were not permitted into that group and invited to attend a future focus group.

5.10 Method of data analysis

The study involved a mixed method approach of analysis combining data from two different research paradigms. The quantitative data employed an ‘intention to treat’ approach and all data obtained from the questionnaires was entered onto an Excel spread sheet. Data was then transferred to the Statistical Package for the Social Sciences (SPSS) 13.0 to perform the various analytical processes. Once data had been entered onto Excel and SPSS 13.0, the statistical treatment of the data involved:

- Independent and paired t tests: This can test for differences on continuous treatment variables
- Chi-square test: This can test for differences between Control and Intervention group on categorical variables. This was applied to non-parametric data and is a test that has great flexibility in terms of situations it can be applied to (Caulcott, 1992; Clegg, 1990).
- Pearson’s Product Moment Correlations: Correlations analysis were applied to explore strength of associations between variables

The qualitative data required a completely different method of analysis, and often the difficulty once data from focus group discussions has been collected is how to analyse the transcribed data (Burnard, 1991). The method chosen
to aid the process of analysing the transcripts was thematic content analysis using ‘Framework’ (Ritchie & Spencer, 1994).

Burnard’s (1991) fourteen stages of analysis was also considered along with Ritchie & Spencer’s (1994) ‘framework’ as both methods offer an analytical process that attempts to represent the beliefs and feelings of participants while providing insights and explanations for behaviour in a systematic and truthful way (Burnard, 1991; Ritchie & Spencer, 1994). The researcher decided on the ‘framework’ as it has proved adaptable in many differing studies (Ritchie & Spencer, 1994), and offered the researcher what appeared a more focused coding procedure and manageable analytical process. However, Burnard’s (1991) guidance on validity proved valuable to offset any bias the researcher might have introduced while attempting to make sense of the focus group transcripts.

Ritchie & Spencer (1994), identify four categories involving questions that may need addressing in any research involving a qualitative method. These are contextual, diagnostic, evaluative and strategic. As the focus of this study was self-management with a primary objective of understanding the possible impact early exposure to self-management approaches may have on participants’ persistent pain management, the priori questions that needed to be addressed were divided into two main categories.

- Diagnostic – to identify the range of factors which inhibit or encourage participants to pursue self-management approaches?
• Strategic – the analysis may generate ideas or ways of overcoming possible barriers to self-management approaches in the management of persistent pain.

However, questions involving the diagnostic and strategic categories could not be disentangled completely from discussions involving a contextual and evaluative focus as participants’ experience, attitudes and effectiveness of current approaches all appeared to be involved in managing persistent pain and were complex and intertwined. Key objectives and characteristics of qualitative analysis identified in framework are:

• Defining concepts
• Mapping range and nature of phenomena
• Creating typologies
• Finding associations
• Providing explanations
• Developing strategies (Ritchie & Spencer, 1994:186)

Although the framework process was followed systematically it was not without its complications. Burnard (1991) suggests that while there is a need for the researcher to be systematic there is also a need for them to remain alert to the complexity of the task of analysing qualitative data. Ritchie & Spencer (1994) describe the basic process involved in analysing the qualitative data as following five key stages. These include:

1. Familiarisation of the data: This involved the researcher in re-listening and re-reading transcripts, reviewing field notes. Listing key ideas and
recurring themes. During this stage thoughts and conceptualisation occurred and a feel for the overview of depth and richness of the data developed.

2. Identification of a thematic framework: Key issues, concepts and themes began to form a thematic framework into which data was sorted.

3. Indexing: at this stage the Index or thematic framework was applied to the transcribed data from the focus groups. All the data was reread and indexing references noted in the margins of each transcript using a numerical system.

4. Charting: This required data to be 'lifted' from its original context and arranged in keeping with its thematic location. Patterns and connections were then searched for and involved two of the researcher’s colleagues to validate the process.

5. Mapping and interpretation: This stage involved reviewing the charts, comparing and contrasting perceptions, accounts and experiences discussed by participants. Patterns and connections were looked for from within the data; by applying this practice and involving the researcher’s ability to interpret and synthesise the data, while incorporating judgements and meaning, so conclusions were gradually drawn. Ritchie & Spencer (1994) suggest this is the most difficult part of the analytical process to describe and a diagram of this stage of the process has been devised to help explain the processes involved (See Figure 7).
Validity is an important consideration in the process of analysing the qualitative data. The focus group data offered insight into participants’ perception of everyday actions associated with managing their pain and it was important the researcher was aware of any bias and subjectivity that could have been introduced while attempting to seek explanations and draw conclusions. Checking that feelings and thoughts of the participants were represented in a systematic and honest way was guided by a process of validation described by Burnard (1991) and involved two of the researcher’s colleagues.
The process of validation involved the clinical health psychologist in the pain management department who was familiar with the process of developing categories in qualitative research analysis, and had facilitated the focus groups. She was asked to review the framework process and indexing of themes. A second colleague who was not involved with any aspect of the study but had experience in the management of pain was then asked review the indexed data. Comparisons were made with the key themes identified and interpretation of the data and adjustments made where needed in order that a systematic and honest process occurred that offered reliable explanations and conclusions (Burnard, 1991).
Results and Analysis

The data was collected over a period of seventeen months from October 2005 to March 2007 and obtained from patients referred to the pain clinic who were patients who continued to seek treatment for their persistent pain symptoms. They were not considered to be patients who had come to terms with their pain symptoms, and therefore 'getting on with their lives' independent of healthcare services. The descriptive data confirmed that no participant included in the study had experienced pain for less than 1 year and the maximum duration of pain experienced was 40 yrs.

All the potential participants had a diagnosis of non-malignant musculoskeletal pain and 301 patients (72% female) were initially written to and invited to take part in the study. The higher proportion of woman referred to the pain clinic is consistent with a greater proportion of women reporting chronic pain (Rustøen et al., 2004a). From this initial invite 78 (26%) patients agreed to participate in the study. Thirty eight (12%) actively declined to take part with 24 (63%) giving a reason and 185 (61%) passively declining by not responding to follow up invites and telephone calls (See consort flow chart Figure 8).

The most common reasons for not taking part were transport difficulties, family and work commitments (see Table 6). A further 6 participants actively dropped out during the study, (3 gave no reason, 1 moved away, 1 developed cancer, 1 developed dementia).
Figure 8: Consort Flow chart
<table>
<thead>
<tr>
<th>Reasons given</th>
<th>Number</th>
<th>Male</th>
<th>Female</th>
</tr>
</thead>
<tbody>
<tr>
<td>Transport difficulties</td>
<td>6</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>Health issues</td>
<td>3</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Work commitments</td>
<td>2</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Family commitments</td>
<td>2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do not want to be in a study</td>
<td>2</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Do not need to be seen in pain clinic</td>
<td>2</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Intervention requires too much time commitment</td>
<td>2</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Referred to traditional Pain Programme</td>
<td>1</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Seeking alternative medicine</td>
<td>1</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Moving house</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Busy social life</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Does not like groups</td>
<td>1</td>
<td>1</td>
<td></td>
</tr>
</tbody>
</table>

**Table 6: Reasons given for declining to take part in study**

The study aimed to collect data involving questionnaires at the following points during the study’s progression: Questionnaire 1 at baseline, questionnaire 2 at mid stage, 3-6 months, and questionnaire 3 at the end of the study, 10-14 months. Of the N=78 participants who initially agreed to take part n=63 (84%) returned questionnaire 1. As the study progressed, the amount of information available from participants reduced, with n=42 (56%) participants returning questionnaire 2 and n=33 (44%) returning questionnaire 3. Some participants needed reminding to return questionnaires and participants recruited nearer the end of the study had less time in the study, hence the time when questionnaires were returned varied slightly. Overall, the majority of data was collected at the specified points and the following table shows the distribution of the data collected (See Table 7).

The problem of missing data in palliative care studies has been attributed to changing health conditions raising issues about whether the data can be considered to be randomly missing (Palmer, 2004). In this study no clear explanation is provided for the declining level of information available.
Nevertheless, the return rate for the initial return of questionnaires was considered ‘good to acceptable’ for a postal questionnaire (Polit et al., 2001).

<table>
<thead>
<tr>
<th>Control group</th>
<th>Questionnaire 1 Returned</th>
<th>Questionnaire 2 Returned</th>
<th>Questionnaire 3 Returned</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 months</td>
<td>82%</td>
<td>3-6 months 86%</td>
<td>4-9 months 35%</td>
</tr>
<tr>
<td>1-3 months</td>
<td>9%</td>
<td>7-12 months 14%</td>
<td>10-14 months 65%</td>
</tr>
<tr>
<td>3-9 months</td>
<td>9%</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Intervention group</th>
<th>Questionnaire 1 Returned</th>
<th>Questionnaire 2 Returned</th>
<th>Questionnaire 3 Returned</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 months</td>
<td>84%</td>
<td>3-6 months 70%</td>
<td>4-9 months 18%</td>
</tr>
<tr>
<td>1-3 months</td>
<td>13%</td>
<td>7-12 months 30%</td>
<td>10-14 months 82%</td>
</tr>
<tr>
<td>3-9 months</td>
<td>3%</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Table 7: Time points for questionnaire returned and percentage**

Data from focus groups was collected at five points. These were 7 months, 8 months, 10 months, 11 months and 12 months into the study though the length of the time participants had been in the study varied. However, all participants attending a focus group from the Intervention group had attended the Intervention EPP.

Results and analysis from the quantitative data collected using postal questionnaires will now be discussed followed by results and analysis of the qualitative data obtained from the focus groups.
6.1 Description of the sample

Data obtained from participants in the Control and Intervention groups at the three points during the study were first analysed for descriptive data and distribution.

The descriptive data obtained on the sample of n=63 (73% women) mirrored the proportion of women in the Service Development Project (SDP) (73% female). As already mentioned this was consistent with a higher proportion of women reporting chronic pain in the population, but was nevertheless higher than for studies reported in the literature (average 58%) (Burns et al., 2005; McCracken, Carson, & Eccleston, 2004; Nicholas & Asghari, 2006).

The age range was 29-83 years (mean 55.3 std.13.8) and compared favourably with the SDP and previous studies using similar populations studied (mean 50.3 std 13.0) (Habib, Morrissey, & Helmes, 2005; Nicholas & Asghari, 2006), and a study exploring individuals’ interest in taking part in an EPP (mean 53 years range 21-82) (Carr et al., 2006). Ages of those who responded to take part in the current study were compared with those who requested not to take part and those who failed to respond. The mean age of participants agreeing to take part was 55 (range 29 to 83) and those who declined or failed to respond mean age was also 55 (range 21 to 90 years). Age was therefore not a variable that influenced participants’ response to a study exploring self-management.
The mean age of leaving school was 16.2 (std 1.4) and n=46 (73%) had undertaken further education. This suggests participants were better educated and is similar to other studies samples involving the PSOCQ (Carr et al., 2006; Jensen et al., 2000; Kerns et al., 1997). Almost half of the sample were employed n=29 (46%) compared to an employment range of 28.5-42.5% reported in similar study populations in the literature (Kerns et al., 1997; McCracken, Carson et al., 2004).

Visits to General Practitioners (GP) in the previous 6 months collected at entry to the study ranged from 0-20 visits (mean 4.7 std 4.0) and attendance at hospital appointments in the last 6 months ranged from 0-9 (mean 1.9 std 2.0). Duration of pain ranged from 1-40 yrs (mean 7.4 std 9.7) comparing well with published studies (mean 7.7 std 9.8) (Nicholas & Asghari, 2006). Pain intensity ranged from 0-10 (mean 5.6 std 1.9) comparing well with published studies (mean 5.3 std. 2.1 range 1-10) (Habib, Morrissey, & Helmes, 2003) and Interference ranged from 14 – 70 (mean 41.6 std. 14.1) (see Table 8).

Distribution curves were constructed of age, pain duration and pain intensity (See Graphs 1,2 & 3) to give visual understanding to data distribution (Bowers, 1996). The distribution of data for duration of pain was skewed towards the lower end (2 patients omitted to give details) this nevertheless reflected data collected in the SDP and published studies (McCracken & Eccleston, 2005). 

Page 120
<table>
<thead>
<tr>
<th>Age</th>
<th>Mean</th>
<th>SD</th>
<th>Minimum</th>
<th>Maximum</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>55.3</td>
<td>13.8</td>
<td>29</td>
<td>83</td>
</tr>
<tr>
<td>Age left school</td>
<td>16.10</td>
<td>1.4</td>
<td>14</td>
<td>21</td>
</tr>
<tr>
<td>Visits to GP in last 6 months</td>
<td>4.7</td>
<td>4.0</td>
<td>0</td>
<td>20</td>
</tr>
<tr>
<td>Attended hospital appointments related to pain in last 6 months</td>
<td>1.9</td>
<td>2.0</td>
<td>0</td>
<td>9</td>
</tr>
<tr>
<td>Duration of pain (years)</td>
<td>7.4</td>
<td>9.7</td>
<td>1</td>
<td>40</td>
</tr>
<tr>
<td>Pain intensity</td>
<td>5.6</td>
<td>1.9</td>
<td>0</td>
<td>10</td>
</tr>
<tr>
<td>Pain interference</td>
<td>41.6</td>
<td>14.1</td>
<td>14</td>
<td>70</td>
</tr>
</tbody>
</table>

Table 8: Mean and standard deviations of the study variables (n = 63)

Graph 1: Distribution Curve for Age
Graph 2: Distribution Curve for Duration of Pain

Graph 3: Distribution Curve for Pain (mean)

The data distribution was discussed with the statistician and no significant difference in F tests between the Intervention Group 1 and Control Group 1’s baseline data was found (See Appendix 12.6). Therefore the assumption was made that the data was normally distributed with equal variability, allowing parametric t-tests and Pearson’s correlations to be applied.
The Intervention and Control groups were well matched in terms of demographic data (see Table 8). It was noted the Control group had a greater duration of pain (mean 7.8 yrs std 11.0) compared with the Intervention group (6.9 std 8.4) but applying independent t-test showed no statistical significance in the difference ($p = 0.71$). The Intervention group reported slightly higher mean Pain intensity scores 6.0 (std. 2.0) and Interference of pain score 43.2 (std. 14.8) compared with the Control group, Pain 5.2 (std1.7) and Interference 40.2std (13.6), but again this difference was not statistically significant ($p=0.07$ and $p=0.41$) (see Table 9).

<table>
<thead>
<tr>
<th>Scale</th>
<th>Interventions 1 (n=30)</th>
<th>Control 1 (n=33)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>54.5 (14.5, 13.2)</td>
<td>56.0 (11.0, 13.2)</td>
</tr>
<tr>
<td>Duration of pain</td>
<td>6.9 (8.4, 7.8)</td>
<td>7.8 (10.0, 8.4)</td>
</tr>
<tr>
<td>Visits to GP in last 6 months</td>
<td>5.0 (4.7, 4.4)</td>
<td>4.4 (3.2, 4.7)</td>
</tr>
<tr>
<td>Age left school</td>
<td>16.1 (1.6, 16.2)</td>
<td>16.2 (1.1, 11.0)</td>
</tr>
<tr>
<td>Number of hospital appointments</td>
<td>1.8 (1.9, 2.0)</td>
<td>2.0 (2.2, 1.9)</td>
</tr>
</tbody>
</table>

Table 9: Baseline data comparing means, std and Independent T-tests for age, duration of pain, visits to GP, age left school and hospital appointment between Control and Intervention Groups

There were no particular difference between age participants had left school or the number who had undertaken further education in either group, though the Intervention group appeared to make on average a greater number of visits to their General Practitioner over the last 6 months (5.0 std 4.7) compared with the Control group (4.4 std 3.3). Again these differences were
not statistically significant when independent t-test were applied ($p \ 0.59$) (see Table 9).

The characteristics for participants returning questionnaires at each stage of the study were then compared for descriptive differences (See Table 10). No obvious pattern was observed for characteristic differences in missing data though, a slightly higher proportion of unemployed participants and participants who had undertaken further education appeared more consistent with returning their questionnaires as the study progressed.
<table>
<thead>
<tr>
<th>Age (M)</th>
<th>Group 1 (n=30)</th>
<th>Group 2 (n=20)</th>
<th>Group 3 (n=16)</th>
<th>Group 1 (n=33)</th>
<th>Group 2 (n=22)</th>
<th>Group 3 (n=17)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Baseline</td>
<td>54.5 (SD14.5)</td>
<td>58.3 (SD14.1)</td>
<td>56.6 (SD14.7)</td>
<td>56.0 (SD13.2)</td>
<td>58.3 (SD11.4)</td>
<td>59.4 (SD10.5)</td>
</tr>
<tr>
<td>Duration of pain (yrs)</td>
<td>6.9 (SD8.4)</td>
<td>9.1 (SD8.5)</td>
<td>9.3 (SD8.8)</td>
<td>7.8 (SD11.0)</td>
<td>11.8 (SD14.4)</td>
<td>9.8 (SD13.4)</td>
</tr>
<tr>
<td>Pain intensity (M)</td>
<td>6.0 (SD2.0)</td>
<td>6.3 (SD1.9)</td>
<td>5.0 (SD2.2)</td>
<td>5.2 (SD1.7)</td>
<td>5.0 (SD2.3)</td>
<td>4.9 (SD1.7)</td>
</tr>
<tr>
<td>Pain interference (M)</td>
<td>43.2 (SD14.8)</td>
<td>44.0 (SD14.3)</td>
<td>35.6 (SD16.3)</td>
<td>40.2 (SD13.6)</td>
<td>33.3 (SD17.3)</td>
<td>36.9 (SD14.7)</td>
</tr>
<tr>
<td>Given a diagnosis</td>
<td>Yes n=20 (67%)</td>
<td>Yes n=18 (90%)</td>
<td>Yes n=15 (94%)</td>
<td>Yes n= 25 (76%)</td>
<td>Yes n=17 (77%)</td>
<td>Yes n=13 (77%)</td>
</tr>
<tr>
<td>No n=10 (33%)</td>
<td>No n=2 (10%)</td>
<td>No n=1 (6%)</td>
<td>No n=8 (24%)</td>
<td>No n=5(23%)</td>
<td>No n=4 (23%)</td>
<td></td>
</tr>
<tr>
<td>Age left school (M)</td>
<td>16.1 (SD1.6)</td>
<td>16.1 (SD1.3)</td>
<td>16.3 (SD1.2)</td>
<td>16.2 (SD1.15)</td>
<td>16.1 (SD1.1)</td>
<td>16.2 (SD1.3)</td>
</tr>
<tr>
<td>Undertaken further education</td>
<td>Yes n= 23 (77%)</td>
<td>Yes n=13 (65%)</td>
<td>Yes n=12 (75%)</td>
<td>Yes n= 23 (70%)</td>
<td>Yes n=19 (86%)</td>
<td>Yes n=14 (82%)</td>
</tr>
<tr>
<td>No n=7 (23%)</td>
<td>No n=7 (35%)</td>
<td>No n=4 (25%)</td>
<td>No n=10 (30%)</td>
<td>No n=3 (14%)</td>
<td>No n=3 (18%)</td>
<td>No n=3 (18%)</td>
</tr>
<tr>
<td>Currently in paid employment</td>
<td>Yes n= 13 (43%)</td>
<td>Yes n=6 (30%)</td>
<td>Yes n=6 (38%)</td>
<td>Yes n=16 (48.5%)</td>
<td>Yes n=9 (41%)</td>
<td>Yes n=7 (41%)</td>
</tr>
<tr>
<td>No n=17 (57%)</td>
<td>No n=14 (70%)</td>
<td>No n=10 (62%)</td>
<td>No n=17 (51.5%)</td>
<td>No n=13 (59%)</td>
<td>No n=10 (59%)</td>
<td>No n=10 (59%)</td>
</tr>
<tr>
<td>Visits to GP in last 6 months (M)</td>
<td>5.0 (SD 4.7)</td>
<td>3.6 (SD2.3)</td>
<td>3.4 (SD 2.4)</td>
<td>4.4 (SD 3.2 )</td>
<td>4.2 (SD 2.8)</td>
<td>4.3 (SD 4.3)</td>
</tr>
<tr>
<td>Hospital pain appts. in last 6/12 (M)</td>
<td>1.8 (SD 1.9)</td>
<td>2.8 (SD 2.2)</td>
<td>2.4 (SD 1.5)</td>
<td>2.0 (SD 2.2)</td>
<td>2.1 (SD 1.4)</td>
<td>3.1 (SD 4.2 )</td>
</tr>
<tr>
<td>Attended A&amp;E in last 6 months</td>
<td>Yes n=4 (13%)</td>
<td>Yes n=4 (20%)</td>
<td>Yes n=0 (0%)</td>
<td>Yes n=3 (9%)</td>
<td>Yes n=3 (14%)</td>
<td>Yes n=1 (6%)</td>
</tr>
<tr>
<td>No n=26 (87%)</td>
<td>No n=16 (80%)</td>
<td>No n=16 (100%)</td>
<td>No n=30 (91%)</td>
<td>No n=19 (86%)</td>
<td>No n=16 (94%)</td>
<td></td>
</tr>
</tbody>
</table>

**Table 10:** Characteristics of the Study Groups
Differences in characteristics between the Intervention and Control group for knowledge of a diagnosis, further education after school, being employed and visits to an accident and emergency department for pain related issues were explored using Chi square tests. These showed no significant differences between the Control and Intervention groups (See Table 11). It was therefore possible to make the assumption that there were no difference in characteristics between the Intervention and Control group at recruitment.

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Value</th>
<th>df</th>
<th>Significance (2-sided)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diagnosis</td>
<td>0.47</td>
<td>1</td>
<td>0.49</td>
</tr>
<tr>
<td>Further education</td>
<td>0.39</td>
<td>1</td>
<td>0.53</td>
</tr>
<tr>
<td>Employed</td>
<td>0.17</td>
<td>1</td>
<td>0.68</td>
</tr>
<tr>
<td>A &amp; E visits</td>
<td>0.29</td>
<td>1</td>
<td>0.59</td>
</tr>
</tbody>
</table>

**Table 11:** Pearson Chi Square tests for diagnosis, further education, employed, A & E visits (baseline data)

**Number of GP visits, Outpatient Appointments and Treatments**

The number of visits to GPs that participants self-reported during the previous six months were compared between the Control and Intervention groups at the start and end of the study. The Intervention group showed a greater reduction in the mean number of visits compared to the Control group. When Independent t-tests were applied no statistically significant difference was found between number of visits to GPs at the start and end of the study for either group. However, when paired t-tests were applied greater reductions in GP visits for the Intervention group were seen but marginally failed to reach a level of significance (see Table 12). The direction of this
change supports findings in previous studies (Lorig & Holman, 1989; Lorig et al., 1993).

<table>
<thead>
<tr>
<th>Group</th>
<th>GP visits Baseline</th>
<th>GP visits (10-14 months)</th>
<th>Std. deviation</th>
<th>T-value</th>
<th>Sig. (2-tailed)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Control</td>
<td>4.24</td>
<td>4.29</td>
<td>3.99</td>
<td>-0.06</td>
<td>0.95</td>
</tr>
<tr>
<td>Intervention</td>
<td>6.88</td>
<td>3.38</td>
<td>6.99</td>
<td>2.00</td>
<td>0.06</td>
</tr>
</tbody>
</table>

**Table 12: Paired Data showing Comparisons between Mean GP visits at baseline and at end of study**

The number of outpatient appointments (OPA) and interventional treatments requiring admission to the Day Surgery unit for the Control and Interventionsal Group were collected for the duration of the study using the hospital’s Patient Administration System (PAS). Differences between the two groups were tested by applying Independent t-tests and revealed no significant differences between the Intervention and Control group for number of outpatient appointments (t -0.55 p 0.58) and interventional treatments (t -0.44 p 0.66).

### 6.2 Stage of Change

Individual Stage of Change scores were analysed to explore if they predicted successful enrolment and completion of the intervention. Previous studies have associated high Action and low Precontemplation scores in individuals with increased probability of completing a Pain Management Programme (Biller et al., 2000). Some overlap of percentages will be noted as several
participants scored more than one scale on PSOCQ as their highest or lowest category.

Baseline scores for the Intervention group revealed that the majority of participants had high Contemplation scores (90%) while 7% had Precontemplation and 3% Maintenance as their highest score. No participant scored Action as their highest score at the start of the study. This compared with the Control group where all participants scored Contemplation as their highest score at the start of the study.

The two participants in the Intervention group who had high Precontemplation scores also had low Action scores, a possible predictor of failing to complete Pain Management Programmes (Biller et al., 2000). This was found to be an accurate predictor; one participant failed to attend EPP and the other dropped out after attending one session of EPP.

The participant in the Intervention group, who scored high on the Maintenance scale and low on the Precontemplation scale at the start of the study, might have been predicted to complete the intervention. However she declined to attend EPP because of transport difficulties and because she felt she could live with her pain. This may accurately reflect her Stages of Change score indicating she was already applying self-care skills in managing her persistent pain.

At the end of the study a higher number of participants in the Intervention group scored Maintenance as their highest score (14%) an increase of 11%,

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while no participant in the Intervention group scored Action as their highest score. No similar shift in PSOCQ scores was seen in the Control group’s data (See Graph 4 & 5). These changes are statistically analysed using t-tests and discussed later.

Graph 4: Baseline Stage of Change Highest score (%)
(IG = Intervention group, CG = Control group, PC=Precontemplation, C=Contemplation, A=Action, M=Maintenance)

Graph 5: End of Study Stage of Change Highest Score (%)
(IG = Intervention group, CG = Control group, PC=Precontemplation, C=Contemplation, A=Action, M=Maintenance)
Lowest PSOCQ scores were also explored. The majority (63%) of the Intervention group had the Action scale as their lowest score, with 37% Precontemplation and 17% Maintenance as the lowest score. In the Control group 76% scored Action as their lowest score, and 30% Precontemplation. Low Precontemplation scores are considered a possible predictor of completing a Pain Management Programme (Biller et al., 2000) but only 9% of participants with low Precontemplation attended all 6 sessions of EPP, while 16% of participants with Action as their lowest score attended all six session of the EPP (See Graph 6).

When lowest PSOCQ scores are examined at the end of the study there is some shift of scores in both groups (See Graph 7). Baseline scores for the Intervention group revealed 17% of participants had Maintenance as their lowest score but at the end of the study no participant scored this stage as their lowest score. A visible increase in the number of participants in both groups scoring Precontemplation as their lowest score is observed. In the Control group there is greater visual movement from Action to Precontemplation as the lowest score at the end of the study suggesting less resistance to taking on a self-management approach. Again the statistical significance of these changes are analysed by applying t-tests and discussed later.
Graph 6: Baseline Stage of Change Lowest Score (%)  
(IG = Intervention group, CG = Control group, PC=Precontemplation, C=Contemplation, A=Action, M=Maintenance)

Graph 7: End of study Stage of Change Lowest Score (%)  
(IG = Intervention group, CG = Control group, PC=Precontemplation, C=Contemplation, A=Action, M=Maintenance)

6.3 Reliability

Internal consistency for the questionnaires, Pain Stage of Change (PSOCQ), Chronic Pain Acceptance Questionnaire (CPAQ) and Brief Pain Inventory (BPI) were measured using Cronbach’s coefficient alpha and were shown to have good internal consistency. The PSOCQ Cronbach’s alpha ranged from 0.77 to
0.85, the CPAQ Cronbach’s alphas ranged from 0.73 to 0.85 and the BPI’s Cronbach’s alphas ranged from 0.91 to 0.93.

The means, standard deviations and Cronbach’s alphas for the PSOCQ and CPAQ baseline data compared well with published data (see Table 13). Mean Pain and Interference scores using the BPI were lower in this study compared with Tan et al. (2004). This difference may reflect the fact that although Tan et al. (2004) recruited participants with long term pains from a pain centre they consisted of mainly male referrals (91.8%) and were unemployed (74.2%).

<table>
<thead>
<tr>
<th>PSCOCQ scale</th>
<th>Total group (n=63)</th>
<th>Published data comparisons (Jensen et al., 2000)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean (SD)</td>
<td>Cronbach’s alpha</td>
</tr>
<tr>
<td>Precontemplation</td>
<td>3.26 (SD 0.78)</td>
<td>0.81</td>
</tr>
<tr>
<td>Contemplation</td>
<td>3.8 (SD 0.55)</td>
<td>0.79</td>
</tr>
<tr>
<td>Activity</td>
<td>3.01 (SD0.73)</td>
<td>0.77</td>
</tr>
<tr>
<td>Maintenance</td>
<td>3.22 (SD 0.77)</td>
<td>0.85</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>CPAQ</th>
<th>Total group (n=63)</th>
<th>Published data comparison (McCracken, Vowles et al., 2004)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean (SD)</td>
<td>Cronbach’s alpha</td>
</tr>
<tr>
<td>Activity engagement</td>
<td>36.21 (SD12.03)</td>
<td>0.85</td>
</tr>
<tr>
<td>Pain willingness</td>
<td>17.4 (SD 8.13)</td>
<td>0.73</td>
</tr>
<tr>
<td>Total</td>
<td>53.6 (SD 16.26)</td>
<td>0.83</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>BPI</th>
<th>Total group (n=63)</th>
<th>Published data comparison (Tan et al., 2004)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean (SD)</td>
<td>Cronbach’s alpha</td>
</tr>
<tr>
<td>Pain</td>
<td>5.58 (SD1.96)</td>
<td>0.91</td>
</tr>
<tr>
<td>Interference</td>
<td>5.94 (SD 2.02)</td>
<td>0.90</td>
</tr>
<tr>
<td>Total</td>
<td>11.53 (SD 3.62)</td>
<td>0.93</td>
</tr>
</tbody>
</table>

Table 13: Means and standard deviations means, and Cronbach’s alphas of the PSOCQ, CPAQ, BPI scores and total scores
6.4 Missing Data

Prior to analysing the data the issue of how to manage any missing data was discussed with the statistician. It was agreed to employ an ‘intention to treat’ approach which is a strategy that can be used for the analysis of randomised controlled trials and compares participants in the groups to which they were originally allocated (Hollis & Campbell, 1999). Hollis & Campbell (1999) suggest there are two reasons for using an intention to treat analysis.

1. Treatment groups are maintained that are similar except for random differences due to the process of randomisation. If the analysis was not carried out on the group produced by randomising then some features might be lost.

2. Non compliance and divergence from guidelines are taken into account.

Where participants missed out answering a question they were written to and requested to complete the questions omitted. When this failed to provide the missing data, the mean value for that question within the group was inserted for participants who had responded to at least half of the questions on a scale. This approach to dealing with missing data has previously been applied when analysing data from lay self-management groups (Barlow et al., 2000). A note of where averaged scores were inserted was kept to see if any particular patterns emerged and percentages of missing data per group and per questionnaire were calculated. The Intervention Group returned a greater number of questionnaires with missing scores 5.9% while the CPAQ had the highest number of missing data (1.9%) and the BPI the least (0.85) (See
Table 14 and 15). It was not possible to compare the proportion of missing data with other studies as either published studies had no missing data for these particular questionnaires because the data was collected in one to one interviews or the proportion was referred to only as small (Strand et al., 2006).

<table>
<thead>
<tr>
<th>Control</th>
<th>Control</th>
<th>Control</th>
<th>Intervention</th>
<th>Intervention</th>
<th>Intervention</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>% of data per group missing</td>
<td>1.6</td>
<td>0.7</td>
<td>1.1</td>
<td>1.7</td>
<td>2.6</td>
</tr>
<tr>
<td>Total</td>
<td>3.4%</td>
<td></td>
<td>5.9%</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Table 14: Percentage of missing data per randomised research group**

<table>
<thead>
<tr>
<th>Questionnaire</th>
<th>PSOCQ</th>
<th>CPAQ</th>
<th>BPI</th>
</tr>
</thead>
<tbody>
<tr>
<td>% of data per question missing</td>
<td>1.6</td>
<td>1.9</td>
<td>0.8</td>
</tr>
</tbody>
</table>

**Table 15: Percentage of missing data per questionnaire**

No particular pattern emerged with the missing data although it might have been expected that the Intervention Group would have been more motivated to complete the questionnaires fully as they were receiving the attention of an intervention. However, they may have experienced more questionnaire fatigue as those attending the Intervention, were routinely asked to complete a lengthy questionnaire at the end of the course to allow the PCT to evaluate EPPs and was unconnected with this study.
6.5 Validation

The quantitative data was independently checked for errors in formulas and copying by an expert in data management, who also checked 20% of the each groups’ data for correct initial entering.

6.6 Analysis

The main purpose of the study was to explore the properties of the PSOCQ in participants with persistent pain in the Intervention and Control groups taken at three measurement points (baseline, 3-6 and 10-14 months) during the course of the study. The analysis involved independent and paired t-tests and correlational tests using SPSS 13.0. Advice on analysis was given by the statistician at the University and the analysed data reviewed.

6.6.1 Independent t-tests

To help answer the principle research question, 'Does exposure to a self-management approach in the early stages of referral to a pain clinic, promote progress through the Stages of Change Scale and impact on Pain, Interference and Acceptance', independent t-tests were performed to determine if there were differences between the Control and Intervention groups.

Analysis of data was treated as 'intention to treat' and independent t-tests were performed on the baseline data between the Intervention and Control groups to determine the overall similarity of the two randomised groups with respect to readiness to self-manage pain, acceptance of pain and pain and
interference levels. Seven tests were performed, one for each of the scores from PSOCQ, and CPAQ, BPI (Pain and Interference). A key to the different groups and corresponding data collection time are given below.

**Key to Groups**

<table>
<thead>
<tr>
<th>Group</th>
<th>Data collected</th>
<th>Group</th>
<th>Data collected</th>
</tr>
</thead>
<tbody>
<tr>
<td>Control 1</td>
<td>Baseline</td>
<td>Intervention 1</td>
<td>Baseline</td>
</tr>
<tr>
<td>Control 2</td>
<td>3-6 months</td>
<td>Intervention 2</td>
<td>3-6 months</td>
</tr>
<tr>
<td>Control 3</td>
<td>10-14 months</td>
<td>Intervention 3</td>
<td>10-14 months</td>
</tr>
</tbody>
</table>

No significant differences were seen between the Intervention and Control groups’ baseline data and Table 16 presents the means, standard deviations and independent t-test results.

<table>
<thead>
<tr>
<th>Control 1 (n=33)</th>
<th>Intervention 1 (n=30)</th>
<th>Scale</th>
<th>Mean</th>
<th>Standard. deviation</th>
<th>t-value</th>
<th>df</th>
<th>Sig. (2-tailed)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Precontemplation</td>
<td></td>
<td></td>
<td>3.29</td>
<td>0.84</td>
<td>0.30</td>
<td>61</td>
<td>0.76</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>3.22</td>
<td>0.72</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Contemplation</td>
<td></td>
<td></td>
<td>3.92</td>
<td>0.49</td>
<td>1.85</td>
<td>61</td>
<td>0.07</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>3.67</td>
<td>0.60</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Action</td>
<td></td>
<td></td>
<td>2.97</td>
<td>0.74</td>
<td>-0.34</td>
<td>61</td>
<td>0.73</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>3.03</td>
<td>0.71</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Maintenance</td>
<td></td>
<td></td>
<td>3.38</td>
<td>0.70</td>
<td>1.76</td>
<td>61</td>
<td>0.08</td>
</tr>
<tr>
<td></td>
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<tr>
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<td>6.17</td>
<td>2.11</td>
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</table>

**Table 16:** Means, Std and Independent t-tests for the PSOCQ, CPAQ and BPI between the Control and Intervention Groups (Baseline)

Independent t-tests were then performed on the Control and Intervention groups at 3-6 months and significant differences were seen for Pain ($p < 0.05$)
and Interference ($p < 0.04$) levels between the groups with the Control group having lower scores for both scales (see Table 17).

<table>
<thead>
<tr>
<th>Scale</th>
<th>Control 2 (n=22)</th>
<th>Intervention 2 (n=20)</th>
</tr>
</thead>
<tbody>
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<td>Std. deviation</td>
</tr>
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</tr>
<tr>
<td></td>
<td>3.11</td>
<td>0.64</td>
</tr>
<tr>
<td>Contemplation</td>
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<td>0.49</td>
</tr>
<tr>
<td></td>
<td>3.65</td>
<td>0.58</td>
</tr>
<tr>
<td>Action</td>
<td>3.24</td>
<td>0.76</td>
</tr>
<tr>
<td></td>
<td>3.13</td>
<td>0.93</td>
</tr>
<tr>
<td>Maintenance</td>
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<td>0.64</td>
</tr>
<tr>
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</tr>
<tr>
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<td>1.81</td>
</tr>
<tr>
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<tr>
<td></td>
<td>6.30</td>
<td>1.86</td>
</tr>
<tr>
<td>Interference</td>
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<td>2.47</td>
</tr>
<tr>
<td></td>
<td>6.28</td>
<td>2.05</td>
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</table>

Table 17: Means, Std and Independent t-tests for the PSOCQ, CPAQ and BPI between the Control and Intervention Groups (3-6 months) (red=significant scores)

At the final 10-14 month data collection point the differences had changed and only one significant difference in Contemplation scores ($p < 0.03$) was seen (Table 18). A significant reduction in Contemplation scores for the Intervention group, indicated progress through the Stages of Change Scales. Both the Intervention and Control groups showed trends for lower Precontemplation, higher Action and Maintenance scores. This shows progress through the Stages of Change occurred in both groups but the differences between the groups were not significant. The differences between Pain and Interference scores seen in data at 3-6 months were not maintained at end of the study (See Table 18).
<table>
<thead>
<tr>
<th></th>
<th>Scale</th>
<th>Mean</th>
<th>Standard deviation</th>
<th>t-value</th>
<th>df</th>
<th>Sig. (2-tailed)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Control 3 (n=17)</td>
<td>Precontemplation</td>
<td>2.91</td>
<td>0.64</td>
<td>0.14</td>
<td>31</td>
<td>0.89</td>
</tr>
<tr>
<td></td>
<td>Contemplation</td>
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<td>0.59</td>
<td>2.31</td>
<td>31</td>
<td>0.03</td>
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<tr>
<td></td>
<td>Action</td>
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<td>0.64</td>
<td>-0.56</td>
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<td>0.58</td>
</tr>
<tr>
<td></td>
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<td>0.50</td>
<td>-0.86</td>
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<td>0.40</td>
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<td></td>
<td>CPAQ</td>
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<td>1.89</td>
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<td>0.95</td>
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<tr>
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<td>Pain</td>
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<td>1.68</td>
<td>-0.22</td>
<td>31</td>
<td>0.83</td>
</tr>
<tr>
<td></td>
<td>Interference</td>
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<td>2.11</td>
<td>0.24</td>
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<td>0.81</td>
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<td>Interference</td>
<td>5.22</td>
<td>2.33</td>
<td>0.24</td>
<td>31</td>
<td>0.81</td>
</tr>
</tbody>
</table>

Table 18: Means, std. and Independent t-tests for the PSOCQ, CPAQ and BPI between the Control and Intervention Groups (10-14 months). (red= significant scores)

Differences were then explored within the Groups using independent t-tests. No significant differences were seen in the Control group’s within group data (see Table 19). However, independent t-tests revealed there were changes in the Intervention group’s data. Significant changes were seen in the Maintenance scale at 10-14 months ($p<0.01$) and trends towards changes in Pain ($p<0.07$) and Action ($p<0.06$) just failed to reach levels of significance (see Table 20).
<table>
<thead>
<tr>
<th>Groups</th>
<th>Scale</th>
<th>Mean</th>
<th>Standard deviation</th>
<th>t-value</th>
<th>df</th>
<th>Sig. (2-tailed)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Control 1 (n=33)</td>
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<td>0.70</td>
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<td>0.76</td>
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<td>1.74</td>
<td>0.32</td>
<td>53</td>
<td>0.75</td>
</tr>
<tr>
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<td>2.27</td>
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<td></td>
</tr>
<tr>
<td></td>
<td>Interference</td>
<td>5.74</td>
<td>1.95</td>
<td>-1.64</td>
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</tr>
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<td>2.47</td>
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<td>1.34</td>
<td>-0.89</td>
<td>48</td>
<td>0.38</td>
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<td>1.89</td>
<td></td>
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<td></td>
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<tr>
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<td>1.74</td>
<td>0.57</td>
<td>48</td>
<td>0.57</td>
</tr>
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<td>1.68</td>
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<td></td>
<td></td>
</tr>
<tr>
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<td>Interference</td>
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<td>1.95</td>
<td>0.78</td>
<td>48</td>
<td>0.44</td>
</tr>
<tr>
<td></td>
<td>Interference</td>
<td>5.28</td>
<td>2.11</td>
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</tr>
</tbody>
</table>

Table 19:  Means, standard deviations and Independent t-tests for PSOCQ, CPAQ and BPI for the Control Groups
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<th>Groups</th>
<th>Scale</th>
<th>Mean</th>
<th>Standard Deviation</th>
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<th>df</th>
<th>Sig. (2-tailed)</th>
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<td>0.48</td>
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<td>2.01</td>
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<td></td>
<td>Interference</td>
<td>6.17</td>
<td>2.11</td>
<td>-0.19</td>
<td>48</td>
<td>0.85</td>
</tr>
<tr>
<td>Intervention 2 (n=20)</td>
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<td>1.88</td>
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<td>2.05</td>
<td>1.63</td>
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<td>0.11</td>
</tr>
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<td>1.56</td>
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<tr>
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<td>0.60</td>
<td>1.68</td>
<td>44</td>
<td>0.10</td>
</tr>
<tr>
<td></td>
<td>Action</td>
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<td>0.71</td>
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<td>0.06</td>
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<td></td>
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<td>1.56</td>
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</tr>
<tr>
<td></td>
<td>Interference</td>
<td>6.17</td>
<td>2.11</td>
<td>1.59</td>
<td>44</td>
<td>0.11</td>
</tr>
</tbody>
</table>

Table 20: Means, std and Independent t-tests for the PSOCQ, CPAQ and BPI, within the Intervention Group (red= significant scores, blue=nearing significance)
6.7 Summary

Independent t-tests showed the Intervention group had marginally lower Precontemplation, Contemplation, Maintenance and Acceptance scores and slightly higher Action, Pain and Interference scores at the start of the study compared with the Control group. However, none of these differences were statistically significant. Therefore no significant differences were seen between the Intervention and Control groups’ baseline data.

At 3-6 months, differences began to emerge between the groups with Pain and Interference scores reaching levels of significance (p 0.05 and P0.04 respectively) (see Table 17). This showed greater reductions in Pain and Interference scores in the Control group. However, these differences were not maintained at 10-14 months. Scores for both the Intervention and Control group display a trend towards progress through the Stages of Change scales, with increased Acceptance and reductions in Pain and Interference levels. These differences only reach significance in the Contemplation scale (p 0.03) suggesting greater progress through the Stages of Change for the Intervention group (Table 18).

Within group Independent t-tests analysis revealed no significant differences in the Control Group during the course of the study. However, the Intervention group’s data showed significant increases in the Maintenance scale (p0.01) at the end of the study with trends towards increases in Action (p0.06) and reductions in Pain at 3-6 months (p0.07) nearing significance (see Table 20). This demonstrates greater progress is made through the
Stages of Change scales in the Intervention group that is not seen in the Control group.

6.7.1 Paired t-Tests
In order to explore the quantitative data further for differences between the Control and Intervention group, the data was paired. All data that could not be paired at each stage of the study (baseline, 3-6 and 10-14 months) was excluded. This reduced the number of completed questionnaires that could be entered into the analysis but provided further opportunities for interpreting the data.

Within the paired Control Group data no significant differences in the PSOCQ, CPAQ or BPI were seen except for an increase in Maintenance (p<0.05) at 3-6 months. This difference was not sustained in data collected at the end of the study. This score was discussed with the statistician and considered due to slightly different pairing because of number of questionnaires returned and probably of no importance. It was a difference that only just reached significance and equally could have been due to chance (type one error) (See Table 21).

Paired t-test analysis of the Intervention groups’ data revealed further evidence of progress through the Stage of Change between data collected at the start of the study and at 10-14 months. These differences reached significant levels in the Precontemplation Scale (p<0.04), Contemplation scale (p<0.05) and Maintenance Scale (p<0.02). There was also a trend towards an
increase in Action scores at 10-14 months but failed to reach significance ($p<0.36$). These findings suggest participants in the Intervention group may have been expressing greater readiness to adopt a self-management approach to managing their persistent pain symptoms (See Table 22).

Significant reductions were also seen in Pain ($p<0.01$) and Interference ($p<0.00$) between baseline and the final data collection point (10-14 months) for the paired data from the Intervention group. In addition higher CPAQ scores suggest an increase in Acceptance of pain, but this score fails to reach significance ($p<0.19$) (See Table 22).
## Table 21: Means, standard deviations and Paired t-tests for the PSOCQ, CPAQ and BPI within the Control Group (red = significant)

<table>
<thead>
<tr>
<th>Scale</th>
<th>Mean</th>
<th>Std. deviation</th>
<th>t-value</th>
<th>df</th>
<th>Sig. (2-tailed)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Control 1 (n=22)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
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<td>Precontemplation</td>
<td>3.13</td>
<td>0.83</td>
<td>0.85</td>
<td>21</td>
<td>0.41</td>
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<td>Contemplation</td>
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Table 22: Means, standard deviations and *Paired t*-tests for the PSOCQ, CPAQ and BPI within the Intervention Group (red = significant)
6.8 Summary

Significant differences occurred between data collected at the start of the study and at 10-14 months in the paired data collected from the Intervention group. These changes were not identified in data collected from the paired Control Group. Although the sample numbers are small reducing the strength of interpretation, the shift in the Intervention groups data for Stages of Change towards a readiness to take on a self-management approach and reductions in Pain and Interference were significant and only occur in the Intervention group as measured by PSOCQ, and BPI.

6.8.1 Correlations

Correlations were conducted with the aim of providing further answers to the research question as to whether early exposure to a self-management approach promotes progress through the Stages of Change Scale and impacts on Pain, Interference and Acceptance scales. Correlational relationships between the variables were examined in the within group data at baseline and at the end of the study by applying Pearson’s product moment correlations. These procedures were computed applying the Statistical Package for Social Sciences (SPSS) version 13 and involved intention to treat data for the Intervention group (see Appendix 12.7).

The only consistent correlation for PSOCQ scales seen across both groups at the start and end of the study were changes in Action scores significantly and positively associated with the Maintenance scale. In the Intervention group the strength of the relationship at the start of the study ($r=0.86 \ p0.00$)
varies little to the strength of the relationship at the end of the study ($r=0.77\ p0.00$). A similar pattern is seen in the Control group ($r=0.82\ p0.00$, and $r=0.81\ p0.00$). This association has previously been noted and considered to be due to the PSOCQ lacking the capacity to distinguish between the dimensions of Action and Maintenance (Carr et al., 2006; Strand et al., 2006).

In the Intervention groups data other significant relationships for components of the PSOCQ seen at the beginning of the study were between Action and Acceptance ($r=0.65\ p\ 0.00$) and Maintenance and Acceptance ($r=0.57\ p\ 0.00$). However, these diminish in strength and significance by the end of the study ($r=0.77\ p\ 0.78$ and $r=0.31\ p\ 0.24$ respectively). The positive relationship between Acceptance and Action and Maintenance Stages of Change are seen in Carr et al. (2006) study. However no similar relationships were seen in the Control groups' baseline or end of study data. Neither is there a consistently negative relationship between Acceptance and Precontemplation and Contemplation in either the Control or Intervention groups' baseline data as found in Carr et al. (2006), though this pattern is found in the end of study data$^3$.

The significance of the relationships between Action, Maintenance and Acceptance in the Intervention group is unclear while the direction of the relationship could have been expected to increase. In other words, as the individual develops greater readiness to self-manage pain so their Acceptance

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$^3$ See Appendices section 12.7 Tables, 28 & 29
of their pain might be expected to increase as they are more likely to be getting on with life despite their pain. Although significant relationships were not found, the direction of the relationships between Acceptance, Precontemplation, Contemplation Action and Maintenance at the end of the study supported findings in Carr et al (2006).

Correlations between CPAQ (Acceptance) and the variables Pain and Interference were explored in the baseline and end of study scores. In the baseline data for both groups, Acceptance significantly correlated with Interference. This relationship strengthened in the Control group \( r = -0.80 \ p < 0.00 \), but surprisingly lessened in significance the Intervention group \( r = -0.56 \ p = 0.02 \). This suggests higher levels of Acceptance were associated with lower levels of Interference, an association reported in the literature (McCracken, 1998). The strength of the relationship between Acceptance and Pain increases significantly at the end of the study in the Control group \( r = 0.63 \ p < 0.01 \). However, this strengthening relationship is not observed in the Intervention group and the strength of the relationship in fact diminishes \( r = 0.36 \ p = 0.17 \) (See Table 23).

Scatter graph were constructed to give visual understanding of these differences (see Graph 8 & 9).
### Table 23: Correlations between Acceptance, Pain and Interference

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<tr>
<th></th>
<th>Pain</th>
<th>Interference</th>
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<td><strong>Intervention group - baseline</strong></td>
<td></td>
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</tr>
<tr>
<td>Acceptance (CPAQ)</td>
<td>r = -0.41 p 0.03*</td>
<td>r = -0.49 p 0.01**</td>
</tr>
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<td><strong>Intervention group – end of study (10-14 months)</strong></td>
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<tr>
<td>Acceptance</td>
<td>r = -0.36 p 0.17</td>
<td>r = -0.56 p 0.02*</td>
</tr>
<tr>
<td><strong>Control group - baseline</strong></td>
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<tr>
<td>Acceptance</td>
<td>r = -0.32 p 0.07</td>
<td>r = -0.50 p 0.00**</td>
</tr>
<tr>
<td><strong>Control group – end of study (10-14 months)</strong></td>
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</tr>
<tr>
<td>Acceptance</td>
<td>r = -0.63 p 0.01**</td>
<td>R = -0.80 p 0.00**</td>
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</table>

** Correlation is significant at the 0.01 level (2-tailed)
* Correlation is significant at the 0.01 level (2-tailed)
Graph 8: Scatter graphs showing relationship between CPAQ (Acceptance) and Interference (red line = significant relationship $p<0.01$)
Graph 9: Scatter graphs showing relationship between CPAQ (Acceptance) and Pain (red line = significant relationship $p$ 0.01)
A further association seen in the Control group’s data was a positive association between Precontemplation and Pain (r=0.59 p<0.00) that increased in strength at the end of the study (r=0.67 p<0.00). In the Intervention group there is no significant association between Precontemplation and Pain at the start of the study (r=0.11 p=0.55), though there is some increase in strength and level of significance at the end of the study (r=0.50 p<0.05). This suggests higher Precontemplation is associated with higher levels of Pain levels.

Finally a significant association between Pain and Interference is seen in both the Control (r=0.63 p<0.00) and Intervention group (r=0.74 p<0.00) and continues to be observed in data at the end of the study (r=0.76 p<0.00 and r=0.86 p=0.00 respectively). This association could be expected as the higher the pain level the more it interferes in an individual’s life.

6.9 Summary

Applying Pearson’s product moment correlations failed to provide further insight into relationships involved in promotion through the Stages of Change Process. However, some interesting differences in strengths of relationships between Acceptance and Pain and Acceptance and Interference were seen in the two groups.

Significant and negative associations were seen between Acceptance and Interference and between Acceptance and Pain in the Control group’s data. These finding were expected as higher Acceptance scores have previously
been associated with lower pain and improved levels of functioning (McCracken, 1998; McCracken & Eccleston, 2003). However, the same strength of association was not seen in the Intervention group's data. While an association between Acceptance and Interference was seen in the Intervention group's data its strength did not increase at the end of the study. Associations observed between Acceptance and Pain in the Intervention’s group baseline data diminished in strength at the end of the end of the study. These associations and their inferences are examined in the context of the overall data in the Discussion Chapter and suggest some differences in strength of relationships between the variables had occurred in the two groups.

6.10 Analysis of Focus Groups

Five focus groups held over a twelve month period consisted of two groups made up of participants from the Control group and three from participants in the Intervention group. Only participants who had attended the Intervention, the Expert Patient Programme (EPP) were invited to the focus groups and a total of 22 participants attended the focus groups (Control group n=12, Intervention group n=10).

Each focus group lasted 1 hour and the clinical psychologist from the pain management service facilitated the groups while the researcher took field notes. Each focus group was recorded with the consent of participants and transcribed by the researcher and this began the process of data familiarisation. During the process of transcribing, issues, concepts, themes
and comparisons began to emerge and were expanded as transcripts were re-read and re-listened to, leading to the development of a thematic framework with seven initial major headings and forty-five subheadings (see Appendix 12.8).

During the subsequent process of indexing and charting of the data these headings were discussed at regular intervals with the focus group facilitator and a number of refinements made. Some categories were developed while others collapsed and four further thematic frameworks developed and discussed before a final revised thematic framework (version 5) agreed. This had seven major headings and thirty subheadings and was considered to most accurately reflect issues, concepts and themes identified in the transcripts (See Box 2).
1. **Pain**
   1.1. Physical
   1.2. Self efficacy (how certain are that you can, coping, responsibility)
   1.3. Acceptance
   1.4. Resentment/anger
   1.5. Misrepresenting pain/feelings
   1.6. Feeling a fraud
   1.7. Feeling a burden
   1.8. Mood
   1.9. Responsibility
   1.10. Fear
   1.11. Perceptions of self

2. **Passive self-management strategies**
   2.1. Passive behavioural
   2.2. Conventional medical
   2.3. Views/current feelings about using passive management

3. **Active self-management strategies**
   3.1. Active behavioural
   3.2. Cognitive
   3.3. Views/current feelings about using active management
   3.4. Contradictions with self-management
   3.5. Conditional management

4. **Medical**
   4.1. Expectations
   4.2. Diagnosis
   4.3. Treatment
   4.4. Confidence in care

5. **Changes to life**
   5.1. Impact on family/friends
   5.2. Impact on work
   5.3. Impact on activity

6. **Effect of attending EPP**
   6.1. Changes to behaviour
   6.2. Views/feelings about EPP

7. **Other Key issues not covered**
   7.1. Views about NHS systems
   7.2. Other issues

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**Box 2: Indexing of Categories (version 5)**

6.10.1 **Charting and Validation**

Having developed the thematic framework, the process of indexing the data in its textual form was undertaken by the researcher. Following this data needed to be 'lifted' from its original context and arranged in keeping with its
appropriate thematic location (Ritchie & Spencer, 1994). The initial charting was then validated involving the facilitator and a Consultant nurse with experience in the management of persistent pain. This involved further re-reading, deliberation and adjustments to the location of the data, and while a lengthy process, it was valuable time for debating and corroborating judgements and developing meaning. During this process a consistent theme emerged indicating data from the focus groups may converge on aspects related to the Sick Role. This involved issues related to entering, maintaining and relinquishing the Sick Role.

During the validation process the seven major headings were replaced with three new main headings while the sub-categories were maintained but redistributed. This refinement to the categories was discussed and supported by the two validators and considered to reflect more clearly the content of the focus group data. The three new main headings were:

1. **Preparing to enter the Sick Role** – this consisted of sensations or feelings that were believed to be associated with symptoms of illness. Pain has been shown to be by far the most important sign of illness compared with other signs (Suchman, 1965; Twaddle, 1969). Gaining a medical diagnosis is seen as proof of suffering (Glenton, 2003) and legitimises the Sick Role provided the individual reciprocates in the relationship with the doctor (Parsons, 1951).

2. **Maintaining the Sick Role** – these are actions taken by those already nominated as being sick either by themselves or others and will usually 
involve the 'utilisation of health services' and a range of dependent
behaviours (Kasl et al., 1966b).

3. **Relinquishing the Sick Role (Health behaviour)** – this may
proceed without too much difficulty in acute illnesses, but can be more
complex for chronic illness (Kasl, Cobb, & Arbor, 1966a; Suchman,
1965).

A revised table was constructed to visualise the Indexing patterns (see Table
24) and a new chart subsequently developed. The revised chart gave a fresh
picture of the data and the analysis of the qualitative data now focused on
associations from within the data with the Sick Role, to give understanding
and help explain changes seen in the quantitative data.

**6.10.2 Explanations sought internally**

Analysis of data from the focus groups is now considered using the three
main headings to guide discussion:


Table 24: Index following collapse of original categories into three headings associated with the Sick Role

6.10.2.1 Preparing to enter the Sick Role

The volume of data assigned to this category was relatively small reflecting the fact that participants involved in the study had all experienced pain for a minimum of 12 months and most for considerably longer. Therefore data
relating to preparing to enter the Sick Role was considered to be retrospective.

At the beginning of each focus group participants were invited to introduce themselves and if they wished say a few words about themselves. This usually led to participants describing their physical pain symptoms; how an individual perceives their physical symptoms can influence their readiness to seek medical assistance and treatment (Campbell & Roland, 1996; Kasl et al., 1966a; Zola, 1973). All participants made reference to the physical symptoms of pain, with several participants describing sudden and obvious onset for their pain following accidents, described here by two of the participants:

'had an accident ... damaged all the nerves and tendons and it's constantly in pain'
[leg] (Intervention group 7/6 p30).

'I had a very bad fall in January this year, which is where I'm am getting my pain from'
(Control group 11/10 p1).

Participants with an obvious injury or clear cause for their pain appeared to find it a simpler process to explain their pain than if the pain was vague in onset and this led some participants to struggle to clarify their pain and its cause. These participants’ descriptions of pain appeared more vivid conjuring up some quite worrying images of the physical consequences of their pain. This is seen in the following description from a participant in the Intervention group:

'I've been told it is something to do with some of the discs probably touching or crumbling or something' (p.14) 'I'm clunking a bit the joints aren't staying
together properly and I'm told there's nothing there can be done’
(Intervention group 13/12 p.19).

Although not specifically measured in this study it would be understandable if this participant’s beliefs for the causes of her pain impacted on her level of activity. There may be understandable fears associated with avoiding certain behaviours such as activity, fearing this may do further damage.

The vaguer the cause for the pain the harder the individual seemed to work to gain the approval of fellow members in the focus group. This was viewed by the researcher observing the focus groups as a process of lay-legitimisation. The following participant clearly struggled to explain the cause of her pain and when her questionnaire data was examined it revealed she did not consider she had a diagnosis:

'Went to the doctors and got progressively worse and then they sent me into hospital and I was really ill for a couple of weeks having morphine and morphine patches and everything and then I had a bad reaction to this and tried me on other pain killers but since then it's travelled all over my body it's in my shoulder my pelvis my legs I can walk but very little have a job to dress myself get my clothes on I've had every test done under the sun bone scan ummm I have got osteoporosis in my back but that doesn't worry it isn't actually in my back it's it's like my arms my shoulders knees it's everywhere' (Control group 11/10 p.2).

Some of the participants used medical diagnostic language to help explain their pain and examples are seen in the following descriptions:

'I'm in constant pain I've got osteoarthritis everywhere' (Intervention group 7/6 p.2).
‘I’ve had back pain for about three years ... because I’ve got degeneration of my spine’ (Control group 11/10 p.8).

The achievement of a diagnosis can be important to explain causes, justify behaviours and reduce anxiety (Glenton, 2003; Herz, 2007), but it can also give more than this as it may suggest what further actions are appropriate while legitimising entering the Sick Role (Glenton, 2003). Struggling for medical recognition of symptoms was evident in the following participants talk:

‘I know a normal doctor should be able to tell you why it is (p.3) .... But they [doctors] never said what it was’ (Intervention group 7/6 p 13).

‘I think we would like to know why we have pain ... what is it that is actually causing it’ (Control group 11/9 p.10).

Questionnaire data had revealed 27% of participants did not consider they had a diagnosis when they entered the study. This compares with Suchman’s (1965) study where 20% of respondents had no knowledge of their doctor ever making a diagnosis. The failure to acquire a diagnosis was clearly a cause of concern and uncertainty:

‘one doctor says one thing and another says no that’s totally wrong and then you go to another doctor who says what the other two said is wrong and you think.. that’s when I give up ... sometimes I feel I don’t get the help I should and need medically although I am under the hospital ..........whether they sort of see so many you know’ [patients with pain] (Control group 17/5 p12).

It has been suggested that without a diagnosis or recognised condition it may not matter how much an individual shows they are suffering, there is often
no clear pathway of care to follow (Dumit, 2006; Glenton, 2003). This can leave participants in what they appeared to describe as being in diagnostic limbo:

'I've seen several doctors who have waved away the fact that it's you know a trapped nerve ... that they don't know what it is either ... well I haven't found any help at all from the local doctors' (Intervention group 7/6 p.12).

Uncertainty associated with failure to acquire a clear diagnosis appeared to link with individuals struggle to be taken seriously by the medical profession and perhaps a fear that the reality of their pain would be questioned.

Individuals with persistent pain are often anxious they will be accused of being a malingerer, hypochondriac or even mentally ill (Glenton, 2003). The following participant describes her fear of being considered a hypochondriac and was helped to manage these fears by her GP who helped her look at the reality of her symptoms and reduce her uncertainty about her condition:

'so when I get a fit of the blues and said I'm a hypochondriac he [doctor] said now look you've had this and this' (Control group 17/5 p.12).

Once the decision to seek diagnosis and treatment has been taken it is more often than not followed by the adoption of the Sick Role (Kasl et al., 1966a), and this can bring its own difficulties (Suchman, 1965). Here one participant describes the difficulty she has with her family's solicitous response to her condition as she struggles to resist some of the behaviours expected of her on entering the Sick Role:

'it was getting to the point when my eldest daughter asked me if I would like a wheelchair which quite horrified me but also they started taking over ...... started
taking over and doing decision making it was like it was like going into early senile dementia’ (Intervention group 13/12 p.11).

This participant’s experience highlights the difficulty of getting the balance right so that some relinquishing of responsibilities is allowed and supported by family and friends but the individual does not lose all independence and retains the ability to relinquish the Sick Role at some point.

6.10.2.2 Maintaining the Sick Role

Entering the Sick Role will usually involve entering into a relationship with health care professionals (Kasl et al., 1966b). Once in this role the individual is expected to get well and is under an obligation to seek professional help and cooperate in the treatment their doctor prescribes (Kasl et al., 1966a; Kassebaum & Baumann, 1965). The individual is expected to faithfully accept the implications of being the doctor’s patient and to ‘do his part’ (Parsons, 1951), and this adherence to medical advice is associated with a successful outcome (Stiggelbout & Kiebert, 1997). Several focus group discussions involved aspects associated with being in the Sick Role. This included expectations to comply with and adhere to medical regimes, and described in the following examples:

'I've got a dodgy back which I was probably initially referred to the pain doctor and they've put me on some tablets...in addition he's putting me some injections in the back or something in due course’ (Intervention group 7/6 p.1).

'I'm just put on the waiting list to have some injections into my back I don't know how long I've been waiting six months now so I would imagine it will be in the next three or four months’ (Intervention group 13/12 p.14).
Even when patient had concerns about a treatment some participants were reluctant to challenge or question their care:

'I find too that the medication is a little bit dodgy was on Vioxx like you umm and then Diclofenac and then they have taken me off that cos' it's effecting my kidneys they have given me stronger Cocodamol but they make me feel a bit sick ... it's dodgy isn't it...side effects...well we just have to get on with it' (Control group 11/10 p.9).

Even the more assertive participants described an unwillingness to directly confront their doctor preferring to initially go along with the advice even if they felt they knew better as described here:

'you go to an appointment that a certain medication or treatment is not going to be any good but because they [doctors] won't take your word you have to go through the damm process of taking medications or waiting three to six months to be able to turn round and say I told you so' (Intervention group 13/12 p.2).

The same approach to passive cooperation with medication advice is also seen with invasive interventions:

'I've now had 2 separate lots of injections in my back and it hasn't really improved a lot and the doctors don't seem to think that there isn't much they can do' (Control group 11/10 p.1).

'I had injections with the doctor but it didn't last too long you see and 3 months the pain was back' (Control group 17/6 p.11).

'The operation that time ... yes absolutely fantastic 98% and it's come back and they're [the doctors] not quite sure what they're going to do' (Control group7/6 p.6).

When a treatment fails to provide the long term outcomes expected it can reinforce passivity in some individuals (Frazier, 1992). However, continuing
to search for a medical solution to the individual’s persistent pain is not just
the domain of the patient. This participant describes here how their doctor
seeks to resolve his pain with a medical solution:

'he's [doctor] going to stick a needle in and put electric current in to it' (p.4)...
'the doctors been brilliant and he's going always thinking of something different ...but
he's going to try this one but we're going to do it at the other hospital instead of here'
(Intervention group 7/6 p.9).

For another participant there was a clear expectation that treatment would
resolve his symptoms and he talked of wanting a guarantee in much the
same way one would when a mechanic fixes a problem on a car. In this
participants case the procedure had made the situation worse and while he
was prepared to get on with life where his pain symptoms were due to
degenerative conditions, he was not prepared to give up seeking satisfaction
with the outcome of his surgical treatment:

'had an operation and its been troubling me ever since worse then it ever was( P2)
what's the score is there a guarantee on this they said [doctor] well what do you
mean so he [GP] said you go back to the man who did it (p13)...... have to live with
that and I live with the other one which was a washed out knee what I won't accept is
the surgical one (pain) ... I shall seek that till the end' (Intervention group 7/6 p15).

Dependency on a medical solution may not be appropriate for all individuals
with chronic conditions (Arluke, 1988; Kassebaum & Baumann, 1965), but
nevertheless, most participants described their hope and expectations that
the medical model would provide some form of help. Although all participants
had had their pain for more than twelve months and many had been seen by
several doctors, their perception of their pain being long term was not always
clear. This was highlighted when discussions were associated with what they 
expected from the pain clinic, some participants hoped it would offer 
solutions to fix their pain:

'I'm here because maybe there is something else you can all recommend that you 
know will help to alleviate so that I can function normally walk normally’ (Control 
group 11/10 p.13).

'anything that can get me back working so getting rid the pain is important’ 
(Intervention group 29/11 p.8).

One participant described her feelings of abandonment, viewing her referral 
to the pain clinic somewhat negatively as a last resort as no other avenue of 
healthcare seemed available:

'I felt I was abandoned and so that was the last resort send me to a pain clinic and 
they will tell you how to control the pain’ (Control group 11/10 p12).

Individuals commonly look to the medical model for a cure (Moore 2004a) 
and Western cultures tend to believe doctors in particular are responsible for 
their health (Denmark, 2004). When it fails to deliver this may result in 
conflict and confusion (Frazier, 1992; Rankin, 2001) and adoption of the Sick 
Role in chronic illness can be ‘marked by dissensus and conflict’ (Arluke 
1988:174). This was apparent in some of the discussion with considerable 
dissatisfaction and criticism voiced concerning aspects of their health care 
within the NHS:

'If everybody (in the NHS) got their act together and not passing it off .. oh well it's 
pain.. it’s pain oh well never mind you know' (Control group 17/5 p.13).
'I don’t like saying this but I find the doctors in my area pretty hopeless' (Intervention group 29/11 p.10).

For some participants feelings of conflict appeared entangled with beliefs of being an unpopular patient:

‘rather a senior doctor there annoyed was when he looked through the records he said you’ve had 3 scans ... obviously he assumed I had 3 free scans and I said well I paid for one ... that shut him up.. I could sense he was glaring at me’ (Intervention group 7/6 p.11).

‘it’s a bit like you’re too much trouble and you feel as if you should be sorry I shouldn’t really be here’ (Control group 17/5 p.13).

There is some evidence to suggests doctors can tend to associate chronic illness with difficult and complaining patients (Davis et al., 2001; Ford, Liske, & Ort, 1961; Griffiths, 2004; Ort, Ford, Liske, & Pattishall, 1965). However, medical students report enjoying and learning from their relationship with chronically ill patients, especially when involved in direct patient care (Davis et al., 2001). It is not clear when or why the view some doctors have of patients with chronic illness should change with time but adding to participants difficulties were indications that they felt they had symptoms that were not of any particular interest to the doctor. This participant described how she equated receiving help conditional on her having a symptom of interest to the doctor:

‘as regards any sort of help from you know doctors things like that... they seemed you know not very interested’ (Intervention group 7/6 p.10).
Another participant described how she became concerned that all avenues of care may not have been offered to her because her pain was seen as chronic. She appears to question whether her symptoms may too easily have been dismissed as mechanical pain. These doubts were confirmed for her by the suggestions of another doctor that she required further medical investigations:

'my GP I found very good because I went to her a few years ago and she referred me to a rheumatologist ... but he said I had mechanical back problem.. so although the pain had been getting worse I kept thinking well it's a mechanical back problem umm and then but the pain [ can't make out word] from my back and into my hips as well .. and in the end it's one of the doctors I work with who .. I was limping cos when I first start walking that I've been sitting for a while that can be very painful and she noticed it on a few occasions and she said isn't your back pain any better you know take paracetamol which I did which didn't help umm and that's how I sort of got picked up and she had me x-rayed and that's when I was referred onto the surgeons and spoke to my GP '(Control group 17/5p13).

Participants described hiding their true feelings in order to protect the doctor from feeling disheartened. This may associate with a fear that the doctor could loose interest in them as patients. There was a sense in discussions of having to please the doctor in order to receive his/her attention and be listened to and cared for. To achieve this, some participants described misrepresenting their true feelings, and two participants concur about the difficulties of being honest with their doctor:

'hold a lot of it back don't we so that I think the same is when you go to the Dr you don't want to depress them you want to go in [to the doctors] and be bright and you don't want to have to be miserable about it ' (Control group 17/5 p15).
One participant described overt disinterest from her doctor and rather than question his behaviour she felt rejected and passively withdrew from the room:

'I presume he was a doctor he was sitting wrestling with a computer he didn't even look up ... he was gripping the sides of this machine... and in the end after 15 minutes when he didn't say a word to me I said well I suppose I'd better go' (Intervention group 7/6 p.11).

Not being able to connect with the doctor was often sited as a reason for dissatisfaction with medical care, perhaps aggravated by healthcare systems that do not promote the patient being seen by the same doctor on consecutive occasions.

'I find it quite disconcerting when I go somewhere here (England) and ask if you can see the Dr you have seen last time and they turn around and then they well we've been looking up on the screen.. I know I don't get a rapport with everybody'.(Control 17/5 p12).

The relationship between patients and doctors is full of complexities (Young, 2004). The doctor is often seen as the role definer for the 'sick' person (Twaddle, 1969), and how the individual's relationship with their doctor develops, may impact on an individual's experience of their illness and sickness and have some bearing on the level of social meaning it achieves (Glenton, 2003). This may have some association with what has been
described as the struggle to behave as a credible patient (Werner & Malterud, 2003).

When participants felt their doctor listened and gave them time, the relationship with their doctor was described in very positive terms with listening appearing to be one of the most valued skills:

'they [doctors] divide into listening and none listening, there are some who are practically reaching for the prescription pad as you walk through the door instead of listening I needed somebody [GP] who listened .... up and till this stage I had really hadn't had' (Intervention group 13/12 p1).

'I mean he [doctor] gives you as much time as you need and I think that's important' (Intervention group 7/6 p10).

Being able to be honest about pain symptoms generated considerable discussion when connected to those outside of the healthcare environment. Truthfulness was not considered an option for all participants in case this was met with disapproval and withdrawal of support from family, friends and colleagues. This is described here by one participant:

'I'm surprised that you say everyone is supportive because I wouldn't dream of telling at work what's going on with me ...ummm' (Control group 11/10 p.7).

However, honesty about pain enabled some participants to openly adopt aspects of Sick Role behaviour resulting in exemption from usual duties:

'I work full time... you know they are very accommodating because people I work with know sometimes I just cannot walk so instead of me rushing here and rushing there everybody comes to me instead they'll bring me the stuff I need to get on with' (Control group 11/10 p.7).
Being truthful about pain symptoms may link with being believed and with feelings of deception related to maintaining what may feel for the individual an inappropriate role. It may also be associated with the Sick Role being seen as a deviant role. This topic of deception was discussed in several groups without prompting from the facilitator and was an obvious area of unease for some:

'I feel a bit of a fraud when I listen to people like Sarah' (Intervention group 7/6p.3)
Participant A: 'but then sometimes I look around and think well... there’s nothing wrong with me if you look at some other people’ (Control group 17/5 p.4)
Participant B: 'when you look at other people I think that as well' (Control group 17/5 p.4).

and one participant describes her discomfort of using her blue (disabled) parking badge:

'I do feel embarrassed with it [blue parking badge] sometimes I can see people looking at me then equally I get cross because there’s people that park there that haven’t got one' (Control group11/10 p.10).

while another participant describes when her family do not accept her pain it has the effect of making her feel that maybe she is imaging it all:

'well it just makes me feel sometimes that ... maybe it’s imagination but I know it’s not... no it’s too painful to imagine' (Intervention group’ 7/6 p.7).

Having a visible injury was viewed as helpful in legitimising symptoms and substantiated in other studies (Glenton, 2003):

'I feel a worse fraud than... that’s visible' [referring to another participants leg] (Intervention group 7/6 p.14).
'well I was actually nagged into applying for a blue badge by a friend cos I didn't that I thought ... you know I'd have to have a leg amputated or something like that' (Control group 11/10 p.11).

Issues associated with taking responsibility for managing pain were prompted by the facilitator and were met with mixed responses. In the Sick Role patients are not considered responsible for the onset of their symptoms (Kassebaum & Baumann, 1965), but here one participant described how she considered she had some part to play in the onset of her back pain as she felt she had allowed her body to de-condition:

'In a way I feel it's my own fault I should have done a bit more to strengthen up a bit so I am trying now with the Pilates which is nice and gentle' (Intervention group 13/12 p.8).

Another participant felt responsible for preventing an increase in symptoms: 'do things which you're supposed to do... which help... if you're not doing it that's your fault then' (Intervention group 29/11 p.12).

However, other participants were more ambivalent about being responsible for their symptoms fitting with the expectation that an individual in the Sick Role is not responsible for his incapacity (Kasl et al., 1966a).

'not really[responsibile] because I mean .. if the pain is there it's there and there's not a lot you can do about it other than put up with it' (Intervention group 7/6 p.6).

Feeling ambivalent about responsibility may be more about not knowing how much responsibility is expected and may connect with social roles. In the next example the participant appears to want guidance:

'well I'm I agree I think I should be more responsible but I'm not sure and that's one reason for coming here' [pain clinic] (Control group 11/10 p.10).
It was noticeable the Intervention groups spent more time talking about Acceptance as a whole and discussion related to acceptance has been divided into negative and positive talk for the purpose of this analysis.

There was a greater volume of talk associated with negative aspects of acceptance of pain in the Intervention group (Intervention group 408 words, Control group 68 words). However both groups had difficulty thinking of their pain as a long term situation, and one participant admits this was the first time she had really acknowledged the causes for her pain and its long term prediction. Acknowledging this was clearly distressing for her:

 It’s the first time I’ve actually said the words together that I have degeneration of the spine and arthritis I’ve never said that before ... maybe to acknowledge it and accept but not actually go down the road of being it p.11 ..I just don’t associate myself with ....disability ....I don’t know don’t acquiesce in to it somehow but just accept it umm I don’t know’ (Control group 11/10 p.10).

Other participants dealt with the prospect that their symptoms could be long term by avoiding facing up to what might be the reality of the situation. The following participant refers to a process he seems to have to work through in order to get to a place where he can cope with admitting and accepting his pain may be something he will always have to manage:

’I’m not ready yet to accept that it can’t be got rid of...I am not ready to accept it ......till I’ve exhausted every possibility I won’t accept .... I’ll get there eventually I know ... but at the moment I am still till I’ve explored every single option I still believe that this pain can go ... I’ll sort it out .. I’ll definitely sorting it out ... get rid of this pain I know there is’ (Intervention 29/11 p.10).
He goes on to talk further about the process he feels he has to go through before he can come to terms with accepting his pain may be long-term:

'The more things I cross off my list its just .. gradually comes to acceptance rather than an abrupt .. if someone was to tell me tomorrow .. that’s it you got to go away there’s nothing we can do...you’ve got to deal with it for the rest of your life I reckon I would crash ... but as I just gently tick off all the boxes .. I slowly get to the acceptance’ (Intervention group 29/11 p.12).

Age was considered a factor in acceptance for one of the older participants:

'I can accept that at my age [pain] that’s a different thing with young people’
(Intervention group 29/11 p.10 aged 80 years).

Acceptance of pain was also associated with age by younger participants:

'it [pain] will come again with old age anyway but try to stave it off you know’
(Intervention group’ 13/12 p.12).

The views expressed by participants on age and pain may reflect societies view that age itself may contribute to legitimising the Sick Role and lower expectations of an older person to get well (Arluke, Kennedy, & Kessler, 1979).

A number of participants talked of accepting their pain but feeling they had no alternative:

'no alternative but to accept it pain’ (Intervention group 7/6 p.6).

'so ... you have to accept that’s perhaps that’s what you are going to be like’ (Control group 11/10 p.11).
'yeah you have to accept that this [pain] is .. I have to what .there's nothing else I can do' (Intervention group 13/12 p.15).

Participants also described different types of passive behaviours associated with managing their pain. These consisted of relying on other people to help them, crying, going to sleep, taking time off from work, not taking part in activities such as shopping or going to the theatre, and were discussed by both groups.

'and if I twiggle my little finger it hurts to the point where you’re sitting crying and shaking with pain and there is just nothing you can do’ (Control group 11/10 p.5)

'going to sound stupid I cry’ [how she puts up with pain] (Intervention group 7/6 p.6).

'sometimes when I'm in pain I go to lie on the bed for half an hour or so in the afternoon’ (Control group 11/10 p.8).

These actions may be behavioural manifestations of the Sick Role, while other participants felt at a loss how to help themselves:

'so it just keeps making me think there is nothing I can do’ (Intervention group 29/11 p.10).

'do I want to wake up today.. you get a couple of hours sleep do I actually want to get up today .. do this again you know’ (Intervention group 13/12 p.15).

In one group several of the female participants mentioned how they felt their pain had changed their bodies and their feelings of femininity. Kasl, Cobb & Arbor (1966a) refer to how chronic illness can lead to lasting identity changes:
'I wouldn’t even put a skirt on now haven’t worn a skirt ...for 2 years now because there’s such a difference in the size of my legs the only thing I am looking forward to is my son is getting married in June I am going to be the mother of the groom and so . I am going to have to wear a skirt p.19 yeah but you know...put a skirt on and look like a lady' [pain effected femininity] (Intervention group 13/12 p.20).

'I think what she is saying with the skirt thing is the same as I feel about same thing it is a femininity thing isn’t it p.21.yeah that’s right yes it would do.. it would do’ [pain changed bodies] (Intervention group 13/12 p.21).

There are suggestions that an individuals self-perceptions are more strongly associated with their tendency to relinquish the Sick Role rather than how they actually behave in the Sick Role (Brown & Rawlinson, 1975). This analysis will now explore aspects of the focus group discussions that make reference to concepts associated with preparing to leave the Sick Role.

6.10.2.3 Relinquishing the Sick Role
There is inconsistency in the literature as to whether individuals have less difficulty relinquishing the Sick Role than assuming it (Arluke et al., 1979; Suchman, 1965), but resuming old roles or developing new ones may not be so straight forward for the individual experiencing a chronic condition (Arluke, 1988).

One participant described particular difficulties when she tried to take on behaviours considered inconsistent with those expected of someone in the Sick Role. Here she describes how this behaviour was met with considerable disapproval from her family:
'my husband says I don’t rest enough p.8 he doesn’t hold it against me the girls seem to hold it against me … they were quite angry oh you can’t do things like that you know or you mustn’t do that you’ll be ill and who is going to look after you poor Dad will get it again and I have gradually fought back because I’m stubborn.. but it eh it has left as I say a bit of a ….. between us about it’ (Intervention group 13/ p.12).

For this participant it was not just about herself trying to relinquishing the Sick Role but also about the beliefs and behaviours of those around her that were working to maintain her Sick Role behaviour. She had to resist the pressure placed on her by her family and their belief she should comply with behaviour more appropriate of the Sick Role, in order to take on a more active role. She was able to express some of her feelings and describes increased awareness of her situation and possible choices. This raising of awareness followed by choosing behaviours is described in the initial stages and processes of the Transtheoretical Model (TTM) as one of the processes of change (Prochaska & DiClemente, 1982, 1992). This particular participant also described awareness that she was not living a normal life and that this was what she wanted:

'I want to be a normal person for once’ (Intervention group 13/ 12 p.9).

Another participant talked of determination of achieving a particular goal as a driver for adopting behaviour that moved outside the Sick Role, and wanted to travel to see family and friends on the other side of the world:

'I mean if there is something that I really want to do … then in the last years of my life then I feel that I’ve got to do them now and I’ve got to have that determination to do it’ (Control 11/10 p.13).
Another participant describes assessing how her problems are impacting on her physical environment. Again this relates to conscious raising and awareness of choice described in the study’s theoretical framework and TTM as one of the initial processes in the Stages of Change (Prochaska & DiClemente, 1982). This participant describes actions she has taken to remain independent and her awareness of possible choices she can take to influence her long term situation:

'one of the reasons I packed up work .. I can cope but I can’t do much but I can sort of cope with it.. I didn’t want to get any worse and end up in a wheel chair not being able to walk at all' (Control 11/10 p.11).

The next participant appears to be going through a process of self re-evaluation as he assesses how he feels and thinks about himself with respect to his problem and choices he might make and is again considered a process of change (Prochaska et al., 1992).

'I can’t make new plans ....Yeah but I am sure I can make plans but I’ve no idea what those plans will be ... I’ve always been a planner but at the moment I just can’t think about the future so I can’t make plans for it yet’. (Intervention 29/11.p16).

Evidence of participants positively accepting their pain is a principal feature of accepting a change in life is required in order to adapt to the predictable effects of persistent pain (Risdon et al., 2003). Being prepared to change and accept some level of pain while getting on with life was seen in the following talk from one participant who had attended the EPP:

'I’m still working I am still trying to get to work but I accept that the pain won’t go away but what I am trying is the target is to get to be part time’ (Intervention group 29/11 p. 11).
Evidence of talk related to positively accepting pain, getting on with life and perhaps adopting new roles and health behaviours were found in the following discussions:

'Oh I don’t know we’re sitting here look at us we’re dressed quite jazzily for our age and you think how our parents would have dressed at our age and our life styles reflect it I’m quite grateful I’m alive now and not stopped' (Intervention group 13/12 p.20).

'It will get worse and I am trying to do all the things that I really want to do now because I do feel that I won’t get any better.. and I’ve actually booked to go to abroad for a month' (Control group 11/10 p.13).

'I’m thinking no I’m doing this I want to be a normal person for once.. I’ll deal with the after effects tomorrow or what ever’ (Intervention group 13/12 p.9).

Developing new roles can be part of rehabilitation (Li & Moore, 1998) and the number of words associated with active behaviours was greater for the Intervention group (words 1,619) compared with the Control group (words 866). Topics associated with active behaviour were similar with reference to working, exercising, walking, swimming, fishing, shopping, and going to the gym,:)

'I go swimming I find it very good it helps’ (Intervention group 29/11 p.2).

'I go for a walk very slowly but although the pains there you do something .. I try I try very ... crawl I do’ (Control group 11/10 p.6).

'I found that exercising every morning strengthens the muscles in my back’ (Control group 11/10 p.3).
'I mean it's not as though I don’t do any exercise I mean I go to the gym I go swimming' (Intervention group 29/11 p.7).

One participant talked of her determination to keep independent driving a considerable distance each day to work and back:

‘and drive all the way to a Sussex town from a Surrey town .. I do it because I have to do it because I want to do it and so I do it’ (Control group 11/10 p.6).

Brown & Rawlinson (1975) have proposed that returning to work could be an area that links with relinquishing the Sick Role and work was mentioned along with a number of other active behaviours by both groups such as seeking help from chiropractors, deep breathing, planning and pacing activities.

Both the Control and Intervention groups made reference to using cognitive approaches to help them manage their pain and these commonly consisted of ignoring pain and using distraction methods:

‘I try and ignore most of the time because I’ve got other things to do more important’ (p.2) ‘Well I distract myself if there’s something good on the radio or TV ... if I’ve got a a good book to read’ (Intervention group 7/6 p.7).

‘yes I find I can forget about pain if I am absorbed in something’ (Control group 11/10 p.5).

Activity and cognitive approaches to managing pain were both included in the EPP and discussions related to attending the intervention are included in the next section.
Impact of the intervention (EPP)

Several participants talked of the EPP changing the perception they had of their situation, improving outlooks and for one participant he felt it had given him his life back:

'support group what I attended given me my life back... my pain was managing me but now I'm managing the pain' (intervention group 7/6 p.1).

'the course [EPP] did give me a better outlook on the future' (Intervention group 29/11 p.14).

'the course was a big turning point for me' (Intervention group 29/11 p.17).

One participant referred to EPP being a catalyst, making him take a reality check and as a consequence he had changed his life.

'you've got to take a reality check and re-evaluate things ... there wasn't a down side to the fact that I can't do this it is there .. I've changed my life’ (Intervention group 29/11 p13).

EPP may have given participants alternative options and approaches to managing their symptoms and one participant described how she now felt able to manage her pain without medical interventions:

'I was supposed to get steroid injections in January but somebody phoned me the other day from the hospital and I said I don't want it anymore because my pain is so much better I'm not ready to put steroids in my body when it's not necessary ... that's right I think I can .. for the time being unless it gets worse for the time being I can manage my pain' (Intervention group 29/11 p.8).
The development of skills to enable individuals to take over some of the management of their own illness is one of EPPs’ aims (Barlow et al., 1999; Macnair, 2005). For another participant she found confirmation of how she was approaching managing her pain gave her greater confidence:

‘on the expert eh management course that we went to you know I did all the things the things there that I was doing before I went on the course .. so it’s not as though you know I was doing anything different but the course was very good because I felt it made you feel a bit more confident when you came out of there I did feel much more confident yeah’ (Intervention group 13/12 p.5).

Gaining more confidence is an outcome described by individuals who have attended EPPs elsewhere (Macnair, 2005; Murphy et al., 2002), and for others participants of this study, EPP seemed to reinforce behaviours and approaches they may have hesitated to commit to previously:

‘you’ve got to do it might help [activity] you know I feel it will help’ (Intervention group 7/6 p.4).

‘It helped me I think umm to get more disciplined to the exercise to do you know what we were told to do because we always had to say okay for the next week this is our aim to do this and this and this’ (Intervention group 29/11 p.2).

However, the latter participant admitted maintaining the discipline once the intervention finished was more difficult:

‘now a week has gone by and I haven’t done anything in the last week’ (Intervention group 29/11 p.2).

Participants also mentioned the value of being with others with similar problems and being in the group was motivating:
'it was nice being able to talk to obviously everybody whose eh got different problems’ (Intervention group 13/12 p.5).

‘it’s also the buzz of being in a group and saying I did it really gave you a sort of self boost’ (Intervention group 29/11 p.2).

Changing the perception of pain symptoms and associated difficulties was discussed and participants referred to getting a sense of proportion about their difficulties when viewed with others individuals’ symptoms:

‘and to listen to all the problems other people have.. and you’re ..mine would say are minor problems’ (Intervention group 29/11 p.9).

‘support group made me feel a bit of a fool because .. I mean mine’s just my leg which infuriates me .. but not what he or she have got’ (Intervention group 7/7 p.4).

‘the rest had got far severe than what I got which made me humble in a way listening to what they’ve got wrong with them’ (Intervention group 29/11 p.9).

However, for one participant listening to other peoples’ difficulties was an uncomfortable and unhelpful process and she attended only one EPP session:

‘I just found it actually lowering a little bit depressing ... listening to all the problems and I thought no I can’t cope with this’ (Intervention group 13/12 p. 6).

Participants positively referred to opportunities that the EPP had provided them with to help each others:

‘helped each other we had a really lovely group .. it was the nicest group .. we were really lucky we had a lovely group’ (Intervention group 13/12 p.22).

and talked of the effect EPP had had on their mood:
'since the support group I plan more and my moods are better' (Intervention group 29/11 p.3).

'I have met up with other people ... the more... it’s unlikely that will I get that low again’ (Intervention group 29/11 p.12).

There were some thoughts that EPP should be made available to patients even earlier and this was interesting as EPP was introduced in this study at a much earlier stage of care than it might usually be accessed:

'I think if that was introduced earlier into someone’s diagnosis that would be a great help to them’ (Intervention group 29/11 aged 38 years).

Another participant felt that not all of the EPP was relevant to him but aspects that were helpful were extremely beneficial and gave him an alternative approach for managing his pain symptoms:

'a lot on that that was on the course I didn’t think was of any help was of any use at all... but the bits that were of use were ... the power of the mind over ... yeah that for me was just incredible’ (Intervention group 29/11 p.7).

One of the participants, who left the EPP during her first session, felt the approach was too informal:

'I didn’t feel it [EPP] was for me I asked to be excused at tea break at the first session ... I found it touchy feely I could understand the need for it there’s a lot of people get isolated by there conditions... not so basic ... a little more serious’.. (Intervention group 13/12 p. 6).

When this particular participant was asked what she was hoping for from EPP, she described wanting a more serious format, similar to the focus group she was currently attending as this would have met her needs better:
'umm what we are having now ......a little bit more serious' (Intervention group 13/12 p.6).

This participant may have associated a more serious approach with authority and the medical model, and suggests the influence of the medical profession is still important in self-care approaches (Chapple & Rogers, 1999). Alternatively, this participant’s experience may describe how important the charisma and leadership skills of EPP tutors are and this is identified as a prerequisite for the success of this self-management approach (Tattersall, 2002). Certainly the abilities and role model that tutors provided were commented on with considerable admiration from participants:

‘we had a new girl that was her first time of doing it .. and she was absolutely right spot on’ (intervention group 13/12 p.22).

‘and the tutor now I mean ... amazing which also makes you think about it what he’s doing.. I can do that as well’ (Intervention group 29/11 p.9).

The latter participant seems to be referring to experiencing the realisation that there may be an alternative and perhaps healthier role to his current one. He describes feeling he can also be like the lay tutor and this suggests how important lay role models may be in influencing behaviour changes.

Overall, the focus groups provided wide ranging topics of discussion related to participants’ management of their persistent pain. The data was rich and complex adding to and complementing the data collected from the questionnaires.
7 Discussion

7.1 Introduction

The main purpose of this study was to explore the impact of introducing a lay led self-care approach to patients at the initial stage of their referral to a District General Hospital’s (DGH) Pain Clinic. Therefore results and discussion can only be generalised to populations of individuals referred to a DGH pain management service with musculoskeletal pain.

Considerable interest in self-management approaches has been generated by the increasing recognition that self-management is an important element in managing persistent pain (Jensen et al., 2004a; NHS Modernisation Agency, 2004). Unlike previous studies this research provides a randomised controlled trial and longitudinal study that attempts to explore the potential benefits of offering a lay led self-care approach in parallel with a medical model approach in a secondary care setting.

This study hypothesised that promoting self-care approaches at the initial referral stage to a chronic pain management clinic would influence and increase individual’s readiness to take on self-management approaches to managing their pain supported with conventional treatments offered by healthcare professionals.

Subsequent to analysis of the data the following two-tailed null hypotheses were rejected:
1. There will be no difference between the Intervention and Control groups’ progress through the Stages of Change following early exposure of the Intervention group to self-care approaches as measured by the PSOCQ.
2. There will be no difference between the Intervention and Control groups Pain and Interference levels following early exposure to self-care approaches as measured by the BPI.

The following null hypothesis was accepted:
3. There will be no difference between the Intervention and Control groups’ level of Acceptance following the Interventions group’s early exposure to self-care as measured by the CPAQ.

7.2 Quantitative data

Characteristics, appointments and treatments

Differences in terms of characteristics, number of appointments and treatments experienced during the course of the study were examined in the two randomly assigned groups (Control n= 33, Intervention n=30). No statistically significant differences were found and the two groups were considered to be well matched. Changes found at the end of the study were therefore considered to be due to the impact of the intervention.

GP Visits

No differences were seen between the Control and Intervention groups use of their GP over the previous six months when independent t-tests were applied to baseline data or at 10-14 months either between groups or within groups.
When Paired t-tests were applied a clear reduction in the Interventions group’s use of their GP during the previous six months was observed at the end of the study. This finding just failed to reach a level of significance ($p<0.06$), and the direction of this change supports previous findings in the literature (Ersek, Turner, Cain, & Kemp, 2004; Lorig & Holman, 1989; Lorig et al., 1993). Reduction in use of healthcare resources is not a totally consistent finding in the literature (Griffiths et al., 2005), but it is of importance as the benefit of self-management approaches will be compared with biomedical interventions. Decisions about its provision may well be made in part on the basis of the cost per quality adjusted life year (QALY) (Bury et al., 2005).

**Pain Stages of Change (PSOCQ)**

This study provides evidence that changes in the Intervention groups data as measured by the Pain Stages of Change Questionnaire (PSOCQ) was consistent with an increase in readiness to take on a self-management approach. Statistically significant decreases in Precontemplation and Contemplation scores along with increases in Maintenance were observed. Increases in Action scores were also noted for the Intervention group but failed to reach significance at $p<0.05$ level. No significant progress through the Stages of Change as measured by the PSOCQ was observed in the Control group.

This result represents a 11% shift towards the Maintenance scale of the PSOCQ for the Intervention group and this direction of change is consistent
with previous studies exploring changes in readiness to self-manage pain (Jensen et al., 2004a; Kerns & Rosenberg, 2000). This study advances findings by involving a RCT and longitudinal design, and offering lay led-self-management approaches at an earlier juncture in referral to a DGH pain clinic alongside medical treatments.

The current study found no indication that readiness to take on self-management behaviours regressed, though this has been observed in Jensen et al (2004) who found some return to pre-treatment scores six months following attendance of a professionally led multidisciplinary treatment programme.

It is possible the improvement and maintenance of scores seen in the Intervention group were the result of two factors:

1. Participants were exposed to a lay led self-management approach at initial stages of their referral to a pain management clinic, complementing a medical approach. A self-management approach was not offered as an alternative approach or an approach to be considered once all other approaches had been optimised or failed. By offering a lay led self-care approach alongside a medical approach, this model may provide synergy and plurality that each approach on its own cannot achieve.

2. Lay led self-management approaches may raise participants’ awareness of choices and the positive consequences of self-care approaches. Lay tutors may provide familiar role models that offer
realistic and attainable objectives that can become part of the participants’ daily approach to life and managing their pain symptoms. Lay tutors can provide a didactic approach to convey information (Von Korff et al., 1998) that may not be acceptable from a healthcare professional.

This study indicates that a synergistic effect occurred when lay led care and medical care was offered together. However, a third group experiencing only the intervention (EPP) would be needed to be confident that a synergistic did occur. This is an aspect self-care that has not previously been investigated in research involving secondary care. Studies are inclined to explore self-care approaches in isolation once a medical model has been optimised or failed (Jensen et al., 2004a; Keefe et al., 2000; Kerns & Rosenberg, 2000; Lorig, Seleznick et al., 1989; Lorig et al., 2001; Sohng, 2003), or alongside established and continuing maintenance medical care (Lorig et al., 1999).

Lay led self-management approaches in primary care in the UK involving RCTs have concluded lay led self-management groups were more effective than usual care in reducing worries, and improving self-care behaviours (Buszewicz et al., 2006; Griffiths et al., 2005) and participants continued to show more favourable outcomes at 6 months in a primary care setting in USA (Von Korff et al., 1998).

When readiness to take on a self-care approach to persistent pain is explored as a ‘stage’ model, patients showing an early decrease in precontemplation
scores along with early treatment increases in Action scores were significantly more likely to experience decreases in pain and depression when exposed to a 4 week multidisciplinary treatment (Burns et al., 2005). However it was not possible to make comparisons as findings from Burns et al (2005) include participants with predominantly Action stage at pre-treatment, while this study found Contemplation the main pre-treatment stage.

Contemplation was the predominant stage for 90% of the Intervention group and 100% of the Control group. The Contemplation stage is associated with the pros and cons of making a decision to adopt a self-management approach coming into balance, although the individual has not yet made a commitment to take action (Prochaska et al., 1992). Individuals in the Contemplation Stages of Change may already be contemplating adopting a self-management approach (Kerns & Rosenberg, 2000) and it is thought that individuals with high Contemplation and low Action and Maintenance scores ‘may benefit from brief interventions designed to increase readiness to engage in pain self-management’ (Jensen et al 2003:536).

High Contemplation scores may have been pivotal in the changes and improvements experienced by participants in the Intervention group in the current study, as they were at the right stage to explore engaging in self-management approaches. Studies exploring behaviour changes in other areas of health behaviour such as fruit intake have equally found participants in the Contemplation Stage of Change more likely to make significant changes to behaviours (de Vet, de Nooijer, de Vries, & Brug, 2007).
High Precontemplation scores were noted in two participants (7%) baseline data in the Intervention group. Both of these participants failed to complete EPP, while no participant in the Control group had Precontemplation as their highest baseline score. Individuals in the Precontemplation Stage of Change have been found less able to take on self-management approaches (Burns et al., 2005) as they tend to believe their pain is a medical condition and professionals are expected to relieve it (Burns et al., 2005). Biller et al. (2000) found individuals with high Precontemplation scores were more likely to fail to complete a pain management programme and supported findings in this study.

The current study had a particularly small number of participants scoring high Precontemplation scores (3%) as compared with the Service Development Project (26%). This compares with 44% of participants in the Precontemplation stage in Keefe et al. (2000) where individuals with high Precontemplation scores tended to have lower pain and disability scores. Unexpected lower pain and disability scores associated with high precontemplation scores were explained by Keefe et al. (2000) as a consequence of individuals’ lacking motivation to take action to self-manage their pain because their pain had minimal impact on their lives. This may be one influence that affected the low percentage of participants recruited to the current study in the Precontemplation stage. Equally participants with high Precontemplation scores may have self-selected themselves out because this stage is associated with greater resistance to self-management approaches and the individual has no intention of changing their behaviour.
Selective drop out has been described in other studies exploring health behaviour intentions, with more volitional participants remaining in the study (de Vet et al., 2007). Participants with high Precontemplation scores may require alternative methods and approaches (Keefe et al., 2000), to help them engage in a self-management approach. It should be remembered that participants may also be at different stages within the medical model and this could influence their motivation to consider alternative approaches.

The issue of individuals’ being at different stages of their care at recruitment appears to be supported when numbers of patients recruited to the current study are compared with numbers recruited to the Service Development Project. The Service Development Project had a 40% response rate while the current study had a response rate of 26%. The Service Development Project offered no intervention but simply asked participants to return a self report questionnaire. Twenty six per cent of participants scored Precontemplation as their highest score compared with the current study (3%). The suggestion of group interaction in the main study may have influenced recruitment responses and is commented on by Von Korff et al (1998) in their study. They report poor recruitment rates (13%) in their RCT exploring lay led self-management approaches, and attribute this level of recruitment passivity as typical when a group intervention is involved (Von Korff et al., 1998).

However, the implication that an individual will self-select themselves either into or out of self-management approaches is not conclusive as individuals in Keefe et al (2000) were all volunteers recruited by advert. What is different
with their sample compared with this study is that all their participants had a confirmed diagnosis of osteoarthritis or rheumatoid osteoarthritis. Differences found in the current study for participants Stage of Change at recruitment is not clear, but individuals with high Action or Maintenance scores may equally have self-selected themselves out. This may have been because they were already ‘getting on’ with their lives despite their pain. Recruitment comparisons with the current study and the Service Development Project are visually described in pie graphs (See Graphs 10).

Graph 10: Pie Charts comparing PSOCQ scores between Service Development Project and Current study
What is notable in terms of completing a self-management programme, individuals in Action or Maintenance Stages of Change have been found to be no more likely to complete a programme than the other stages (Kerns & Rosenberg, 2000). Therefore completion may not necessarily be associated with Stages of Change; what may be of greater importance is that their Stage of Change could be helpful in guiding an individual towards an approach they are more likely to successfully engage in and ultimately benefit from.

**Pain and Interference - Brief Pain Inventory (BPI)**

When paired t-tests were applied to Pain and Interference scores as measured by the BPI, this study indicates that reductions in Pain scores reached levels of significance in the Intervention group (P < 0.01), at mid and end stage points. Pain scores decreased by an average of 18% in the Intervention group and no significant reduction was seen in the Control group’s Pain and Interference levels. Reductions of between 16 -20% are seen in the literature (Lorig et al., 1998; Lorig & Holman, 1989), though reductions in pain intensity has not been observed in all self-management studies (Griffiths et al., 2005; Von Korff et al., 1998). This is explained in Von Korff et al. (1998) by the fact that the intervention was not designed to reduce pain intensity but to enhance confidence in self-care.

The Intervention in Von Korff et al. (1998) was modelled after the Stanford University lay person led self-management programme for arthritis (ASM) from which EPP is developed. The difference in Von Korff et al. (1998) was
that the self-management programme offered was four 2 hour sessions compared with the current study’s EPP which offered six 2 hour sessions. The number of sessions offered in lay led programmes may have critical impact on their level of benefit, and more limited reductions in pain intensity of 7% were seen when the ASM was reduced to three 2 hour sessions (Lorig et al., 1998).

This study also provides evidence of significant reductions in Interference scores in the Intervention group ($p<0.00$). This finding could be expected in view of the strength of relationship previously noted between Pain and Interference (Tan et al., 2004). The direction of this finding concurs with Von Korff et al (1998) study although none of their score changes reached levels of significance.

**Acceptance (CPAQ)**

Independent t-tests indicated small increases in levels of Acceptance for both groups but neither groups’ data reached significance (Intervention group $t=-1.09$ $P=0.28$, Control group $t=-0.89$ $P=0.38$). When the data was paired and paired t-test applied the Intervention groups data showed trends towards higher Acceptance scores but again the data fails to reach significance ($t=-1.75$ $P=0.10$). What is interesting is that the Control group’s data shows a smaller trend in their reduction in Acceptance and while failing to reach significance ($t=0.22$ $P=0.83$), the implication is that there was some regression in the Control groups’ level of Acceptance of their pain at the end of the study.
This finding suggests there was a greater indication in the Intervention group for recognising their pain may be a continuing reality. They may have been beginning to avoid futile attempts to control their pain perhaps realising that quality of life is possible with pain (McCracken, 1999). These increased levels of Acceptance in the Intervention group were seen in association with reductions in Pain and Interference levels, and support previous findings (McCracken et al., 1999). Improvements with pain and functioning have also been observed in participants attending an acceptance-based interdisciplinary treatment programme (McCracken et al., 2005), while experimental acceptance based approaches have also rated self-report pain levels as lower compared with control or suppression approaches (Keogh, Bond et al., 2005; Masedo & Esteve, 2007).

The implication is that by attending EPP some influence on levels of acceptance of pain occurred in the Interventions group that was not seen in the Control group. One explanation may have been the influence from healthcare professionals endeavoring to change pain through treatment. This may have had a greater influence on participants in the Control group and their expectations of treatment outcomes impacting on Acceptance as they had no alternative role models to influence them. The influence of clinicians expectation is seen immediately following pain procedures for persistent pain where clinicians expectations of pain relief correlated with patient reported pain scores (Galer, Schwartz, & Turner, 1997).
The aspect of influence appears complex and Galer et al. (1997) suggests a number of variables are involved in influencing participants’ treatment outcomes. While a clinician’s optimistic expectations of pain relief may positively influence patients’ pain scores in the short term, their expectations may also influence acceptance (McCracken, 1998). It is proposed that without the impact of EPP, other influences may have had a greater impact leading the Control group to regress in the Acceptance of their pain. This finding may link with outcomes of the correlation analysis.

**Correlations**

When Pearson Product Moment Correlations was applied to the data Pain and Interference levels were significantly and positively associated with each other in both groups and at all stages of the study. The strength of their association increases by the end of the study (Intervention $r=0.86$ $p<0.00$, Control $r=0.76$ $p<0.00$), and it is suggested that as Pain increases or decreases it is association with more or less Interference in quality of life domains. This is a physical and rational consequence of pain accounting for the strength of association (Tan et al., 2004).

The relationship between Acceptance and Pain and Acceptance and Interference is not straightforward in the current study. In the Intervention group, the strength of association between Acceptance and Pain lessens at the end of the study ($r=-0.36$ $p<0.17$) while it significantly increases in the Control group ($r=-0.63$ $p<0.01$). Greater acceptance of pain has previously been associated with less pain and disability (McCracken & Eccleston, 2003),
and does not explain the findings in the Intervention group. However, a reduced strength of association between Acceptance and Pain has previously been observed, and it was considered to be due to acceptance being not ‘simply a function of having a low level of pain’ (McCracken 1998:24).

Therefore the Intervention group may not have needed to experience lower levels of pain in order to experience greater levels of acceptance, possibly linking with an increased sensation of ‘getting on’ with life despite their pain. This may explain findings in the Intervention group, but does not explain why the association between Acceptance and Pain should strengthen in the Control group at the end of the study. Possible explanations are again sought in the Control group’s exposure to only healthcare professionals as their role model. It has previously been suggested that if healthcare professionals who provide treatment for pain consider persistent pain unacceptable, then individuals are also likely to ‘behave similarly’ (McCracken, 1998). It may be that healthcare professionals’ expectations of outcomes from interventions are too high and unrealistic. As a result patients’ expectations are influenced and their acceptance of small or moderate treatment benefits (Macfarlane et al., 2006), may impact on the level of pain an individual considers acceptable.

It is tentatively proposed that the influence exerted by healthcare professionals in this study influenced both the Intervention and Control groups. However, this influence was not counterbalanced in the Control group by the influence of lay role models and their expectations and acceptance of
pain. This may have led to an increased strength of association between Acceptance and Pain in the Control group, while the Intervention group was tending to get on with life despite their pain and Acceptance was indeed no longer a function of having a lower Pain level.

Lay role models may have conveyed to the Intervention group aspects of acceptance that suggest that unpleasant feelings are part of life, and to a great extent uncontrollable (McCracken, Vowles et al., 2004). Acceptance may have become less ‘conditional’ in the Intervention group on levels of pain, perhaps suggesting as described in the literature a degree of ‘disengagement from struggling with pain’ (McCracken & Eccleston, 2003).

Similar associations were seen between Acceptance and Interference when correlations were applied and this was predicted because of the strength of association between Pain and Interference.

7.3 Discussion of the qualitative data

The qualitative data derived from focus groups held at intervals over twelve months provided an intricate picture of how persistent pain, medical care and self-care operate over time. Analysis of the data revealed three distinct stages through which participants with persistent pain appeared to progress: Preparing to enter the Sick Role, maintaining the Sick Role and relinquishing the Sick Role.
There is much debate about the usefulness of the Sick Role in chronic illness (Bury, 1982; Gallagher, 1976; Gerhardt, 1979). Criticisms relate to failure of the Sick Role to take into account variations in human behaviour and cultural norms when an individual faces illness and for omitting to take into account the difference between acute and chronic illness (Bowling, 1997). Kasl & Cobb (1966b) in their conceptual framework attempt to identify the main factors that may influence Sick Role norms. These include the affinity the doctor and patient have with treatment expectations as well as the influence of other social roles. They highlight the complexity of interactions that occur between the dimensions of health and illness and the involvement of facets associated with the individual’s identity. These interactions are modified by a number of characteristics the individual may have and by their environment. Bury (1982) supports the complexity of these interactions suggesting that chronic illness is a particular kind of disruptive experience and changes to an individual’s behaviour is determined by many factors.

However, the Sick Role is the role individuals enter when they believe they are unwell (Wade & Halligan, 2007). Individuals involved in this study where at the initial stage of referral to a pain management clinic and involvement with medicine a central part of their pain. The Sick Role was possibly a role they could identify with from previous experiences of acute illness, while they may have been less familiar with others roles such as rehabilitation or convalescence. Also individuals will often adopt a role that is determined by their goal (Wade & Halligan, 2007), and in the absence of alternative social roles, entering the Sick Role and cooperating with health professionals is
seen as part of the process of trying to get better (Parsons, 1951). It has been proposed that some individuals will find it difficult to give up the Sick Role if a positive social role is not available for them to return: recovery being synonymous with relinquishing the sick role and resuming usual social responsibilities (Kasl et al., 1966b).

The data will now be discussed using the three identified stages of the Sick Role to interpret the data.

7.4 Preparing to enter the Sick Role

Descriptions of entering the Sick Role were considered retrospective as all participants had experienced pain for at least twelve months and some for considerably longer. Every participant made reference to some process of entering the Sick Role even if was just about becoming aware of physical symptoms which is often the first step in illness behaviour (Young, 2004). Once symptoms have been acknowledged they usually require some form of sanctioning by the medical profession and this normally require a diagnosis (Nettleton, 2006; Stone et al., 2002), followed by treatment and leads to the adoption of the Sick Role (Kasl et al., 1966a).

Seeking medical knowledge is related to questions of legitimisation, but this is usually only part of what is happening. Individuals also want to gain a measure of control over their symptoms by finding explanations that make sense within their context. Along with this is a need to get a better sense of perspective about their symptoms and re establish credibility following the
disruption to their personal self and circumstances (Bury, 1991). Gaining a medical diagnosis is seen as proof of suffering (Glenton, 2003) as well as legitimising entry into the Sick Role, and this process of legitimisation requires the individual to reciprocate appropriately in the relationship with the doctor (Parsons, 1951).

Entry into the Sick Role might be straightforward in acute illness but is more complex when chronic conditions are involved and particularly when pain is the condition considered. Issues of credibility occur because ‘pain is a sensation that can be directly perceived only by the person who feels it’ (Baszanger 1989:427). Confusion and struggle for credibility were evident in participants’ discussions when a diagnosis was lacking. For some participants this led to their questioning the ability of their doctor as a possible explanation for their failing to acquire a diagnosis. Individuals with medically unexplained symptoms can perceive doctors as incompetent and inexpert if the explanation for their symptoms questions the reality of them (Peters, Stanley, Rose, & Salmon, 1998).

The credibility of an individual’s pain is in less doubt if the cause for the pain is obvious. The visibility of symptoms has long been observed as important in the context of credibility for some persistent conditions and achieving legitimisation can be made even more difficult if the condition is widely experienced in milder forms by the normal population (Bury, 1991). Some of the participants with widespread musculoskeletal pains but no specific diagnosis appeared to struggle with feeling believed and trusted. Seeking
Credibility has been observed to take up huge amounts of energy that could be better directed in adjusting to and coping with persistent pain (Werner & Malterud, 2003). This misdirecting of energy was seen in the lengthy descriptions of pain and of treatments sought by some of the participants. This contrasted with one participant who had a visible injury to his leg. This injury was taken as unquestioned evidence of his credibility and appeared to be viewed with some desire by other participants. Furthermore, an individual’s credibility will increase if their report of their pain fits with those expected by the healthcare professional (Baszanger, 1989).

Many participants in this study appeared to have acquired an uncertain role; neither had they attained clear legitimate access to the Sick Role or had they been able to resume an alternative health behaviour role. Their energies appeared directed at acquiring credibility through accessing the Sick Role despite its inappropriateness and this was associated with doctor shopping, seeking ever more investigations, and taking medication with no clear benefit.

The association between diagnosis and legitimisation of the Sick Role is acknowledged in the literature (Glenton, 2003), and without a diagnosis the individual may be even more dependent on the doctor for guidance and a pathway out of their suffering (Dumit, 2006; Glenton, 2003; Suchman, 1965). Most individuals want to be assigned a label or explanation for their symptoms (Carr & Moffett, 2005) and depriving the individual of a diagnosis not only deprives them of legitimate access to the Sick Role but also of social,

When a diagnosis is not available it can complicate the situation as the individual battles for recognition (Dumit, 2006). Some participants described feeling abandoned by the medical profession, with others struggling to be taken seriously by doctors, possibly fearing the reality of their pain will be questioned and they will be accused of being a malingerer, hypochondriac or even mentally ill (Glenton, 2003). One participant in the current study was heard questioning the reality her pain, and reassures herself that it cannot be in her imagination because ‘it is too painful to imagine’. Another participant describes seeking reassurance from her doctor that she was not a hypochondriac.

In total 27% of participants in the current study considered they had no diagnosis; if issues of legitimacy are explored in other long term conditions where a diagnosis has been given such as rheumatoid arthritis or osteoarthritis, there is less uncertainty about roles for the individuals concerned (Braden, 1990). Legitimacy in diabetic patients is not questioned in the same way that it is with other long term illnesses such as persistent pain, and therefore there is not the need for defensive reaffirmation that is so often required by some other long term conditions (Kassebaum & Baumann, 1965).
With the development of medicine has come dependence on the acute care approach to managing illness in ‘which the patient as a whole person can so easily be lost’ (Husband, 1996:4) but while the acute medical model dominates (Davies et al., 1997; Engel, 1980), it may not be so easy for individuals with persistent pain to find an appropriate balance to their care approach. Medical treatments tend to take principle place and reinforce the need for a diagnosis in order to make sense of their pain. Frustrations felt by both patients and healthcare professionals can be made worse if either or both are working to an inappropriate model of curing the pain (Seers & Friedli, 1996). However, if this model is adopted it requires the individual to take on and maintain the Sick Role until the episode of illness resolves and this may not be appropriate when the condition is persistent pain.

7.5 Maintaining the Sick Role

Participants described their willingness to comply with medical treatments, and this is expected if they are to be seen to be conforming to the Sick Role; by seeking the best possible care it proves they are acting reasonably (Baszanger, 1989). Findings in this study suggest participants appeared reluctant to openly challenge their clinician if the benefit of treatment was limited or side effects worried them. This reluctance may have been associated with a fear of not conforming or being discharged for non compliance (Glenton, 2003), and implies the clinician has considerable power that may contribute to maintaining the Sick Role.
The power patients may feel doctors posses has previously been identified and described as attitudes of 'reverence' (Thorne, 1993), and it is not just the patient who perceives the doctor as powerful, but the doctors themselves. In a study exploring medical consultants' roles in the management and delivery of services in the NHS, patients' expectation of their consultant to cure or improve their condition, was cited by the doctors as the reason for their power and on that premise alone they expected to be powerful (Thomson, 2003).

Fear of being discharged by the clinician may link with participants' descriptions of misrepresenting their feelings and their symptoms perhaps to gain the approval and attention of their doctor. Bury (1991:457) describes a 'crisis of credibility' can occur when individuals continue to report symptoms 'after their share of attention has been used up'. In these circumstances pathways of support and information can become closed off and possibly explains why participants' chose to hide their true feelings from their doctor, in order it is suggested to maintain their doctor's attention. One participant illustrated this behaviour in her description of accepting prescriptions she did not want rather then say how difficult she was finding it to manage her pain. However, this behaviour was not conducted with all doctors as with other doctors she felt able to be honest. This varying behaviour described by participants may link with a need to get the balance right with clinicians in order to maintain the relationship and therefore the legitimacy of their Sick Role (Werner & Malterud, 2003).
Participants appeared sensitive to what may or may not be of interest to their doctor and discussions about symptoms can close prematurely if the doctor indicates he is not interested (Mechanic, 1995). This was illustrated by one participant when her doctor appeared to be struggling with his computer and she describes, 'in the end after 15 minutes when he didn’t say a word to me I said well I suppose I’d better go'. The doctor’s behaviour may have been more complex than just finding the patient uninteresting or that the patients their share of attention had been used up. There could have been a number of reasons for this patient’s view of her experience and the doctor’s behaviour. However, doctors have been observed to take actions that consist of ignoring the patient and indulging in activities to the exclusion of the patient in order to assert authority and gain control (Nettleton, 2006). Alternatively, the doctor may have been experiencing a sense of powerlessness which is described as an uncomfortable position for the doctor (Wileman et al., 2002:181).

However, doctors can find themselves misjudged by patients as patients can perceive them as inexpert if they attempt to provide explanations that question the realness of the symptoms (Peters et al., 1998). Either way, these behaviours may reinforce unhelpful and or passive behaviour from the patient associated with the Sick Role, and undermine the individual’s ability to achieve an alternative role.

There was also no shortage of approving comments from participants about the care they received from their doctors. These comments were often
associated with listening skills, being given sufficient appointment time and
the doctor persevering with treatments aimed at resolving the individual’s
pain. The latter may nevertheless, become complicated by the medical
professions’ focus on medical solutions they have been trained in and know
how to do (Fordyce, 1997; Mechanic, 1995). Some clinicians have observed a
tendency to repeat treatments that have been unsuccessful in achieving long
term benefit in the hope that ‘that was then and this is now’ (Stannard,
2000). Evidence of long term benefit from some invasive treatments for
chronic conditions is conflicting (Bendix et al., 1996; Crook et al., 1989;
Davies et al., 1997; Fairbank et al., 2005; Seers & Friedli, 1996; Wynne,
2002), and when a treatment fails to deliver it can result in further conflict
and confusion (Rankin, 2001).

Further complicating the situation with treatment outcomes is that treatment
can be successful but it may not have had the desired effect and resolve the
individual’s symptoms. For example not all knee and hip replacements relieve
pain while the joint replacement surgery is in itself successful. Individuals can
then find themselves placed in another category where avenues of support
and information become closed off (Bury, 1991). These issues may contribute
to the disagreement and conflict that is sometimes associated with individuals
suffering from chronic symptoms and was apparent in some of the
participants in this study as they struggled to maintain a role that was not
appropriate for long term conditions (Arluke, 1988).
Participants’ accounts of some clinicians’ disinterested behaviour may reflect the following comments that medicine is sadly no longer as satisfying as it was in the past, with many of the more interesting conditions having simply disappeared. A general practitioner (GP) is now ‘lucky to see a patient with a serious acute medical problem from one week to the next’ (Le Fanu, 2000:398). Equally criticism of clinicians may reflect the high expectations that are held of medicine (Bury, 1982), and it may be impossible to meet individuals expectations in all areas of healthcare. Nevertheless, this study suggests that individuals may struggle to get clinicians attention and be interesting patients and get caught in a vicious circle as the harder they try to convince clinicians of their suffering the more likely their symptoms may be interpreted as psychological. It has been shown that the greater the number of physical symptoms a patient complains of the more likely it will be seen as non organic and predictive of a psychiatric disorder (Kroenke et al., 1994).

Falling into this a no-win situation was observed in the focus group where one participant struggling with her failure to achieve a diagnosis, described eight different areas of pain on her body in an attempt to express her suffering. Patients with persistent pain that is not medically recognised can sometimes feel they are in the uncomfortable position of being questioned by clinicians and judged to be either not in pain or suffering from imaginary symptoms (Dumit, 2006; Werner & Malterud, 2003). This may then require them to work even harder at maintaining the credibility of their Sick Role. Another participant described having sought three scans of her back in an
effort to acquire a diagnosis, one of which she paid for and was sensitive to criticism from the doctor at the cost to the NHS for these investigations. This participant’s perseverance with seeking a diagnosis and the clinicians less enthusiastic response confirm how important a diagnosis can be in opening up or closing down avenues of therapeutic support and information.

Individuals with chronic illness or unexplained medical symptoms are often associated with difficult, frustrating and complaining patients (Davis et al., 2001; Ford et al., 1961; Wileman et al., 2002). Even patients with acute pain who are perceived to be coping less well with their pain are assessed by nurses as unpopular and demanding (Salmon & Manyande, 1996). However neither the Sick Role or those critical of it can explain the complex relationship between the patient and their clinician (Young, 2004), but being believed has been reported as the most important factor in managing persistent pain (Seers & Friedli, 1996). When medical recognition for a symptoms is uncertain everyone including the individual themselves can come to think of the patient as ‘not really sick and not really suffering’ (Dumit 2006:579), perhaps even suffering from an imaginary illness (Werner & Malterud, 2003). This was evident in a number of the discussions that took place in the focus groups with one participant questioning whether her pain was indeed all in her imagination.

Being in a group seemed to give participants additional confidence to explore issues such as feeling a fraud or imagining their symptoms and they appeared comforted to find they were not alone with these uncomfortable
feelings. This is in keeping with Parsons (1951) view of the Sick Role as a deviant role and participants in the current study gave examples of the authenticity of their sick status being questioned, for instance by members of the public when some of them used their blue disabled parking badge. One participant described her reluctance to reveal her pain condition to her work colleagues for fear they would be met with limited sympathy. She felt she could not expect special consideration, and was reluctant to depart from what might be considered normal behaviours.

Departure from what are considered appropriate behaviours are often avoided as this ‘carries its own specific disadvantages’ and will depend to a degree on the flexibility of colleagues and friends and what they will allow (Bury, 1982:177). The Sick Role was clearly not a comfortable role for some participants who either hid their true feelings or misrepresented them in order to be accepted within their social circle. Quite often individuals with persistent pain can be seen as failures and their failure to recover somehow seen as being the individual’s fault (LeMaistre, 1999).

Entry into the Sick Role implicitly demands a ‘no-fault basis’ and society does not freely and readily grant the Sick Role to those with non-organic or psychological illness (Kwan & Friel, 2002). To accept anything less than being a victim of external forces would require them to fully accept responsibility for their condition (Bury, 1982). However one of the complicating factors of pain is that as it persists, psychological consequences evolve that become secondary factors in maintaining it (Baszanger, 1992), and this can only
aggravate the fear and anxiety that may already be associated with the individuals pain. As the complexity of maintaining the Sick Role increases it may result in greater difficulty in relinquishing it. Participants in this study held a mixture of views on responsibility which ranged from feelings of not being at all responsible for their symptoms to having considerable responsibility for them.

The majority of participants in this study were in the Contemplation Stage of Change, the stage associated with weighing up the pros and cons of making decisions to take on self-management approaches. They may also have been making decisions to relinquish their uncertain Sick Role and making progress through the Stages of Change and adopting self-management approaches may be an essential prerequisite if an individual is going to be able to relinquish the Sick Role. However, discussions in the focus groups centered on behaviours and issues associated with maintaining the Sick Role and credibility for their pain symptoms. Only in the Intervention group did discussions begin to focus on issues that were associated with processes of change and adopting different behaviours or roles.

Figure 9 describes a composite model involving concepts discussed here that consistently emerged from the thematic content analysis and appeared to link with unintentionally maintaining individuals in an inappropriate Sick Role. These include: no organic cause found to explain symptoms, diagnosis uncertainty, uncertain role, conflict with care and seeking credibility. The problems of uncertainty, doctor/patient conflicts and difficulties managing
symptoms and treatments are all recognised in the sociological literature (Bury, 1991).
Figure 9: Composite model for the maintenance of an inappropriate Sick Role
7.6 Relinquishing the Sick Role

Relinquishing the Sick Role in individuals with chronic illness is not an area that has received particular attention in the literature. Papers that do explore this tend to focus on aspects associated with entry into the Sick Role (Becker, Drachman, & Kirscht, 1974; Kwan & Friel, 2002). Outcomes in this study suggest aspects associated with relinquishing the Sick Role in individuals suffering from persistent pain are immensely complex. They also appear of critical importance if individuals are to achieve the resumption of healthier roles, but unless an alternative social role is offered, they are likely to remain in the patient role (Wade & Halligan, 2007).

Findings in this study provide evidence of the difficulties experienced when participants attempted to move away from the Sick Role. One participant from the Intervention group, described the anger her family felt when she tried to take on more active self-care behaviours, suggesting that if she got worse as result of taking on these behaviours, she would only have herself to blame for any increase in her symptoms. This clearly illustrates the dichotomy that may be experienced by individuals with persistent pain as they try to take on more self-management approaches but are criticised for behaviours perhaps not considered consistent with the Sick Role.

There is also a danger that if an individual adopts a self-management approach they are perceived to have the power to control the conditions that give rise to their ill health (Segall & Goldstein, 1989). This is seen in the last participant’s description of her family’s reaction to her being more proactive...
in managing her symptoms. The suggestion made by her family was that she would be to blame for any increase in her symptoms. The inference is that if she conformed to behaviours required of the Sick Role then she would not be held responsible for her condition or any increase in symptoms. This could suggest self-management approaches are vulnerable to encouraging victim blaming, and this view is not helped by the continued dominance of the acute medical model for treatment for persistent pain (Davies et al., 1997; Middleton, 2004). Social obligations and expectations of the medical profession, family and friends may all contribute to the individual’s difficulties in relinquishing the Sick Role.

What was obvious in the Interventions group’s dialogue and not seen in the Control group’s data, was an apparent realisation of an alternative role or way out of the Sick Role and the resumption of a healthy status and health behaviour role. References were made by participants in the Intervention group to resuming old roles and developing new ones as participants talked of the EPP ‘giving them their life back’ and ‘having a better outlook on the future’ as well as it being a turning point in their life. EPP is also referred to as a catalyst in changing one participant’s life, and while this participant saw his life had changed, no external factors had in reality changed, such as where he lived, family or friends. Therefore it is proposed that something internal had influenced how he perceived his role had changed. Certainly the discussions associated with the influence EPP had had on some participants was powerful.
While EPP may explicitly focus on helping individuals to find ways to manage their long-term conditions (NHS Expert Patients Programme, 2002), its impact may be more on how it can help individuals manage the transition from a Sick Role to an alternative and more appropriate role, while maintaining credibility.

Brown & Rawlinson’s (1975) study is one of the few studies that explore issues related to relinquishing the Sick Role in chronic illness. Their participants all had chronic heart disease and had undergone heart surgery. Their study provides some interesting comparisons to the qualitative data in this study. They found individuals tended to perceive their health prior to heart surgery as better than most other sick people’s health. The suggestion is that they held a much more positive view of their health than it actually had been.

What is important from Brown & Rawlinson’s (1975) findings is that chronically ill people may in general perceive themselves as fitter then they actually were prior to the onset of their current long term condition; this may give a distorted view of their health and therefore the goals they may set themselves in order to resume usual roles could be unrealistic. In persistent pain conditions this could contribute to difficulties individuals may have relinquishing their Sick Role and accepting their pain, as the perception they have of their usual role is of someone considerably more active and independent.
This distorted perception it is suggested was seen in one of the participant's descriptions of her level of activity before the onset of her pain ten years ago. Now in her late sixties, she recalls regularly walking several miles to see her sister and mother, blaming her current inability to walk this distance on her pain. It is proposed the level of fitness she recalls may have been longer ago than she remembers and that with increasing age there may be a natural reduction in her capacity for activity. However, her goal may still be to resume this previous level of fitness and failing to achieve this may contribute to difficulties relinquishing the Sick Role while reinforcing it.

Other findings in Brown & Rawlinson (1975) that have relevance to this study's findings is there questioning of Parsons (1951) long held association of deviance with the Sick Role. The Sick Role did not appear to hold stigma related issues for participants in their study who had all undergone heart surgery. Participants rated individuals suffering from heart disease as 'good, clean and fair' individuals. It has to be acknowledged that Brown & Rawlinson's (1975) study is now over thirty years old, and society as a whole may be less complacent in freely granting the Sick Role to individuals with heart disease. There is now greater awareness of factors that the individual may be considered responsible for controlling, such as the associations between, inactivity, diet, smoking and heart disease (Lee, 1991; Yudkin, 1992). Raised awareness of factors that may contribute to onset of a long term condition may be helpful for preventing its onset; however, it may also contribute to the individual having to work harder to legitimise their Sick Role.
The impact of the lay tutors leading EPP was considered of critical importance to its success and in moving participants towards engaging in self-management approaches that may lead to relinquishing the Sick Role. Some tutors were singled out for the impression they made on participants. One participant describes this as 'amazing which also makes you think about it what he is doing I can do that as well'. However, not all participant found the EPP helpful and one participant describes the approach too 'touchy feely', and the information too basic and format not serious enough. This may all reflect how important the lay leaders are in delivering EPP and that equally it is an approach that may not suit everyone.

The outcomes from the quantitative and qualitative methods are now combined to support and explain the findings in the quantitative and qualitative data.

7.7 Combining and Discussion of the Quantitative and Qualitative Data

Introduction

The primary goal of the analyses was to determine if early exposure to a self-management approach (EPP) would promote participants progress through the Pain Stages of Change thereby influencing their readiness to adopt a self-care approach to managing their pain. The quantitative data had shown participants in the Intervention group had made significant progress through the Stages of Change following early exposure to a self-management
approach as measured by the PSOCQ. Significant progress was not observed in the Control group’s data. Participants in the Intervention group also experienced significantly improved levels of Pain and Interference as measured by the BPI, and again these changes were not observed in the Control group’s data. The qualitative data had revealed participants in both groups were caught up in maintaining the Sick Role and that there was greater evidence of relinquishing the Sick Role in the Intervention group. There was also evidence that maintaining and relinquishing the Sick Role was a complex task.

By combining the two methods of data collection, associations emerged between the Stages of Change and Kasl’s et al (1996) Continuum from Health to Disease. The Continuum incorporates aspects of the Sick Role and this study is the first to suggest an association between the Stages of Change process and the Sick Role. No link has previously been made between progression through the Stages of Change and an individual’s ability to take on self-management approaches that permit the Sick Role to be relinquished and usual social roles resumed. The current study adapted the Continuum from health to disease model to incorporate the Stages of Change (See Figure 10). This study’s theoretical framework (Figure 5) support this and together help to explain significant changes that occurred in the Intervention group and why similar levels of change were not seen in the Control group. This adapted model is identified here as the Phases of Persistent Pain (PPP) and three phases are identified (See Figure 10).
This study offers the Phases of Persistent Pain as a model to assist in explaining how participants may be assisted to relinquish their Sick Role and in doing so progress from Phase Two to Phase Three of this model. Previously models have been developed to analyse social patterns associated with illness behaviour and medical care such as the Stages of Illness (Suchman, 1965). Suchman’s (1965) model divides the sequence of medical events into five stages and helps explain ‘what’ is happening; it is proposed the PPP goes further by explaining ‘how’ it happens and why progress occurs.

<table>
<thead>
<tr>
<th>Persistent Pain</th>
<th>Phase 1</th>
<th>Phase 2</th>
<th>Phase 3</th>
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</thead>
<tbody>
<tr>
<td><strong>Behaviour</strong></td>
<td>Illness behaviour</td>
<td>Sick Role behaviour</td>
<td>Health behaviour</td>
</tr>
<tr>
<td><strong>Role</strong></td>
<td>Preparing to enter the Sick Role</td>
<td>Maintaining the Sick Role</td>
<td>Relinquish the Sick Role</td>
</tr>
<tr>
<td><strong>Stages of Change</strong></td>
<td>Precontemplation</td>
<td>Contemplation</td>
<td>Action</td>
</tr>
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**Figure 10:** Composite model - Three Phases of Persistent Pain

Suchman’s (1965) five Stages of Illness contribute to the interpretation of the current study’s data, by identifying processes participants may be indulging in at each Phase of the three ‘Phases of Persistent Pain’ (See Table 25). Each of the three phases of persistent of pain encapsulate a specific and complex phase individuals with persistent pain experience and progress through before being able to resume health behaviours. The current study’s quantitative data indicates that participants may for a variety of reasons become trapped in the ‘revolving door’ stage of Phase 2. This is supported by
the Control group’s failure to experience promotion through the Stages of Change in the same way seen in the Intervention group.

Further interpretation suggests individuals may have difficulty progressing if only a medical model approach is offered. Possibly the Intervention group were empowered by the impact of EPP to move towards or into Phase 3 where they had opportunities to adopt an alternative role suggested in this study as the Persistent Condition Role (PCR). This should not be confused with a rehabilitation role which infers a temporary role aimed at restoring health (Oxford, 1994); persistent pain by its very nature is long term for which no treatment has been found (Melzack & Wall, 1996).

<table>
<thead>
<tr>
<th>Three Phases of Persistent Pain</th>
<th>Stages of Illness (Suchman, 1965)</th>
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<tbody>
<tr>
<td>Phase 1</td>
<td></td>
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<tr>
<td>• Illness behaviour</td>
<td>1. The symptom experience stage</td>
</tr>
<tr>
<td>• Preparing to enter the Sick Role</td>
<td>2. The assumption of the Sick Role stage</td>
</tr>
<tr>
<td>• Precontemplation Stage of Change</td>
<td>3. The medical care contact stage</td>
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<td></td>
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<td>Phase 2</td>
<td></td>
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<tr>
<td>• Sick Role behaviour</td>
<td>4. The dependent-patient role stage</td>
</tr>
<tr>
<td>• Maintaining the Sick Role</td>
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<tr>
<td>• Contemplation Stage of Change</td>
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<tr>
<td>Phase 3</td>
<td></td>
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<tr>
<td>• Health behaviour</td>
<td>5. The recovery or rehabilitation stage</td>
</tr>
<tr>
<td>• Relinquishing the Sick Role</td>
<td></td>
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<tr>
<td>• Action &amp; Maintenance Stages of Change</td>
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Table 25: Phases of Persistent Pain and Relationship to the Stages of Illness

While there is recognition in pain clinics that patients may ‘become ready for change after considerable effort on the part of the physician’ (Reddy,
2004:17), explanations for why some patients become what are commonly referred to as revolving door patients is less clear. A revolving door patient has been described as a person who living with persistent pain can become stuck in a vicious cycle, ‘Many feel like revolving door patients, leaving one healthcare professional door, and entering into another’ (Chronic Pain Policy Coalition, 2007:18). The solution offered by Reddy (2004) is to increase the amount of professional input for these individuals. For example specialist nurses are suggested as appropriate to see these ‘revolving door’ patients in order to free up the doctor’s time to see more complex patients. Based on findings in this study it is suggested that such a solution can only reinforce the medical model and its associated expectation of a cure, resulting in a greater need for the individual to put energy into maintaining their Sick Role and escalating features associated with revolving door patients.

**The Three Phases of Persistent Pain**

**Phase One:** When participants first experienced their pain they moved from health behaviour into illness behaviour which is synonymous with preparing to enter the Sick Role. At this stage participants were guided by the medical model and sought help from their doctor. This was seen in all participants and verified by having been referred to the DGH pain clinic. Seeking professional help not only served the purpose of legitimising their pain but was an expected behaviour of those in the Sick Role (Kasl et al., 1966a; Parsons, 1951). When individuals present their symptoms to clinicians, an implicit requirement of the Sick Role is that the individual presents with something that has a no-fault basis; in other words that it looks like a disease and
psychological symptoms were minimised and the physical symptoms maximised (Kwan & Friel, 2002). Endeavoring to meet these requirements was evident in participants’ descriptions of their pain and their focus on its physical origins.

Previous experience with acute illness will tell most individuals that adherence to medical advice is usually and legitimately essential for a successful health outcome (Becker et al., 1974). It provides a pathway of care that as long as they continue to conform to, then the cause for their symptoms will be cured. They are unlikely to be considering taking on a self-management approach at this stage of their pain experience, believing it is a medical condition. Professionals are expected to relieve it (Burns et al., 2005), and the disappearance of pain through cure is often seen by individuals as a way of making sense of their pain (Eccleston, De C Williams, & Stainton Rogers, 1997). Therefore a proportion of participants would have been expected to be in the Precontemplation stage as found in the Service Development Project.

However, the majority of participants in this study were in the Contemplation Stage having progressed from the Precontemplation Stages of Change to the Contemplation stage. While it was likely that these participants had self-selected themselves into the study, it was also likely that participants in the Precontemplation Stage had selected themselves out. Participants also had durations of pain of at least one year and were possibly beginning to become aware of the limitations of the medical model as seen by discussions in the
focus groups. They may already have begun to consider alternative approaches including developing self-management and this would correspond with being in the Contemplation Stage of Change as measured by the PSOCQ.

**Phase Two:** This phase is considered the main focus for the outcomes seen in this study as the majority of participants in the Intervention and Control groups were in the Contemplation Stages of Change. They had adopted behaviours associated with the Sick Role that included receiving treatments such as taking medication and utilisation of health care resources (Kasl et al., 1966a; Wade & Halligan, 2007) and had assumed the Sick Role. While Kasl et al (1966a:246) may argue that behaviour taken to define a diagnosis and 'discover a suitable remedy', is illness behaviour, this study found this behaviour in individuals with persistent pain where a diagnosis was unavailable. Behaviour taken to define their state of health was enmeshed within behaviours associated with the Sick Role and amalgamated within Phase 2 of the PPP. At the same time these individuals were actively cooperating towards a 'cure' often viewed as the only way an individual can return to their normal role and resumption of health (Suchman, 1965). While this may be effective for acute illnesses, it can appear to trap individuals with persistent pain conditions in Phase 2 of the PPP and in the Sick Role, where there is often no clear pathway that will lead to its end (Wade & Halligan, 2007)
Combining the data provided evidence to suggest many individuals in the Intervention and Control group were caught up in a vicious cycle of actions aimed at maintaining the credibility of their Sick Role; by doing so this may have redirected energies away from more appropriate behaviours and opportunities to find successful treatment pathways out of Phase 2. The vicious cycle described in Phase 2 of the PPP is allied with ‘revolving door patient’ who move between a variety of different services without any true strategy to deal with their individual needs, as they experience repeated appointments ‘with poor or unresolved outcomes’ (Chronic Pain Policy Coalition, 2007:23).

What appeared critical at this stage was whether the patient had acquired a diagnosis. Achieving a clear diagnosis can be a dominate factor in individuals’ beliefs about their pain. They have been shown to believe that it is essential for the cause of their pain to be established and that ‘other people do not believe in the pain of a person without a firm diagnosis’ (Allcock, Elkan, & Williams, 2007:248). While initial validation can be from family and friends, the individual is soon expected to have an exact diagnosis that gives them a label. This generally indicates whether their Sick Role is reasonable (Wade & Halligan, 2007).

Individuals in this study who were without this label described activities such as requesting repeat investigations and considerable energy was directed at maintaining the credibility of their Sick Role. These behaviours it is suggested link with those of revolving door patients who often have no clear diagnosis.
leading to activities such as doctor shopping (Moore 2004b). A diagnosis is important to legitimise entry into the Sick Role but what may be forgotten is that it provides an idea of what the future may hold for the individual and identifies a pathway of care. Gordon’s (1966) research provides important insight into validation of the Sick Role, and prognosis was considered the most important factor in validation of the Sick Role by all socioeconomic groups in society. Without a diagnosis it is argued it is impossible to have a prognosis, defined here as the long term course and outcome of an individual’s disease (Oxford, 1994).

There was also evidence that individuals may for a mixture of reasons not want to let go of the Sick Role because they associated it with a ‘curative’ model. This was particularly evident in one participant’s story of his pain where he was more accepting of degenerative changes and pain experienced in his knees, but would not let go of the curative medical model when it came to managing pain associated with a surgical procedure. There is some evidence that if pain is believed to be the fault of an individual’s employer, this is associated with greater distress (DeGood & Kiernan, 1996), and there may be some parallels if a clinician is considered at fault. This participants reluctance to accept his pain may also link with his reluctance to take responsibility for managing his pain symptoms and the no fault basis of the Sick Role previously discussed.

Data from the focus groups provides vivid descriptions from participants in both the Intervention and Control groups of their struggle to get the balance
of their Sick Role behaviour right with clinicians and their pain legitimised. A large proportion of the discussions were taken up with accounts of interactions between individuals and healthcare professionals, in particular doctors. This relationship appeared complex with several participants describing behaviours such as misrepresenting their pain and feelings to the doctor in order to protect the doctor from feeling depressed. These actions may link with wanting to appear an interesting patient and ensure the doctor/patient relationship is preserved. Preservation of this relationship may be paramount if the individual is going to be able to maintain the credibility of their symptoms especially once they have used up what might be considered to be their share of the doctors attention (Bury, 1991). This is illustrated by Reddy’s (2004:17) suggestion that patients requiring longer term support should be seen in nurse-led clinics rather than doctors’ clinics, thereby preventing ‘revolving door patients over-utilising healthcare resources’. A picture builds of individuals who are working to fit into an (uncertain) Sick Role that is neither suitable nor comfortable but nevertheless adopted because no other legitimate role is offered.

The Control group remained in Phase 2 of the PPP as measured by their failure to make any significant progress through the Pain Stages of Change or to experience improved Pain and Interference levels. The lack of change in their quantitative data supported discussions in the qualitative data that was associated with being caught up in maintaining the legitimacy of their Sick Role. Maintaining legitimacy of the Sick Role requires compliance with the medical model (Arluke, 1988), and to relinquish it necessitates individuals to
participate in their own care. This is in direct conflict with one of the obligations of the Sick Role, which is to unquestioningly comply with the opinions of health care professionals' (Faulkner & Aveyard, 2002).

While behaviour apposite to the Sick Role was identified in both groups the Intervention group’s accounts of experiences were notable for their references to the impact attending EPP had had on them. Some of their descriptions were considerably more powerful than just describing an educational encounter, and illustrated a life changing experience. This might imply that EPP can offer individuals an alternative pathway and all together more suitable role where they can get on with their lives even though they have persistent pain. Their comments may reflect improvements in well-being as seen in other studies (Haas et al., 2005), but was not a variable measured in this study and therefore only observational evidence from the focus groups is offered.

Attending EPP was not considered beneficial by all participants. One participant found it ‘depressing’ listening to other peoples’ problems and preferred the format and content of the focus group. She describes being able to relate to the focus group because it had a more serious approach. This might equate with the focus group having a professional approach as it was facilitated by a professional. This suggests some individuals may find greater benefit from professionally led groups, but may also reflect the power of the medical model sanctioning an approach and giving it credibility. This
power should not be ignored in delivering EPP and the power of medicine has been discussed at greater length in the Policy Review.⁴

In Phase 2 of the PPP it is the important to consider the possible impact lay role models can have. By attending EPP, the Intervention group was exposed to lay role models of EPP tutors who were getting on with life and no longer focusing on behaviours associated with maintaining the Sick Role. Through exposure to lay role models and supported by the content of EPP, individuals were offered an alternative approach that created new and substantial opportunities for gain. If this gain was seen as sufficient it may have shifted participants’ views. Becoming aware of new gains and perceived losses that could be experienced if they failed to adopt aspects of this new role, may contribute to raising their consciousness that perhaps relinquishing the Sick Role was possible (Kasl et al., 1966b; Kwan & Friel, 2002).

The current study’s theoretical framework (Figure 5) is referred to, to give visual understanding of the processes that occurred in the Intervention and Control group and the promotion through the Stages of Change seen in the Intervention group. It is recognised that because the majority of participants were in the Contemplation Stages of Change this was pivotal in outcomes seen as participants were more receptive to engaging in a self-management approach. The influence of the lay tutors as role models may also have been of crucial importance in influencing participants at this receptive point in their experience of pain. The potential of modeling to achieve changes in health

⁴ See Policy Review Part Two
behaviours has previously been identified (Bandura, Jeffery, & Wright, 1974), and the important function of lay role models on multidisciplinary pain management programmes is recognised through the role modeling participants on programmes can provide for each other (Dysvik, Guttormsen Vinsnes, & Eikeland, 2004). Opportunities existed in this study for participants to provide proactive role models through helping and supporting their fellow members and comparisons of outcomes between lay-taught and professionally-taught self-management has shown little overall difference in their outcomes (Cohen, Van Houten Sauter, DeVellis, & McEvoy DeVellis, 1986; Lorig et al., 1986).

Nevertheless, the impact the lay tutors had on participants cannot be ignored. Discussions in the focus groups suggested the approach of the lay tutors was critical in either engaging or disengaging the participant in EPP. However, as Lorig & Holman (1989) suggest, it is not possible to identify exact mechanisms which mediate improved health status and it is beyond the scope of this study to identify precise mechanisms. Nevertheless, the following five are tentatively offered as critical to the taking on of a self-management approach to managing persistent pain:

1. Participants being in the Contemplation Stages of Changes
2. Lay-role modeling
3. Self care approaches given equal importance and credibility to the medical model approach
4. Self care approaches offered in parallel to curative models
5. Individuals being allowed to choose/self select themselves in and out of different approaches. This does not mean they can waste resources by just not turning up but that they must be proactively engaged in the process and use resources responsibly.

6. Acquiring a diagnosis.

**Phase Three:** Phase Three requires a 'relinquishing' of the Sick Role to order to allow the resumption of previous social roles (Kasl et al., 1966a) that will enable the individual to return to their former well status. This may be fairly straightforward following an acute illness (Suchman, 1965), but in chronic illness 'sickness rarely resolves rapidly, and there is often no clear procedure for terminating the Sick Role' (Wade & Halligan 2007:295).

Although there were discussions in both groups about behaviour changes it was only the Intervention group who appeared to perceive their lives could be different if alternative behaviours or roles were adopted. The Intervention group talked of taking on different behaviours that were associated less with maintaining the Sick Role and more with adopting health styled behaviours. To leave the Sick Role the individual needs ‘other attractive roles to return to or enter anew’ (Wade & Halligan, 2007:296). Wade & Halligan (2007:296) suggest that ‘sometimes patients are not given adequate guidance on their future to encourage them to find new roles and in the absence of any alternative social role, some people can remain in the patient role’. This study proposes an alternative and accessible role called the Persistent Condition Role (PCR). Critical to the PCR is for individuals to acquire a diagnosis and be
able to direct their energies at regaining health behaviours and a role associated with maintaining well being.

This has some similarities with Gordon’s (1966) ‘impaired role’. The impaired role was seen to ‘aid and maintain normal behaviours’, while the Sick Role served to ‘insulate and protect the ill person’ (Gordon, 1966:99). In keeping with this study’s findings Gordon (1966:100) advises that the appropriateness or inappropriateness of the role response of the unwell individual can ‘delay prevent or promote’ their recovery. He suggests ‘misappropriate responses can keep a person an invalid’ but this is where the similarities between the impaired role and the PCR cease. When an individual is ‘defined as ‘impaired’ not only is he denied certain supports but there is some discouragement of his seeking medical care’ (Gordon, 1966:100). The PCR promotes supporting and involving medical care as one approach but complemented by a self-care approach in order that the individual may resume healthy behaviours and either avoid entry into the Sick Role or facilitate a prompt exit.

The PCR is different to convalescence, an approach advocated by Wade & Halligan (2007) to ‘facilitate an exit from the Sick Role’. Convalescence as identified earlier infers a temporary role aimed at restoring health and may be appropriate for some long term conditions where gradual recovery is a viable aspiration. However persistent pain is by its nature is for the duration of the individual’s life and recovery may not be a realistic goal (Bury, 1991).
What may also be important in enabling individuals to relinquish the Sick Role is the length of time they have spent in it. Individuals with prolonged experience of the Sick Role can go through lasting identity changes (Kasl et al., 1966a). Studies have found that the shorter the period of illness experienced by the individual, the easier they were likely to find it to revert to the status and role of healthy (Brown & Rawlinson, 1975). This gives strong support for introducing self-management approaches in the very early stages of pain management to complement medical models, particularly as the tendency to retain or relinquish the Sick Role can be closely associated with the speed, completeness, and ease of the recovery phase (Brown & Rawlinson, 1975).

This study also indicates that combining a self-management approach with a medical model approach had synergistic effects that were not seen when solely a medical model was offered. As already mentioned a third group receiving only the intervention (EPP) is needed to claim this with greater confidence. However, this study showed that 11% of participants in the Intervention group moved from Contemplation and Precontemplation Stages of Change to a Maintenance stage by the end of the study and none had regressed. Meanwhile participants in the Control group exposed only to a medical model, showed no movement in their Stage of Change, and all remained in the Contemplation Stage. They also failed to experience the improvements in Pain and Interference levels seen in the Intervention group. Evidence from this study suggests if individuals are not provided with a way out of the Sick Role they are unlikely to relinquish it. If other social roles are
absent then some individuals are 'likely to stay in the patient role' (Wade & Halligan, 2007); EPP could offer a way out but this study proposes it requires a medical model in tandem to achieve optimum effect. Similarly a medical model is unlikely to achieve optimum effect without a self-management approach complementing it.

7.8 Conclusion

The findings propose that being trapped in the Sick Role is central to the impact persistent pain can have on an individual’s life. An alternative and equally sanctioned role to that of the Sick Role needs to be accessible and suggested here as the 'Persistent Condition Role' (PCR). Individuals could then access an appropriate role that is accepted by society and has strategy to deal with the individuals needs. This may involve both medical and self-care approaches that guide individuals back to resuming their usual social roles preventing them from becoming trapped in Phase 2 of the PPP. The PCR may give individuals greater opportunity to relinquish what they perceive as the 'curative' Sick Role and prevent escalation of revolving door patient syndrome. There is already some evidence that movement away from beliefs in a medical cure during the early treatment stages may be vital in contributing to improvements in later treatment outcomes (Glenn & Burns, 2003). The current study adds further evidence to this importance through the outcomes observed following early introduction of a self-management approach alongside usual care in managing persistent pain.
The outcomes in this study have been guided by the integrated theoretical framework (Figure 5) which proposed that for the individual to make a decision they need to be made aware of the choices; this only becomes possible if they are exposed to them. While decision making is a complex process (Janis & Mann, 1977), the two major categories influencing decisions to change behaviour, that of pros and cons (Prochaska et al., 1994) are seen in participants accounts. Some of them describe a process they have to go through in order to reach a decision to leave behind certain behaviours associated with Sick Role behaviours.

Because participants in this study were also receiving care from a medical model approach it was not possible to identify whether the degree of changes found were due to the impact of EPP or the synergistic effect of the two approaches. However, the RCT design can recommend that a medical model alone does not appear as effective in promoting self-management behaviours and improving Pain and Interference levels as an approach that integrates both medical and lay led self-management approaches.

Having discussed the results it is important to review possible limitations imposed by the research design and methodology that may restrict interpretation of the results.
8 Limitations of the study

While the research methodology was considered appropriate to explore the issues related to self-management approaches there were limitations in the design, and several require consideration. These were the time intervals for collecting data, non-blinding of the study, influence of completing a self-report health related questionnaire on behaviour, and sample number.

8.1 Time interval for collecting the data and attending EPP

Because the intervention EPP was organised through the local Primary Care Trust (PCT) and relied on availability of tutors it was not possible to offer EPP to participants at exactly the same time point in the study. During the summer months most tutors were away and the researcher was unable to organise an EPP to run for several months. Nevertheless, participants continued to be recruited in order to optimise recruitment. Inevitably this led to participants experiencing the intervention at slightly different points against their data collection times and time following referral to the pain service.

Adding to these differences was the fact that participants themselves were not necessarily able to attend the EPP allocated to them because of other commitments or the time of the course did not suit them. Despite these difficulties the majority of data was collected at the planned times.

A further difficulty related to the lower than expected recruitment rate to the study. Because of this it was necessary to advertise the EPPs in local papers.
in the same way that EPPs are normally recruited in the Community in order to have sufficient numbers of individuals to make it viable to run each programme. No part of the EPP format was changed in anyway and participants from the study and participants from the general public were treated identically. It was felt by involving a mix of participants from the general public and participants’ recruited from the study, this ensured that the EPPs involved in this study were identical to those any member of the general public might access. This ensured outcomes found in the study were due to the impact of EPPs and not influenced by the research study and adds confidence to generalisation of the findings.

8.2 Non-blinding and influence of completing a self-report health-related questionnaire on behaviour

In the design stage of this study there were concerns that sending out invite letters to potential participants that included details about the study and information on the self-management intervention (EPP), participants could be influenced. The main concern was influencing the Control group and some studies exploring self-management programmes have avoided telling participants about other groups in the study and the purpose of the study (Lorig et al., 1986). However, all participants were provided with the same information and were aware of being randomised and of the intervention and purpose of the study. This does highlight ethical concerns of having a control group and has in part explained why RCTs exploring EPP have only been run for short periods of time (Bury et al., 2005). Because this study was offering EPP at a much earlier stage than participants might usually consider it and
the Control group were offered usual care and denied no usual treatment, it was considered ethical to have a control group.

Asking participants in both groups to answer questions connected to their pain and health related behaviours this could potentially impact on their awareness of their condition and self-management aspects of managing it. However, a recent study exploring the effect of health-related questionnaires on behaviours found questionnaires did not affect standard consulting behaviours even for the conditions under investigation (Jeffrey, Jinks, & Jordan, 2006).

Further limitations that require considerations was the choice of employing self-report questionnaires to gather the data. The return rate for the baseline data was high (84%) lessening the possibility of bias that can be seen in low response rates. However, the response rate did reduce as the study progressed with 57% return rate at 3-6 months and 40% at 9-12 months. The questionnaires enabled a greater number of participants’ data to be gathered complementing qualitative data gathered from the focus groups. Nevertheless, questionnaires do eliminate those participants who simply cannot fill out a questionnaire, for example because of poor eye sight, elderly or illiterate.

Using a self-report questionnaire had obvious advantages as it allowed information to be gathered which would otherwise have been impossible due to limited time and resources available for a solo researcher. However, self-
report methods have added weaknesses that need recognising, the most serious being the question of validity and accuracy of self-reports’ (Polit et al., 2001). It is not always possible to be sure participants felt and acted the way they said they did, or gave answers that they felt were expected. Despite these concerns it has to be assumed that participants recruited answered the questionnaires truthfully.

8.3 Sample number

The sample number (N=63) while small compared to some RCTs exploring self-management approaches (Barlow et al., 2000; Buszewicz et al., 2006; Griffiths et al., 2005; Lorig, Seleznick et al., 1989; Von Korff et al., 1998), is comparable to others (N=65-86) (Burns et al., 2005; Cohen et al., 1986; Habib et al., 2005) and a single researcher study recruited smaller numbers (N=41) (Sohng, 2003).

The sample number was smaller than predicted and inevitably reduced the power of the study and confidence that the changes seen were due to the intervention. However, as Cohen et al (1986) identify in their study the issue rests on the researcher’s judgement of how big a difference is important. As in Cohen et al (1986) the sample number was considered adequate for important differences to achieve statistical significance.

The recruiting process in itself raised awareness of the current negative view many individuals have of treatment approaches that focus on their own behaviour and has been associated with deligitimation of their pain (Eccleston
et al., 1997). Carr et al (2006) experienced a response rate of 31% to their study exploring interest in self-management using EPP where no intervention was involved. The Service Development Project (SDP) recruited 40% of individuals approached when no intervention was involved while the main study involving a self-management approach recruited 26% of potential participants approached, suggesting self-selection occurred. As in Carr et al (2006) there are concerns to the extent to which the sample represented the clinic population, but outcomes are strengthened and supported by information acquired from the SDP.5

Once recruited to the study 47% of participants dropped out which was similar to the predicted drop out rate of between 30-60%. Drop out rates have been reported of between 28-32% (Lorig et al., 1999; Von Korff et al., 1998). Overall the sample was considered a heterogeneous group of individuals referred to a DGH Pain Clinic.

8.4 Missing data

The amount of data missing was considered small (1.4%) but weakens the confidence that can be afforded to the outcomes. The size of the study meant it was not feasible when analysing the data to leave out questionnaires that were not fully completed. All questionnaires were more than half completed and mean values were inserted where data was missing and was the approach adopted from and previously used in a self-management study (Barlow et al., 2000).

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5 See Service Development Project Part Two
9 Implications for Clinical Practice and Future Research

Findings in this study have significant implications for how persistent pain is managed within the current paradigmatic shift towards self-management as an effective approach for its treatment. While results can only be generalised to populations of individuals referred to a DGH pain management service with musculoskeletal pain, this study has shown that individuals who are ready to consider taking on a self-management approach can benefit from its early introduction in parallel with medical model treatments. Together the approaches have a synergistic effect and individuals are empowered to begin relinquishing the inappropriate Sick Role and to take on a more helpful and safer role, suggested as the Persistent Condition Role (PCR).

However, healthcare professionals need to actively assist individuals towards a self-care approach during the early stages of their pain management. While self-care approaches should not be seen as a replacement for professional care, they can be a natural complement (Bentzen, Christiansen, & Møller Pedersen, 1989). There can be a tendency for self-care to be associated with de-legitimising an individuals pain (Eccleston et al., 1997) and this is an unhelpful outcome and must be avoided. It is therefore important that different approaches to managing pain are given equal importance (Bendelow & Williams, 1996) and that this parity is seen from the perspective of both patients and professionals.
Engaging patients in their care is not an approach to care that is universally accepted by patients and clinicians (Cahill, 1998). Therefore pain management services may need to consciously adjust the initial emphasis on applying the 'curative' medical model to patients also associated with the Sick Role. It can often appear that it is only once the medical model has been optimised or failed that the balance swings towards a biopsychosocial approach through the involvement of a pain management programme. This incorporates cognitive behavioural therapies where the overarching goal is to enable the individual to manage their pain independent of professional health care support. Alternatively, individuals may access lay led self care approaches, but this linear process of accessing medical model methods first, followed by approaches aimed at developing self-management needs to change. This would allow the synergistic value of the two approaches to be offered in tandem and their combined value fully recognised.

There is sufficient evidence now to show lay led self-management approaches are appropriate in the management of long-term conditions (Kennedy, Reeves et al., 2007; Lorig et al., 2001). Therefore they should be treated as part of a range of formal and informal approaches that can be chosen by the patient (Bury et al., 2005), with the emphasis on individuals choosing to opt into a self-management approach alongside a medical model. This study and the SDP has shown between 26% and 37% of the population referred to a DGH pain management service will be amenable to adopting self-management approaches at much earlier stages in referral pathways than presently offered. This represents a considerable number of patients referred
to a pain service and the focus needs to shift more towards involving self-
management approaches in care pathways at the initial point of contact with a pain management service.

As this study has shown individuals will tend to self-select themselves into intervention approaches that fit the Stages of Change they are in. Stages of Change may be a valuable measure for stage matching approaches individuals are most likely to successfully engage in rather than approaches they are likely to complete. Studies have shown that individuals are no more or less likely to complete a programme if they are in the Action and Maintenance Stages of Change (Kerns & Rosenberg, 2000), but along with those in the Contemplation Stage they may be more likely to engage in the approach. Neither are individuals more likely to change behaviours if the information they are given is stage matched (de Vet et al., 2007). However, Stages of Change may be critical to incorporate in clinical practice to guide healthcare services in providing approaches individuals are likely to be receptive to and therefore able to engage in and benefit from. This could involve lay or professionally led self-management approaches, or purely a medical approach or a combination of the two approaches.

Healthcare professionals involved in pain management services may need to relax the control they currently exert over judging who is or is not appropriate for inclusion in self-management approaches and employ measures such as the PSOCQ to assist them. Individuals considered not ‘ready’ by professionals to adopt a self-help pain management approach have
nevertheless shown improvements following attendance of a shortened version of the traditional pain management programme (Arthur & Hamling, 2003). While it is acknowledged that some patients will consider that it is ‘their right to be cared for by experts at a time when they are unwell and may resent having to participate in their care’ (Saunders, 1995:43), this study argues that when individuals are shown an alternative and credible role to the Sick Role, which is endorsed by the medical model, they may feel this is a preferable and safe option.

Nonetheless, self-management approaches should not be seen as a rigid prescription that individuals ‘should do’ but rather that they ‘can do’ if they are at the right stage. Some researchers have voiced concern that self-management approaches will declare what patients ‘should think and do’ (Newbould, Taylor, & Bury, 2006). These concerns need balancing against the current emphasis on encouraging patients to participate in their own care that appears to conflict directly with one of the obligations of their Sick Role, that of complying unquestioningly with the opinions of health professionals (Faulkner & Aveyard, 2002). Evidence suggests that patients do actually want to participate in their care, but professionals while admitting the potential of patient participation (Kennedy, Rogers et al., 2007), may prefer patients to be passive recipients (Cahill, 1998; Wilson, Kendall, & Brooks, 2006).

Achieving changes to the delivery of care for long-term conditions is complex and not just about re-educating patients and preparing professionals for more facilitative roles that will advance patient participation. It may also be about
patients and clinicians feeling comfortable with a change in the balance of behaviours associated with the provision of healthcare. Only then may the management of long term conditions be more effectively managed and some of the psychosocial consequences addressed early on.

Despite the advantages adopting a self-management approach can have, there will be patients who prefer to assume a passive role or will not be at an appropriate stage in their condition to consider adopting this approach. Different mechanisms will be required for these individuals and health care professionals must guard against providing a one size fits all approach to managing persistent pain. Patients need to be allowed to participate in different approaches without restrictions imposed internally and externally which may only increase their endeavours to fulfil the obligations of their Sick Role.

To offer lay led self-management programmes in parallel with medical model approaches for many pain management services will not be without its complications. This model of care will have practical implications for lay led programmes that may require modifications to its delivery in order that the demands on such a model can be met effectively and efficiently in clinical practice. While some lay led programmes have demonstrated they are no less effective than professionally led programmes (Cohen et al., 1986; Lorig et al., 1986) and 'likely to be cost effective’ (Kennedy, Reeves et al., 2007:260), there are practical issues associated with running lay led programmes that are specific to a service provided by volunteers. Difficulties
that transpired during the course of this study were the availability of tutors due to recruitment difficulties, sickness and holidays. Understandably tutors also wanted to limit their involvement because of other personal commitments. These issues raise concerns regarding how much can be expected from people volunteering to provide a service while at the same time there is a need to provide a regular and dependable service that can cope with the demands placed on it.

The whole ethos of being a volunteer is that actions are brought about by free choice, but if as this study is advocating, lay led self-management programmes are to be provided alongside professionally led services in pain management departments, how well can this balance work? Can the standards that are expected of professionally led services be equally applied to volunteer led services? Perhaps it is not reasonable to expect equity of service delivery and the answer may lie in providing professionally led self-management services supported with lay input.

Currently the NHS is piloting an ‘add on’ persistent pain module to the broader Expert Patient Programme. This module is being delivered with the support of professionals (Bray, 2006) in both community and hospital settings. While there are cost implications for running professionally led programmes supported by lay input rather than the other way round, it is suggested that if this approach is going to be taken seriously by professionals and patients alike, then a professionally led delivery needs to be pursued.
However, involving the medical model in leading the delivering of Expert Patient Programmes may be just what is needed to engage clinicians in the benefits of lay delivered self-management programmes and resolve the antipathy felt; this issue is discussed in greater detail in the Policy Review. While a synergistic model of care delivery may represent a positive challenge to professional power, it may also be a model of care that could go some way to healing the power struggle between political and clinical decisions associated with some self-management approaches. A synergistic model of care could encourage professionals to work differently and achieve a shift in culture within the NHS that supports self-management and currently considered a huge challenge to achieve within the NHS (Lewis & Dixon, 2004).

Furthermore, studies involving self-management approaches can shy away from involving control groups in clinical practice, citing ethical and practical problems with research design (Mead et al., 2007). This needs overcoming so that a greater volume of robust evidence is available to add to current RCT studies (Buszewicz et al., 2006; Griffiths et al., 2005; Haas et al., 2005) and support how self-management approaches can be best implemented and in what format. It is also important that future studies explore the synergistic effect of self-management approaches combined with the medical model. The current inclination is to explore self-management approaches independent of medical treatments, and after all the EPP was never designed to run in

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6 See Policy Review Part Two
isolation but alongside treatments provided by healthcare professionals (Chronic Pain Policy Coalition, 2007).

One of the few other studies to explore the early introduction of self-management approaches alongside medical treatments (Mead et al., 2007), base their shortened self-management programme on the 'same model and principles' of a traditional pain management programme. Although Mead et al (2007) does not have the strength of a RCT, they found evidence that such an approach offered at an earlier stage may be an effective intervention for individuals experiencing persistent pain. The debate over when and how self-management approaches should be offered in current health care systems is clearly beginning to open up and further robust studies are needed to guide its development.
10 Conclusions and Recommendations

This study is the first to suggest an association between the Stages of Change process and the Sick Role. It concludes that improvements seen in the Intervention group were associated with progress through the Stages of Change and linked with participants adopting self-management approaches and relinquishing their Sick Role; this allowed them to take on a more appropriate role described as the Persistent Condition Role (PCR). Early exposures to a self-management approach (EPP) impacted on participants who were in the Contemplation Stages of Change and enabled them to consider and adopt self-care behaviours. These behaviour changes were interlinked with social roles and an awareness of alternative roles, but in order to take on a self-management approach participants had to progress through the Stages of Change; in doing so they began to relinquish the Sick Role for a more appropriate role, the PCR.

The lay led self-management programme (EPP) was responsible for participants in the Intervention group making significant progress through the Stages of Change. This was also associated with significant improvements in Pain and Interference levels, and trends for reducing routine use of their General Practitioner. Individuals in the Control group showed no significant progress through the Stages of Change nor did they experience improved levels of Pain and Interference. Their levels of Acceptance regressed slightly and they showed a small increase in the use of their GP, though neither of the latter two measures reached levels of significance.
Outcomes in participants in the Control group suggest exposure to purely a medical model does not promote adoption of self-management approaches and participants become caught in the Sick Role described in this study as Phase Two of the Persistent Pain Phases. Implications are that self-management approaches have to be delivered with equity to the more traditional medical model and health care professionals need to positively challenge their preference for passive patients. Medicine has an important place in facilitating and constraining the adaptation of individuals in the management of persistent conditions (Bury, 1982), and its ability to facilitate this needs fully unleashing. Perhaps neither the biomedical or self-management model of care is adequate on its own, but together this study suggests their synergistic effect may reduce some of the distress, cost and psychosocial disruption that can accompany persistent pain conditions.

Further development in biopsychosocial mechanisms will it is hoped lead to greater understanding of complex issues associated with persistent pain and its maintenance (Gatchel, Peng, Fuchs, Peters, & Turk, 2007). It is proposed that the contribution laid self-management approaches can add to this understanding must be included in future research. Addressing the needs of those with long term conditions and involving self-management approaches to reduce distress and other costs they impose has taken a position of greater importance on the healthcare agendas of all 'rich' world nations (Bury et al., 2005). Nevertheless, political drivers in the development and implementation of polices such as EPP need to be balanced with robust research to ensure its social bearing and capacity to 'deliver value for money'
are met (Bury et al., 2005). Further research must meet these clinical needs and when evaluating self-management approaches, their ability to deliver value for money needs fairly comparing with medical model approaches. While a 20 – 30% drop out rate for EPP has been reported (Lorig et al., 1999), a typical Pain Clinic can experience 17.5% non-attendees of medical consultant clinics which may have greater overall cost implications than a higher drop out rate for a lay led self-management programme.

However, there is concern that with well intended innovations such as EPP any harm that could occur might be overlooked (Bury et al., 2005). Safety has to be paramount in any approach and the potential of self-care approaches to cause harm needs addressing in future studies. Additional concerns aimed at current evidence for lay led self-management approaches suggest benefits are 'short as opposed to long-term’ (Newbould et al., 2006) and recent longitudinal studies in the UK have addressed this (Buszewicz et al., 2006). Nevertheless, this evidence should be measured against increasing evidence that medical model treatments offered for some persistent pain conditions, can fail to provide effective long term reductions of pain symptoms (Brox et al., 2006; Fairbank et al., 2005; Moore et al., 2003). By engaging the benefits of both approaches in parallel, they may complement each other and a synergistic effect generated that is greater than each approach delivered independently. Greater emphasis is now needed to design research studies that recognise that EPPs were never designed to run independent of treatments provided by healthcare professionals, but to run alongside these treatments (Chronic Pain Policy
Coalition, 2007). Only then it is suggested will the true value of lay self-management approaches be identified.

Furthermore health care professionals must guard against their apparent eagerness to conclude results from lay led EPP are less effective than professionally led self-management programmes. Recent comparisons between lay led EPP and cardiac, diabetic and pulmonary professionally-led self-management and rehabilitation programmes suggest outcomes for EPP were disappointing (Griffiths, Foster, Ramsay, Eldridge, & Taylor, 2007). What Griffiths et al (2007) overlook in reaching these conclusions is that individuals attending the professionally-led programmes may have experienced shorter periods of illness, were unlikely to be struggling to legitimise their diagnosis, and where not up against a perception that they may have used up their share of healthcare professionals time. By comparison the psychosocial consequences of their condition may be considerably less complex then individuals attending an EPP. All these factors may impact on why some professionally-led programmes for some chronic illnesses appear to gain better results. Lorig et al (1986) and Cohen et al (1986) have demonstrated that when fair comparisons are made, lay led self-management programmes are no less effective than professionally led self-management programmes.

The most important clinical development in persistent pain over the last twenty years may not have been the development of new treatments but a thoroughly revised interpretation of the mechanisms that act to maintain it
(Nurmikko et al., 1998). This has important connotations when it is realised that the incidence of persistent pain conditions such as low back pain remains stable but the incidence of disability continues to rise (Evans & Richards, 1996). Therefore, the health economy needs to understand that what is required are not new treatments but support for new approaches: these need to correspond with our understanding of pain mechanisms and achieve a positive shift in culture within the NHS that will support self-management approaches on an equal par with traditional medical models.
11 References


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12 Appendices

12.1 Titles, Definitions and Representative Interventions of the Processes of Change (Prochaska et al., 1992)

<table>
<thead>
<tr>
<th>Process</th>
<th>Definitions</th>
<th>Interventions</th>
</tr>
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<tbody>
<tr>
<td>Consciousness raising</td>
<td>Increasing information about self and problem</td>
<td>Observations, confrontations, interpretations, bibliotherapy</td>
</tr>
<tr>
<td>Self-re-evaluation</td>
<td>Assessing how one feels and thinks about oneself with respect to a problem</td>
<td>Value clarification, imagery, correction emotional experience.</td>
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<tr>
<td>Self-liberation</td>
<td>Choosing and commitment to act or belief in ability to change</td>
<td>Decision-making therapy, New Year’s Eve resolutions, logo therapy techniques, commitment enhancing therapies</td>
</tr>
<tr>
<td>Counter conditioning</td>
<td>Substituting alternatives for problem behaviours</td>
<td>Relaxation, desensitisation, assertion, positive self statements</td>
</tr>
<tr>
<td>Stimulus control</td>
<td>Avoiding or countering stimuli that elicit problem behaviours</td>
<td>Restructuring one’s environment (e.g. removing alcohols or fattening foods) avoiding high risk cues, fading techniques</td>
</tr>
<tr>
<td>Reinforcement management</td>
<td>Rewarding one’s self or being rewarded by others for making changes</td>
<td>Contingency contracts, overt and covert reinforcement, self reward</td>
</tr>
<tr>
<td>Helping relationships</td>
<td>Being open and trusting about problems with someone who cares</td>
<td>Therapeutic alliance, social support, self help groups</td>
</tr>
<tr>
<td>Dramatic relief</td>
<td>Experiencing and expressing feelings about one’s problem and solutions</td>
<td>Psychodrama, grieving losses, role playing</td>
</tr>
<tr>
<td>Environmental re-evaluation</td>
<td>Assessing how one’s problem affects physical environment</td>
<td>Empathy training, documentaries</td>
</tr>
<tr>
<td>Social liberation</td>
<td>Increasing alternatives for non problem behaviours available in society</td>
<td>Advocating for rights of repressed, empowered, policy interventions</td>
</tr>
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</table>
12.2 Invite Letter to Participants

Pain Management Clinic

Date

Direct Line:
Helpline:

Study no:

Dear

I would like to invite you to take part in a study researching the benefits of self-care approaches in the management of persistent pain. You have been selected as one of 240 patients to participate in this study and this letter is to ask if you are willing to participate. Accompanying this letter is a patient information sheet and you are under no obligation to respond. Taking part in this study is optional and failure to respond or unwillingness to take part will in no way affect your referral or treatment by the Chronic Pain Management Service.

Ethical review from North West Surrey Local Research Ethics Committee has been sought and given and my work is supervised through the University of Surrey, as this study is part of a Doctorate in Clinical Practice I am currently undertaking.

Pleased find enclosed the information sheet. If you have any queries or concerns about this study or any of the information attached, please do not hesitate to contact me on one of the following telephone numbers:

01932 723998 Helpline (24 answer phone)
or
01932 722579 (Barbara Criford will take a message)
or page me on
01932 87200 Pager 8456 (Wednesdays is one of the best days to contact me).

Please telephone me or complete the attached form in the stamped addressed envelope if you would like me to contact you with further information or are interested in taking part.

Thank you for taking your time to read this.
Yours sincerely

Heather Hawksley MSc BSc(Hons) RGN
Consultant nurse
12.3 Information sheet

Information for Patients

Promoting a Self Care Approach for Managing Persistent Pain

You are being invited to take part in a research study exploring the possible benefits of self-care approaches for managing persistent pain. Before you decide it is important for you to understand, why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask me if there is anything that is not clear or if you would like more information.

What is the purpose of the study?
Self-management is becoming increasingly important in the management of conditions such as persistent pain because of the possible benefits it can give. This study aims to explore if greater benefit is gained from introducing a self care approach earlier in the care of patients suffering from persistent pain.

Why have you been chosen?
You are one of 240 patients who have been chosen because you have been referred to the pain clinic, and you maybe someone who could benefit from a self-support approach as part of your care.

Do you have to take part?
It is up to you to decide whether to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care you receive.

What will happen to me if I take part?
If you decide to take part, you will be allocated to one of 2 groups. One group receives the self-support treatment and the other group receives usual treatment. This is called a randomised trial; sometimes when we do not know which way to treat patients is best, we need to make comparisons. The two groups will be selected using a computer, which has no information about the individual, i.e. chance. This study will occur during the time you on the waiting list for an appointment with the pain clinic. It will not delay or affect the date of your first appointment in anyway.

What do I have to do?
If you decide to take part in the study, you will be allocated to either the group that receives the treatment or the group that has no extra treatment. There is a 50% chance of being allocated to the treatment group.

Treatment group
If you are allocated to the treatment you will be asked to attend a 2.5 hour session once a week for 6 weeks. A specially trained Expert Patient will teach this. The programme will be held at St. Peter’s Hospital in the Pain Management Department or at a centre in the community and the day and time of day will be organised to try and fit in with your needs.

Control group (no treatment group)
If you are allocated to this group, you will receive no additional treatment.
Patients in both groups will be sent a questionnaire to complete at the start and at 4 and 9 months. This can be completed in your own home and returned in the stamped addressed envelope.

You will also be asked if you would like to volunteer take part in a focus group. These are small groups of patients (8-12) who will meet with the researcher at 4 months and 9 months after the date you started the study. Focus groups are discussion groups that will provide information to help us understand if the self care approach is improving care.

The focus groups will be held in the pain management department at St. Peter’s Hospital at a date and time that will suit most patients attending. Travel costs for public transport or petrol but not taxis will be paid for those attending focus groups.

What is the treatment being tested

The treatment being tested is introducing the self-management programme taught by Expert Patients at the beginning of treatment, rather than possibly introducing it at a much later stage.

What are the possible disadvantages of taking part?
There are no known disadvantages or risks in taking part in self-management programme.

What are the possible benefits of taking part?
We hope there may be benefits from a self-care approach introduced at the beginning of treatment. The information we get from this study may help us to treat future patients with persistent pain better.

Will my taking part be kept confidential?
All information, which is collected about during the course of research, will be kept strictly confidential. Any information about you which leaves the hospital will have your name and address removed so that you cannot be recognised from it. Direct quotes may be used in study findings but they will be anonymised and it will not be possible to trace them back to the individual.

Your GP will be informed you are taking part in the study and your taking part will be documented in your hospital notes. It may be possible for research audit purposes that your medical records will be examined by staff working in the NHS who would not normally have access, but all information about yourself will be kept confidential.

What will happen to the results of the research study?
The results of the study will submitted to the University of Surrey as part completion of my Doctorate in Clinical Practice. A report will be written for the hospital and for publication in a recognised medical or nursing journal. It is expected this will be written within 12 months of the last patient completing the study. You will be welcome to request a copy of the report.

Who is organising and funding the research?
xxxxx Hospitals is sponsoring this research. Any additional funding required will obtained from charitable grants to pay essential costs of the study.

Contact for further information

Heather Hawksley, Consultant Nurse
Telephone xxxxxx
Helpline: xxxxxx
Pager for urgent calls: xxxxxx
Thank you for your assistance

Promoting a Self Care Approach for Managing Persistent Pain
Please telephone me on xxxxxxxx if you would like further information about this research study or if you are interested in taking part in this study or
Complete the following details and return in stamped addressed enveloped and I will get in touch with you
Name: ..................................................................
Address: ..................................................................
..........................................................................
Post code: ........................................
Telephone Number: .................................
Best day and time to contact you: ..........................
Please return to: Heather Hawksley, Consultant Nurse
12.4 Ethical Reviews

- Local Research Ethics Committee

- NHS Research and Development Committee

- University of Surrey Ethical Committee
NORTH WEST SURREY LOCAL RESEARCH ETHICS COMMITTEE

LIST OF SITES WITH A FAVOURABLE ETHICAL OPINION

For all studies requiring site-specific assessment, this form is issued by the main REC to the Chief Investigator and sponsor with the favourable opinion letter and following subsequent notifications from site assessors. For issue 2 onwards, all sites with a favourable opinion are listed, adding the new sites approved.

<table>
<thead>
<tr>
<th>REC reference number:</th>
<th>05/Q1908/66</th>
<th>Issue number:</th>
<th>1</th>
<th>Date of issue:</th>
<th>13 September 2005</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chief Investigator:</td>
<td>Mrs Heather Hawksley</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Full title of study:</td>
<td>Promoting a Self Care Approach to Managing Persistent Pain</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

This study was given a favourable ethical opinion by North West Surrey LREC on 13 September 2005. The favourable opinion is extended to each of the sites listed below. The research may commence at each NHS site when research governance approval from the relevant NHS care organisation has been confirmed.

<table>
<thead>
<tr>
<th>Principal Investigator</th>
<th>Post</th>
<th>Research site</th>
<th>Site assessor</th>
<th>Date of favourable opinion for this site</th>
<th>Notes (£)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mrs Heather Hawksley</td>
<td>Consultant Nurse</td>
<td>Ashford &amp; St Peter's NHS Trust</td>
<td>North West Surrey LREC</td>
<td>13 September 2005</td>
<td></td>
</tr>
</tbody>
</table>

Approved by the Chair on behalf of the REC:

............................................................ (Signature of Chair/Administrator*)

(*delete as applicable)

............................... (Name)

£ The notes column may be used by the main REC to record the early closure or withdrawal of a site (where notified by the Chief Investigator or sponsor), the suspension of termination of the favourable opinion for an individual site, or any other relevant development. The date should be recorded.

SF1 Site approval form
Version 3, June 2005
Reference: 2005HH01

20 September 2005

Mrs. Heather Hawksley
Consultant Nurse
SPH, Guildford Road, Chertsey
Surrey KT16 0PZ

Dear Mrs. Hawksley

Re: Promoting a self-care approach for managing persistent pain (REC Ref: 05/Q1908/66)

I am very pleased to inform you that your project was considered by the R&D Committee on Thursday 28 July 2005 and was approved subject to Ethics approval. The R&D office has received LREC approval and has no objection to your proceeding with this study. However, the R&D Office would highly appreciate to receive final report of your study and any dissemination(s) from this work.

Best wishes,

Yours sincerely,

Dr. Isaac John
Assistant Director R&D
E-Mail: Isaac.John@asph.nhs.uk
05 October 2005

Mrs Heather Hawksley
Ashford & St Peter's Hospital
Nightingale House
Guildford Road
CHERTSEY
Surrey KT16 0PZ

Dear Mrs Hawksley

Promotion of self-care approaches for managing persistent pain
(EC/2005/105/EIHMS) – FAST TRACK

On behalf of the Ethics Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the submitted protocol and supporting documentation.

Date of confirmation of ethical opinion: 05 October 2005

The list of documents reviewed and approved by the Committee under its Fast Track procedure is as follows:-

Document Type: Application
Dated: 21/09/05
Received: 28/09/05

Document Type: A Copy of the NHS REC Application Form
Version: 4.1
Dated: 10/08/05
Received: 28/09/05

Document Type: Approval Letter from the North West Surrey LREC
Dated: 13/09/05
Received: 28/09/05

Document Type: Research Proposal
Dated: 07/05
Received: 28/09/05

Document Type: Appendix 1 – Research Study Flow Chart 1
Received: 28/09/05

Document Type: Appendix 2 – Patient & GP Letters and Information Sheet
Received: 28/09/05
This opinion is given on the understanding that you will comply with the University's Ethical Guidelines for Teaching and Research.

The Committee should be notified of any amendments to the protocol, any adverse reactions suffered by research participants, and if the study is terminated earlier than expected with reasons.

You are asked to note that a further submission to the Ethics Committee will be required in the event that the study is not completed within five years of the above date.

Please inform me when the research has been completed.

Yours sincerely

Catherine Ashbee (Mrs)
Secretary, University Ethics Committee
Registry

cc: Professor T Desombre, Chairman, Ethics Committee
    Professor K Bryan, Supervisor, EIHMS
    Dr S Faithfull, Supervisor, EIHMS
12.5 Pain Management Service Questionnaire

There are 4 sections to the following questionnaire. It is not expected to take you longer than 15 minutes to complete the whole questionnaire, so please put down your first thought/answer. If you wish to contact me about any aspect of the audit please ring 01932 722579.

This questionnaire is not a test but to help us develop the pain service – so please be honest! Thank you for your help

Study no:

Section A: About Yourself (Please tick or fill in appropriate box)

A1. What is your age? Years

A2. Are you....? Male: Female:

A3. How long have you experienced pain?

A4. Have you been given a diagnosis? Yes No

A5. What age did you leave school

A6. Have you undertaken any form of education after school? Yes No

A7. Are you currently in paid employment? Yes No

A7. How many times in the last 6 months have you seen your GP?

A8. How many times have you attended for hospital appointments related to your pain in the last 6 months?

A9. Have you attended an Accident & Emergency Hospital department (A& E) for care related to your pain in the last 6 months? Yes No
Section B  

The Pain Stages of Change Questionnaire

This questionnaire is used to help us better understand the way you view your pain problem. Each statement describes how you *may feel* about this particular problem. Please indicate the extent to which you tend to agree or disagree with each statement by circling the appropriate number. In each example, please make your choice based on how you feel right now, not how you have felt in the past or how you would like to feel.

<table>
<thead>
<tr>
<th>Circle the response that best describes how much you agree or disagree with each statement</th>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Undecided or Agreed</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I have been thinking that the way I cope with my pain could improve.</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. I am developing new ways to cope with my pain</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. I have learned some good ways to keep my pain problem from interfering with my life.</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. When my pain flares up, I find myself automatically using coping strategies that have worked in the past, such as a relaxation exercise or mental distraction technique.</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. I am using some strategies that help me better deal with my pain problem on a daily basis.</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. I have started to come up with strategies to help myself control my pain.</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. I have recently realized that there is no medical cure for my pain condition, so I want to learn some ways to cope with it.</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. Even if my pain doesn’t go away, I am ready to start changing how I deal with it.</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9. I realize now that it’s time for me to come up with a better plan to cope with my pain problem</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10. I use what I have learned to help keep my pain under control.</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>11. I have tried everything that people have recommended to manage my pain and nothing helps.</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>12. My pain is a medical problem and I should be dealing with doctors about it.</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>13. I am currently using some suggestions people have made about how to live with my pain problem.</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>14. I am beginning to wonder if I need to get some help to develop skills for dealing with my pain.</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Contd.</td>
<td>Circle the response that best describes how much you agree or disagree with each statement</td>
<td>Strongly Disagree</td>
<td>Disagree</td>
<td>Undecided</td>
<td>Agree</td>
</tr>
<tr>
<td>-------</td>
<td>------------------------------------------------------------------------------------------</td>
<td>------------------</td>
<td>---------</td>
<td>----------</td>
<td>-------</td>
</tr>
<tr>
<td>15.</td>
<td>I have recently figured out that it's up to me to deal better with my pain.</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>16.</td>
<td>Everybody I speak with tells me that I have to learn to live with my pain, but I don't see why I should have to.</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>17.</td>
<td>I have incorporated strategies for dealing with my pain into my everyday life.</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>18.</td>
<td>I have made a lot of progress in coping with pain.</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>19.</td>
<td>I have recently come to the conclusion that it's time for me to change how I cope with my pain.</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>20.</td>
<td>I'm getting help learning some strategies for coping better with my pain.</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>21.</td>
<td>I'm starting to wonder whether it's up to me to manage my pain rather than relying on doctors.</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>22.</td>
<td>I still think despite what doctors tell me, there must be some surgical procedure or medication that would get rid of my pain.</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>23.</td>
<td>I have been thinking that doctors can only help so much in managing my pain and the rest is up to me.</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>24.</td>
<td>The best thing I can do is to find a doctor who can figure out how to get rid of my pain once and for all.</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>25.</td>
<td>Why can't someone just do something to take away my pain?</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>26.</td>
<td>I am learning to help myself control my pain without doctors</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>27.</td>
<td>I am testing out some coping skills to manage my pain better</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>28.</td>
<td>I have been wondering if there is something I could do to manage my pain better</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>29.</td>
<td>All of this talk about how to cope better is a waste of time</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>30.</td>
<td>I am learning ways to control my pain other than with medications or surgery</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
## Section C  Chronic Pain Acceptance Questionnaire (CPAQ)

Below you will find a list of statements. Please rate the truth of each statement as it applies to you. Use the following rating scale to make your choices. For instance, if you believe a statement is ‘Always True’ you would write a 6 in the blank next to that statement.

<table>
<thead>
<tr>
<th></th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
</tr>
</thead>
<tbody>
<tr>
<td>Never true</td>
<td>Very rarely true</td>
<td>Seldom</td>
<td>Sometimes true</td>
<td>Often true</td>
<td>Almost always true</td>
<td>Always true</td>
<td></td>
</tr>
</tbody>
</table>

1. I am getting on with my business of living no matter what my level of pain is.
2. My life is going well, even though I have chronic pain.
3. It’s OK to experience pain.
4. I would gladly sacrifice important things in my life to control this pain better.
5. It’s not necessary for me to control my pain in order to handle my life well.
6. Although things have changed, I am living a normal life despite my pain.
7. I need to concentrate on getting rid of my pain.
8. There are many activities I do when I feel pain.
9. I lead a full life even though I have chronic pain.
10. Controlling pain is less important than any other goals in my life.
11. My thoughts and feelings about pain must change before I can take important steps in my life.
12. Despite the pain, I am sticking to a certain course in my life.
13. Keeping my pain level under control takes first priority when ever I’m doing something.
14. Before I can make any serious plans, I have to get some control over my pain.
15. When my pain increases, I can still take care of my responsibilities.
16. I will have better control over my life if I can control my negative thoughts about pain.
17. I avoid putting myself in situations where my pain might increase.
18. My worries and fears about what pain will do to me are true.
19. It’s a relief that I don’t have to change my pain to get on with my life.
20. I have to struggle to do things when I have pain.
Section D  
**Brief Pain Inventory (BPI)**

Please circle your response or ask for help if you are having problems.

1. Please rate your pain by circling the one number that best describes your pain at its **WORST** in the past week.

<table>
<thead>
<tr>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
</tr>
</thead>
<tbody>
<tr>
<td>NO Pain</td>
<td>IMAGINE</td>
<td>PAIN AS BAD AS YOU CAN</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

2. Please rate your pain by circling the one number that best describes your pain at its **LEAST** in the past week.

<table>
<thead>
<tr>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
</tr>
</thead>
<tbody>
<tr>
<td>NO Pain</td>
<td>IMAGINE</td>
<td>PAIN AS BAD AS YOU CAN</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<td></td>
</tr>
</tbody>
</table>

3. Please rate your pain by circling the one number that best describes your pain on the **AVERAGE**.

<table>
<thead>
<tr>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
</tr>
</thead>
<tbody>
<tr>
<td>NO Pain</td>
<td>IMAGINE</td>
<td>PAIN AS BAD AS YOU CAN</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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</tr>
</tbody>
</table>

4. Please rate your pain by circling the one number that tells how much pain you have **RIGHT NOW**.

<table>
<thead>
<tr>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
</tr>
</thead>
<tbody>
<tr>
<td>NO Pain</td>
<td>IMAGINE</td>
<td>PAIN AS BAD AS YOU CAN</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<td></td>
</tr>
</tbody>
</table>

5. Circle the one number that describes how during the past week, **PAIN HAS INTERFERRED** with your:

   A. **General activity**

      | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
      |---|---|---|---|---|---|---|---|---|---|----|
      | DOES NOT INTERFERE | COMPLETELY INTERFERES |

   B. **Mood**

      | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
      |---|---|---|---|---|---|---|---|---|---|----|
      | DOES NOT INTERFERE | COMPLETELY INTERFERES |

   C. **Walking ability**

      | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
      |---|---|---|---|---|---|---|---|---|---|----|
      | DOES NOT INTERFERE | COMPLETELY INTERFERES |

   D. **Normal work (includes work both outside the home and housework)**

      | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
      |---|---|---|---|---|---|---|---|---|---|----|
      | DOES NOT INTERFERE | COMPLETELY INTERFERES |

   E. **Relationships with other people**

      | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
      |---|---|---|---|---|---|---|---|---|---|----|
      |   |   |   |   |   |   |   |   |   |   |    |
F. Sleep

<table>
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<th>COMPLETELY INTERFERES</th>
</tr>
</thead>
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<td>0 1 2 3 4 5 6 7 8 9 10</td>
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</tbody>
</table>

G. Enjoyment of life

<table>
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</tr>
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<tbody>
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<td>0 1 2 3 4 5 6 7 8 9 10</td>
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</tbody>
</table>

Please return this completed questionnaire in the S.A.E. provided.

Thank you for taking the time to complete this questionnaire.

Heather Hawksley
Consultant nurse
Tel: 01932 722579
### 12.6 Independent T-tests of baseline characteristics

#### Independent Samples Test

<table>
<thead>
<tr>
<th></th>
<th>Levene's Test for Equality of Variances</th>
<th>t-test for Equality of Means</th>
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<td></td>
<td>F</td>
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<tr>
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<tr>
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<td></td>
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<td>What age did you leave school?</td>
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<td>How many times in the last 6 months have you seen your GP?</td>
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### 12.7 Correlations

**Correlations Control Group 1**

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**.** Correlation is significant at the 0.05 level (2-tailed).

**.** Correlation is significant at the 0.01 level (2-tailed).

**Table 26: Correlations Control Group 1 Baseline Data**
**Correlations Intervention Group 1**

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*: Correlation is significant at the 0.05 level (2-tailed).

**: Correlation is significant at the 0.01 level (2-tailed).

**Table 27: Correlations Intervention Group 1 Baseline Data**
# Correlations Control Group 3

## Correlations

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<td>-.467</td>
<td>-.591*</td>
<td>-.469*</td>
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<td>.053</td>
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*: Correlation is significant at the 0.05 level (2-tailed).

**: Correlation is significant at the 0.01 level (2-tailed).

**Table 28: Correlations Control Group 3 Data at 10-14 months**

Page 289
Correlations Intervention Group 3

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</tbody>
</table>

**. Correlation is significant at the 0.01 level (2-tailed).
*. Correlation is significant at the 0.05 level (2-tailed).

Table 29: Correlations Intervention Group 3. Data 10-14 months
**Topic Guide**

**Self-management:**
- What do you currently do to help yourself with your pain?
- What would help you to manage your pain?
- What is your understanding of self-care/self-management?
- What attitude do you take to your pain, does acceptance play a part?

**Pain Clinic:**
1. What is your understanding of why you have been referred to the pain clinic?
2. What are your expectations of the pain clinic?

**Pain:**
- How do you see your pain in the future?

**Research notes & jottings:**
- Active/passive SM
- Humour in FG’s important
- Different outlooks
- Inter group support
- Anger with medical profession
- Feeling a burden to NHS & others financial & emotional

**Index**

1. **Pain**
   1.1. Physical
   1.2. Self efficacy (how certain are that you can, coping, responsibility)
   1.3. Acceptance
   1.4. Resentment/anger
   1.5. Misrepresenting pain/feelings
   1.6. Feeling a fraud
   1.7. Feeling a burden
   1.8. Hope
   1.9. Mood
   1.10. Other issues

2. **Passive self-management strategies**
   2.1. Passive behavioural
   2.2. Conventional medical
   2.3. Views/current feelings about using passive management
   2.4. Conflicts with medical model
   2.5. Conditional management
   2.6. Other issues

3. **Active self-management strategies**
   3.1. Active behavioural
   3.2. Cognitive
   3.3. Views/current feelings about using passive management
   3.4. Conflicts with medical model
   3.5. Conditional management

4. **Medical**
   4.1. Expectations
   4.2. Diagnosis
   4.3. Treatment
   4.4. Confidence in care
   4.5. Conflict/contradictory
   4.6. Being ignored by Drs
   4.7. Number of Drs seen
   4.8. Care from other HCP’s
   4.9. Other issues

5. **Changes to life**
   5.1. Impact on family/friends
   5.2. Impact on work
   5.3. Impact on activity
   5.4. Other issues

6. **Effect of attending EPP**
   6.1. Changes to behaviour
   6.2. Views/feelings about EPP
   6.3. Other issues

7. **Other Key issues not covered**
   7.1. Views about NHS systems
   7.2. Other issues

---

12.8 **Development of Thematic Framework**
### 12.9 List of Acronyms

<table>
<thead>
<tr>
<th>Acronym</th>
<th>Description</th>
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<tbody>
<tr>
<td>BPI</td>
<td>Brief Pain Inventory</td>
</tr>
<tr>
<td>CPAQ</td>
<td>Chronic Pain Questionnaire</td>
</tr>
<tr>
<td>DGH</td>
<td>District General Hospital</td>
</tr>
<tr>
<td>EPP</td>
<td>Expert Patient Programme</td>
</tr>
<tr>
<td>HBM</td>
<td>Health Belief Model</td>
</tr>
<tr>
<td>NHS</td>
<td>National Health Service</td>
</tr>
<tr>
<td>PCR</td>
<td>Persistent Condition Role</td>
</tr>
<tr>
<td>PPP</td>
<td>Phases of Persistent Pain</td>
</tr>
<tr>
<td>PSOCQ</td>
<td>Pain Stages of Change Questionnaire</td>
</tr>
<tr>
<td>RA</td>
<td>Rheumatoid Arthritis</td>
</tr>
<tr>
<td>RCT</td>
<td>Randomised Controlled Trial</td>
</tr>
<tr>
<td>SDP</td>
<td>Service Development Project</td>
</tr>
<tr>
<td>SDP</td>
<td>Service Development Project</td>
</tr>
<tr>
<td>SPSS</td>
<td>Statistical Package for the Social Sciences</td>
</tr>
<tr>
<td>TTM</td>
<td>Transtheoretical Model</td>
</tr>
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CLINICAL ACADEMIC PAPER

The impact of lay led self-management in managing persistent pain: A randomised controlled trial

September 2007
Abstract

This study explores whether patients with persistent pain described as revolving door patients are one and the same class of patients as those who become stuck in the sick role. Participants were 63 patients with musculoskeletal pain referred for treatment of persistent pain. They were randomised to a Control (n=30) and Intervention group (n=33). The intervention was early access to a lay led self-management programme (Expert Patient Programme) and usual care. Analysis provided evidence that improvements seen in the Intervention group were associated with progress through the Stages of Change and linked with the participants adopting self-management approaches and relinquishing the sick role.

Failure for participants in the Control group to progress was linked with becoming stuck in the sick role. Many attributes of these participants were the same as those associated with 'revolving door' patients and mechanisms that may contribute to their development are explored. Acquiring a diagnosis is considered pivotal in preventing escalation of unhelpful behaviours, and facilitating an exit out of the sick role is essential if progress with care is to be made. The Persistent Condition Role (PCR) is offered as an alternative role.

Conclusion: This study is the first to suggest an association between the Stages of Change process and the Sick Role and a connection with 'revolving door' patients. Self-management approaches involving lay role models are an important factor in relinquishing the sick role and avoiding revolving door patients. To be effective they need to be offered in parallel with traditional medical approaches so their synergistic effect can be experienced by patients.

Key words: Stages of Change, Sick Role, Revolving door patient, Diagnosis, Self-management.
1 Submission of paper

The journal identified for the submission of this paper was: 'PAIN' The Journal of the International Association for the Study of Pain

Evidence of submission is found in Appendix 1 and guidance for authors submitting to 'PAIN' is found in Appendix 2.

2 Introduction

Self-management approaches are attracting considerable interest from Government policy makers as it emerges a central factor in the planning of care in the National Health Service (NHS) for those with long term conditions (Department of Health, 2001, 2005a, 2005b, 2005d; NHS Modernisation Agency, 2004; Tattersall, 2002). Problems associated with managing long term conditions are not new, but resist solutions, and promoting the benefit of self-care approaches is considered significant to how future long term conditions will be managed (Department of Health, 2004, 2005c; Kennedy, Rogers, & Bower, 2007).

The Sick Role introduced by Parsons (Parsons, 1951) implied that in society there are 'explicit and implicit rules about being sick' (Kasl, Cobb, & Arbor, 1966:247). These rules were developed at a time when the majority of illness was acute, and it was logical for the sick role to be sited within the traditional biomedical model of illness. While it may be helpful for managing many acute illnesses, the prevalence in society of acute and chronic illness conditions has
altered. Conditions such as persistent pain are referred to as, the silent epidemic, with 7.8 million people now living with persistent pain in the United Kingdom (Chronic Pain Policy Coalition, 2007).

Although the sick role was never intended to apply to long term illness, it may exert considerable power in influencing how it is viewed and managed. When it is applied to chronic illness it addresses only part of the problem and ignores a range of associated possibilities (Mechanic, 1978, 1995). Enormous efforts are now being made by the NHS and other bodies to change our culture’s approach to managing long term illness (Chronic Pain Policy Coalition, 2007; NHS Modernisation Agency, 2004; Palmer, Walsh, Bendall, Cooper, & Coggon, 2000). This is also seen in the World Health Organisation’s International Classification of Functioning (WHO ICF). They have developed a framework that takes into account social aspects, shifting the focus away from cause to impact and from disability being purely a medical and biological dysfunction (WHO ICF, 2001).

The concept of revolving door patients is relatively new in the management of persistent pain (Jenner, 2007). Revolving door patients are associated with poor or unresolved outcomes for these patients as well as contributing to increasing the economic burdens of the NHS (Chronic Pain Policy Coalition, 2007). Patients are described as individuals who move, ‘between a variety of different services without any real strategy to deal with their individual needs’; the process involving repeat appointments with uncertain outcomes (Chronic Pain Policy Coalition, 2007:23). Revolving door patients have though
been associated with areas of mental health for much longer (Harris, Linn, & Hunter, 1980; Hiday & Scheid-Cook, 1991; Rose, Hawkins, & Apodaca, 1977; Shaw, 2004), but not until 2004 does the term appear linked with individuals experiencing persistent pain (Reddy, 2004).

Clinicians are now encouraged to consider factors stretching far beyond the conventional focus on symptoms and disease, and this study explores factors associated with relinquishing the sick role and preventing revolving door patients.

3 Method

This study was a longitudinal randomised control trial. It involved a mixed method approach by combining the analysis of the quantitative and qualitative data. Used in combination data from a quantitative and qualitative approach can provide more complete data that complement one another (Creswell, Fetters, & Ivankova, 2004). Quantitative data came from self-report postal questionnaires collected at initial entry into the study, at 3-6 months and at 10-14 months. Qualitative data was collected from 5 focus groups (2 Intervention group, 3 Control group) held at intervals over 12 months.

3.1 Subjects

All potential participants were patients referred to a NHS District General Hospital’s Pain Management Service and had a diagnosis of non-malignant
musculoskeletal pain and met the study's inclusion and exclusion criteria (See Table 1 and 2).

3.2 Randomisation

Participants were randomised using a computer random number generator. This allowed unbiased assignment of participants to either the Control or Intervention group.

<table>
<thead>
<tr>
<th>Inclusion criteria</th>
<th>Justification</th>
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</thead>
<tbody>
<tr>
<td>Aged 18-85 years</td>
<td>Reduction of variables and allowed comparison with studies in the literature exploring aspects of persistent pain and self-management</td>
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<tr>
<td>Experienced continuous/intermittent non-malignant pain for 3 months or longer</td>
<td>This met the International Association for the Study of Pain's (IASP) criteria for chronic pain (IASP, 1994)</td>
</tr>
<tr>
<td>Referred to DGH Pain Clinic</td>
<td>One site sample framework</td>
</tr>
<tr>
<td>Referred with a diagnosis of musculoskeletal pain</td>
<td>Ensure safe practice and appropriate care offered. Reduce number of variables in the study by limiting the cause of pain.</td>
</tr>
<tr>
<td>Adequate literacy to be able to complete questionnaire</td>
<td>Study will not be able to collect and analyse meaningful data if participant unable to complete questionnaires</td>
</tr>
<tr>
<td>Willing to take part in the study and sign a consent from</td>
<td>Uphold ethical principles and ensure patient has capacity to consent</td>
</tr>
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</table>

Table 1. Subject Inclusion Criteria

<table>
<thead>
<tr>
<th>Exclusion criteria</th>
<th>Justification</th>
</tr>
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<tr>
<td>Gender reassignment</td>
<td>Adds additional variables and complexity to study</td>
</tr>
<tr>
<td>Urgent referral</td>
<td>Ensure safe practice and care for patients: a self-management approach may not initially be appropriate for urgent referrals</td>
</tr>
<tr>
<td>History of malignancy, HIV or diagnosis requiring the involvement of the palliative care team</td>
<td>Ensure safe practice and appropriate care offered: a self-management approach may not be appropriate for these patients.</td>
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<tr>
<td>Significant sight impairment</td>
<td>Resources not available to provide questionnaires in Braille</td>
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Table 2. Subject Exclusion Criteria
3.3 Intervention

Intervention was an invite to attend a lay led self-management programme, known as the Expert Patient Programme (EPP) at the individual’s initial referral to the pain management service. This consisted of six two hour per week sessions (See Table 3). The Intervention group were also offered usual care which consisted of an initial consultation with a medical or nurse consultant and a plan of care created, including various medical model approaches such as medications, injection interventions, transcutaneous electrical nerve stimulation (TENS) and physiotherapy. The Control group received only usual care. See consort flow chart (Figure 1).

<table>
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<tr>
<th>Week</th>
<th>Course Content</th>
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<tr>
<td>1</td>
<td>Overview of self-management and chronic health conditions, making action plans, relaxation and cognitive symptom management, better breathing</td>
</tr>
<tr>
<td>2</td>
<td>Feedback/problem solving: making action plans, dealing with anger/fear/frustration and introduction to fitness and exercise</td>
</tr>
<tr>
<td>3</td>
<td>Feedback/problem solving: making action plans, relaxation/cognitive symptom management, fitness/exercise, dealing with fatigue</td>
</tr>
<tr>
<td>4</td>
<td>Feedback/problem solving: making action plans, relaxation/cognitive symptom management, nutrition, living wills or community resources, communication</td>
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<tr>
<td>5</td>
<td>Feedback/problem solving: making action plans, relaxation/cognitive symptom management, medications management, making treatment decisions, dealing with depression</td>
</tr>
<tr>
<td>6</td>
<td>Feedback/problem solving: making action plans, relaxation/cognitive symptom management, informing the health care team, working with your health care professional, future plans</td>
</tr>
</tbody>
</table>

Table 3. EPP Course Content (NHS Expert Patients Programme, 2002)

Ethical review from the Local Research Ethics Committee and NHS Research and Development Committee and the University of Surrey Ethical Committee was sought and given
Figure 1: CONSORT Flow Chart.
3.4 Measures

The quantitative data was collected using the following measures:

- **Descriptive data**: This was gathered to elicit age, gender, duration of pain, whether they had acquired a diagnosis, age on leaving school, employment status and use of health care resources within the previous 6 months.

- **Pain Stages of Change Questionnaire (PSOCQ)** (Kerns, Rosenberg, Jamison, Caudill, & Haythornthwaite, 1997): The development and initial validation of the PSOCQ was designed to assess an individual’s readiness to adopt a self-management approach to their persistent pain condition. Five stages of change have been identified in studies exploring health related behaviour associated with addictive behaviour and smoking (DiClemente et al., 1991; Prochaska, DiClemente, & Norcross, 1992). These are Precontemplation, Contemplation, Preparation, Action and Maintenance. Kerns et al (1997) found the Contemplation and Preparation scales were closely linked, so combined these into one stage called Contemplation. Internal consistency was acceptable, Precontemplation 0.77, Contemplation 0.64, Action 0.86, and Maintenance 0.88. These internal consistencies were largely replicated in a later study evaluating further the PSOCQ, thereby supporting its validity (Jensen, Nielson, Romano, Hill, & Turner, 2000).

- **Chronic Pain Acceptance Questionnaire (CPAQ)** (McCracken, Vowles, & Eccleston, 2004): The original study developing the CPAQ consisted of four factors; activity engagement, pain willingness, thought control and
chronicity (Geiser, 1992). McCracken et al (2004) recommended dropping factors related to thought control and chronicity as they proved unreliable with item inter correlation. Internal consistency and predictive validity were strongly supported in the application of two layer factors comprising of activity engagement (0.82) and pain willingness (0.78).

- Brief Pain Inventory (BPI) (Tan, Jensen, Thornby, & Shanti, 2004): The BPI was originally developed as a quick and simple tool to measure pain and extent of interference in the lives of those suffering from pain related to cancer intensity (Cleeland & Ryan, 1994). It has since been translated into many languages and used in numerous countries to assess cancer pain. Tan et al (2004) (n=440) showed good internal consistency (0.85 for the intensity items, 0.88 for the interference items) when applied to patients experiencing chronic non-malignant pain referred to a pain clinic. This study was limited by being a one centre study. Nevertheless, correlations with the Roland Morris Disability questionnaire concluded that the psychometric properties of the BPI are valid, suggesting its use can be extended to those people experiencing persistent non-malignant pain.

3.5 Analysis

Analysis was by intention to treat. Statistical Package for the Social Sciences (SPSS) 13.0 was used to analyse the data using t-tests, Chi Square test, and Correlations. The qualitative data involved a thematic content analysis guided by ‘Framework’ (Ritchie & Spencer, 1994). This offered a coding process and analytical process.
3.6 Sample size

Power calculations suggested a sample number of N=158 (Control n=79, Intervention n=79) was required to distinguish possible differences in participants scores. The study was powered to detect a 0.2 effect size and a significance of 0.05. The power size was guided by previous studies exploring behavioural changes involving individuals with chronic conditions (Artinian, Magnan, Sloan, & Lange, 2002; Ersek, Turner, Cain, & Kemp, 2004; Griffiths et al., 2005).

4 Results

An initial 301 patients (72% female) were invited to take part in the study. From this 78 (26%) agreed to participate in the study and 63 (21%) (73% female) returned their baseline questionnaire. Thirty eight (12%) actively declined to take part while 185 (61%) passively declined by not responding. The most common reasons for declining to take part were transport difficulties, family and work commitments. A further 6 participants actively dropped out during the study (3 gave no specific reason, 1 moved away, 1 developed cancer, 1 developed dementia).

Ages range 29-83 years (mean 55.3 std.13.8). Mean age of leaving school was 16.2 (std 1.4) and n=46 (73%) had undertaken further education while n=29 (46%) were employed. Visits to general practitioners (GP) in the previous six months ranged from 0-20 (mean 4.7 std 4.0) and attendance at
hospital appointments in the previous six months ranged from 0-9 (mean 1.9 std 2.0).

Duration of pain ranged from 1-40 years (mean 7.4 std 9.7), pain intensity ranged from 0-10 (mean 5.6 std 1.9) and Interference scores ranged from 14-70 (mean 41.6 std 14.1).

The data distribution showed no significant differences in F tests between the Intervention and Control groups’ baseline data. Therefore assumptions were made that the data was normally distributed with equal variability, allowing parametric t-tests and Pearson’s correlations to be applied (See Table 4).

<table>
<thead>
<tr>
<th>Scale</th>
<th>F</th>
<th>Sig.</th>
<th>Mean</th>
<th>Std.</th>
<th>t-value</th>
<th>df</th>
<th>Sig. (2-tailed)</th>
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<td>14.5</td>
<td>0.45</td>
<td>61</td>
<td>0.66</td>
</tr>
<tr>
<td>Duration of pain</td>
<td>1.34</td>
<td>0.25</td>
<td>6.9</td>
<td>8.4</td>
<td>0.37</td>
<td>61</td>
<td>0.71</td>
</tr>
<tr>
<td>Visits to GP in last 6 months</td>
<td>0.24</td>
<td>0.63</td>
<td>5.0</td>
<td>4.7</td>
<td>-0.54</td>
<td>61</td>
<td>0.59</td>
</tr>
<tr>
<td>Age left school</td>
<td>1.31</td>
<td>0.26</td>
<td>16.1</td>
<td>1.6</td>
<td>0.40</td>
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<td>0.69</td>
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<tr>
<td>Number of hospital appointments</td>
<td>0.07</td>
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<td>0.45</td>
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<td>0.65</td>
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<td>Control 1 (n=33)</td>
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<td>56.0</td>
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</tbody>
</table>

Table 4. Baseline data comparing means, std and Independent T-tests for age, duration of pain, visits to GP, age left school and hospital appointment between Intervention Group and Control group

4.1 Stage of Change

Baseline scores for the Intervention group revealed that the majority of participants had Contemplation as their highest score (90%) while 7% had
Precontemplation and 3% Maintenance as their highest score. No participant scored Action as their highest score at the start of the study. This compared with the Control group where all participants scored Contemplation as their baseline highest score. Independent t-tests showed no differences between and within the Intervention and Control groups Stage of Change scores at baseline, 3-6 months or 10-14 months points. Paired t-tests were applied in the same way. Significant differences occurred between baseline data and data collected at 10—14 months for the Intervention group. These changes were not identified in the Control group’s data (See Table 5 & 6).

4.2 Pain and Interference Scores

Significant reductions in Pain and Interference scores were seen in the paired data for the Intervention group when paired t-tests were applied. These changes were not seen in the Control group’s data (See Table 5 & 6).

4.3 Acceptance of Pain

No significant changes in Acceptance scores were seen in either the Intervention of Control groups’ data at any stage of the study when independent and paired t-tests were applied (See Table 5 & 6).
<table>
<thead>
<tr>
<th>Scale</th>
<th>Control 1 (n=22)</th>
<th>Control 2</th>
<th>Control 3</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean</td>
<td>Std. deviation</td>
<td>t-value</td>
</tr>
<tr>
<td>Precontemplation</td>
<td>3.13</td>
<td>0.83</td>
<td>0.85</td>
</tr>
<tr>
<td></td>
<td>3.00</td>
<td>0.70</td>
<td></td>
</tr>
<tr>
<td>Contemplation</td>
<td>4.01</td>
<td>0.52</td>
<td>1.24</td>
</tr>
<tr>
<td></td>
<td>3.90</td>
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Table 5. Means, std and Paired t-tests for the PSOCQ, CPAQ and BPI in the Control Groups (*significant at p<0.05 level)

Key to Groups

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<td>-------------------</td>
<td>------------------</td>
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</tr>
<tr>
<td>Interference</td>
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Table 6. Means, standard deviations and Paired t-tests for the PSOCQ, CPAQ and BPI within the Intervention Group (*significant at p 0.05 level. **significant at p 0.01 level)
4.4 Use of healthcare resources

Paired t-tests were applied and revealed greater reductions in number of GP visits for the Intervention group. However, this marginally failed to reach a level of significance (see Table 7), though the direction of this change supports findings in previous studies (Lorig & Holman, 1989; Lorig, Mazonson, & Holman, 1993).

<table>
<thead>
<tr>
<th>Group</th>
<th>GP visits Baseline</th>
<th>GP visits (10-14 months)</th>
<th>Std. deviation</th>
<th>T-value</th>
<th>Sig. (2-tailed)</th>
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<td>0.95</td>
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<td>3.38</td>
<td>6.99</td>
<td>2.00</td>
<td>0.06</td>
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Table 7. Paired Data showing Comparisons between Mean GP visits at baseline and at end of study

The number of outpatient appointments with the pain clinic and interventional treatments for pain requiring admission to the Day Surgery unit for the Control and Intervention Group were collected for the duration of the study, using the hospital’s Patient Administration System (PAS). Differences between the two groups were tested by applying Independent t-tests and revealed no significant differences for number of outpatient appointments (t = -0.55 p 0.58) and interventional treatments (t = -0.44 p 0.66).

4.5 Focus groups

Each focus group was recorded with the consent of participants and transcribed verbatim by the researcher. The method chosen to aid the process of analysing the transcripts was a thematic content analysis using
'Framework' (Ritchie & Spencer, 1994). During the analysis and validation process three main headings emerged, being: Entering the Sick role, maintaining the Sick role and Relinquishing the Sick role.

### 4.5.1 Entering the sick role

At the start of each focus group participants were invited to introduce themselves and if they wished say a few words about themselves. This usually led to participants focusing on descriptions of their physical pain symptoms, and some struggled with a diagnosis:

'I've been told it is something to do with some of the discs probably touching or crumbling or something' (Intervention group 13/12 p14).

Others were able to explain the cause of their pain, because they were aware of a diagnosis:

'I'm in constant pain I've got osteoarthritis everywhere' (Intervention group 7/6 p.2).

The achievement of a diagnosis can be important to explain causes, justify behaviours and reduce anxiety (Glenton, 2003; Herz, 2007). It can also give more than this as it may suggest what further actions are appropriate while legitimising the individuals entry into the sick role (Glenton, 2003).

### 4.5.2 Maintaining the sick role

Many participants appeared to have acquired an uncertain role; neither had they attained full legitimate access to the sick role with 27% of participants declaring they had no knowledge of a diagnosis, nor had they been able to
resume a health behaviour role. Confusion and the struggle for credibility was particularly evident in participants’ discussions where a diagnosis was lacking, and issues of credibility can occur because ‘pain is a sensation that can be directly perceived only by the person who feels it’ (Baszanger, 1989:427).

One participant struggling with her failure to achieve a diagnosis described eight different areas of pain on her body in an attempt to express her suffering. She was an example of how patients can get caught in a vicious circle, as the harder they try to convince clinicians of their suffering the more likely their symptoms may be interpreted as psychological (Kroenke et al., 1994). This in turn can make it more difficult to acquire legitimate entry into the sick role as society does not freely and readily grant the sick role to those with non-organic or psychological illness (Kwan & Friel, 2002).

Some participants described areas of conflict as they questioned the ability of their clinician as a possible explanation for failing to acquire a diagnosis.

'I know a normal doctor should be able to tell you why it is .... But they [doctors] never said what it was' (Intervention group 7/6 p 13).

Some participants described feeling abandoned by the medical profession, with others struggling to be taken seriously by doctors. This appeared to involve doctor shopping and repeat investigations and appointments. Legitimisation can be made more difficult if the condition is widely experienced in milder forms by the normal population (Bury, 1991) such as musculoskeletal pains. Seeking credibility has been observed to take up huge amounts of energy as described by participants in this study, that could be
better directed in adjusting to and coping with persistent pain (Werner & Malterud, 2003).

'one doctor says one thing and another says no that’s totally wrong and then you go to another doctor who says what the other two said is wrong and you think... that’s when I give up ... sometimes I feel I don’t get the help I should and need medically although I am under the hospital ..........whether they sort of see so many you know [patients with pain]’ (Control group 17/5 p12).

However, continuing to search for a medical solution to the individual’s persistent pain is not just the domain of the patient (Pither, 1994). This participant describes how their doctor sought to resolve their pain:

'[the doctor] going to stick a needle in and put electric current in to it...’ the doctors been brilliant and he’s going.. always thinking of something different’ (Intervention group 7/6 p.4 & 9).

Participants seemed reluctant to challenge treatment when benefits were limited and side effects concerned them. This may be associated with a fear of being discharged for non-compliance (Glenton, 2003), and implies the clinician has power that may contribute to maintaining the sick role.

'you go to an appointment that a certain medication or treatment is not going to be any good but because they [doctors] won’t take your word you have to go through the damm process of taking medications or waiting three to six months to be able to turn round and say I told you so’ (Intervention group 13/12 p.2).

Failure to connect with clinicians was sited as a reason for dissatisfaction with medical care, and some participants struggled to feel they got their clinicians attention and to be interesting patients. This appeared entangled with beliefs of being an unpopular patient.
'It's a bit like you're too much trouble and you feel as if you should be sorry I shouldn't really be here' (Control group 17/5 p.13).

Participants sited feeling let down by the healthcare system wondering why clinicians appear to be failing to help their pain as they passed from one clinician to another, until finally ending up in a pain clinic:

'I felt I was abandoned and so that was the last resort send me to a pain clinic and they will tell you how to control the pain' (Control group 11/10 p.12).

If there is no alternative social role offered to the sick role, it is understandable that patients may fear relinquishing it; leaving the sick role may be associated with entering a place empty of potential help. 'Help' quite often is the aspect of care in pain management that makes a patient feel better (McQuay, Moore, Eccleston, Morley, & C de C Williams, 1997). Understanding and social support may quite often be the most appropriate management, but instead patients end up receiving medical treatments. This observation has also been found with patients seeking help for symptoms of distress (Shaw, 2004).

4.5.3 Relinquishing the sick role

Findings in this study provide evidence of the difficulties experienced when participants attempted to move away from the sick role. The dichotomy that may be experienced by individuals as they try to take on more self-management approaches and relinquish the sick role is described here by one participant:
'my husband says I don’t rest enough ... he doesn’t hold it against me the girls seem to hold it against me ... they were quite angry oh you can’t do things like that that you know or you mustn’t do that you’ll be ill and who is going to look after you poor Dad will get it again and I have gradually fought back because I’m stubborn.. but it eh it has left as I say a bit of a ...... between us about it’ (Intervention group 13/ p.12 12).

What was noticeable in the Interventions group’s dialogue and not seen in the Control group’s data, was an apparent realisation of an alternative role or exit route out of the sick role following attendance of EPP, with the potential resumption of a health behaviour role.

‘support group what I attended given me my life back... my pain was managing me but now I’m managing the pain’ (intervention group 7/6 p.1).

The impact of the lay tutors leading EPP was considered critical to its success and in moving participants towards engaging in self-management approaches that could lead to relinquishing the sick role:

‘and the tutor now I mean ... amazing which also makes you think about it what he’s doing.. I can do that as well’ (Intervention group 29/11 p.9).

EPP role modelling has previously been identified as carrying a strong message that can make the message of self-management approaches more influential (Moore 2004). Overall, the focus groups provided wide ranging topics of discussion related to participants’ management of their persistent pain. The data was rich and complex adding to and complementing the data collected from the questionnaires.
4.6 Combining the quantitative and qualitative data

This study found participants allocated to the Intervention group made significant progress through the Pain Stages of Change. Behaviour changes were associated with factors related to relinquishing the sick role and participants in the Intervention group also experienced improvements in Pain and Interference levels, and showed trends for reducing routine use of General Practitioners.

Findings suggest the following energy was directed at unhelpful behaviours associated with failure to acquire a diagnosis and maintenance of the sick role:

- working to avoid discharge as no other pathway of care was available
- working at keeping the balance right with clinicians
- trying to appear an interesting patient to keep the clinician interested
- working at focusing on the physical aspects of their pain symptoms and reducing emphasis on psycho social issues
- complying with clinicians even when the individual disagreed
- seeking further/repeat investigations to confirm cause
- continuing to take medications even when they were not considered helpful

Exposure to the EPP appeared to facilitate a way out of the sick role for participants in the Intervention group and provided a vision of an alternative social role to that of the sick role. If alternative social roles are not offered individuals are likely to remain in the patient role (Wade & Halligan, 2007a).
The Control group failed to make behaviour changes associated with relinquishing the sick role because no viable exit route was offered. In addition they were exposed only to the impact of medical role models. Clinicians’ endeavours to change pain through investigation and treatment may inadvertently influence and raise patients’ expectations of treatment outcomes, reducing patients’ acceptance of their pain, and contributing to maintenance of the sick role. This influence has been reported elsewhere (Galer, Schwartz, & Turner, 1997; McCracken, 1998; Pither, 1994), and the role of healthcare professionals in shaping the sick role has been offered by other authors as a factor in its maintenance (Wade & Halligan, 2007b).

A composite model for the maintenance of the sick role is offered (See Figure 2), suggesting many of the factors associated with maintenance are similar factors and complications as those linked with revolving door patients.
Figure 2: Composite model for the maintenance of an inappropriate sick role

- Pain
  - Denied therapeutic support
  - No organic cause found
  - Maintenance of inappropriate sick role
    - ‘Revolving door patients’
  - Uncertain role
    - Compliance & passivity
  - Conflict with care
    - Repeat appointments & investigations
    - Increased Psychological consequences
  - Seeking credibility
    - Denial
- Diagnosis
- Sick role
- Treatment
  - Symptoms resolved
  - Treatment fails
  - Individual resumes social role
  - For example:
    - Diagnosis lacking
    - Failure of treatment
    - Sense of being an unpopular patient
    - Getting attention
    - Being an interesting patient
    - Feeling ignored
    - Accepting unhelpful medications
5 Discussion

Up to now difficulties relinquishing the sick role and issues of revolving door patients have been discussed as separate entities in the literature (Chronic Pain Policy Coalition, 2007; Moore 2004; Reddy, 2004; Wade & Halligan, 2004, 2007b). Analysis of data from this study together with published studies suggests they are one and the same class of patient (See Table 8).

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<td>Frequently no organic cause for symptoms</td>
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<td>Individuals in the ‘Contemplative’ Stage of Change</td>
</tr>
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<td>Individuals have difficulty accepting their pain and the medical model’s failure to resolve it</td>
<td>Individuals have difficulty accepting their pain and the medical model’s failure to resolve it</td>
</tr>
<tr>
<td>Move between different services without clear strategy (doctor shopping)</td>
<td>Move between different services without clear strategy (doctor shopping)</td>
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<tr>
<td>Uncertain outcome</td>
<td>Uncertain outcome</td>
</tr>
<tr>
<td>Damage to quality of family life</td>
<td>Damage to quality of family life</td>
</tr>
<tr>
<td>Repeat appointments and treatments</td>
<td>Repeat appointments</td>
</tr>
<tr>
<td>Denied therapeutic support</td>
<td>Associated with early discharge</td>
</tr>
<tr>
<td>Conflict with medical care</td>
<td>Frustration associated with failure of treatment</td>
</tr>
<tr>
<td>Sense of being an unpopular patient, feeling ignored</td>
<td>Guilt of constantly complaining about pain</td>
</tr>
<tr>
<td>Uncertain role, unable to identify more fulfilling role</td>
<td>Loss of productivity and efficiency</td>
</tr>
<tr>
<td>Seeking credibility</td>
<td>Seeking credibility</td>
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<td>Cost to the NHS</td>
<td>Cost to NHS</td>
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Table 8. Comparisons of patients with persistent pain who are unable to relinquish the sick role or revolving door patients (Hawksley, 2007; Jenner, 2007; Moore 2004; Reddy, 2004; Wade & Halligan, 2007b)

If the sick role and revolving door patients are one and the same, then factors associated with their generation and perpetuation need tackling as a single entity as this could be more productive for reducing their incidence.
This is an important aim not only because of the misery persistent pain causes but because funding the mounting demand from long term illness is a constant struggle for the NHS (Bradshaw, 2000).

Failure to acquire a diagnosis is of paramount importance and is associated with behaviours linked with maintenance of the sick role and revolving door patients. A diagnosis can be pivotal in opening up and closing down avenues of social, therapeutic and practical help (Henningsen, Zipfel, & Herzog, 2007; Lillrank, 2003; Nettleton, 2006), but only recently has the importance of acquiring a diagnosis been highlighted in the management of chronic illness (Allcock, Elkan, & Williams, 2007; Moore 2004; Wade & Halligan, 2007b).

Studies looking at frequent attenders in secondary care have found 69% have back pain and their symptoms are medically unexplained (Reid, Wessely, Crayford, & Hotopf, 2001). If these studies are compared with surveys exploring the most common location of pain, the back is most commonly identified by 24% of respondents (Breivik, Collett, Ventafridda, Cohen, & Gallacher, 2006). Yet studies fail to explain why out patient appointments and sick leave for back pain has risen disproportionately to the rise in prevalence of the condition (Palmer et al., 2000). Insight from the patient's perspective is provided by Moore (2004). He describes doctor/therapy shopping occur because individuals feel they have not received a clear diagnosis when first seen by a clinician. This behaviour may relate to reassurance seeking, considered a distinct behavioural response linked to experiencing pain (Hadjistavropoulos, Owens, Hadjistavropoulos, &
Asmundson, 2001), and failure to acquire a diagnosis may connect all three categories of patients, i.e. frequent attenders, revolving door patients and those who become stuck in the sick role; perhaps it is just a question of which categorisation is chosen.

Wade & Halligan (2007) suggest that patients, who present with symptoms that have no clear organic cause, should be given a simple explanation and clinicians need to avoid actions that may reinforce the sick role. These are described as, rationalising follow-up appointments, discouraging involvement with other clinicians and ensuring good communication between clinicians regarding diagnosis and advice given.

Re-establishing the role of ‘convalescence’ is offered as a way to facilitate an exit from the sick role. This could influence two current and unhelpful assumptions; firstly that people consider that unless a person is fully well they are sick. Secondly, health care services should be able to offer treatments that will restore their health (Wade & Halligan, 2007b).

However, convalescence deals with the problem of being stuck in the sick role once it becomes established. This study offers an alternative role, that of the Persistent Condition Role (PCR). It is proposed this role should be offered at initial engagement with pain management services. Key to its effectiveness are: rebalancing the emphasis on a curative model of care, providing a diagnosis and offering medical treatments in parallel to lay-led self-management approaches.
Despite advantages adopting a self-management approach can have, there will be patients who prefer to assume a passive role or will not be ready to consider it. Different mechanisms will be required for these individuals and clinicians must guard against providing a one size fits all approach. Patients need to be allowed to participate in different approaches without restrictions imposed internally and externally. This may only increase their endeavours to fulfil obligations of their sick role.

However, the PCR is a role that individuals referred to a pain management service should become familiar with, although approaches to resume healthy behaviours may take pathways that differ. It is suggested the ‘core’ or ‘self’, which has been described as part of the individual’s personality, needs to be effected by the pain management approach in order for the individual to regain health and resume normal roles. This needs to occur to a degree where they can look back and see their sick role as a learning experience that is now over (Beckingham, 1995). This is aptly described by Moore (2004:20) when he refers to himself as once being a revolving door patient and now self-managing his pain ‘very well’. It is also described in this study by participants as EPP giving them their life back and being a turning point.

Findings in this study have significant implications for how persistent pain is managed within the current paradigm shift towards self-management as an effective approach for its treatment. These are complex patients and rarely is the acute medical model’s aim of a cure a realistic goal. However, to avoid a tendency for self-care to be associated with de-legitimising an individuals
pain (Eccleston, De C Williams, & Stainton Rogers, 1997), it is important that these approaches to managing pain are given equal importance (Bendelow & Williams, 1996), and that this parity is seen from the perspective of both patients and professionals.

To offer lay-led self-management approaches in parallel with medical model approaches will not be without its complications. This synergistic model will have practical implications for lay-led programmes that may require modifications to its delivery in order that demands on such a model can be met effectively and efficiently in clinical practice. While some lay-led programmes have demonstrated they are no less effective than professionally led programmes (Cohen, Van Houten Sauter, DeVellis, & McEvoy DeVellis, 1986; Lorig et al., 1986) and ‘likely to be cost effective’ (Kennedy, Reeves et al., 2007:260), there are practical issues associated with running lay-led programmes that are specific to a service provided by volunteers. Difficulties that transpired during the course of this study were the availability of tutors due to recruitment difficulties, sickness, holidays and other personal commitments.

It is proposed that involving the medical model in leading the delivery of EPP may be just what is needed to engage clinicians in its benefits and resolve any antipathy that could be felt. A synergistic model of care delivery may represent a positive challenge to professional power, but it might achieve a shift in culture within the NHS that supports self-management, currently considered a huge challenge to accomplish (Lewis & Dixon, 2004).
However, there is evidence clinicians still believe that in order to avert revolving door patients the solution is to increase the amount of professional input (Reddy, 2004). It has also been suggested that clinicians should reduce their efforts with making a diagnosis, and instead try to be clear about symptoms and treating the symptoms (Groen, 2006). This may only reinforce the medical model and its associated expectation of a cure, resulting in a greater need for the individual to put energy into maintaining their sick role and behaviours associated with revolving door patients.

The main limitation of this study stems from recruiting a smaller than predicted sample number. This inevitably reduced the power of the study and confidence that the changes seen were due to the intervention. However, as Cohen et al. (1986) identify in their study the issue rests on the researcher’s judgement of how big a difference is important. In this study a 13% shift towards Maintenance scale of the PSOCQ occurred in the Intervention group and Pain scores decreased by 18%. These are both considered to be important differences with 16-20% reductions in pain associated with self-management interventions reported in the literature (Lorig, González, Laurent, Morgan, & Laris, 1998; Lorig & Holman, 1989). The failure to recruit a higher number of participants also raised awareness of the negative view many individuals have of group treatment approaches that focus on their own behaviour (Von Korff et al., 1998) and has been associated with deligitimation of their pain (Eccleston et al., 1997). There were also implications that participants may have self-selected themselves either in or out of the self-management approach.
Despite these limitations, results extend prior studies exploring the impact of self-management approaches. It is the first study to suggest an association between relinquishing the sick role, revolving door patients and the Stages of Change process. It concludes that improvements seen in the Intervention group were linked with participants adopting self-management approaches and relinquishing their sick role, and not adopting behaviours associated with revolving door patients.

Providing an alternative and legitimate PCR could be part of the solution and medicine has an important place in facilitating and constraining the adaptation of individuals in the management of persistent conditions (Bury, 1982). This ability needs fully unleashing, as neither the biomedical or self-management models of care may be adequate on their own when long term conditions are involved. Together they can complement each other, letting their synergistic effect work to reduce some of the distress, cost and psychosocial disruption that accompany many persistent pain conditions.
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6 References


Shaw, I. (2004). Doctors, 'dirty work' patients, and 'revolving doors'. *Qualitative Health Research, 14*(8), 1032-1045.


Appendix 1

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Guide for authors submitting to:

PAIN
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PAIN
The Journal of the International Association for the Study of Pain

Guide for Authors
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OVERVIEW OF THE INTEGRATION OF KNOWLEDGE, RESEARCH AND PRACTICE

October 2007
Overview of the Integration of Knowledge, Research and Practice

1 Introduction

This paper describes an overview of how taught elements on the Doctorate of Clinical Practice (DClinPrac) linked, and together with the research project\(^1\) contributed to the integration of research knowledge and understanding in my area of practice. I approached this reflective task by viewing the DClinPrac as a series of steps; each step marking a definitive point of knowledge that required a process of learning, and this achievement indicated by the completion of Summative assignments (see Figure 1).

Figure 1: DClinPrac Process

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\(^1\) See Research Project Part One
The Summative assignments were chosen as markers of learning as disentangling and isolating the knowledge acquired from the taught elements proved too complex. Reflecting back a considerable amount of tacit knowledge was also involved in the process, but by definition cannot be articulated (Eraut, 1985). Tacit knowledge acquired while undertaking the DClinPrac and from clinical practice were important resources I had not fully considered before exploring its contribution to learning in the taught elements on Emotions, Leadership and Innovations in Organisations and Communities of Practice.

Overall, and core to the process of extending my knowledge has been the ability to develop skills to think creatively and critically; only with good thinking can vision emerge and vision was essential for energising and directing leadership skills as I embarked on the various projects.

2 Healthcare Policy Review

Reviewing a policy was the first Summative assignment. I saw this as key to shaping and developing a thread of influential factors that would link the taught elements and underpin the background for the Service Development Project (SDP). The SDP would go on to underpin the reasoning and ethical values critical in setting the context for the research project (RP) and support its successful implementation.

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2 See Service Development Project Part Two
However, it was not possible arrive at the policy review step without first developing competencies that would assist in the growth of core skills required to advance the research pathway. These were identified during the Introduction to Doctoral studies element through writing a reflective review of learning and development needs\(^3\), and included developing critical thinking, extending reading, writing and research skills, and improving literature searching abilities, and time management skills.

Prior to undertaking the ‘Policy, Politics and Power’ taught element I was comparatively politically naive of the influence of policy on healthcare with a tendency to allow ‘top down’ filtration of politically driven targets. I quickly grasped that a bottom up approach was vital if clinical practice was going to change in my area of expertise. Reading around issues and policies related to persistent pain, I chose the Expert Patient Policy to review.

Looking back I realise this choice determined the future direction of my research thinking and vision. Through undertaking the review I developed a comprehension of where Government models of self-care linked or failed to link into main stream delivery of care. The emerging message was clear; the National Health Service (NHS) needed to provide the right level of support and care for the various areas of health care; for long term illness these needs were specific and self-care an important component (NHS Modernisation Agency, 2004).

\(^3\) See Appendix 1: Review of Learning and Development Needs as an Expert Practitioner and Researcher
My review of policy led to questions triggered during discussions in the Policy and Professional Ethics element. These asked why there was minimal awareness and integration of Expert Patients Programmes (EPP) in clinical practice, conscious that there were no overt drivers developing or involving lay led self-care approaches in the management of persistent pain in secondary care settings.

As I endeavoured to understand the reluctance of clinicians to engage with lay led self-management approaches, the element on Professional Ethics provided insight through the six dimensions of reasoning. These can influence behaviours of stakeholders and the dimensions that need considering are: reasoning, evidence, procedure, values, assumptions and defences. These can link with political and stakeholder drivers accounting for why some policies are taken up while others ignored.

Even at this stage integration of knowledge into clinical practice occurred as I raised awareness of EPPs in practice by asking colleagues of their experience. Their understanding was limited with a negative edge, but on discussing this with a non-clinical colleague, I found encouragement for developing links between EPP and our service. This perhaps resulted from greater awareness of Government drivers, and completing this policy review was instrumental in developing and shaping my critical thinking⁴.

⁴ See Policy Review Part Two
3 **Service Development Project (SDP)**

The next step in the DClinPrac involved a number of skills to develop that were specific to the taught element on Emotional Leadership. This element widened my understanding of how an ability to think and make decisions may depend on emotional skills, and that these emotions can lead to actions. My vision for this project would also be a vital part of project leadership skills and to steer it to successful completion; but this would not be possible if my colleagues did not share in the vision. It was not about imposing vision but through developing my communication skills I set about promoting a research culture that would support exploring self-care support models.

During the process of conducting the SDP, I championed the value of lay led self-care approaches and found a number of colleagues enthused at the idea of a project that might influence our service’s delivery of care. Reflecting back, I am aware my understanding of the Expert Patient Policy was a critical part of defending this approach, but important my views were balanced. I predicted antipathy from some colleagues towards Expert Patient approaches, so when it came to presenting outcomes of my SDP to the team, I placed emphasis on service flow and efficiency of care pathways (waiting list management)\(^5\). This was a powerful way of influencing colleagues by introducing a new perspective on the problem in a way that they could relate to and understand. It allowed a vision of how improvements and clinical developments could be made in the pain service by involving lay led care.

\(^5\) See Appendix 2: Team Presentation Waiting List Management
At this time the pain service was working towards achieving accreditation as
a Practice Development Unit (PDU). My links with the University and research
were important components in this and PDU accreditation assisted the
positive synthesis of my SDP⁶ and research project into the overall aims of
the pain service. Presentations were made to the Trust to disseminate our
work and included the SDP and updates of my ongoing research project⁷.
The setting up of rehabilitation Pilates and Yoga classes offered an additional
self-care approach directly influenced by this work and demonstrated the
successful diffusion of knowledge into practice. A summary of the aims and
objectives of the nursing services were presented in the PDU portfolio⁸.

4 Research Project

This step in the DClinPrac process found the element on ‘Advanced Research
Methods for the Reflective Researcher’ fundamental for advancing skills that
would underpin the research project. My original research question
progressed to explore an original perspective and with guidance from my
supervisors, the question refined. A research proposal, initial plan of
research⁹ and theoretical framework¹⁰ were developed and explored an area
of advanced practice.

Choosing the appropriate methodology and design were a critical part of the
research project. The SDP had led me to venture into the qualitative

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⁶ See Service Development Project Part Two
⁷ See Appendices 3,4,5: PDU presentations and poster
⁸ See Appendix 6: Summary of the aims and objectives of the nursing service presented in the
  pain management service PDU Portfolio
⁹ See Appendix 7: Initial Research plan
¹⁰ See Research Project Part One
paradigm by conducting semi-structured telephone interviews. This approach had been triggered by two areas of learning and thinking; firstly lectures on the Advanced Research element had explored use and benefits of interviews and focus groups; secondly, in clinical practice I realised I use a mixed method approach everyday through asking patients semi-structured questions and combining this information with quantitative findings from blood, x-ray and scan results.

Deciding a mixed method approach would be appropriate led to researching triangulation, combining data and use of focus groups to confirm understanding. I took every opportunity to attend lectures, study days and support groups that involved issues related to mixed method approaches. The DClinPrac student research conferences proved helpful in this area\textsuperscript{11} and were another area where the dissemination of the SDP occurred\textsuperscript{12}.

Skills and knowledge to design a research proposal and achieve favourable reviews from the Research Ethics Committee (REC), the NHS Trust’s Research and Development Committee (R&D) and the University’s Ethics committee were necessary\textsuperscript{13}. My awareness of research governance, professional ethics and leadership helped this challenging process go without difficulty, supported by an improved ability to articulate my research design to the committees and defend any areas of concern.

\textsuperscript{11} See Appendix 8: Workshop Researching Complex Health Interventions: Moran-Ellis J. Multi-methods research as a way to understand complexity
\textsuperscript{12} See Appendix 8: Workshop Researching Complex Health Interventions: Health Service Evaluation
\textsuperscript{13} See Appendix 9: REC, R&D and UNIS letters confirming favourable ethical reviews
Concerns raised by REC related to ensuring the Control group would not be denied any part of usual care and explanations and reassurances were given. The R&D committee presentation provoked discussion around consent, randomisation and intention to treat analysis. This proved instructive as I built on the discussions and used intention to treat analysis in the research project.

An area of knowledge not previously familiar to me was recognising the complexities of Communities of Practice (CP). From the CP taught element I gained awareness of not only my own CP and its relationship with others, but how the complexities of working in a CP can link with individuals' differing values and are influenced and link with professional ethics. This was important understanding when I came to conducting the research project as I found myself engaging with a number of different communities (See Table 1).

During development of the SDP and research proposal, I contacted leads for EPP in the Primary Care Trust (PCT). I was fortunate to find the Health Promotion Specialist quickly shared my vision for the research project but it was more difficult to convince the national and regional trainers. They appeared less flexible in their approach to involving EPP in an independent research study. Developing links and gaining the confidence of other CPs was a challenge. It required awareness of empathy and sensitivity to my peers, and the effective transfer of knowledge and clinical skills. Cultivating these skills involved steep learning curves that linked constituents found in both the elements on Communities of Practice and Emotions and Leadership.
Table 1: Communities of Practice involved with the research project

Later, I realised the research project had developed its own CP (See Table 1), and this involved a learning partnership. Without good teamwork it would have been impossible to deliver the research project, while working in a CP that included volunteers and professionals brought my attention to how differently the balance of power was weighted both in meetings and in service delivery.

Conducting and managing the research project required all the knowledge and skills gained on the DClinPrac to merge. Essentially they consisted of leadership, communication, research and time management skills, and
ensuring ethical principles were upheld, though in reality it was more complex and the knowledge boundaries less clear.

Analysing the data was another area of learning. Needs to extend these abilities and develop new skills were met through a combination of the Advanced Research Element, individual meetings with the statistician and supervisors, the PhD support group, and training specific to SPSS and NVivo. Reflecting back I can see how my ‘know how’ for different analysis methods has grown through application.

5 Summary

The work carried out for the DClinPrac has been instrumental in developing awareness, changing attitudes and integrating lay led self-care strategies into clinical practice. The influence of the SDP and research project have been prominent in changing the nature of discussions around self-management in the pain service, and instrumental in bringing about a gradual change in cultural attitudes to lay-led approaches. A critical change has been the pain service’s increasing acceptance of these approaches alongside medical models of care.

Prior to this work there was little understanding and support for EPP in practice; it is now seen as an additional resource for some patients as colleagues ask for information to give to patients they consider would benefit from this approach. Care plans incorporating EPP are copied to patients’
General Practitioners, thereby widening the clinical field of awareness, and posters advertising EPP are displayed in the hospital.

Further integration comes from the clinical psychologist’s plan to provide DVD’s promoting self-management at much earlier stages of referral; a change in practice directly influenced by this research project. Plans are in place to introduce a model of professionally led, lay supported self-management programmes, and will be offered to patients at initial stages of referral to the pain service.

Recognition of this work has led to a request to take the position of Clinical Lead for Ongoing Care in the Pain Management Service; this will incorporate where appropriate self-management approaches to complement medical models of care. An additional area of change has been a developing interest by clinicians in the value of Patient Support Groups; together with a medical colleague, I have been co-opted to lead this project.

Evidence of dissemination in the community is seen as discussions take place to deliver a ‘pain specific’ EPP to complement the medical model offered. Wider dissemination of the research findings are found through submission of the research paper for publication\textsuperscript{14, 15} and FoNS webpage\textsuperscript{16} and presentations.

\textsuperscript{14} See Clinical Academic Paper Part One
\textsuperscript{15} See Appendix 10: Confirmation of research paper submission for publication in the journal ‘Pain’
Overall the integration of knowledge, research and practice resulting from this work is considered successful; one of the most difficult things to achieve in the NHS is a change of culture. These changes have and are continuing to happen in the pain service, as the value of patient and lay involvement in managing persistent pain is recognised and incorporated into main stream practice.

A summary of the process of integrating knowledge, research and practice is shown in Figure 2.
Figure 2: Overview of integration of knowledge, research and practice process
6 References


Appendices

Appendix 1

Review of Learning and Development Needs
as an Expert Practitioner and Researcher

Introduction

Learning is described in The Oxford Illustrated Dictionary (1962) as the ‘Possession of knowledge got by study’ with development expressed as a ‘Gradual unfolding or growth’. Both feel appropriate descriptions of the learning and development that will need to experience as I start out on this journey of advanced learning as an expert practitioner and researcher.

While it feels both a daunting and an exciting place to be, I am also aware that I am by no means an empty vessel in terms of research knowledge and clinical practice, but conscious I will need to set targets for my learning and development needs in order to demonstrate:

- Advanced and comprehensive knowledge
- The ability to evaluate knowledge at doctorate level
- The capability of applying knowledge, theory and research methodology in a creative manner to complex themes.
- The skill to identify, conceptualise, design and put into practice research that tackles complex areas

While reflecting on my learning and development needs I have identified six main areas that in particular I will be conscious of actively progressing, although more will emerge as I progress along this voyage of advanced learning.

1. Development of a Realistic Timetable

The development of a realistic timetable will be a crucial part of not only my study needs. Rudd (1985a) suggests that lack of an overall plan can be a major contributory cause of post graduates failure to write up in time, and I very aware from previous experiences that I can set myself unrealistic targets. However, I am not someone who can absorb information and write up effectively when under too much pressure.

My timetable will need to be pragmatic, acknowledging not only study and work time needs but also other activities that are important in order to have balance in my life. This requires discipline which is something I think I am quite practiced at, but it still calls for the initial plan to be realistic. In addition I aware of the pressure of my current clinical work that requires NHS targets to be met regardless of other commitments.

2. Methodology Proficiency

Proficiency in a wide range of methods and techniques of research employed to obtain results is required at this advanced level of study and not just an understanding of the results alone (Potter2002). My practical experience of research methods is quantitative and broadening my understanding of research methods through reading, discussion and supervision will all be part of my learning and development curve.
Reviewing my learning needs has allowed me to acknowledge that my comfort zone is currently quantitative research, and studying at doctorate level will require me to move out of this zone. My initial thoughts regarding my research thesis may well require the use of several different research approaches sometimes described as triangulation (Bowling 1997). In order to conduct investigative study at an advanced level, I will need to gain a much wider understanding of research methodology. To achieve this will need me to actively use self directed learning, consisting of a number of learning approaches, such as enquiry based learning, reading, discussion, supervision and attending lectures and conferences.

3. Reading Skills

Although I have a great affection for books I recognise I am a slow reader and will need to widen my range of reading skills. This may require me seeking out a formal class or just through practice and understanding of different reading skills. Being able to get the gist of the argument, as well as pulling out the significant material or details within a short span of time are reading skills necessary when carrying out research (Blaxter et al 1996). An equally difficult challenge for me will be allocating sufficient time to read while avoiding wanting to start writing too soon.

4. Identifying Boundaries

Developing my ability to separate out, simplify and focus on what is important in a particular situation, research study or article and what is less important and what can be ignored, are all skills identified by Thomas et al (1998). These are skills I need to develop at this level of study.

5. Critical Analysis Skills

Being able to critically analyse and evaluate knowledge are skills I possess but not at an advanced level. As yet I am not sure how I will move from Master to Doctorate level of study skills but currently plan through reading and practice of critiquing papers, feedback from class work and supervision that these skills will advance.

6. Communication Skills – Written and Oral

As Potter (2002) suggests, there is more to writing than just using an academic style and Rudd (1985b) suggests poor writing can create problems with understanding and thesis construction. Being able to write clearly and communicate logically and effectively is a ability that I find requires constant working at. There is considerable literature on how to develop writing skills and accessing this along with practical application, feedback and guidance from supervision I hope will allow this area of my learning and development needs to be met.

I also recognise I lack experience discussing and defending research while I am a complete novice at oral examinations. During the course I will need to develop discussion skills and the ability to argue research outcomes both as an expert practitioner and as a researcher.

Summary

Reviewing my learning needs has been a valuable exercise enabling me to identify skills I have, but that need building on at an advanced level of study and skills I am quite a novice in. The onus is on me to be proactive in developing these advanced
skills in order to meet my learning and development needs as an expert practitioner and researcher.

References

Rudd E. (1985b) *A New Look at Postgraduate Failure*, mcgraw-hill.co.uk/openup/chapters/0335212840
www.sacssp.org.za/Santie/Final
Waiting List Management
Service Development Project
Promoting the Concept of Self-Care Support for Managing Persistent Pain
PDU Accreditation Criteria
Numbers: 6, 9, 10

Waiting Times
- New patients: 17 week target
- Acupuncture: 18 week
- TENS: 2-3 weeks
- DSU treatments: 1-9 months wait
- F/U appts: 5-7 months

The Challenge
Medical Condition
Solution
Culture
Resources

Systematic approach to care for people with long-term conditions
(NHS Modernisation Agency, June 2004)

Aims & Objectives

Aims
- Determine if Governments' proposed systematic stratification approach can be applied to patients referred to the pain service
- Identify population at risk
- Identify if self care support models can be applied to the population referred to the pain service

Objectives:
- Audit
  - Descriptive data
  - PSOCQ
  - CPAQ
  - Telephone interview
- Examine reliability & validity of assessment tools for use in main research project

Audit
- Sample n=110 (65.7% female) all pts referred in Dec 2004
- Questionnaires returned n= 44 (40%) female 73%
- Age range 19-82 yrs (mean 55.7 std 16.9)
- Length of pain 0.5 - 34 years (mean 7.7 yrs std 8.5yrs)
- Have you been given a diagnosis yes 65%
- Semi structured telephone calls:
  - Number agreed to be contacted 86%
  - Number of calls made 20
  - Number of interviews conducted 12

Audit Outcomes

PSOCQ
Precontemplation - believes chronic pain a medical condition that HCP should relieve
Contemplation - serious consideration of change
Action - accept need to self manage pain actively seek new skills & enrich existing ones
Maintenance - active efforts to sustain change

CQA
- Maintenance
- Contemplation
- Precontemplation
- Action

The Challenge

Medical Condition
Solution
Culture
Resources
• 41% scored their average pain as mild to lower limits of moderate

• 10% low interference scores

Strength of relationships
(Correlational coefficient analysis)

<table>
<thead>
<tr>
<th>Relationship</th>
<th>Strength (r)</th>
<th>Sig (p)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acceptance &amp; interference</td>
<td>-0.808</td>
<td>0.000</td>
</tr>
<tr>
<td>Pain &amp; interference</td>
<td>0.761</td>
<td>0.000</td>
</tr>
<tr>
<td>Acceptance &amp; pain</td>
<td>-0.562</td>
<td>0.001</td>
</tr>
<tr>
<td>Acceptance &amp; action</td>
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<td>0.005</td>
</tr>
<tr>
<td>Acceptance &amp; maintenance</td>
<td>0.435</td>
<td>0.014</td>
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</tbody>
</table>

Summary Telephone Interviews

• 24% made greater reference to active strategies

• 76% made greater reference to passive strategies

Propose

1. Patient referrals assessed for eligibility
2. Research study
   • RCT
   • Self-care support model
   • Musculoskeletal pain (exclude CRP, malignancy, trigeminal neuralgia)
3. Primary outcome - reduction of pts contemplation
4. Secondary outcomes
   • Reduced utilisation healthcare resources
   • Reduction interference
   • Increase acceptance
   • Increase in function
   • Reduction pain

Self Management Pain Service Model
Appendix 3

Practice Development Unit Presentation

Accreditation Stage 1 November 2005
Motives for Pain Management Service

- Increase/improve quality & efficiency
  - Reduce waiting times
  - Develop interdisciplinary approach
  - Reduce/maintain costs
  - Work in partnership with medical colleagues
  - Compliment medical colleagues
- Better outcomes for patients

Motives behind nurse-led care

- Health policy change & modernisation of health services (DoH 1977) gave opportunities to reconsider & challenge traditional health care roles & professional boundaries
- Nurse-led care - key opportunity to challenge current models of care
- 'Making a Difference' (DoH 1999) advocated nurses to work in new ways extending roles/making better use of skills & knowledge
- 'The National Plan' (DoH 2000) set out future direction with emphasis the way staff work

Process Involvement

<table>
<thead>
<tr>
<th>Stakeholders</th>
<th>Opportunities identified</th>
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<tbody>
<tr>
<td>Users</td>
<td>Nurse-led clinic</td>
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<tr>
<td>Pain Consultants</td>
<td>Nurse-led inpatient</td>
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<tr>
<td>Management</td>
<td>Pain management programme</td>
</tr>
<tr>
<td>Primary Care Teams</td>
<td>Teaching</td>
</tr>
<tr>
<td>Strategic Health Authority</td>
<td>Leadership</td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
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</table>

<table>
<thead>
<tr>
<th>Resource Issues</th>
<th>Outcomes</th>
</tr>
</thead>
<tbody>
<tr>
<td>1999</td>
<td>Nurse-led clinic X1 F/T nurse PMP</td>
</tr>
<tr>
<td></td>
<td>Pain management programme</td>
</tr>
<tr>
<td></td>
<td>New patients, follow ups, TENS</td>
</tr>
<tr>
<td>2005</td>
<td>Nurse-led consultant nurse</td>
</tr>
<tr>
<td></td>
<td>X1 P/T specialist practitioner</td>
</tr>
<tr>
<td></td>
<td>Inpatient 160 new referrals per year</td>
</tr>
<tr>
<td></td>
<td>TENS waiting time reduced from 1 year to 7 weeks</td>
</tr>
<tr>
<td></td>
<td>Helpline: approx 45 calls/month</td>
</tr>
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</table>

Summary Nurse-led services

- Nurse-led clinics seeing:
  - Pain Management
  - Telephone Helpline
- Nurse-led Inpatient Service
- Leading Research Project
- Lead Benchmarking for Pain Management Service
- Member Pain Management Programme Team
- Teaching
- Pilates & Yoga Classes
PDU
Systematic approach to care for people with long-term conditions

Level 3:
Patients with highly complex conditions

Level 2:
Higher risk patients

Level 1:
Low risk patients

Supporting Care and Self Management
70-80% patients

Specialist Disease Management

Case Management

Pain total
Interference total

Acceptance

Stages of Change

- Maintenance
- Action
- Contemplation
- Precontemplation

Outcome of Service Development project
Approx. 27% of patients referred to pain service appeared to fit Level 1 category & 37% to be amendable to a self-care approach
Chronic Pain Management Service

'Promoting Nurse-led Services' (transforming delivery of care)

Heather Hawksley Consultant nurse
Caroline Tyrrell Specialist nurse
Sue Beer Specialist nurse

Motives for promoting nurse-led services

Aim: Better outcomes for patients

Objectives: Increase/improve quality & efficiency
- Reduce waiting times
- Develop interdisciplinary approach
- Reduce/maintain costs
- Work in partnership with multidisciplinary colleagues
- Complement multidisciplinary professional colleagues
- Explore lay-led approaches

At Stage One

Outcomes
- Introduced new template for TENS clinic
- Doubled number of TENS patients seen per week
- TENS waiting time reduced from 6 months to 2 weeks

Focus Stage Two

Aim:
- Promote nursing skills to the patients advantage
- Show impact
- Provide the evidence (research & audit)
- Disseminate practice

Objective:
- Systematic approach
- 2 audits
- Longitudinal research project exploring impact of lay led self-management programmes

Promoting nursing skills to the patients advantage as a team

- Replaced TENS clinic with nurse-led follow up clinic - need to develop skills
- Continued to develop skills within other nurse-led clinics
- No longer loan out TENS units
  - Reduced staff time managing & maintaining equipment
  - Reduced costs
  - Reduce health & safety issues related to loaning equipment out

Promoting nursing skills - competent & safe

- Support from the whole team
- Shadowed colleagues
- Recognised weekly support session from clinical lead
- Regular supervision from medical colleagues (via feedback clinic letters & in clinic)
- Planned MDT meetings
- Development guidelines & pathways
- Developing competency for examining patients with back pain & discharging patients
- Discussion stage of nurse-led minor treatment session
**Impact**

- 270 additional F/U appts (per year)
- Waiting times F/U reduced/stabilised
- Small increase in TENS waiting time
- Cost for Tens unit - nil
- Developed transferable nursing skills cover for sick & A/L - clinics & PMP

**But**

are patients needs being met & quality of service maintained?

Where’s the evidence?

- longitudinal research project
- 2 audits
- No incidences or complaints

**Research**

- Longitudinal RCT - impact of early introduction of lay-led self-care approaches n=74 (supervised UNIS)

- Compare outcomes pts. (control) first seen by medical consultants (pain, interference, no appts) - is quality service maintained?

**Audit 1**

March 06

- Retrospective audit review notes patients seen in consultant nurse clinics n=79 (new 37 f/u 42)

- outcome of appt - is this clinic freeing up appts with medical colleagues

**Optimise CN clinics**

Reduce any unnecessary duplication of appts by:

- Utilising back pain pathway
- Choose & book - Identify patients appropriate
What were patients views of being seen in a nurse-led clinic?

For your appointment today would you have preferred to be seen by:

Overall, how do you rate your care today:

Audit 2

May - June 06

Retrospective satisfaction survey - involving patients seen in nurse-led clinic
n=59 (new13: f/u 28: TENS 17)

Patients were asked if they wished to add any comments and 37% did. Some of these were:
1. Nurse dealt very well with all aspects of the appointment. Have nothing but compliments for the way pain clinic is run and have been fully informed of everything.
2. I know that if I need to see the doctor I will be referred after meeting the nurse
3. A very worthwhile service
4. I was highly satisfied, thank you
5. I was more than happy with the lady I saw
6. Very informative appointment

How are we disseminating our practice?

- Annual Trust Report
- University research groups
- Networking (south east pain group)
- Consultant nurse UK group
- Foundation Nursing Studies visit & publish paper
- RCN Pain Forum

Summary

- Extended boundaries of practice
- Systematic approach planning & delivering care
- Making the patient's journey smooth and uneventful
- Problem solving
- Supported practice developments with audit evidence
- ? future evidence gained from study
Appendix 6

Summary of the aims and objectives of the nursing service presented in the pain management service PDU Portfolio

Introduction

The Chronic Pain Management Nursing Service at Ashford and St. Peter’s Hospital has been established since January 2000. The aim of the service is to support, advise, treat and empower patients suffering from persistent pain, throughout their plan of care and treatment. In addition the nursing service aims to complement other members of the interdisciplinary team in providing this care.

Objectives

- To continue to develop the range of services offered to patients suffering with chronic pain
- To support the development of Chronic Pain services at Ashford and St Peter’s Hospital trough the interdisciplinary pain management team
- To support Orthopaedic, Surgical, Medical and Psychiatric firms in the provision of inpatients and outpatient support services for patients with chronic pain
- To provide specialist nursing input to achieve and maintain the highest possible standards of chronic pain management within the hospital and community it serves
- The development of suitable and appropriate information for patient and carers
- To ensure that the service provided is capable of responding to anticipated changes in need, nursing standards and advances in the management of pain
- To actively promote the views of patients in the development and delivery of the chronic pain management service
- To promote and undertake audit and research activity to develop evidence to support extended nursing practice
- To continually review service provision to ensure effective quality services are offered to patients and carers

Clinical Activities

- Outpatient consultations in specific nurse-led clinics
- In patient nurse led care to a range of patients suffering from chronic pain
- Telephone advisory service for GPs, patients, relatives and carers
- An education service to nursing staff and other professionals from the Trust and Primary Care
- Maintenance and updating of policies and standards in relation to chronic pain management
- Research project
### Appendix 7

**Initial Research Plan November 2005**

<table>
<thead>
<tr>
<th>Date</th>
<th>Action</th>
<th>Person responsible</th>
<th>Completed</th>
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<tbody>
<tr>
<td><strong>Sept</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>12</td>
<td>Meeting JK/BC to discuss plan and amend update etc</td>
<td>HH</td>
<td>Sept 12</td>
</tr>
<tr>
<td>14</td>
<td>Meeting HH, JB, BC and Terry and Pat to discuss arrangements</td>
<td>HH</td>
<td>Oct</td>
</tr>
<tr>
<td></td>
<td>Confirm BC hours/ payment method</td>
<td>HH</td>
<td>Sept 05</td>
</tr>
<tr>
<td></td>
<td>Order envelopes</td>
<td>H/Kim</td>
<td>Sept 05</td>
</tr>
<tr>
<td></td>
<td>Put together Information invitation letters &amp; packs</td>
<td>HH</td>
<td>Sept/Oct 05</td>
</tr>
<tr>
<td></td>
<td>Order participants handbook from Jane B</td>
<td>HH/BC</td>
<td>Oct 05</td>
</tr>
<tr>
<td><strong>October</strong></td>
<td>Referral letters reviewed – unsuitable patients identified</td>
<td>All medical consultants</td>
<td>Commenced Oct 05</td>
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<tr>
<td>1</td>
<td>Pass referral letters to HH for review patients fitting study’s inclusion criteria identified</td>
<td>JK/BC</td>
<td></td>
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<tr>
<td></td>
<td>Patients suitable for inclusion identified &amp; added to study database</td>
<td>HH</td>
<td></td>
</tr>
<tr>
<td></td>
<td>All referrals placed on W/L list &amp; written to inform on W/L</td>
<td>JK/BC/SP</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Put together questionnaires</td>
<td>HH / BC?</td>
<td></td>
</tr>
<tr>
<td><strong>Oct/Nov</strong></td>
<td>Identify from letters returned patients willing to participate</td>
<td>HH</td>
<td></td>
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<tr>
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<td>Contact patients to discuss further &amp; offer information session if requested</td>
<td>HH</td>
<td></td>
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<tr>
<td></td>
<td>Send reminder to patients failed to respond</td>
<td>HH/BC</td>
<td>Commenced Oct 05</td>
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<tr>
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<td>Organise information session or send consent</td>
<td>HH/BC</td>
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<td>Patients consenting added to study database</td>
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<td></td>
<td>All patients participating sent questionnaire</td>
<td>HH/ BC</td>
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<td>Send reminder to patients failed to respond</td>
<td>HH/BC</td>
<td></td>
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<tr>
<td></td>
<td>Patients participating randomised using SPSS</td>
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<tr>
<td></td>
<td>Patients in control group written to inform in control group</td>
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<tr>
<td></td>
<td>Patient randomised to intervention group written to with dates of EPP</td>
<td>HH/BB</td>
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<td><strong>Nov</strong></td>
<td>Helpline calls returned</td>
<td>HH</td>
<td></td>
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<tr>
<td>7</td>
<td>Reminder &amp; details of course sent to tutors Terry &amp; Pat</td>
<td>HH/BC</td>
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<td>15</td>
<td>Reminder to attend EPP sent to participants</td>
<td>HH/BC</td>
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<td>23</td>
<td>EPP week 1 - Tutors Terry &amp; Pat</td>
<td>HH/JB</td>
<td>Jan 06</td>
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<td>30</td>
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<td><strong>Dec</strong></td>
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<td>HH/JB</td>
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<td>21</td>
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<td>HH/JB</td>
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<td>EPP week 6</td>
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<tr>
<td><strong>Feb</strong></td>
<td>Send out 4 month questionnaire control &amp; intervention group</td>
<td>HH</td>
<td>April 06</td>
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<td>Arrange focus groups</td>
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# Researching Complex Health Interventions

**EIHMS Research Conference**

**Wednesday 28 June 2006**

<table>
<thead>
<tr>
<th>Time</th>
<th>Speaker[s]</th>
<th>Topic</th>
<th>Room/Venue</th>
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</table>
| 10:00am    | Professor Christine Norton  
Nurse Consultant at St Marks Hospital, Middlesex                         | "Evaluating outcomes: The case of bowel care"                        | 01 DK 03   |
| 10:30am    | Dr Wesley Scott-Smith  
Lecturer in Medical Health Care  
University of Surrey                       | "Researching reasoning in Primary Care"                              | 01 DK 03   |
| 11:00am    |                                                                                 | **Coffee Break (15 minutes)**                                         |            |
| 11:15am    | Ms Jo Moran-Ellis  
Senior Lecturer in Sociology  
University of Surrey                       | "Multi-methods research as a way to understand complexity"            | 01 DK 03   |
| 11:45am    | Professor Jill Dawson  
Senior Research Scientist  
University of Oxford                       | "Patient-reported outcomes assessment: Uses and possible abuses"  
(Followed by discussion)              | 01 DK 03   |
| 12:45pm    |                                                                                 | **Lunch Break (1 hour)**                                               |            |
| 1:45pm     | Isabel White  
PhD student, University of Surrey                       | **Workshop:** Observational Conundrum                                  | 01 DK 03   |
| 1:45pm     | Lisa Musselwhite  
Head of Healthcare Standards  
Heather Hawksley  
Consultant Nurse                       | **Workshop:** Health Service Evaluation                                | 17 DK 02   |
| 2:45pm     |                                                                                 | **Coffee Break (15 minutes)**                                         |            |
| 3:00pm     | Dr Vasso Vydelingum  
Director of Studies: MSc Advanced Practice  
University of Surrey                       | **Workshop:** Your health in their hands: are we safe with politicians? | 01 DK 03   |
|            | Dr Sara Faithfull  
Director of Studies: Doctorate of Clinical Practice  
University of Surrey                       | **Workshop:** Introduction to Statistics                                | 15 DK 00   |
| 4:00pm     | End                                                                          |                                                                      |            |

Please contact Andy Cross to book your place
Tel: 01483 684640  Email: research@ihs@surrey.ac.uk
Appendix 9

Letters from:

1. Regional Ethics Committee
2. Research and Development NHS Committee
3. University of Surrey Ethics Committee
# NORTH WEST SURREY LOCAL RESEARCH ETHICS COMMITTEE

## LIST OF SITES WITH A FAVOURABLE ETHICAL OPINION

For all studies requiring site-specific assessment, this form is issued by the main REC to the Chief Investigator and sponsor with the favourable opinion letter and following subsequent notifications from site assessors. For issue 2 onwards, all sites with a favourable opinion are listed, adding the new sites approved.

<table>
<thead>
<tr>
<th>REC reference number:</th>
<th>05/Q1908/66</th>
<th>Issue number:</th>
<th>1</th>
<th>Date of issue:</th>
<th>13 September 2005</th>
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<tbody>
<tr>
<td>Chief Investigator:</td>
<td>Mrs Heather Hawksley</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Full title of study:</td>
<td>Promoting a Self Care Approach to Managing Persistent Pain</td>
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This study was given a favourable ethical opinion by North West Surrey LREC on 13 September 2005. The favourable opinion is extended to each of the sites listed below. The research may commence at each NHS site when research governance approval from the relevant NHS care organisation has been confirmed.

<table>
<thead>
<tr>
<th>Principal Investigator</th>
<th>Post</th>
<th>Research site</th>
<th>Site assessor</th>
<th>Date of favourable opinion for this site</th>
<th>Notes (1)</th>
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</thead>
<tbody>
<tr>
<td>Mrs Heather Hawksley</td>
<td>Consultant Nurse</td>
<td>Ashford &amp; St Peter's NHS Trust</td>
<td>North West Surrey LREC</td>
<td>13 September 2005</td>
<td></td>
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Approved by the Chair on behalf of the REC:

(Delete as applicable)

(Signature of Chair/Administrator*)

(Name)

---

(1) The notes column may be used by the main REC to record the early closure or withdrawal of a site (where notified by the Chief Investigator or sponsor), the suspension of termination of the favourable opinion for an individual site, or any other relevant development. The date should be recorded.

SF1 Site approval form
Version 3, June 2005
Reference: 2005HH01

20 September 2005

Mrs. Heather Hawksley
Consultant Nurse
SPH, Guildford Road, Chertsey
Surrey KT16 0PZ

Dear Mrs. Hawksley

Re: Promoting a self-care approach for managing persistent pain (REC Ref: 05/Q1908/66)

I am very pleased to inform you that your project was considered by the R&D Committee on Thursday 28 July 2005 and was approved subject to Ethics approval. The R&D office has received LREC approval and has no objection to your proceeding with this study. However, the R&D Office would highly appreciate to receive final report of your study and any dissemination (s) from this work.

Best wishes,

Yours sincerely,

[Signature]

Dr Isaac John
Assistant Director R&D
E-Mail: Isaac.John@asph.nhs.uk
05 October 2005

Mrs Heather Hawksley
Ashford & St Peter's Hospital
Nightingale House
Guildford Road
CHERTSEY
Surrey KT16 0PZ

Dear Mrs Hawksley

**Promotion of self-care approaches for managing persistent pain**
**(EC/2005/105/EIHMS) – FAST TRACK**

On behalf of the Ethics Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the submitted protocol and supporting documentation.

Date of confirmation of ethical opinion: **05 October 2005**

The list of documents reviewed and approved by the Committee under its Fast Track procedure is as follows:-

Document Type: Application
Dated: 21/09/05
Received: 28/09/05

Document Type: A Copy of the NHS REC Application Form
Version: 4.1
Dated: 10/08/05
Received: 28/09/05

Document Type: Approval Letter from the North West Surrey LREC
Dated: 13/09/05
Received: 28/09/05

Document Type: Research Proposal
Dated: 07/05
Received: 28/09/05

Document Type: Appendix 1 – Research Study Flow Chart 1
Received: 28/09/05

Document Type: Appendix 2 – Patient & GP Letters and Information Sheet
Received: 28/09/05
This opinion is given on the understanding that you will comply with the University's Ethical Guidelines for Teaching and Research.

The Committee should be notified of any amendments to the protocol, any adverse reactions suffered by research participants, and if the study is terminated earlier than expected with reasons.

You are asked to note that a further submission to the Ethics Committee will be required in the event that the study is not completed within five years of the above date.

Please inform me when the research has been completed.

Yours sincerely

Catherine Ashbee (Mrs)
Secretary, University Ethics Committee
Registry

cc: Professor T Desombre, Chairman, Ethics Committee
    Professor K Bryan, Supervisor, EIHMS
    Dr S Faithfull, Supervisor, EIHMS
Appendix 10

Confirmation of research paper for publication

Journal: PAIN
Title: The impact of lay led self-management in managing persistent pain: A randomised controlled trial
ID: PAIN-D-07-3807
Format: Full-Length Article
Authors: Heather R Hawksley, MSc, BSc(Hons); Sara Faithfull, PhD, MSc, BSc(Hons); Karen Bryan, PhD, BSc, CertMRCSLT

Dear Mrs Hawksley,

Your submission entitled "The impact of lay led self-management in managing persistent pain: A randomised controlled trial" has been assigned the following manuscript number: PAIN-D-07-3807.

You will be able to check on the progress of your paper by logging on to Editorial Manager as an author.

The URL is http://pain.edmgr.com/
username: hrhawksley
password: hawksley582

Thank you for submitting your work to this journal.

Kind regards,

Kathy E. Havers
Editorial Office
PAIN
ADVANCING HEALTHCARE PRACTICE

Small grants awarded during 2005

Promoting a Self-Care Approach to Managing Persistent Pain

Project leader:
Heather Hawksley

Location:
Ashford and St.Peter's Hospitals NHS Trust

Summary of initiative:
Self-care approaches are now considered a fundamental part of managing long term conditions (Department of Health 2001a, 2001b, 2005) and for some patients it may offer opportunities to regain self respect, meaning, dignity, purpose and a sense of well-being that an approach dominated by an acute medical model may inhibit (Hanson and Gerber, 1990) Such an approach requires shifting patients' beliefs towards a greater commitment to self management, and this is unlikely to happen without healthcare professionals endorsing and reinforcing the approach with their patients (Chappie and Rogers, 1999).

This project aims to explore the benefits of a lay-led self-care pain management programme (known as the Expert Patient Programme) on longer-term outcomes as patients progress through the pain services treatment model.

References:


For further information about this project please contact: Heather.Hawksley@asph.nhs.uk

back to 2005 grants
Promoting a Lay Led Self-Care Approach to Managing Persistent Pain

by

Heather RM Hawksley

THESIS
Submitted for the degree of Doctor of Clinical Practice

PART TWO
Policy Review
Service Development Project

Faculty of Health and Medical Sciences
Division of Health and Social Care

University of Surrey

March 2008
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POLICY REVIEW

The Expert Patient:
A New Approach to Chronic Disease Management in the 21st Century

October 2004
Abstract

This policy analysis reviews the impact of introducing and implementing ‘The Expert Patient: A new approach to chronic disease management for the 21st Century’ (TEP). It is a policy aimed at changing how chronic illness is managed and has implications for the author’s area of practice and research within a chronic pain management service. The Government has proposed that by 2007 the National Health Service will have established a user self-management approach to dealing with issues associated with chronic illness, and TEP is considered a policy that will help deliver this vision. However, its implementation has been met with difficulties that mainly relate to relationship problems particularly with healthcare professionals.

This analysis unravels how a user self-management approach to providing healthcare has been permitted and whether cultural beliefs within the NHS alongside complex healthcare beliefs of society, may make it difficult for this policy’s aim to be realised. Suggestions are also made that this policy was never intended to be implemented successfully but is merely a means to an end for a government that needs to be seen to be delivering their healthcare agenda.

Overall it is concluded that this policy may be pivotal in influencing much needed improvements for those with chronic illness but it requires additional investment not only in resources but also in research evidence to support it. Finally it is suggested that to have any chance of engaging the medical profession in its implementation and long term success, a less controversial term for Expert Patient must be found.

Is it just a placebo policy?

*Placebo* – a medicine given to humour the patient *(Oxford Press, 1962)*

**Introduction**

Traditionally governments propose policy and delegate its implementation to agents giving the impression the process follows a clear rational and linear sequence. In reality the diffusion of policy into practice is complex and cyclical, with the very introduction influencing the character and content of it in many ways. Some of these influences are obvious but others may be less overt *(Hunter & Killoran, 2004)*. However, the making of policy should never be assumed to be a rational process *(Stockwell, 1993)* and its analysis by no means a simple exercise *(Bond, 1999; Nicoll & Beyea, 1999)*.

Policy can be likened to adopting a plan of action *(Collins English Dictionary, 2003)*; how Government instigates a course of action can enhance our comprehension of how we go about everyday life in both a professional and personal capacity *(Cheek & Gibson, 1997)*, and the analysis of a policy can be helpful to evaluate its potential outcomes allowing alternatives to be considered and questioned *(Nicoll & Beyea, 1999)*.

This paper will conduct a review of The Expert Patient: A new approach to chronic disease management for the 21st Century *(TEP)* *(Department of*
Health, 2001a), a policy aimed at changing how chronic illness is managed. It has been chosen for analyses because of its potential to impact on the provision and delivery of some healthcare services in secondary care. The viewpoint is taken from the perspective of the management of chronic pain, a branch of medicine that perhaps throws up more ‘irreconcilable paradoxes’ than most other areas (Scargill House, 2004).

The Government has proposed that by 2007 The National Health Service (NHS), influenced by the introduction of TEP will have established a user self-management approach to dealing with issues and care associated with chronic illness (Tattersall, 2002). The ‘Expert Patient’ a new expression in healthcare (Wilson, 2001), was first introduced in the White Paper, Saving Lives: Our Healthier Nation (OHN) (Department of Health, 1999), and both OHN and TEP are policies that firmly identify New Labour’s intention to address the needs of people with chronic illness and diseases, while exemplifying the government’s new ‘partnership’ approach to managing healthcare. This partnership approach was heralded as ‘the Third Way’ in the White Paper The New NHS: Modern and Dependable (Department of Health, 1997), and after seven years in power, New Labour now considers much of the policy framework for improving health and tackling health inequalities established; the emphasis now on effective implementation (Hunter & Killoran, 2004).

This analysis will explore how implementation of TEP is contributing to the government’s ‘Third Way’ approach and will attempt to unravel the rationale
and aims of a self-management approach to providing healthcare, and how this approach has been permitted. Whether it is developing into a successful approach for both patients and healthcare professionals is questionable and cultural beliefs relating to self managed care will be probed raising concerns that the policymakers may have overlooked the complexity of society’s beliefs about health that may not have shifted at the same speed as the implementation of this policy.

Further questions considered relate to why lay-led self-management programmes for chronic illnesses have been chosen to promote rather than similar evidence based professionally led programmes, and what the consequences of this choice are. The analysis will conclude with a discussion focused on evaluating the implementation of the policy exploring possible uncertainties around its intention, questioning if it is just a placebo policy. The hidden agenda may well be that it is cheap to administer and has been developed to placate powerful stakeholders in the voluntary sector, whilst distracting healthcare professionals and the public from the escalating problems that an aging society generates for the NHS.

In order to conduct this analysis the literature was explored for a framework to guide the process. Frameworks identified (Bond, 1999; Harrison, 2001; Helms, 2002; Nandan, 2003; Nicoll & Beyea, 1999; Ryder, 1996; Thomas, Chataway, & Wuyts, 1998; Wilson et al., 2001), failed to provide a structure that allowed easy progression for this analysis and a composite framework was adapted from existing frameworks to aid the process (Figure 1).
An outline spider diagram is included to help describe the diverse number of links with TEP that may influence how problems and values associated with chronic illness are viewed, approached and translate into policy. Some of
these influences are obvious but others may be less evident but no less intrinsic to shaping the policy and how it has been implemented.

**Map to show links with**
The Expert Patient: A New Approach to Chronic Disease Management in the 21st Century

**Background**

TEP (Department of Health, 2001a) is a policy aimed at utilising both the work of patients and clinical organisations in developing self-management initiatives to support patients with chronic medical conditions. For many with chronic illnesses the goals are not about cure but improving quality of life and minimising the consequences of conditions through improved management.
OHN (Department of Health, 1999) describes Expert Patient Programmes (EPP) as a way to address the needs of those with chronic illness and further commitment to implementing such a formal programme was made in The NHS Plan (Department of Health, 2000). TEP (Department of Health, 2001a) describes a self-management approach as being within the boundaries of a conventional medical approach, with emphasis on giving patients skills to become equal partners, while taking over some of the management of their own illness (NHS Expert Patients Programme, 2002). These documents appear transparent, conveying the government's intention to make self-management an approach to healthcare that is not only acceptable but integral to how the NHS in England provides care for those living with some form of chronic illness.

OHN (Department of Health, 1999) set out how New Labour aimed to achieve its healthcare vision of 'saving lives, promoting healthier living and reducing inequality in health'. These ideologies considered part of a new model for a new century incorporated the 'Third Way', described as a system based on partnership and driven by performance (Department of Health, 1997). TEP's contribution is proposed as a way to address failures in the past to assist people with chronic conditions to be part of managing their own condition and is the final strand to the Health Citizens initiative in OHN (Department of Health, 1999). Following publication of OHN a Task Force was set up chaired
by the Chief Medical Officer, resulting in TEP and highlighted expectations that relationships between EPPs and the NHS would develop. Importantly, it also aimed to shift the balance of care from acute to chronic health issues establishing the needs of those with chronic illness as central to care provide by the NHS, (Department of Health, 1999).

Defining the Issue

'The greatest medical problem in the United States and Great Britain is chronic illness' (Kent, 1952) and this has been accelerated by an increasing and aging population (Scheele, 1956). Modern society has not evolved a satisfactory way to care for the disabled (Roberts, 1953), and the growing problem of preventing and detecting chronic disease has increased such that it requires the participation of the State and of other agencies (Chapman & Bergsma, 1956).

By reviewing the literature from the 1950’s it is possible to see that the management of chronic illness is not a new problem but one that resists solutions and may continue to do so because of shifts in the demographic age of the United Kingdom (UK) population towards an older population. As we all live longer so an increasing number of us may experience chronic disease and its associated burden on healthcare provision (Department of Health, 1999, 2001a). Improvements aimed for in living and healthcare have been achieved, and so people live longer (National Statistics, 2002a), and for the first time since censers were kept there are more people aged over sixty years then children resulting in diminishing numbers of taxpayers available to
support the growing size of the older population (National Statistics, 2002a,)
(Graph 1).

Graph 1: Demographic Change in Age of UK Population 1951-2001

It is predicted that many NHS services funded through taxation will be outside the NHS’s financial means by 2020 (Bradshaw, 2003), a view dismissed more recently by John Reid the Health Secretary in an address to European Union ministers. He was optimistic that the tax-funded NHS could cope with an aging population (Carvel, 2004a), but may only reflect the importance the NHS holds politically. The government cannot risk confrontation and electoral unpopularity with a general election expected in the next 12 months, and political parties are preparing to fight major issues, especially the NHS (Morgan, 2004).

The belief that greater longevity is associated with the burden of increasing numbers of chronic conditions such as pain, heart disease, arthritis, diabetes mellitus, and asthma (Department of Health, 2001a), cannot be ignored when statistics show 7.2 million (13 per cent) of the total number of
residents in Great Britain, are now recorded as having a long term illness (HMSO, 1995) (see Graph 2).

Graph 2: Trends in percentages of males and females reporting illness and restricted activity: Great Britain, 1972 to 2002 (National Statistics, 2002b,)

Looked at more closely these statistics reveal two thirds of those aged over 75 years suffer from long standing illness or disability (Department of Health, 1999). Other figures relating to sickness and invalidity benefits for chronic back pain show notable rises in costs over the last fifty years, (Graph 3), and theories are emerging in this area suggesting conventional medical treatment may actually increase the problem of chronic musculoskeletal pain (Anon, 2001; Indahl, Velund, & Reikeraas, 1995; Peters, 2004) raising interesting questions as to why the medical profession persist with these common treatments (Peters, 2004).
A picture emerges of an increasingly aging, disabled and expensive population, and the cost of funding the mounting demand from chronic illness is a perpetual struggle for Government (Bradshaw, 2000a). The success of the NHS is seen to add to the problem as the more work it does, the more is demanded of it; while society escalates its requirements because it is free at the point of delivery, and there is minimal control over management of that demand (Bradshaw, 2000b, 2003). Adding to this is failure of the public and healthcare professionals to alter models of care, and an acute model of medical care continues to be applied to most diseases failing to effectively manage those that require a chronic approach (Fraiser, 1992; Gorman, 2004; NHS Modernisation Agency, 2004; Zola, 1973).

**Examining the Context**

When New Labour came to power in 1997 there were two principle issues concerned with delivering the NHS. These were:
1. Funding of services in the future

2. Who will and how will these services be delivered (Bradshaw 2003).

In order to address these concerns the 'Third Way' can be seen as a vehicle to help drive change in public views of healthcare provision, instilling expectations that they must work together with government taking a proactive role to improve their own health (Department of Health, 1999) Thus the 'Third Way' was seen not only as an enabler and provider, but also as an organiser, as it encouraged the participation of a wide range of stakeholders in the development of policy to deliver its ideology (Taylor, 2000). This pluralist approach is not entirely new as governments have been seen to embrace the concept of pluralism since 1979 (Savage, Atkinson, & Robbins, 1994), but the theory is helpful to understand how autonomous and interdependent groups, sharing wide ranges of resources are now contributing to power.

However the emphasis on self help in New Labour’s healthcare policies (Department of Health, 1997, 1999, 2001a) has been criticised for confusing the role of the State (Taylor, 2000; Wilson, 2001), despite the fact that involving patients in healthcare is not entirely new. It has been part of government policy for at least 30 years (DHSS, 1976; Heini, 2004), but only within the last 25 years has it received attention from academics as the fact that people do actually take care of themselves has been discovered. Since then self help has been greatly debated in the medical arena based on an increasing interest in the relationship between self help and wellness.
(Kickbush, 1989). It was perhaps inevitable that the concept of self help would become an academic and political issue because of increasing pressure on resources, both influencing and at times opposing each other’s ability to change healthcare provision (Kickbush, 1989).

What the ‘Third Way’ has provided is an ideal framework on which to hang a self-management approach to healthcare and this is currently endorsed across central policies of the NHS (Department of Health, 1997, 1999, 2000, 2001b, 2001a; Wanless, 2004). Current health policy has a vision of patients with chronic conditions becoming equal partners in the management of their health, taking increasingly active roles, such as exercise and user-led self-management (NHS Expert Patients Programme, 2002; Thomas, 2004). This ethos has been reinforced by an emerging shift in beliefs about healthcare, and a reduction of faith in conventional medicine (Department of Health, 2001a; Ham, 1999), suggesting it is no longer acceptable for the public to pursue past beliefs that healthcare professionals, in particular doctors, are responsible for their health (Department of Health, 2001a). No longer can they consider their own contribution to health as of minor importance (De Valck & Vinck, 1996).

What is the expert patient policy?

TEP (Department of Health, 2001a) policy has three aims:

1. The maintenance of increased health and improved quality of life
2. The empowerment of the individual in managing his/her chronic disease/illness or disability
3. The provision of appropriate support to facilitate individuals in the self-management of their condition/disease

The policy is divided into five sections; briefly these are:

1. The Vision: This section emphasises the involvement of new policies to modernise the NHS and in particular the role of patient centred policies to enable fundamental changes to occur in the way the NHS operates. Ultimately the vision of the EPP is a programme that will deliver improvements to the lives of current and future generations of patients with chronic diseases.

2. The Challenge: This section identifies the enormous problem chronic disease poses in most industrialised countries and what core common requirements generically focused programmes could address.

3. The Current Position: The focus of healthcare provision is currently aimed at acutely ill people, and the need to swing the balance towards those with chronic diseases is identified in this section. The gaps in healthcare provision for chronic illness are acknowledged and why it is now opportune to expect this group of patients to play a fuller part in decisions about their illness and treatment. Forces driving these changes are listed and include:

   - increasing availability of information
   - developments in technology
   - greater acceptance by patient to take responsibility for their health
• emphasis in healthcare training for professionals on the importance of developing relationships with patients as partners in planning care
• increased awareness by patients of limitations of the biomedical model and the demand for alternative approaches.

Ways in which the government and NHS are supporting a self-management approach to chronic diseases are identified and include among them National Service Frameworks, NHS Direct helpline and the Patient Partnership Strategy. A full list can be found in Appendix 1.

4. Evidence and Experience: This section sets out the evidence and benefit of taking a self-management approach to chronic illness and is supported by studies conducted by Professor Kate Lorig and her colleagues at Stanford University in The United States of America (USA) along with work produced in the United Kingdom (UK) by Professor Julie Barlow.

5. The Programme: The final section concentrates on the recommendations and actions that need to occur to implement self-management programmes. (Department of Health, 2001a; Tattersall, 2002)

TEP proposes what appear skilful ideas for managing the growing problem of chronic illness. It is easy to read but fails to address many practical aspects of policy implementation; other criticisms suggest the document is ‘indigestible, repetitive, short on detail and filled with jargon and slogans’ (Tattersall, 2002) :227).
To deliver the EPP, the policy adopted the Chronic Disease Self Management Programme (CDSMP) previously developed at Stanford University under the leadership of Professor Lorig. The CDSMP focus is on teaching patients with chronic disease how to better manage their symptoms, adhere to medications regimes and maintain their level of function (Kass-Bartelmes, 2002). The adapted version for the NHS EPP, delivers the same self-management philosophy but introduces a different emphasis, ones that challenges the competency of the medical profession. The premise is that patients with chronic illness will often understand their condition better than the doctor (Department of Health, 2001a), with the intention of helping patients to become ‘experts’ in their knowledge about their illness in order to develop self-management skills (Department of Health, 2001a; NHS Expert Patients Programme, 2002).

The different stance taken by the NHS EPP is curious for the obvious conflict it invites from healthcare professionals (Shaw & Baker, 2004), but may reflect forces within New Labour that wish to challenge the dominance and power that the medical profession has enjoyed largely unchallenged since the inception of the NHS in 1948 (Ham, 1999; Thomson, 2003). Discussions in the literature suggests that even the choice of the term ‘Expert Patient’ is provocative to doctors as it builds an image of a more demanding and time consuming patient (Shaw & Baker, 2004). Yet, it has been found that patients who attend self help groups do indeed put more demand on healthcare professionals (Trojan, 1989), and resistance to the idea of expert patients by the medical profession was confirmed in a survey of 200 doctors.
which found only 21% were in favour of this approach (The Association of the British Pharmaceutical Industry, 1999).

Doctors are not the only group put off by the term expert patient. The national evaluation of Primary Care Trust (PCT) pilot sites for the EPP, found patients disliked the term. They felt it labelled them as a 'patient' and the expectation that they would be experts of their condition was not welcomed. In addition they were well aware of the conflict the term was causing amongst healthcare professionals (Kennedy, Gately, Rogers, & EPP Evaluation Team, 2004).

However, it is not only the title that may have caused unease but also the aim of the policy. Both healthcare professionals and patients may feel uncomfortable at having their assumptions about healthcare challenged, with three primary assumptions being that:

1. The professional is the expert
2. The healthcare system is the legitimate gatekeeper for socially supported healthcare services
3. The ideal patient is both complaint and self reliant

(Thorne, Nyhlin, & Paterson, 2000)

The policy makers appear to have failed to recognise that roles and relationships in the NHS and within the domain of healthcare are complex and made up of respect, trust and control that are of critical importance to
the quality of life for those with chronic illness (Ham, 1999; Thorne et al., 2000). Healthcare professionals still give greater patient knowledge and disease self-management an ambiguous reception (Thorne et al., 2000), while patients themselves have concerns that improving their self knowledge may affect their relationship with the doctor (Ziebland, 2004). It also needs acknowledging by policy makers that patients do not always perceive that improved knowledge and informed self care behaviours are intrinsic to their treatment plan (Cagle, 2004). Failing to recognise the significance of these relationships can complicate and increase the burden of chronic illness for those afflicted (Thorne et al., 2000), and empowering patients to self manage their condition will not happen unless they are given both the freedom and explicit approval by healthcare professionals to change their way of treatment (Tattersall, 2002). This clearly is a vital component to the success of implementing TEP and healthcare professionals support needs to prevail not be alienated.

*How did TEP policy evolve?*

The ‘third way’ promoted as a new way of running the NHS (Department of Health, 1997), can be viewed as further development of an approach that began evolving during the previous Conservative government’s stay in power. In the 1980s the Conservatives introduced the notion of enabling that was integral to facilitating changes in health policy that took place during the early part of the Thatcher years (Taylor, 2000). Right wing concepts such as privatisation were seen as notable changes that allowed competition and contracting out, while stimulating the development of an internal market for
public goods and supply side economics (Taylor, 2000). This led to a change of approach to managing the NHS, as local government found itself actively involved in facilitating the ‘enabling’ process through the development of a contract culture. As a result a number of public, private and voluntary agencies became involved in delivering a broad range of services based on giving value for money (Taylor, 2000).

The Conservative government had been skilful in managing to introduce the concept of enabling as something to be viewed as both positive and empowering. This approach was partly responsible for engineering a reduced role for government in providing some services in the NHS (Taylor, 2000). As a consequence, the government’s reduced role as provider for the NHS was accepted and led to a revival of the voluntary sectors involvement, which previously had been seen as very subordinate to the statutory sector (Hoad, 2002).

This change in relationship with the voluntary sector was not driven purely by Conservative ideology but by changing economic needs as a result of an aging population, higher unemployment and increasing cost of benefits (Allsop, 1995; Hoad, 2002), and is important for understanding how New Labour came to accept many of the enabling characteristics of the Thatcher years (Taylor, 2000).

New Labour was designed to achieve a party that would reassure those nervous of voting Labour that the socialist old Labour approach was in the
past and this aim was achieved in 1997 by a convincing election win (Curran, 2004). But in order to achieve its ideologies of both state and the market, in other words old Labour and the New Right had had to be combined (Department of Health, 1997). This led to criticisms that Labour’s approach to healthcare policy was no more than adopting a middle way approach (Bradshaw, 2002; Taylor, 2000). Suggestions were made that the public may never really have understood concepts such as the internal market and were unaware that many of the Conservative’s original ideas, although modified were still in existence (Bradshaw, 2000a, 2003).

When New Labour came to power it was judicious, recognising that valuable lessons could be learned from the previous achievements and failures of the Conservatives. In doing so they commissioned a review of the Conservatives White Paper, The Health of the Nation: A Strategy for England (HOTN) (HMSO, 1992). At the time this was an important paper because it was the first overt attempt by any government to provide a strategic approach to improving overall health of the people of England (Cornish & Knight, 2000; Department of Health, 1998; Savage et al., 1994), and drew selectively on the World Health Organisation’s strategy, ‘Health for All’ (WHO, 1998). Nevertheless, HOTN was met with criticism as the Conservatives were accused of shifting the focus on health improvement from NHS organizations and service inputs onto the public and their health. New Labour’s White Paper OHN (Department of Health, 1999), is seen as an enormous advancement since HOTN and although not perfect, is felt by some to offer hope for those developing public health policy (HSJ, 1999).
This shift of focus can be seen to link with New Labour’s ability to move away from the original Labour pledge in 1948, that said the NHS would provide the public with all medical, dental and nursing care as and when needed (Department of Health, 1997). What has now emerged is a Labour Government directed NHS that considers a central part of tackling poor health to be the responsibility of both individuals and government (Department of Health, 1999). This transfer of emphasis in healthcare provision is seen as essential development by New Labour if the NHS is going to meet the needs of the public as healthcare requirements change (Department of Health, 2001b, 2001a).

At the start of New Labour’s reign of power their White Paper The New NHS: Modern Dependable (Department of Health, 1997) identified three pressures as critical and having the potential to overwhelm the NHS’s ability to deliver unless changes occurred. These were:

1. Public expectations
2. Medical advances
3. Demographic changes.

However, these considerable pressures were seemingly dismissed by New Labour, and strong support for the NHS remaining a universal healthcare service, identified in a social attitudes survey (Department of Health, 1997), may have allowed the government to convince the public that by accepting their part in a pluralist system and by using the services of the NHS ‘wisely’ so the NHS would survive.
An additional process introduced to bring about change in the NHS was New Labour's concept of 'modernisation' (Department of Health, 1997). This was promoted as something positive and comparisons with the Conservatives' introduction and use of 'enabling and empowerment' to achieve acceptance of their ideologies can be made. Although, The New NHS; Modern Dependable (Department of Health, 1997) introduced the idea of modernisation it was OHN (Department of Health, 1999) that delivered the action plan, incorporating modernisation as a vehicle to tackle poor health. Fifty three initiatives can be identified in OHN to help deliver this vision, and includes the Healthy Citizens initiative, with seven strands to it; one of these strands being EPP (see Table 1).

| 1. NHS Direct – a nurse led telephone helpline and Internet service providing information and advice on health |
| 2. Health Skills for first aid |
| 3. Health skills – defibrillators |
| 4. Health foundation skills for young people |
| 5. Health skills for parents |
| 6. Health skills for later life |
| 7. *Expert Patients Programmes* to help people manage their own illness |

**Table 1: The Seven Strands to Healthy Citizens** (Department of Health, 1999)

A number of approaches are proposed to deliver the governments intention to help those living with long term illness and include advances in technology.
to promote self care and individual responsibility for health. This change of balance is welcomed by some believing the public have previously been encouraged to take little or no responsibility for themselves or their families, leading to health issues such as obesity (Heffer, 2004). This approach is not isolated to healthcare policy as similar approaches are seen in issues relating to alcohol and unsocial behaviour associated with its abuse; the emphasis is now with the individual taking responsibility for their own behaviour (Morris, 2004).

The principle of collectivism once favoured in the early part of the century is once again finding favour with its emphasis on prevention and tackling the unhealthy aspects of environmental, economic and social systems (Ham, 1999). However, as with the development of other policies their progress can often rest on a particular set of assumptions (Allsop, 1995), and some of those relating to the development of TEP will now be explored.

Examining the Assumptions

'TEP (Department of Health, 2001a) it is suggested, had a number of strongly influential stakeholders shaping its development. In total 114 people made up the Task Force with the voluntary sector represented by 54 members (47%) and healthcare professionals numbering less than half of this (n=25, 22%) (See Graph 4).
Graph 4: Balance of Representatives on Expert patient Task Force

The Long Term Medical Conditions Alliance (LMCA) from the voluntary sector clearly see part of their role is to influence Government policy and to ensure the availability of high quality lay led self-management programmes (Cooper, 2001). The bias towards the voluntary sector on the Task Force may have been welcomed by policy makers keen to see their course of action agreed, but could be responsible for some research assumptions going unchallenged.

The Living with Long Term Illness project (Lill) also represented on the Task Force, had previously been instrumental in being one of the first groups back in 1996 when self-management programmes were new to adopt ideas from research carried out by Professor Kate Lorig from Stanford University, California, USA (Cooper, 2001). The Lill Project was Department of Health, Kings Fund and GlaxoWelcome funded and was the first project to present outcomes from widespread use of lay self-management courses in the UK (Cooper, 2001). Nevertheless the sample is relatively small (n=114) and
biased (women 73%, White/European 96%, formal education 82%), making generalisations difficult.

Average programme participation completion rates were 69% comparing unfavourably with a professionally led self-management programme (n=89%) (Hawksley, 2004 unpublished). Perhaps even less encouraging were findings suggesting no change for hospitalisation or visits to GPs occurred although visits to specialist dropped, but may only reflect that the four month data collection did not coincide with annual or biannual visits to specialists (Cooper, 2001). Additional concerns are the number of double references included. However the positive findings of the report should not be ignored as they suggest participants experienced a number of changes which included increased self efficacy and greater use of self-management skills. Nonetheless, the evidence from this study is far from convincing and may explain why it was not included in the evidence used to support TEP.

A key issue in the design of EPP was meeting needs of cultural minorities (Department of Health, 2001a) yet there is no evidence in the literature to support its effectiveness with these groups. Lay led self-management approaches can fail to reach individuals and groups who have most difficulty gaining access to services (Eakin, Bull, Glasgow, & Mason, 2002), and results from Expert Patient Programme pilot sites confirm these difficulties. The average attendance by ethnic minority groups was only 1.9% (Kennedy et al., 2004), with 77% of participants attending a local pilot site describing
themselves as white, 62% retired and only 8% unemployed (Murphy, Larsen, & Smith, 2002).

While Lorig’s work has been enormously influential in the UK, only two of her studies, both conducted in USA (Lorig & Holman, 1989; Lorig, Mazonson, & Holman, 1993) are included in the evidence supporting TEP (Department of Health, 2001a). This limited evidence is supported by a study and a literature review carried out in Britain by Professor Barlow (Barlow & al, 2000; Barlow, Williams, & Wright, 1999). Lorig’s studies describe outcomes of the Arthritis Self Management Programme (ASMP), a lay led self-management programme developed for patients suffering from arthritis and later adapted for various chronic diseases as the Chronic Disease Self Management Programme (CDSMP).

Lorig’s & Holman (1989) earlier study proposes that to be worthwhile, self-management interventions must prove themselves effective over time. They introduce reinforcement to prevent attenuation of the effects of self-management programmes found in a previous study (Lorig, Lubeck, Kraines, Seleznick, & Holman, 1985). However, reinforcement did not alter the beneficial effects of a self-management programme and questions why the effects attenuated in one study and not the other. No explanation can be offered, suggesting our understanding of how self-management programmes provide their effect is far from understood.
The second study by Lorig’s (1993) sets out to determine the effects of the ASMP four years after participation. Outcomes as in many of Lorig’s later studies (Lorig, Ritter, & González, 2003; Lorig, Sobel, Ritter, D, & Hobbs, 2001; Lorig et al., 1999) measure use of healthcare services, and may in part explain the interest healthcare providers in USA, UK and Australia have taken in Lorig’s work. Lorig et al (1993) found numbers of physician visits reduced, but these results need to be viewed with caution as visits to physician are measured differently in the treatment and comparison group. Differences are reconciled using data from the national averages of visits to physicians, while a further weakness is the lack of a control group. Although results suggest a decline in pain and visits to doctors, physical disability had increased, and interpretation of results is further complicated due to the development of medical treatments during the course of the study which may have influenced measures such as pain. Overall the effect of the lay self-management programme is thought to improve the quality of life of those who attend it, but its contribution to reducing healthcare costs may be more difficult to measure.

Barlow Williams & Wright’s (1999) study involved a sample recruited by Northamptonshire Adult Education Service through advertisements with its obvious sample bias. A relatively small and gender biased sample is involved (n=89, 80% woman), and although outcomes suggest significantly increased levels of arthritis self efficacy, there is no evidence of change in level of physical functioning or reduction in use of healthcare resources.
The three studies used to support the development of TEPs do not provide clear evidence that such an approach improves healthcare outcomes and when researched, studies can be found proposing that self-management, far from reducing demands on healthcare resources, may in fact do just the opposite. Patients have been found to increase their use of some services while it is an approach that does not suit everyone or is appropriate for all disorders (Chapple & Rogers, 1999; Trojan, 1989). There appears no clear consensus as to the value of self-management approaches, but there is agreement that further research does need conducting in this area (Barlow et al., 1999; Department of Health, 2001a).

There are notions that the approach taken to managing some diseases depends largely on ‘who among the stakeholders has the greatest positional power’ (Harrison 1999:1). While TEP appears to have evolved from an assumption driven by the powerful voluntary sector stakeholders with their belief that it is an effective ways to manage chronic illness (Long-term Medical Conditions Alliance, 2001), there needs mention that the charismatic characters of the leading authorities on the subject may have had a part in influencing this conviction. Questions have already been raised in the literature as to whether the CDSMP is an approach that requires a particular type of leadership to be effective. Is it that the charismas of these leaders make it difficult to generalise their results, and if strong leadership skills is a prerequisite for the success of this self-management approach, will units who lack such leadership abandon the ideals of self-management for the ‘favoured’ biomedical approach? (Tattersall, 2002).
Another factor noticeable for its exclusion in the development of TEP (Department of Health, 2001a) is the successful outcomes that established professionally led self-management programmes for managing chronic illnesses have already shown. The Cochrane Central Register of Controlled Trials, sites three professionally led self-management interventions (Coleman et al., 2001; Leveille et al., 1998; Riley, Glasgow, & Eakin, 2001) with outcomes that propose reductions in hospitalization, use of emergency department, and better use of community resources and adherence to medications can be achieved. Bandolier provides additional evidence with a large review of 25 trials (n=1672) suggesting both cognitive and behaviour therapy are effective in improving positive behaviour expression, appraisal and coping in individuals with chronic pain conditions (Morley, Eccleston, & Williams, 1999).

Nevertheless, not all professionally led programmes provide such convincing evidence. Symptom control improved in a study by (Winkler, Underwood, Fatovich, James, & Gray, 1989), but use of medication, visits to healthcare providers and time off work did not differ from the control group. Again as with user led programmes, further studies are advocated exploring the long term benefits of a self-management approach (NHS Centre for Reviews and Dissemination, 2000).

TEP’s policymakers’ omission to recognise the considerable interest already expended by healthcare professional into the values of a self-management approach is puzzling. In the seventies these were key to the debates in
healthcare, but have since failed to be at the forefront of debates (Kickbush, 1989). What needs to be asked is why healthcare professionals whose views are felt to predominate in the management of diseases (Harrison, 1999) have not advanced this concept. Is it because as current research reveals this approach has failed to deliver clear measurable outcomes that would convince healthcare managers of their cost benefit, or is it a failure of healthcare providers to understand the different needs of those with acute and chronic diseases? Another possibility is that the medical model is conceivably challenged to the point that doctors in the more vulnerable areas of healthcare provision are now noticing their reduced role in influencing some policies (Ham, 1999).

A further conjecture offered is that with increasing demands on healthcare resources the government may have been forced to consider evidence from the USA with the explicit aim of saving resources. If Marxist theory is applied here, it can be argued that as demand for health services has surpassed the ability of the state to fund them so restructuring of expenditure has occurred to the disadvantage of state health services (Ham, 1999). Professionals need to examine the power issues in TEP and decide whether it is aimed purely at saving resources or reinforcing the social construction of chronic illness, while facilitating a shift of power (Wilson, 2001). Either way EPP appears so far to have failed to capture either the imagination or support of healthcare professionals considered intrinsic to the long term success of healthcare policies (Ham, 1999; Tattersall, 2002).
Who intends to implement it

Between 2004 and 2007 EPP is to be mainstreamed throughout the NHS, with the onus on PCTs [and formally Primary Care Groups] to implement it. However, wide variations in the position of the person implementing it range from Directors of Partnership and Commissioning to staff nurses, suggesting a lack of strategic planning from policy implementers; additional concerns relate to funding. The pilot phase was funded by The Department of Health, but long-term funding is expected to come from mainstream NHS funds, principally PCTs and other interested social and health agencies (Kennedy et al., 2004). PCTs now considered fundamental to leading change in primary and secondary healthcare systems and central to ‘shifting the balance of power’ (Department of Health, 2001b) are themselves the subject of reorganisation.

Some concern has been raised why these reorganisation plans are to be found ‘buried in the fine print’ of the new public service agreement (Carvel, 2004c:3), and along with considerable demands to meet funding needs across the NHS, and the failure of TEP to provide hard evidence to convince PCT boards and others of the case for funding local programmes of self-management for chronic illness, there is apprehension that EPP may become marginalised (Healthy Living Centre, 2004; Kennedy et al., 2004). Additional concerns are practical problems involving a lack of coordination and administrative support for the programmes which may have contributed to 20% of pilot PCTs failing to recruit a single tutor, and only a quarter
considered successful implementers of the programme (Kennedy et al., 2004).

**Intended Outcomes**

TEP (Department of Health, 2001a) appears cautious in expressing what the intended outcomes from EPP might be suggesting only ‘if’ EPPs are successful will they lead to a number of improvements in the lives of those suffering from chronic illness (Department of Health, 2001a 14). The inclusion of the word ‘if’ appears unnecessary and conjures up a picture of failure; although the outcomes are listed and if accomplished will be a considerable achievement. These outcomes are listed below:

<p>| | |</p>
<table>
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<tbody>
<tr>
<td>1.</td>
<td>health for those with chronic disease</td>
</tr>
<tr>
<td>2.</td>
<td>reduced fatigue, sleep disturbances</td>
</tr>
<tr>
<td>3.</td>
<td>greater gain and retain of employment</td>
</tr>
<tr>
<td>4.</td>
<td>appropriate use of health and social services</td>
</tr>
<tr>
<td>5.</td>
<td>use of adult education and employment training programmes</td>
</tr>
<tr>
<td>6.</td>
<td>feelings of empowerment in relationships with healthcare professionals</td>
</tr>
<tr>
<td>7.</td>
<td>reduction in days spent in hospital and attending outpatient departments</td>
</tr>
</tbody>
</table>

**Table 2: Summary of Intended Outcomes for EPP (Department of Health, 2001a)**
Discussion - Evaluating Implementation and Outcomes

The Primary Care Research and Development Centre commissioned by the Chief Medical Officer to provide a national evaluation of the pilot EPP had a principle aim, ‘to identify barriers to establishing functional self-management programmes in the NHS’ (Kennedy et al., 2004:i). Their report considers EPP an effective and innovative means of managing chronic conditions. However, considerable challenges are identified and associated with achieving effective implementation (Kennedy et al., 2004). These relate to:

- Recruitment difficulties
- Organisational problems
- Relationship problems particularly with healthcare professionals.

While Kennedy et al (2004) provides what can be interpreted as a cautious report, other actors view the outcomes of the pilot phase as hugely successful (Expert Patient Update Newsletter, 2004). This perhaps indicates the complexity of interactions between peripheral and central bodies as they attempt to influence each other. Despite Kennedy et al (2004) concerns, EPP has been unequivocally promoted in the recent Modernisation Agency document, ‘10 High Impact Changes for Service Improvement and Delivery’ (NHS Modernisation Agency, 2004). In this document EPP is considered an approach that will provide better outcomes for patients with chronic illness and reduce attendances at hospitals. These claims are made despite an expressed need for hard evidence to convince PCT boards to support self-management programmes for chronic illness (Kennedy et al., 2004), and may
indicate some urgency on governments part to be seen to be delivery its healthcare policies.

Kennedy et al (2004) also recommend a number of strategies to ensure the Expert Patient Programme is implemented successfully beyond the pilot phase of which two points are given emphasis for attention. These are:
1. The Expert Patient Programme needs a higher profile in the business of PCTs
2. Healthcare professionals need to be engaged in the benefits of self-management programmes and the antipathy felt by healthcare professionals resolved

Realistically, Expert Patient Programmes may have difficulty raising their profiles with PCTs as funding issues mentioned earlier in this analysis will inevitably be an issue. EPP is viewed by government as an approach to save resources in an overstretched healthcare system (Wilson, 2004), and funding the NHS is currently among the 'hottest of political potatoes' (Adams, 2004:17), while Ministers fear the consequences of reallocating resources from well healed areas to those found to be under funded (Carvel, 2004b). Nevertheless, if this policy has such encouraging potential to reverse the gaps in healthcare provision, why have policy makers not identified appropriate funding to ensure its success? The answer may lie in New Labour's obsession with targets for acute conditions that means the needs of those with chronic conditions remain neglected (Carvel, 2004b; Lewis &
Collectivism, along with 'inclusiveness and a shared understanding of the strong commitment to democracy' Curran (2004:23) argues is a vital component of a common value system. He suggests that if New Labour is going to deliver a social and economic model that expounds fairness and equity then it needs to sign up to this model and fears New Labour may have failed to understand this value system.

The second point highlighted in Kennedy et al (2004) relates to a central issue with health policy implementation, that of persuading doctors to organise their work in a way that is consistent with central and local policies (Ham, 1999). It is argued in this analysis that had the medical profession experienced greater involvement, the outcome may have been different. Doctors in particular could have ended up as part of the delivery of EPP rather than ending up as opponents of a seemingly untested idea, which appears to have gone straight from concept to policy. This is not just about collectivism but also about shifting cultures, and developing a culture within the NHS that will support self-management is seen as a huge challenge (Lewis & Dixon, 2004).

This culture change is not made any easier when it is remembered that as a society we allocate less importance to collective, preventative and welfare approaches to health (Ham, 1999). The care of the chronically ill has never
been a popular area for doctors, nurses, the public or governments. Doctors tend to associate chronic illness with difficult and complaining patients (Ford, Liske, & Ort, 1961; Griffiths, 2004; Ort, Ford, Liske, & Pattishall, 1965), nurses find the chronically sick boring (Abrams, 2003), while the public have prejudices and discriminate against those with chronic illness (Ford et al., 1961). Meanwhile governments see chronic illness as an ever growing burden on limited state resources (Department of Health, 2001a; Grant, 2003; Kent, 1952).

What cannot be ignored by TEP is the considerable authority the medical profession continues to command and its influence is fundamental for reinforcing a self-care approach from their patients (Chapple & Rogers, 1999). Changing structures does not in itself achieve getting people to work differently, but also requires a change in culture (Department of Health, 2001b). While the education of doctors continues to focus primarily on therapeutic recommendations rather than working in partnership with their patient (Clark & Gong, 2000), changes in attitudes may be hard and slow to achieve, and may jeopardise self-management approaches to care.

Despite criticisms of TEP (Department of Health, 2001a) and its implementation it has to be applauded for attempting to address current gaps in healthcare provision for those suffering from chronic conditions; not an easy task in an NHS where rationing is now an inherent part of it, and has even seen services denied to the elderly on the basis that they have had their life (Bradshaw, 2003). The latter may be the consequence of applying
pluralist systems with efficiency and broad coverage of services prioritised, and justice a secondary consideration (Beauchamp & Childress, 1994). Vulnerable patients may find their needs neglected and Marxism would explain its occurrence as an attack on a subordinate class, explaining the inequalities in service provision between groups of patients in terms of their lack of productivity. In other words because this group of patients cannot make a significant contribution to the economy, they will therefore receive a lower quality of service than other more productive groups (Ham, 1999).

Certainly some chronic illness can be associated with high levels of sickness and use of benefits (Clinical Standards Advisory Group, 1994), and adopting a Marxist perspective it is possible to construe the use of volunteers to deliver self-management programmes rather than professionals, as a cheaper and lower level of service to a group of what may be seen by some as unproductive patients.

At a macro level pluralist and Marxists theories and collectivists principles have been applied to help understand the implications of implementing a self-management approach to healthcare, and illustrates that there is no single theoretical perspective that provides an adequate explanation for policy development (Ham, 1999).

Possible Consequences
The consequences of opting for user led rather than professionally led self-management programmes may have a number of consequences. While
combined professionally and user led programmes have shown some promise (Taylor, 2004), professionals may not be able to ignore the considerable amount of evidence that supports professionally led programmes (Fursland, 2001; Gibson et al., 2004; Kent, 1952; Monninkhof et al., 2004; Powell & Gibson, 2004; The Royal College of Anaesthetists & The Pain Society, 2003; Williams et al., 1996; Wolf, Guevara, Grum, Clark, & Cates, 2004). This evidence appears to have been overlooked in TEP, and what is causing considerable concern amongst healthcare professionals is how their programmes are struggling more than ever to establish their worth, and secure the necessary funding to survive in an NHS keen to cut costs (Ward, 2004).

There are even suggestions that some of these programmes are being ‘bullied into obscurity’ (Ward, 2004), and while funding issues are causing these programmes to falter, healthcare professionals may find their ethical principles challenged as they relinquish power to user led programmes. To act ethically is to care and also to find ways to resolve moral problems (Candee & Puka, 1984), but, reconciling the disquiet felt amongst healthcare professionals towards user led programmes that may well benefit some patients while delivering the Governments healthcare vision could be difficult. Supporting this uneasiness is recent evidence suggesting a ‘mismatch’ between evidence available from randomised controlled trails that support self-management education programmes and the ‘enthusiasm with which they have been adopted by healthcare providers and consumers’ (Foster, Taylor, Eldridge et al 2007:14). However, the authors do conclude that self-
management education programmes may result in some small though short
term improvements.

The influence the voluntary sector may have had in this apparent change of
balance cannot be ignored, but in their struggle to influence it is suggested
they must not forget that lay led self help groups can never replace
professional help, and making cuts in healthcare provision as a result of
introducing self-management can never be justified (Trojan, 1989). The
virtues of a user led self-management approach should be valued on its own
merit, through improved self efficacy, psychological well being and feelings of
empowerment that participants report (Cooper, 2001; Cooper, Jones, &
Thompson, 2004; Long-term Medical Conditions Alliance, 2001; Murphy et
al., 2002; Wilson, 2001).

Nevertheless, the assumption that a self-management approach suits all
(Chappie & Rogers, 1999; Nicoll & Beyea, 1999), must not be made and
unwanted outcomes may even occur as a result of implementing it. Wilson
(2001:139) argues that there is inconsistency with the Expert Patient
approach that may imply it has a double edge to its sword. She proposes
self-management promotes a, ‘Form of pastoral power where the lifestyle
habits and way of life of a person with a chronic condition comes under
scrutiny’. She argues Foucault would see it as both a liberator and subjugator
and the approach may inadvertently create tensions not previously
considered, because of its relationship with a form of pastoral power.
Adding to these concerns is the potential for self-management approaches to cultivate victim blaming in society. Self care is based on the assumption that the patient has the power to control conditions which give rise to ill health (Segall & Goldstein, 1989). This fear is reflected in individual feedback from pilot EPPs. with one patient saying, ‘Oh my goodness, I shall never be an expert patient, I don’t wanna be an expert patient’ (Kennedy, 2004:23). The illness may become associated with a failure on the patient’s part to control it and in this way the sick person may find themselves blamed, in other words victimised. Even more worrying is that self care may be seen as ethical justification for reducing some levels of formal health care as the emphasis is on individuals taking responsibility (Segall & Goldstein, 1989). Employing utilitarian principles it might be argued that overall the consequences of such action may be the ‘right thing to do’, as individuals are encouraged to take ownership of their health and resources are freed up for other services. However as with all ethical decisions there will be inherent differences of opinion (Beauchamp & Childress, 1994), and self care may in effect distract government attention from seeking to explore further the social, political and economic aspects of related ill health (Segall & Goldstein, 1989).

There is even evidence that the environment may in fact be more significant than life-style in influencing health issues (Ham, 1999), and this analysis suggests the voluntary sectors power must be harnessed in order that it does not unbalance governments approach to healthcare for patients with long term illnesses. Although the voluntary sector’s involvement with chronic illness is not new (Getting, 1950), today they place great importance on their
power to influence policy through lobbying as evidenced by their websites and literature (Cooper, 2001; Long-term Medical Conditions Alliance, 2001) and a National Self-Management (SMP) Network has even been set up by LMCA with the aim to contribute to the policy debate on models of self-management (LMCA Alliance for health, 2004).

Conclusion

Political and organisational settings are complex, often making it difficult work to implement policy successfully and improve health (Hunter & Killoran, 2004), but in attempting to use what appears a top down approach to implement change, TEP policy makers may have failed to harness in equal strengths the power of the main drivers involved. The NHS still has no agreed model of care for managing chronic diseases (Lewis & Dixon, 2004) and it is not simply about opinion and allocation of resources, but much more deep-rooted influences entangled with cultural influences that are part of the management of chronic illness (Ort et al., 1965).

Despite controversy surrounding the EPP, there clearly appears a role for user led self-management programmes that could benefit lower risk patients, while those with more complex symptoms or difficulties are referred to professionally led programmes. This system is endorsed by the Modernisation Agency (NHS Modernisation Agency, 2004) and currently operates with success in managed care organisations (MCO) in USA, though unlike the Expert Patient Programme, patients in MCOs are given limited choice in whether or not to participate in a disease management programme (King's
Fund, 2004). In the NHS patients’ self refer themselves onto EPP, excluding professionals from involvement. While considered an important element of this approach (Healthy Living Centre, 2004), it may lead to biased self selections of patients, with those most needing it failing to register. Opening up referral to healthcare professionals could help engage the medical profession to work in partnership with EPP, while also complementing their work, and services based in secondary care may need to develop their links with the community if they are going to deliver government advocated seamless journeys of care for their patients, (NHS Modernisation Agency, 2004).

New Labour is clearly committed to evidence based care (NHS Modernisation Agency, 2004) and to piloting policies ahead of national implementation (Walker, 2000). Although commendable the reality is that pilot studies can be flawed as the principles of good piloting are sacrificed in order to meet the demands of political expediency (Walker, 2000). It is proposed this may have occurred with EPP as change advocated as a result of the pilot studies is unlikely to happen quickly enough for politicians keen to bring about rapid change. Regardless of the need for these modifications EPP has been endorsed (NHS Modernisation Agency, 2004), and the reality that cannot be overlooked, is that British politics may be more about fulfilling pledges and the imperative being to be seen to be doing something, that may over ride the details of policy design (Walker, 2000).
Self-management may be a valuable hidden health care resource (Chapple & Rogers, 1999), but this paper suggests that to impact significantly on the delivery of healthcare services it needs time, funding and doctors support to show what it can really deliver. While government policies and targets for acute sector managers and health commissioners remain strongly focused on the elective sector, TEP may in fact only succeed in drawing attention to the power struggle between political and clinical decisions (Chapple & Rogers, 1999).

EPP may prove a policy pivotal in influencing much needed improvements for the care of those with chronic diseases, but uncertainties surrounding its true intention may lead to suspicions that it is no more than a placebo policy developed to appease the powerful stakeholders and distract others from issues related to the management of chronic illness. EPP may require not only additional research evidence but further development of a self-management culture before it can be successfully integrated into the ethos of the NHS. Furthermore as Shaw and Baker (2004) advise, in the interests of doctor and patient relationships, another term must be found for Expert Patient that does not provoke hostility and allows the medical profession to engage fully in its implementation and long term success.
References


Cagle, C. (2004). Commentary on 3 themes described how self management was learned and experienced by patients with chronic illness. Evidenced Based Nursing, 7(3), 94.


Appendix 1

Range of measures to help support a new style of service identified in
Expert Patient: A New Approach to Chronic Disease Management for
the 21st Century

- National service Frameworks
- NHS Home Health Care Guide
- NHS Direct helpline
- Public Health Electronic Library
- Patient Partnership Strategy
- Healthy Living Centres
- Health improvement Programmes
- Healthy Schools Initiative
- Health action Zones
- Life Skills Courses and Programmes
- Emphasis on Skill mix
- Healthy Workplace and healthy Neighbourhood Projects (Department of Health, 2001a:21)
Appendix 2

**Glossary of Acronyms**

HOTN  The Health of the Nation - a policy assessed
Lill  The Living with Long-term Illness Project
LMCA  The Long-term Medical Conditions Alliance
NHS  National Health Service
SMP  National Self Management Network
OHN  Saving Lives: Our Healthier Nation (Department of Health, 1999)
PCT  Primary Care Trust
EPP  Expert Patient Programme
UK  United Kingdom
CDSMP  Chronic Disease Self Management Programme
MCO  Managed Care Organisations
ASMP  Arthritis Self Management Programme
TEP  The Expert Patient: A new approach to chronic disease management for the 21st century (Department of Health, 2001a)
SERVICE DEVELOPMENT PROJECT
&
PRESENTATION

Promoting the Concept of
Self-Care Support for Managing Persistent Pain

April 2005
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Promoting the Concept of Self Care Support for Managing Persistent Pain

Introduction


Self-management is now considered a fundamental part of the coping and management of these conditions (Department of Health, 2001, 2005a; DH Long-term Conditions NSF Team, 2005; NHS Modernisation Agency, 2004), and this project aimed to identify if self-care support models promoted by the Government (Department of Health, 2004) can be applied to the population referred to the pain service (See Diagram 1 and 2).
The objective was to determine if the Government’s proposed systematic stratification framework can be used to identify low risk patients referred to
the pain service, suitable for supportive self care approaches (NHS Modernisation Agency, 2004) (See Diagram 3).

![Diagram 3: Long-term Conditions Stratified by Level of Risk (NHS Modernisation Agency, 2004)](image)

**The Project**

Audit involving 3 postal questionnaires followed by telephone semi-structured interviews gathered information on the population referred to the pain clinic in December 2004 (See Table 1 and Appendix 1 and 2).

<table>
<thead>
<tr>
<th>Questionnaires</th>
<th>Questionnaire Components</th>
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<tbody>
<tr>
<td>1 Chronic Pain Acceptance Questionnaire (CPAQ) (McCracken et al 2004)</td>
<td>•Active engagement (pursuit of life activities regardless of pain</td>
</tr>
<tr>
<td></td>
<td>•Pain willingness (recognition that avoidance and control are often unworkable methods of adapting to chronic pain)</td>
</tr>
<tr>
<td>2 Stages of Change Questionnaire (PSOCQ) (Jensen et al 2000)</td>
<td>•Precontemplation (not considering any change of behaviour)</td>
</tr>
<tr>
<td></td>
<td>•Contemplation (serious consideration of change sometime in the future)</td>
</tr>
<tr>
<td></td>
<td>•Action (concrete activities that will lead to the desired change)</td>
</tr>
<tr>
<td></td>
<td>•Maintenance (active efforts to sustain the changes made)</td>
</tr>
<tr>
<td>3 Brief Pain Inventory (BPI) (Cleeland &amp; Ryan 1994)</td>
<td>•Pain</td>
</tr>
<tr>
<td></td>
<td>•Interference</td>
</tr>
<tr>
<td>4 Telephone semi-structured interview</td>
<td>•6 questions focused around self management</td>
</tr>
</tbody>
</table>

**Table 1: Audit Questionnaires and Components**
Audit Results and Evaluation

Table 2 presents response rates, means, and standard deviations. The referral sample consisted of females (n=69.7%) consistent with higher female referrals to pain clinics in the literature (Rustøen et al., 2004), and the mean age and length of pain experience were comparable to studies involving patients suffering from persistent pain (McCracken, 1998; McCracken & Eccleston, 2005; McCracken, Vowles, & Eccleston, 2004; Viane, 2003; Von Korff et al., 1998).

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<tbody>
<tr>
<td>Questionnaires</td>
<td>n=109 (69.7% female)</td>
<td>n=118 (100%) (questionnaire conducted as part of programme assessment)</td>
<td>n=255</td>
</tr>
<tr>
<td>returned</td>
<td>n=44 (40%)</td>
<td>Average 90%</td>
<td></td>
</tr>
<tr>
<td>Questionnaires</td>
<td>Female n=32 (73%)</td>
<td>Female 64%</td>
<td>Female 62.3%</td>
</tr>
<tr>
<td>returned by gender</td>
<td>Male n=12 (27%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age Range</td>
<td>Mean 55.7 yrs (range 19-82 years std 16.9 years)</td>
<td>Mean 44.2 yrs (std 10.7)</td>
<td>Mean 49.8 yrs (std 11.3 yrs)</td>
</tr>
<tr>
<td>Length of pain</td>
<td>Mean 7.7 yrs (std 8.5 yrs) Range 6 months - 34 yrs</td>
<td>Mean 7.29 yrs Range 1-44 yrs</td>
<td>57% pain longer than 3 months</td>
</tr>
<tr>
<td>experience</td>
<td>Have you been given a diagnosis</td>
<td>Yes n=28 (65%) No n=15 (35%)</td>
<td>Data not given</td>
</tr>
</tbody>
</table>

Table 2: Response Rate and Descriptive Data

<table>
<thead>
<tr>
<th>Factor</th>
<th>Audit Project</th>
<th>McCracken et al 2004a</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>M</td>
<td>std</td>
</tr>
<tr>
<td>Activity engagement</td>
<td>30.02</td>
<td>16.19</td>
</tr>
<tr>
<td>Pain willingness</td>
<td>17.29</td>
<td>10.31</td>
</tr>
</tbody>
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Table 3: Comparison of Mean Data Scores for CPAQ Subscales
Distribution Curves

Distribution curves of the variables were constructed giving visual understanding of data distribution (Bowers, 1996) and suggested a range for the variables of pain, interference, acceptance and stages of change components (See Appendix 3).

Correlational Coefficient Analysis

Correlational coefficient analysis was performed to explore the strength of relationships between the variables. Applying Spearman’s rho, relationships with strength and significance were identified (See Table 5), with the most significant identified in Table 4.

<table>
<thead>
<tr>
<th>Relationship</th>
<th>Strength (rs)</th>
<th>Significance (p)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acceptance and Interference</td>
<td>-.808</td>
<td>0.000</td>
</tr>
<tr>
<td>Pain and Interference</td>
<td>.761</td>
<td>0.000</td>
</tr>
<tr>
<td>Acceptance and Pain</td>
<td>-.562</td>
<td>0.001</td>
</tr>
<tr>
<td>Acceptance and Action</td>
<td>.514</td>
<td>0.005</td>
</tr>
<tr>
<td>Acceptance and Maintenance</td>
<td>.435</td>
<td>0.014</td>
</tr>
</tbody>
</table>

Table 4: Correlational Coefficient analysis - relationships, strength and significance established
To better understand the provided fragments, we can infer that the content is related to a study or research involving correlations between various factors. Here is the extracted text in a comprehensible format:

### Table 5: Correlations

<table>
<thead>
<tr>
<th></th>
<th>Active Engagement</th>
<th>Pain Acceptance</th>
<th>Pain Willingness</th>
<th>Precontemplation</th>
<th>Maintenance</th>
<th>Pain</th>
<th>Interference</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acceptance</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Spearman's Rank</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rho</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Correlation</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Coefficient</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>N (tailed)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>N (2-tailed)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

The table includes correlation coefficients with significance levels indicated by asterisks. The significance levels are as follows:
- *: p < 0.05
- **: p < 0.01
- ***: p < 0.001

For example, the correlation coefficient for Pain Acceptance and Active Engagement is 0.453**, indicating a strong positive correlation at the 0.01 level of significance. The table also includes p-values for each correlation, with values ranging from 0.000 to 0.014.
**Scatter Graphs**

Scatter graphs demonstrated the line of fit, visually describing the strength of relationship between the variables (See Appendix 4).

**Semi structures Telephone Calls**

A high proportion (86%) of patients gave agreement to telephone follow up interviews. Table 6 gives details of calls made.

<table>
<thead>
<tr>
<th>Description</th>
<th>Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total number of patients who agreed to be contacted for interview</td>
<td>38 (86%)</td>
</tr>
<tr>
<td>Number of follow up calls made</td>
<td>20</td>
</tr>
<tr>
<td>Number semi-structured telephone interviews</td>
<td>12</td>
</tr>
<tr>
<td>Patients not in when called phone interview</td>
<td>6</td>
</tr>
<tr>
<td>Number declined to be interviewed when contacted due to illness</td>
<td>2</td>
</tr>
<tr>
<td>Numbers unobtainable</td>
<td>1</td>
</tr>
</tbody>
</table>

**Table 6: Details of Telephone Interview calls made**

Using Blyth F, March L, Nicholas M, Cousins M, (2005) guidance on active and passive coding (See Appendix 5), the interview data was analysed and active and passive management strategies identified (See Table 7).
<table>
<thead>
<tr>
<th>Question</th>
<th>Main answer</th>
<th>Additional details</th>
</tr>
</thead>
<tbody>
<tr>
<td>Why do you think you have been referred to pain clinic?</td>
<td>n=11 because of pain n=1 because of problem drug use</td>
<td>1 had asked to be referred 2 mentioned abuse of analgesia as a reason 1 referred to help with self managing her pain</td>
</tr>
<tr>
<td>What do you think is the reason for your pain?</td>
<td>n=7 did not understand why they had pain n=5 thought they understood why they had pain</td>
<td>3 mentioned arthritis 2 made reference to managing pain a difficulty</td>
</tr>
<tr>
<td>Who have you seen about your pain?</td>
<td>n=1 seen x 1 Dr’s n=6 seen x 2 Dr’s n=3 seen x 3 Dr’s n=1 seen x 4 Dr’s n=1 seen x 6 Dr’s</td>
<td>3 seen x1 additional health care professional (HCP) 2 seen x 4 additional HCP’s 1 seen alternative therapists 2 had already attended a pain management programme</td>
</tr>
<tr>
<td>What do you currently do to help yourself manage your pain?</td>
<td>Active self management strategies 24% made reference to active strategies</td>
<td>Passive self management strategies 75% made reference to passive strategies</td>
</tr>
<tr>
<td>What are your expectations of the pain clinic?</td>
<td>n=3 made mention to ‘cure’ n=5 made mention to reduction of pain n=3 made mention of help n=2 made mention of help with management of pain n=3 made mention of having no idea what the pain clinic did n=1 thought the pain clinic would be a waste of time n=1 saw pain clinic as a life line</td>
<td></td>
</tr>
<tr>
<td>How does your pain impact on your life?</td>
<td>n=7 indicated a lot. n=4 moderate. n=1 not asked</td>
<td></td>
</tr>
</tbody>
</table>

Table 7: Summary of Telephone Semi Structured Telephone Interviews

Overall PSOCQ scores revealed it was possible to classify 37% of the sample into the action and maintenance stage (See Graph 1). Both of these concepts are associated with a readiness for self-management, and linked with use of pain coping strategies and reductions in lifestyle interference from pain (Glenn & Burns, 2003; Jensen, Nielson, Turner, Romano, & Hill, 2004)). The contemplation stage of change was the largest single classification (37%)
consistent with the literature (Jensen, Nielson, Romano, Hill, & Turner, 2000).

Graph 1: PSOCQ Classification of Data

Supporting these findings, overall CPAQ scores identified 28% of patients’ demonstrated greater acceptance of their persistent pain symptoms (See Graph 2); a valuable concept, associated with making appropriate adaptations to pain symptoms (Li & Moore, 1998; McCracken & Eccleston, 2003; McCracken, Spertus, Janeck, Sinclair, & Wetzelb, 1999)
Furthermore, the strong relationships demonstrated in correlational coefficient analysis between acceptance of pain and other variables (See Table 4) suggests acceptance is an important concept in the managing pain and patient function (McCracken & Eccleston, 2005).

Also revealed by this audit was the relatively large proportion of patients (41%) who scored their average pain between mild to lower limits of moderate. Traditionally pain scores of 3 or 4 have been regarded as the upper limit for mild pain and 4 or 5 as the lower limit for moderate pain.(Serlin, Medoza, Nakamura, Edwards, & Cleeland, 1995) (See Graph 3).
Overall, the spread of the data from the audit may indicate patients referred to the pain clinic can be at different places or stages in the management of their pain symptoms. However, the quantitative questionnaire data indicated it might be possible to categorise 37% of referrals as developing some concepts associated with self-management approaches, while the qualitative interview data supported this, indicating 24% were addressing some form of active self-management.

Further analysis of the data consisted of critically reviewing the data from six patients for possible trends. Three patients displaying high precontemplation scores (1, 2 and 23) and three patients displaying lower precontemplation scores (6, 19, and 20) were identified (See Graph 4).
Patients 1, 2 and 23 identified with higher precontemplation scores

Patients 6, 19 and 20 identified with lower precontemplation scores

Graph 4: Individual Data for Precontemplation Stage of Change (PSOCQ)

Patients 1, 2 and 23 identified with lower action scores

Patients 6, 19 and 20 identified with higher action scores

Graph 5: Individual Data for Action Stage of Change (PSOCQ)
Exploring PSOCQ scores for these patients it was found that those with higher precontemplation scores, scored lower action scores and those with lower precontemplation scores, scored higher action scores (see Graph 5).

Analysis of CPAQ for these selected patients (1, 2, 23, 6, 19, and 20) was less conclusive due to missing data, but there were indications that patients demonstrating higher action scores may experience greater acceptance, consistent with the literature (McCracken & Eccleston, 2003) (See Table 8).

<table>
<thead>
<tr>
<th>Patient Number</th>
<th>Individual CPAQ Acceptance Scores</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Data missing</td>
</tr>
<tr>
<td>2 (lower action scores)</td>
<td>31</td>
</tr>
<tr>
<td>23 (lower action scores)</td>
<td>59</td>
</tr>
<tr>
<td>6 (higher action scores)</td>
<td>52</td>
</tr>
<tr>
<td>19</td>
<td>Data missing</td>
</tr>
<tr>
<td>20 (higher action scores)</td>
<td>74</td>
</tr>
</tbody>
</table>

Table 8: Individual Acceptance Score for Patients 1, 2, 23, and 6, 19, 20

Analysis of the qualitative semi-structured telephone interviews from these six patients revealed patients with higher precontemplation scores were more likely to mention passive strategies for managing their pain than patients with higher action scores who made more mention of active strategies (Table 9).
<table>
<thead>
<tr>
<th>Patients displaying higher Precontemplation &amp; lower Action scores on PSOCQ</th>
<th>Passive strategies blue</th>
<th>Active strategies green</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>What do you currently do to help yourself manage your pain?</strong></td>
<td><strong>What are you expectations of the pain clinic?</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Patient number 1</strong>&lt;br&gt;Takes pain killing tablets, coddymol and paracetamol, causes constipation so doesn’t take regularly. Not sure if she could take both together (advice from researcher given at this point). Also carries out exercises from physiotherapist.</td>
<td>Looking forward to one of those pain-killing injections. To be given something to relive the pain.</td>
<td></td>
</tr>
<tr>
<td><strong>Patient number 2</strong>&lt;br&gt;Takes tablets (analgesics) but these make her dizzy so she can’t take them when wants to drive or go to work. Has just smashed up her face from fainting due to taking tablets.</td>
<td>If operation does not get rid of pain then either you’ve got pain or you haven’t. Doesn’t see how healthcare professionals who do not have pain can be advising her on how to manage her pain.</td>
<td></td>
</tr>
<tr>
<td><strong>Patient number 23</strong>&lt;br&gt;Takes painkillers at night otherwise wouldn’t sleep. Sits down a lot more.</td>
<td>No idea what they do.</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Patients displaying lower precontemplation and higher action scores on PSOCQ</th>
<th><strong>What do you currently do to help yourself manage your pain?</strong></th>
<th><strong>What are you expectations of the pain clinic?</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Patient number 6</strong>&lt;br&gt;Work arranged for her to see private physiotherapy. Goes to Jacuzzi and pays for private massage. Now shops at Tesco that has shop mobility so can be independent. If out for a walk will stop and lean against a tree. Has a stool in the garden to help her garden.</td>
<td>Pain clinic has other ways &amp; means to help people.</td>
<td></td>
</tr>
<tr>
<td><strong>Patient number 19</strong>&lt;br&gt;Tried Pilates&lt;br&gt;Lies flat on bed and listens to relaxation tapes. That helps even if when she gets up she still has pain.</td>
<td>Sees pain clinic as a lifeline. When you’ve got pain all you want to do is to get rid of it. (This patient had been through another pain management programme).</td>
<td></td>
</tr>
<tr>
<td><strong>Patient number 20</strong>&lt;br&gt;Wants to learn how to help to control and manage her pain. Uses heat pad, rests when absolutely has to, good at keeping positive, self taught about what pain clinics do, takes pain killers and keeps active.</td>
<td>To be taught better ways to manage to live with pain, realizes will never go away and that can be difficult to deal with.</td>
<td></td>
</tr>
</tbody>
</table>

Table 9: Summary Interview Data for Patients 1, 2, 23 and 6, 19, 20
Discussion

Although this audit captured only a small percentage of referrals with some data missing, it can be cautiously offered that at least a quarter (27%) of patients referred to the pain service may fit Level 1 lower risk category and 37% could be amenable to self-care approaches (See Diagram 5).

While the more familiar acute illness models may predominate amongst patients with persistent pain, it can lead to maladaptive coping efforts. Changing the goals of these patients from a medical model to a self-management model, requires the patient to take responsibility and accept cure is unlikely, (Baird, Schmeiser D, & Yehle KT, 2003; Department of Health, 2001; Hanson & Gerber, 1990; Lorig, Ritter, & González, 2003; Lorig et al., 2001; Lorig et al., 1999). This change is often difficult but can reduce dependence on medical interventions that may not work (Hanson & Gerber, 1990; Stannard, 2000).

This project’s findings may emphasise the importance of person-centered services and treatments matching patients needs, rather than the expectation that patients should fit into particular treatment or models of approach (DH Long-term Conditions NSF Team, 2005; Hanson & Gerber, 1990). With appropriate support and encouragement from health professionals to actively engage in taking responsibility, those identified as possibly fitting the low risk category patients (Level 1) may find self-management offers opportunities to regain self respect, meaning, dignity, purpose and sense of well being, that
an approach dominated by a biomedical approach may well inhibit (Hanson & Gerber, 1990).

Diagram 4: Identify attitudes/concepts that may allow some patients to be categorised as Level 1 Low Risk Patients
**Recommendations**

The Government is keen to develop and promote person-centered services for managing long-term conditions. A longitudinal randomised controlled trial research project to explore the impact of self-care support introduced in the early stage of a patient’s referral to the pain service will now be conducted. The PSOCQ, CPAQ and BPI appear valid measurements that combined with qualitative data to indicate patients’ development of self-care approaches can complement understanding and allow patients’ Level of Risk to be the categorised.
References


Appendix 1

Pain Management Service Audit

There are 3 sections to the following audit and returning it to the audit department will be taken as your agreement to participate in this audit. It is not expected to take you longer than 10-15 minutes to complete the whole audit, so please put down our first thought/answer. If you wish to contact me about any aspect of the audit please ring 01932 722579.

This audit is not a test but to help us develop the pain service – so please be honest! Thank you for your help

Section A: About Yourself (Please tick appropriate box)

A1. What is your age? Years
A2. Are you...? Male: Female:
A3. How long have you experienced pain?
A4. Have you been given a diagnosis? Yes No

Chronic Pain Acceptance Questionnaire (CPAQ)

Below you will find a list of statements. Please rate the truth of each statement as it applies to you. Use the following rating scale to make your choices. For instance, if you believe a statement is 'Always True' you would write a 6 in the blank next to that statement.

<table>
<thead>
<tr>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
</tr>
</thead>
<tbody>
<tr>
<td>Never true</td>
<td>Very rarely true</td>
<td>Seldom</td>
<td>Sometimes true</td>
<td>Often true</td>
<td>Almost always true</td>
<td>Always true</td>
</tr>
</tbody>
</table>

1. I am getting on with my business of living no matter what my level of pain is..........
2. My life is going well, even though I have chronic pain .................
3. It's OK to experience pain .................
4. I would gladly sacrifice important things in my life to control this pain better............
5. It's not necessary for me to control my pain in order to handle my life well.........
6. Although things have changed, I am living a normal life despite my pain ............
7. I need to concentrate on getting rid of my pain .................
8. There are many activities I do when feel pain ..............
9. I lead a full life even though I have chronic pain ..............
10. Controlling pain is less important than any other goals in my life ..............
11. My thoughts and feelings about pain must change before I can take important steps in my life ..............
12. Despite the pain, I am sticking to a certain course in my life ..............
13. Keeping my pain level under control takes first priority when ever I’m doing something .......
14. Before I can make any serious plans, I have to get some control over my pain ..............
15. When my pain increases, I can still take care of my responsibilities ..............
16. I will have better control over my life if I can control my negative thoughts about pain ........
17. I avoid putting myself in situations where my pain might increase ..............
18. My worries and fears about what pain will do to me are true ..............
19. It’s a relief that I don’t have to change my pain to get on with my life ..............
20. I have to struggle to do things when I have pain ..............

The Pain Stages of Change Questionnaire

This questionnaire is used to help us better understand the way you view your pain problem. Each statement describes how you may feel about this particular problem. Please indicate the extent to which you tend to agree or disagree with each statement. In each example, please make your choice based on how you feel right now, not how you have felt in the past or how you would like to feel.

<table>
<thead>
<tr>
<th>Circle the response that best describes how much you agree or disagree with each statement</th>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Undecided or Unsure</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I have been thinking that the way I cope with my pain could improve.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>2. I am developing new ways to cope with my pain</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>3. I have learned some good ways to keep my pain problem from interfering with my life.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>
Circle the response that best describes how much you agree or disagree with each statement

<table>
<thead>
<tr>
<th></th>
<th></th>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Undecided or Unsure</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>4.</td>
<td>When my pain flares up, I find myself automatically using coping strategies that have worked in the past, such as a relaxation exercise or mental distraction technique.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>5.</td>
<td>I am using some strategies that help me better deal with my pain problem on a daily basis.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>6.</td>
<td>I have started to come up with strategies to help myself control my pain.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>7.</td>
<td>I have recently realized that there is no medical cure for my pain condition, so I want to learn some ways to cope with it.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>8.</td>
<td>Even if my pain doesn’t go away, I am ready to start changing how I deal with it.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>9.</td>
<td>I realize now that it’s time for me to come up with a better plan to cope with my pain problem.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>10.</td>
<td>I use what I have learned to help keep my pain under control.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>11.</td>
<td>I have tried everything that people have recommended to manage my pain and nothing helps.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>12.</td>
<td>My pain is a medical problem and I should be dealing with doctors about it.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>13.</td>
<td>I am currently using some suggestions people have made about how to live with my pain problem.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>14.</td>
<td>I am beginning to wonder if I need to get some help to develop skills for dealing with my pain.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>15.</td>
<td>I have recently figured out that it’s up to me to deal better with my pain.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>16.</td>
<td>Everybody I speak with tells me that I have to learn to live with my pain, but I don’t see why I should have to.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>17.</td>
<td>I have incorporated strategies for dealing with my pain into my everyday life.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>18.</td>
<td>I have made a lot of progress in coping with pain.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>19.</td>
<td>I have recently come to the conclusion that it’s time for me to change how I cope with my pain.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>20.</td>
<td>I’m getting help learning some strategies for coping better with my pain.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Contd</td>
<td>Circle the response that best describes how much you agree or disagree with each statement</td>
<td>Strongly Disagree</td>
<td>Disagree</td>
<td>Undecided or Neutral</td>
<td>Agree</td>
<td>Strongly Agree</td>
</tr>
<tr>
<td>-------</td>
<td>-------------------------------------------------------------------------------------</td>
<td>------------------</td>
<td>----------</td>
<td>---------------------</td>
<td>-------</td>
<td>-----------------</td>
</tr>
<tr>
<td>21.</td>
<td>I’m starting to wonder whether it’s up to me to manage my pain rather than relying on doctors.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>22.</td>
<td>I still think despite what doctors tell me, there must be some surgical procedure or medication that would get rid of my pain.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>23.</td>
<td>I have been thinking that doctors can only help so much in managing my pain and the rest is up to me.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>24.</td>
<td>The best thing I can do is to find a doctor who can figure out how to get rid of my pain once and for all.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>25.</td>
<td>Why can’t someone just do something to take away my pain?</td>
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<td>26.</td>
<td>I am learning to help myself control my pain without doctors</td>
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<td>27.</td>
<td>I am testing out some coping skills to manage my pain better</td>
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<td>28.</td>
<td>I have been wondering if there is something I could do to manage my pain better</td>
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<td>29.</td>
<td>All of this talk about how to cope better is a waste of time</td>
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<td>30.</td>
<td>I am learning ways to control my pain other than with medications or surgery</td>
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**Brief Pain Inventory (BPI)**

Please circle your response or ask for help if you are having problems

1. Please rate your pain by circling the one number that best describes your pain at its **WORST** in the past week

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2. Please rate your pain by circling the one number that best describes your pain at its **LEAST** in the past week

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3. Please rate your pain by circling the one number that best describes your pain on the **AVERAGE**

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4. Please rate your pain by circling the one number that tells how much pain you have **RIGHT NOW**

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5. Circle the one number that describes how during the past week, PAIN HAS INTERFERRED with your:

A. General activity

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B. Mood

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C. Walking ability

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D. Normal work (includes work both outside the home and housework)

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E. Relationships with other people

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F. Sleep

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G. Enjoyment of life

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Thank you for taking the time to complete this audit. If you would be happy to be contacted for an informal telephone discussion relating to how you feel and cope with your pain symptoms please write your name and telephone number below.
Appendix 2

Telephone Analysis

1. Why do you think you have been referred to the pain clinic?

A. Been referred because she has chronic pain. Awaiting an operation in March at SPH because the pain doesn’t go away.

B. Referred because she has arthritis. Also has Parkinson’s. The two types of medications can interact. Says has real pain in her joints

C. Pain

D. Because has damage to spine. Was admitted as an emergency via GP before Christmas. Was commenced on a medication which seemed to help and sent home. Prior to this seen in Dr Baxter endochronology clinic, mentioned pain in spine. CT and MRI organised. CT shows damage T10 and MRI brilliant as organised in 6 days but does not have results. Didn’t like to be a burden to hospital but was his wife who insisted on calling GP to house and then admitted.

E. Pain all over body. Has pain from head to toe

F. Been seen by all other specialists, don’t know what’s wrong, so can’t sort the problem out so now going to see if can help with pain symptoms

G. She has RA and degenerative disc in spine.

H. Osteoarthritis. No body seems to be able to do anything about it. Living on pain killers now on steroids – helping a bit.

I. Asked to be referred by GP. Has been to pain management programme at Unsted Park

J. Drugs. GP not happy been taken morphine for sometime. Use of morphine related to pain. GP has referred him he thinks

K. Excruciating pain

2. What do you think is the reason for your pain

A. Understands why she has pain that’s why she is having an operations but doesn’t understand why she has been referred to the pain clinic. Said it doesn’t make sense until after the operation when might have to come to pain clinic if pain doesn’t go away.

B. Arthritis

C. Several little things wrong. Has damaged discs – nothing they can do about that. Also has gouty arthritis. Seeing rheumatologist doing lots of blood tests. Has got into bad happy of eating pain Killers. Finding it difficult to manage her pain

D. Neural damage. Legs will go dead Has a number of health problems, Con syndrome. Pouch in throat.
E. All started after back injury at work. Pulled ligament lifting. Healed in 4-5 months but did not want to continue working. Husband of work on incapacity benefit, she has to do everything at home in the garden & has 2 children. This made pains worse. Before Christmas exhausted, thought she was dying. Feels cause is not only ligaments but blood circulation no good something blocked. Treated by Tai monk has told her circulation poor.

F. No one knows why she has pain. All theories have been thrown out. Pain getting worse since first seen about symptoms

G. Wants to learn how to can help to control and manage her pain. To be taught how to find better ways of dealing with pain realises not going to go away, but wants help to make it easier to live with

H. Pain - not clear why referred to pain clinic possibly because drs don’t know what to do

I. Back pain. Has surgery when 22 years old now 58 years old. Had back pain all the time

J. Knows why he has pain has been given a diagnosis

K. Doesn’t really understand why referred to pain clinic. Has not given much explanation about his pain, in fact told very little about pain. He complained about pain control and Dr Irani said he would refer to pain clinic. No has suggested how he could help manage his pain

3. Who have you seen about your pain?

A. Question not asked

B. Dr at SPH for Parkinson’s. She was looking forward to one of these pain killing injections but has been told her joints are too ‘knocked’ about to have injections. Also seen physiotherapist – given exercises

C. Rheumatologist – doing blood tests. Physiotherapist for neck & back pain. Afraid to say she only gave her exercises to do and didn’t treat her, Now pays to go to a private physio who gives massage, as well as exercises. This is enormously helpful. If could afford it would go each week. Helps for 10 days

D. Dr Baxter, GP and admitting Dr when came in as emergency

E. Rheumatologist, Acupuncturist, Chinese medicine Tai ancient massage, osteopath, pain killers

F. Four consultants and numerous tests

G. Rheumatologist, GP Physiotherapist

H. GP, x2 consultants at hospital, had xrays

I. Seen a lot of different people. 6 medical consultants before start to count other HCP’s
J. Has been through Unsted Parks pain management programme. Frankly a waste of time

K. Rheumatologist, GP Physiotherapist

4. What do you currently do to help you manage your pain

A. Doesn’t eat & that makes her faint. She has just smashed her face up from fainting. Takes tablets (pain killers) but these make her dizzy so can’t take when she wants to drive/go to work. Doesn’t want to sit & think about pain

B. Takes pain killing tablets, cocodymol and paracetmol. Causes constipation, so doesn’t take them regularly. Not sure if she could take both together (Advice on medication given at this point). Also carries out exercises shown by physiotherapist

C. Work arranged for her top see their private physio for 6 weeks. He manipulated spine & feet; gave U/S and exercises. Has plantar fascitis due to being overweight. This was very helpful. Goes to Jacuzzi, pays for private physio every 2 weeks for massage can’t afford more often. Has a special cahir at work to support back & neck. Work also arranged for ergonomic keyboard & mouse. Keeps a stick in car but embarrassed to use. Now shops at a TESCO that has shopmobility so can be independent. Sits down a lot she saw thais as a bad thing to be doing. If out for a wiak will stop and lean against a tree. Has a stool to garden – loves gardening. Went to talk on what you should not eat when have arthritis and used to eat lots of cherry tomatoes which she grew. Since stopped eating these 50% reduction of pain and also stopped Aspirin as read should not take if have gout. Realises overweight has put herself on no fat diet

D. Borrowed a TENS but not sure if used correctly and worried might effect heart. Doesn’t feel it has helped. Prescribed valium and Gabapentin. Doesn’t take valium because both tablets work on nerves unsure if safe to take both. Think Gabapentin has helped

E. Try anything, nothing so far worked, so why not try pain clinic. Goes for sauna/steam. Given up all pain killer, antidepressants sleeping tablets. Continues with tablet to help indigestion helps her to sleep. Used to go to gym but tensed muscles up no longer gores. Rheumatologist recommended pilates

F. Problem in feet and lower legs. Burning all the time, therefore wears very little on feet and lower legs. Spent lots of money on shoes. Pain better if keeps changing activity, worse when lying down. Take tablets prescribed by rheumatologist. Has adopted certain aspects i.e. doesn’t go to London walking around all day

G. Heat pad. Rest when absolutely has to. Good at keeping positive. Self taught about what pain clinic does partly as a result of depression when children younger – had to look at self help. Takes pain killers. Keeps active

H. Take pain killers at night otherwise wouldn’t sleep. Not now taking pain killers during the day. Takes cod liver oil. Sitting down a lot more. Going to think of going to an exercise class

I. Did try Pilates – not helping. Walking increases pain. Lies flat on bed and listens to relaxation tapes. That helps even if when gets up still has pain.
J. Does quite a lot of things, but about what he doesn’t do. Knows if he digs the
garden decorates going to increase pain. Takes morphine that helps and will
take a little more if there is something else he wants to do.

K. Takes paracetamol and went to GP last week to see if anything else to help.
Prescribed co codamol. They seem to make it worse. Has a cycling machine
uses at home. Carries out exercises taught at home

5. What are your expectations of the pain clinic?

A. If operation doesn’t get rid of pain then either you’ve got pain or you’ve got to
live with it or you haven’t. Doesn’t see how health care professionals who not
have pain can be advising her on how to manage her pain. If people never had
pain how can they tell her how to live with it. Doesn’t mean to criticise but this
is what she feels. She feels it is bad having to wait for her operation, while she
understands that they are having to put a team of gynaecologists and
surgeons together for the op she feels that simple operations get done
quickly.

B. To be given something to relieve the pain. At the moment nothing relieves the
pain

C. Anything that will give slightest glimmer of help to mage to reduce pain or a
miracle cure to get rid of pain. Would get another massager if could afford it.
Pain clinic has other ways & means to help people

D. Assumes they will play around with medication. Have to careful because of
Con syndrome. Feels has been going round in circles. Can’t get pouch in throat
sorted until Con syndrome stabilised falls need to get health sorted. Also has
psoriasis, nails falls out etc Really doesn’t know what the pain clinic does
except heard of TENS

E. Talking top people who understand pain nad have pain both patients and
healthcare professional. Hope to talk to people with experience. Feels very
alone with her pain, doesn’t know who she can talk to. Feels resentful of pain
and effects family. Hoping to get acupuncture from pain clinic as can’t afford
her own. Hope that one day these pains will be gone and she will feel normal.
Before Christmas thought she was disabled. Tai Monk helped her come
through that with massage got her energy back. Prior to that had seen 3 drs
in one week and desperate for help so contacted Tai Monk. Had tai massage
twice daily for 4 days. Really needs help. Family Asian and wants to feel better

F. In ideal world wants pain to be lessened so can sleep through the night.
Doesn’t really know anything about pain clinic but a member of family went to
pain clinic had TENS

G. To be taught better way to manage to live with pain realises will never go
away and that can be difficult to deal with

H. No idea what they do

I. Sees pain clinic as a life line. Does not want to be a group GP said our pain
clinic was not like that. Pain management programme at Unsted Park had so
much psychology – got sick of it. She had so much pain all very well but when
you've got pain all the time, all you want to do is to get rid of it. Hoping to get more out of our pain clinic than Unsted Park in terms of pain relief.

J. Complete and utter waste of time unless got something different to what already been offered

K. Hopeful will relieve pain

6. How does your pain impact on your life?

A. Terrible at the moment.

B. Question not asked

C. Stops her getting on a train and going into town. Because of pain she realises she became depressed and ate too much. Now very overweight. This stops her going to the gym because she can't walk on treadmill.

D. When bad can only lie in bed. Not confident to go out as went to British Legion Club and legs went. Wife had to organise taxi and to get car back. On good days does go out in garden and with wife. Very happy to talk as nothing else to do

Used to be very active. She is the strong person in the family because of husbands health. Has to look after everyone else. Even when really ill has to drag her self up but has to for children. Feels children missing out. One of the children has asperger's syndrome.

E. Would impact less if could sleep.

F. Moderate

G. Used to be a dancer, can't dance now. Used to love walking & shopping. Pain means she has put weight on. Doesn't get enough exercise. Coping with pain moderate impact on life

H. Impacts a lot

I. 'Utterly buggers you up’

J. A lot can't go walking any distance and equally impacts on wife
Appendix 3

Distribution Graphs for Age, Length of Pain, Pain, Interference, Acceptance and Stages of change

Pt's age

Pain for how long

Interference

Pain total

Mean = 55.75
Std. Dev. = 16.9758
N = 44

Mean = 7.712
Std. Dev. = 8.5688
N = 40

Mean = 49.3448
Std. Dev. = 13.4387
N = 44

Mean = 24.3488
Std. Dev. = 8.07372
N = 43
Appendix 4
Scatter Graphs Demonstrate Strength of Relationship and Line of Fit

Telephone Semi-structured Questions
**Appendix 5**

**Coding for Self-Management Strategies**  
(Blyth, March, Nicholas, & Cousins, 2004)

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<td>Distraction</td>
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<td>Modified use</td>
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<td>Usual tasks</td>
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SERVICE DEVELOPMENT PROJECT
PRESENTATION

(5 PowerPoint Slides with notes)
Promoting the Concept of Self-Care Support for Managing Persistent Pain

(Notes to accompany slides)

Heather Hawksley
Service Development Project
Doctorate in Clinical Practice
April 19th 2005
EIHMS

• The NHS is looking at finding effective ways to provide the option of self support.
• Key element is enabling patients to take greater control of their own treatment while gaining support from health professionals to effect a shift from reliance on external health professionals to the adoption of active internal approaches to their condition [15].

• The NHS is keen to give patients the right level of support and care to patients, and this centres around individualised-tailored care [1, 34]

• Considered by Department of Health consider that patients can be broadly divided into 3 groups that require different levels of support, and that the greater majority of patients with a long term condition may be able to manage their own conditions, providing they are given the right level of support [34].

• The Government very keen to find ways to promote option of self care support for some patients with long term conditions.

Key to self care support:
• Enabling patient to greater control of treatment
• Affect a shift from reliance on external healthcare professionals
• Adoption of active internal approaches to manage their condition [1, 2, 34, 35]
**Medical Condition**
- The population aging; the incidence of chronic conditions rising; persistent pain is one of these [35].
- The prevalence self reported long standing illness has risen 21% in 1972 to 35% 2002 [3].
- Management of long term illness is not a new problem but one that resists solutions, while long term conditions are greatest cost to NHS [1, 33, 15, 16].
- Current approaches need to change and self management considered a fundamental part of managing long term conditions [36, 37].

**Resources**
- Funding the mounting demand from chronic illness is a perpetual struggle [46].
- Predicted many NHS services funded through taxation will be outside the NHS’ financial means by 2020 [38].
- For the first time since censers were kept there are more people aged over sixty then children resulting in diminishing numbers of taxpayers available to support the growing size of the older population [3, 39].

**Culture**
- NHS may contribute to passivity in some patients [6, 7, 9].
- Influence medical model (doctor centre of care, & belief that providing patient complies with doctor they will ‘fix you’). Sick role model requires:
  - Sick role: a) exemption of responsibility
  - b) requirement to do all in their powers to get better,
  - c) seeking care from medical professionals [8, 41].
- People now less accepting and challenge the traditional model medical care [4, 5, 14, 25].
- Increasing influence from the voluntary sector, who see their role as influencing Government into providing quality lay led self management programmes [2, 48].
- Health professionals need to take responsibility for making patients aware of the options available to them to choose from [33, 34, 35, 36].
- Promotion self care support and management [1, 2, 33, 34, 35], considered key to how these conditions are managed.
Current Service Model

- Question whether current pain service model of care is perpetuating the pain cycle [23, 24] and encouraging dependence [47].
- Gill’s cycle looks at medication dependence but may be able to apply cycle to dependence on medical treatment in general.

Evidence

- Has been suggested the biomedical model may inhibit self-management [27].
- With appropriate support and encouragement to actively engage in taking responsibility, some patients may find self-management offers opportunities to regain self-respect, meaning, dignity, purpose and sense of well-being, that an approach dominated by a biomedical approach may well inhibit (Hanson & Gerber, 1990) and possibly reduce over reliance on treatment success.
- Considerable evidence suggesting self-management approaches are appropriate for long term conditions, [2, 18, 28, 29, 30], and the Government has proposed that by 2007 the NHS will have established a user self management approach to dealing with issues associated with chronic illness [45].
- Acceptance is emerging as a potentially valuable concept and may be more successful in predicting pain, disability, depression, and related to patient function [13, 22, 42, 43].
- Non-linear nature of pain severity and interference relationship, may have implications for persistent pain sufferers [32].

- Self management skills often missing essential component for successful adaptation. Self care complex & may involve: Transtheoretical model of change [1, 17]
Acceptance and commitment therapy [12]
Motivation model [49]
Expert patient/lay self management [2]
Multidisciplinary team source of care [16]
Systematic approach to care for people with long-term conditions.

- DoH has a long term conditions strategy for supporting people with long term conditions [1, 34, 35, 37]. An NHS and social care model to support local innovation and integration [34] provides a framework for improving the care of patients and groups the population affected into three categories according to their different levels of need:
  
  **Level 1** – those requiring more support with self-management and self care so they can take an active role in managing their conditions. This group makes up 70-80% population with long term conditions  
  **Level 2** – those needing better disease management from multidisciplinary teams providing high quality, evidenced based care  
  **Level 3** – those patients with complex, often multiple conditions who need case management approaches [35]

- Self management approach offers opportunity to improve sense of well being [27, 28, 29, 30]  
- By 2007 user self management NHS proposed [45]

**Audit (See Notes Appendix 2)**
- Descriptive data, age, gender, how long experienced pain, diagnosis?  
- Pain Stages of Change Questionnaire (PSOCQ) [44]  
- Chronic Pain Acceptance Questionnaire (CPAQ) [43]  
- Brief Pain Inventory (BPI)  
- Telephone semi structured interviews focused on self care (See Notes Appendix 3)
1. **Unfreezing**
   - *Disconfirmation status quo*
     - Is best practice being offered to patients?
     - Has the latest evidence in literature been discussed and implemented where appropriate?
     - Are latest recommendations being offered?
   - *Guilt*
     - Develop a culture which recognises and responds to the needs of the user
   - *Survival anxiety*
     - Are Government targets being met?
     - Is our service both effective in terms of outcomes and efficient in its use of resources
   - *Creating psychological safety*
     - Key to effective change is balancing disconfirmation status with sufficient psychological safety to allow those involved to accept the information, feel survival anxiety & become motivated to change.
     - Can create psychological safety through working in groups/team and the use of evidenced based practices

2. **Moving**
   - *Learning approach, involves thought processes, feeling, values & attitudes*
     - Team involvement - micro & macro team meetings to discuss ideas
     - Audit to understand referral population
     - Support from team & management for study
     - Research study proposing introducing an alternative model of care.

3. **Refreezing**
   - *New behaviour*
     - Possible Implementation of new model.
     - Re audit Re-evaluate
### Process Involvement

<table>
<thead>
<tr>
<th>Stakeholders</th>
<th>Ethical Issues</th>
</tr>
</thead>
<tbody>
<tr>
<td>Users (expert patients)</td>
<td>Audit supported by Trust</td>
</tr>
<tr>
<td>Team</td>
<td>Pt free to refuse to take part</td>
</tr>
<tr>
<td>Primary Care Teams</td>
<td>Confidential</td>
</tr>
<tr>
<td>Voluntary sector</td>
<td>Research – ethical approval</td>
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<tr>
<td>Management</td>
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### Audit Critique

<table>
<thead>
<tr>
<th>Strengths</th>
<th>Outcomes</th>
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<tbody>
<tr>
<td>Validated</td>
<td>30% self-management</td>
</tr>
<tr>
<td>Quantitative/qualitative</td>
<td>32% pain scores</td>
</tr>
<tr>
<td>Data matched literature</td>
<td>mild/lower moderate</td>
</tr>
</tbody>
</table>

**Weaknesses**

- Small sample n = 110
- Lengthy/postal
- 44% return rate
- 44% return rate

### Outcomes

- 30% self-management
- 32% pain scores mild/lower moderate
- Overall
- 28% sample Level 1 Risk

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**Stakeholders**

- **Users -** Patient member of pain service practice development unit steering committee
  - Expert patients involved in delivery self support programmes
- **Team -** Macro/micro meetings. Team involved in delivering service
- **Primary Care Teams involved via link with researcher, a member of Primary Care Trust Managed Care Group**
- **Voluntary sector have contributed to Expert Patient Policy [2], but need to develop further links**

**Ethical Issues**

- Audit developed with support of Trusts Audit department.
- Patient free to take part with no impact on their treatment or care
- Confidential
- Research study applying for ethical approval

**Audit Critique**

- **Strengths**
  - Questionnaires validated
  - Quantitative & Qualitative approach to data collection
  - Total population referred in December used as sample
- **Weaknesses**
  - Lengthy
  - Self report and postal
  - Missing data high for some questionnaires
  - No reminders sent out

**Outcomes**

- See Notes & accompanying slides for full evaluation and discussion