The Development of an Activity Pacing Questionnaire for Chronic Pain and/or Fatigue

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Chapter 7. Stage III: Exploring the acceptability of the activity pacing questionnaire (APQ)

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Abstract
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Introduction: Activity pacing is often advised as a coping strategy for managing chronic conditions (such as chronic low back pain, chronic widespread pain and chronic fatigue syndrome/myalgic encephalomyelitis). Despite anecdotal support for activity pacing, there is limited and conflicting research evidence regarding the efficacy of this strategy. Pacing has not been clearly operationalised, and existing descriptions are diverse and include strategies that encourage both increasing and decreasing activities. Moreover, there are few validated scales to measure activity pacing.
Aim and objectives: The aims of the studies contained within this thesis were to develop an activity pacing questionnaire (APQ) for adult patients with chronic pain and/or fatigue, and to determine its psychometric properties and acceptability.
Methods: The study had a three stage mixed method design. Stage I, the Delphi technique involved a three-round consensus method to develop the initial items of the APQ using an expert panel of patients and clinicians. Stage II, the psychometric study, implemented a cross-sectional questionnaire design study, involving a large sample of patients with chronic conditions. This stage assessed the underlying pacing themes of the APQ using factor analysis, internal and test-retest reliability using Cronbach's α and intraclass correlations (ICCs); and validity using correlations with validated measures of pain, fatigue, anxiety, depression, avoidance, and mental and physical function. Stage III, the acceptability study, explored patients' opinions of the APQ, together with the concept of activity pacing via telephone interviews. The qualitative interview data were analysed using framework analysis.
Results: Forty-two participants completed Stage I, the Delphi technique (4 patients, 3 nurses, 26 physiotherapists and 9 occupational therapists). The resulting APQ contained 38 questions involving a number of different facets, including breaking down tasks, gradually increasing activities and setting goals. Stage II, the psychometric study, was completed by 311 patients, of whom 69 were involved in a test-retest analysis. Following factor analysis, eight items were removed from the APQ. Five themes of pacing were identified in the 30-item APQ: Activity limitation, Activity planning, Activity progression, Activity consistency and Activity acceptance. These demonstrated satisfactory internal consistency (Cronbach's α=0.724-0.933), test-retest reliability (ICC=0.50-0.79, $p<0.001$), and construct validity against validated measures. Activity limitation, Activity planning, Activity progression and Activity acceptance correlated with worse symptoms and Activity consistency correlated with improved symptoms. Sixteen patients participated in Stage III, the acceptability interviews. The APQ was found to be generally acceptable. Four activity behaviour typologies emerged through the interviews: Task avoidance, Task persistence, Task fluctuation (boom-bust) and Task modification (activity pacing).
Conclusion: This is the first known study that has engaged both patients and clinicians in the development of an activity pacing questionnaire. Developed to be widely used across a heterogeneous group of patients with chronic pain and/or fatigue, the APQ is multifaceted, comprehensive and contains more themes of pacing than existing pacing subscales.

Declaration

No portion of the work referred to in the thesis has been submitted in support of an application for another degree or qualification of this or any other university or other institute of learning.

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The Author

The author graduated from the School of Physiotherapy, University of Manchester in 2002. Following the achievement of her BSc (Hons) in Physiotherapy, she commenced her clinical career in North Manchester General Hospital, The Pennine Acute Hospitals NHS Trust. During this time, she developed a special interest in the management of complex chronic conditions, such as chronic low back pain, chronic widespread pain and chronic fatigue syndrome/myalgic encephalomyelitis.

The author was excited to have the opportunity to return to academia by commencing a part-time MPhil in the School of Translational Medicine, University of Manchester in 2009. Following the successful transfer from her MPhil, her PhD continued in the School of Nursing, Midwifery and Social Work, University of Manchester. This has been the first time she has undertaken a large research study, together with implementing mixed methods. This study has led to her first publication in the *Physiotherapy* journal, and she hopes to pursue a future continuing to develop her research skills and applying these to clinical practice.

Abbreviations

APQ	Activity Pacing Questionnaire
APT	Adaptive Pacing Therapy
CBT	Cognitive Behavioural Therapy
CFS/ME	Chronic Fatigue Syndrome/Myalgic Encephalomyelitis
CORS	Coping with Rheumatic Stressors
CPCI	Chronic Pain Coping Inventory
GET	Graded Exercise Therapy
GP	General Practitioner
HADS	Hospital Anxiety and Depression Scale
KMO	Kaiser-Meyer-Olkin test
LBP	Low Back Pain
NRS	Numerical Rating Scale
PARQ	Pain and Activity Relations Questionnaire
PASS	Pain Anxiety Symptoms Scale
POAM-P	Patterns of Activity Measure-Pain
SF-12	Short Form-12
UK	United Kingdom

Chapter 1. Introduction

Activity pacing involves the modification of patients' behaviour to improve activity levels and manage symptoms while reducing the chance of future relapses or disability (Nielson et al., 2001; NICE, 2007; Nijs et al., 2008). This study involves the development of an activity pacing questionnaire for patients with chronic pain and/or fatigue. This chapter reports the epidemiology of the chronic conditions to which the study refers: chronic low back pain, chronic widespread pain, fibromyalgia and chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME). This chapter closes by describing the structure of the thesis. Activity pacing will be discussed in more detail in Chapter 2, Literature review.

1.1 Background to the study population

Patients frequently seek healthcare services for the management of chronic conditions such as chronic low back pain, chronic widespread pain, fibromyalgia and CFS/ME (Reid et al., 2002; NICE, 2007; NICE, 2009). The impact of these conditions includes pain, fatigue, disability and reduced quality of life, together with societal costs with regards to loss of employment (Wolfe et al., 1995; Maniadakis and Gray, 2000; NICE, 2007). Such patients place a heavy burden on healthcare services in terms of repeat physician appointments, cost of diagnostic examinations and medications, together with referrals to allied health professionals (Maniadakis and Gray, 2000; McCarthy et al., 2006; Berger et al., 2007).

1.1.1 Chronic low back pain

Back pain in the general population has a one year incidence of 6.3%-15.4% for a first episode which increases in range to 1.5%-36% for a first or recurrent episode (Hoy et al., 2010). Of these incidences, higher rates have been found in the United Kingdom (UK) in comparison to countries such as Denmark or Canada (Hoy et al., 2010). Furthermore, low back pain affects 70%-85% of the population during their lifetime and approximately 10% do not recover from an episode of low back pain within three months of onset (Andersson, 1999). Low back pain that has been present for >3 months is commonly referred to as chronic low back pain (Frank, 1993; Heneweer et al., 2009). The rate of recurrence of chronic low back pain has been estimated between 35%-79% (Manchikanti, 2000).

Previous studies have found that women report a higher frequency and greater impact of back pain (Schneider et al., 2006; Chenot et al., 2008; Macfarlane et al., 2012). Other factors associated with increased occurrences of back pain include: increasing age (between 30-60 years), increased weight, poor education level, low social class, psychosocial factors (including unemployment/low job satisfaction), low physical activity, anxiety and depression (Manchikanti, 2000; Macfarlane et al., 2006; Schneider et al., 2006; Hoy et al., 2010). For the majority of low back pain cases, a specific aetiology cannot be identified (Snook, 2004; Hoy et al., 2010). Therefore, low back pain is often diagnosed from self-reports of pain (Manchikanti, 2000).

Chronic low back pain manifests in terms of loss of functional and social activities, together with an impact on relationships and quality of life (Maniadakis and Gray, 2000; Hansen et al., 2010). Back pain comes at a great cost in terms of healthcare demands. Indeed, one in every 15 people in the UK will seek their GP regarding low back pain (NICE, 2009). Part of the economic burden of back pain is accounted for by absenteeism from work and reduction in activity (Hoy et al., 2010).

1.1.2 Chronic widespread pain and fibromyalgia

Chronic widespread pain has been classified by the American College of Rheumatology as pain present for $\geq$ 3 months, bilaterally, in the upper and lower body, together with spinal pain (Wolfe et al., 1990). Chronic widespread pain affects up to 11% of the population, of whom 19% will be diagnosed with fibromyalgia by the presence of 11 out of 18 tender points on palpation (Wolfe et al., 1995). Fibromyalgia has a prevalence in the community of approximately 2%-4%, which increases to between 6%-8% in general practice and hospitals (Wolfe, 1993). The prevalence of chronic widespread pain is 1.5 times greater in females than males (Clauw and Crofford, 2003). However, fibromyalgia is over nine times more prevalent in women (Wolfe, 1993). Furthermore, fibromyalgia is more common with increasing age (Wolfe et al., 1995).

Chronic widespread pain and fibromyalgia may be accompanied by symptoms of sleep disturbance, fatigue, morning stiffness, irritable bowel syndrome, paraesthesia, headaches, memory difficulties and psychological distress such as anxiety and depression, together with poor health perception (Wolfe et al., 1990; Clauw and Crofford, 2003; Rohrbeck et al., 2007). The presence of fibromyalgia is associated with lower education and lower household income, together with a history of depression,

increased claims for disability benefits and increased visits to physicians (Wolfe et al., 1995). Indeed, patients with fibromyalgia in the United States were four times as likely to visit their doctor and cost the healthcare services three times as much as their comparison group (without fibromyalgia) (Berger et al., 2007).

Chronic widespread pain is diagnosed from subjective reports of symptoms, and fibromyalgia is diagnosed following responses to palpation, in the absence of objective markers (Wolfe et al., 1990). It may be difficult to differentiate these diagnoses from other medical conditions due to a wide range of overlapping symptoms and high incidences of co-morbidities, such as circulatory and gastric problems, together with psychological conditions (Berger et al., 2007).

1.1.3 Chronic fatigue syndrome/myalgic encephalomyelitis

Chronic fatigue syndrome (CFS) has traditionally been referred to as myalgic encephalomyelitis or encephalopathy (ME). The term CFS/ME has been advised by the Chief Medical Officer's working group (Sharpe, 2002). CFS/ME has a prevalence of at least 0.2%-0.4% in the UK (NICE, 2007). CFS/ME is more prevalent in females, and often diagnosed in those aged 30-40 years old (Afari and Buchwald, 2003).

CFS/ME has been defined as intermittent or continuous episodes of fatigue that have been present for $\geq$ 6 months, together with a minimum of four out of eight other symptoms from the following: unrefreshing sleep, disproportionate fatigue after activity, muscle pains, joint pains, impaired memory or concentration, headaches, sore throat and tender lymph nodes (Fukuda et al., 1994). To fulfil the classification of CFS/ME, all other explanatory pathology must be excluded (Fukuda et al., 1994). Therefore, similarly to low back pain, chronic widespread pain and fibromyalgia, CFS/ME is diagnosed from subjective reports and negative findings on investigations as opposed to positive diagnostic tests. Indeed, despite studies into the biomedical explanation for CFS/ME, such as neurological, viral, endocrine, or psychiatric causes, the aetiology of the condition is unclear (Afari and Buchwald, 2003; NICE, 2007).

The impact of CFS/ME may include a reduction in employment, personal and social activities (Fukuda et al., 1994). Additional symptoms may include dizziness, reduced tolerance to stimuli and nausea (Afari and Buchwald, 2003). Moreover, there is an

increased likelihood of depression and anxiety among those with CFS/ME compared to both healthy controls, and other chronic conditions (Afari and Buchwald, 2003).

1.1.4 Overlapping symptoms and coexisting conditions

There are a number of commonalities between chronic low back pain, chronic widespread pain, fibromyalgia and CFS/ME. Similar symptoms are reported, (for example, pain, fatigue and disability), together with similar cognitive effects (for example, impaired memory) and psychological co-morbidities (for example, anxiety and depression). There is a higher prevalence among females and middle-older ages. The impact of the conditions can lead to significant reductions in functional activities and employment. Additionally, the above conditions are often diagnosed on the basis of self-report after excluding other conditions in the absence of definitive objective tests.

Previous research has found the above conditions frequently overlap and possibly coexist (Clauw and Crofford, 2003). Up to 70% of patients diagnosed with CFS/ME fulfil the criteria for fibromyalgia and vice versa (Afari and Buchwald, 2003). Low back pain has been found to coexist with other regional pains (Schneider et al., 2006; Rohrbeck et al., 2007; Chenot et al., 2008). Specifically, low back pain was reported in 20% of patients with fibromyalgia (Wolfe et al., 1990). Furthermore, it is proposed that the disease progression of the conditions and resulting psychosocial effects, may be similar (Afari and Buchwald, 2003). Moreover, there is an overlap of symptoms between patients who frequently attend healthcare services with multiple chronic regional pains and chronic widespread pain/fibromyalgia (Rohrbeck et al., 2007).

1.1.5 Medically unexplained symptoms and somatoform disorders

Chronic low back pain, chronic widespread pain, fibromyalgia and CFS/ME share a further similarity of being among many conditions that have been referred to as medically unexplained symptoms, somatoform disorders or functional somatic syndromes (Wessely et al., 1999; Reid et al., 2001; Clauw and Crofford, 2003; Schur et al., 2007). That is, conditions that may not be explained by an underlying pathology (Aggarwal et al., 2006). Medically unexplained symptoms may be seen across the medical specialities, for example, irritable bowel syndrome in gastrointestinal medicine and headaches in neurological medicine (Reid et al., 2001; Wessely and White, 2004). It is thought that approximately 4% of the population are affected by somatoform disorders (Clauw and Crofford, 2003).

There is an ongoing debate into the terminology and classification of such conditions (Wessely and White, 2004; Hatcher and Arroll, 2008; Creed et al., 2010). The term 'medically unexplained symptoms' has been criticised as it is proposed that conditions are often medically "unexamined", as opposed to "unexplained" (Dimsdale et al., 2013). Incorporating the term 'somatic' in the classification acknowledges the presence of somatic symptoms as opposed to the absence of a medical explanation (Creed et al., 2010; Dimsdale et al., 2013). The term 'functional disorder' may be advised as this refers to a condition affecting an individual's function (Hatcher and Arroll, 2008). Indeed, the term 'functional somatic disorder' may be most agreeable for patients and clinicians (Creed et al., 2010). Recently, the term 'somatic symptom disorder' has been proposed. However, this term underpins a psychiatric disorder (Dimsdale et al., 2013). Indeed, the above terms have been criticised for creating a 'mind/body dualism' where the absence of medical explanations alludes to psychosomatic conditions which may be less socially acceptable (Wessely and White, 2004; Creed et al., 2012). It may be argued that conditions should not be classified together under such terms since different disease pathways are potentially emerging through research (Wessely and White, 2004).

For the purpose of the study, patients will be referred to as having 'conditions of chronic pain and/or fatigue' since the included conditions may be referred to as medically unexplained/functional somatic disorders, but form only a small number of conditions that have been labelled by such terms.

1.1.6 Holistic management

Since conditions of chronic pain and/or fatigue overlap and coexist, treatment interventions that target specific symptoms in isolation may overlook symptoms that have not yet been reported or recognised (Aggarwal et al., 2006). This may lead to repeated referrals to health services and future financial demands on healthcare providers (Wessely et al., 1999). Indeed, it has been found that patients with "medically unexplained conditions" account for one fifth of referrals to secondary care, and incur greater costs to healthcare services in terms of investigations compared with other frequent attenders (Reid et al., 2002). Consequently, holistic treatment interventions that manage the complexity of symptoms are recommended (Reid et al., 2002; Aggarwal et al., 2006). In particular, biopsychosocial approaches are advised in recognition of physiological, psychological and social factors (Creed et al., 2012).

Since the underlying causes of chronic conditions cannot always be medically explained, the focus of treatment involves promoting self-management strategies and rehabilitation as opposed to cure-seeking (Reid et al., 2002; Clauw and Crofford, 2003; NICE, 2009). Specifically, there is growing evidence recommending cognitive behavioural therapy (CBT) and graded exercise therapy (GET) for the management of chronic low back pain, chronic widespread pain, fibromyalgia and CFS/ME (Schur et al., 2007; Nijs et al., 2008; van Koulil et al., 2010; McBeth et al., 2011; White et al., 2011). Activity pacing has been suggested to be a key aspect of both CBT and GET (Birkholtz et al., 2004a; Wallman et al., 2004; Hansen et al., 2010; McBeth et al., 2011).

1.2 Rationale for the study conditions

The conditions that have been selected for the study include chronic low back pain, chronic widespread pain, fibromyalgia and CFS/ME. The justification for this selection is that these conditions are frequently referred to healthcare professions, and in particular physiotherapy. Individuals with such conditions have historically been advised to pace their activities as a management strategy (Nielson et al., 2013). Due to the prevalence and complexity of these chronic conditions, management strategies are required that have evidence of efficacy. Despite the frequent recommendation of activity pacing in the management of chronic conditions, there is a paucity of empirical evidence regarding the benefits of activity pacing *(see Chapter 2, Literature review, Section 2.3.4.7).*

It is acknowledged that activity pacing is recommended for many other conditions, including conditions that may be medically explained, such as rheumatoid arthritis and osteoarthritis. However, it is beyond the scope of the study to explore pacing among all conditions. The specific chronic conditions were selected due to sharing similarities (for example, epidemiology), while exhibiting a heterogeneous bank of symptoms (for example, pain, fatigue, anxiety, depression, avoidance and reduced function).

1.3 Structure of the thesis

In order to develop an activity pacing questionnaire (APQ) for chronic pain and/or fatigue, the study consists of three stages involving mixed methods. To report this multi-stage study, the thesis has been organised into 8 chapters. Chapters 1 and 2 provide the introduction and background to the study. Chapter 2 reports the findings of the literature review regarding activity pacing. Chapter 3 proposes a conceptual framework for the study. Chapter 4 summarises the processes of mixed methodologies.

Chapter 5 reports Stage I of the study: The development of the APQ using a Delphi technique. Chapter 5 has been subdivided to include the methods, results and discussion of the findings from the Delphi technique. Chapter 6 reports Stage II of the study: Assessing the psychometric properties of the APQ, to include the methods, results and discussion. Chapter 7, Stage III: Exploring the acceptability of the APQ, includes the methods, findings and discussion of this stage. Chapter 8, Discussion, integrates the findings from all three stages of the study, with reference to the conceptual framework that was outlined in Chapter 3. Chapter 8 includes the clinical implications, suggestions for future research and the Conclusion. The references are then detailed. The appendices are attached on a CD-ROM due to the volume of letters, questionnaires, tables and figures that correspond to the three stages of the study.

Chapter 2. Literature Review

2.1 Introduction

The literature review details the background to the studies reported in this thesis, to include the development and management of chronic conditions. The current literature as it relates to activity pacing as a coping strategy is discussed, reviewing the effects of pacing, together with the existing pacing subscales. This leads to the justification of the aim of the study to develop a new activity pacing questionnaire for chronic pain and/or fatigue. The literature review begins by reporting the literature search that was undertaken.

2.2 Literature search strategy

The databases that were searched included: MEDLINE, Pubmed, the Cochrane Library, PsycINFO, EMBASE, CINAHL, AMED, DARE and the Web of Knowledge. The journals *Pain, European Journal of Pain, Clinical Journal of Pain* and *Physiotherapy* were individually searched to ensure that articles in press were included. In addition, SIGLE was searched for grey literature, and article reference lists were searched for original articles and textbook citations.

The databases were searched using the following search terms related to pacing: "pacing", "quota", "activity pattern*", "activity behavio*", "activity management", "coping strateg*", and "envelope theory". The search was limited by the inclusion of literature containing the above search terms in the title or abstract, written only in English and published before October 2013 (no specific start date was applied). This search yielded over 84,000 references (including duplicates). To manage the amount of literature that was found, and to direct the search towards the current study population, the search was restricted to the application of activity pacing to conditions of chronic pain and/or fatigue (using the search terms: "chronic low back pain", "chronic pain", "chronic widespread pain", "fibromyalgia", "chronic fatigue syndrome" and "myalgic encephalomyelitis"). Five hundred and thirty-eight references were retrieved, of which 173 were duplicated across different databases. On reviewing the titles/abstracts, 292 were not relevant for the current study due to exploring pacing as it relates to cardiology, neurology (for example, multiple sclerosis, spinal cord injury and cerebral palsy), oncology, dental pain, phantom limb pain and paediatrics. Articles referring to

pacing among people with osteoarthritis and rheumatoid arthritis were retained. Seventy-three articles explored pacing in relation to the current study population. However, on reading the full article, 43 of these 73 articles mentioned the concept of pacing minimally. For example, pacing was mentioned briefly as one of many coping strategies, with no further details of either a definition or the effects of pacing. Such articles were not included in the literature review due to adding little information. Thirty articles remained that focused on the concept of activity pacing in the field of chronic pain and/or fatigue (of which, 25 appeared in more than one database). By exploring the reference lists of the 30 included articles to search for relevant and original records and relevant individual journals for articles in press, the number of references included in the literature review increased to 48 *(see Figure 2.1 Flow diagram of the literature search).*

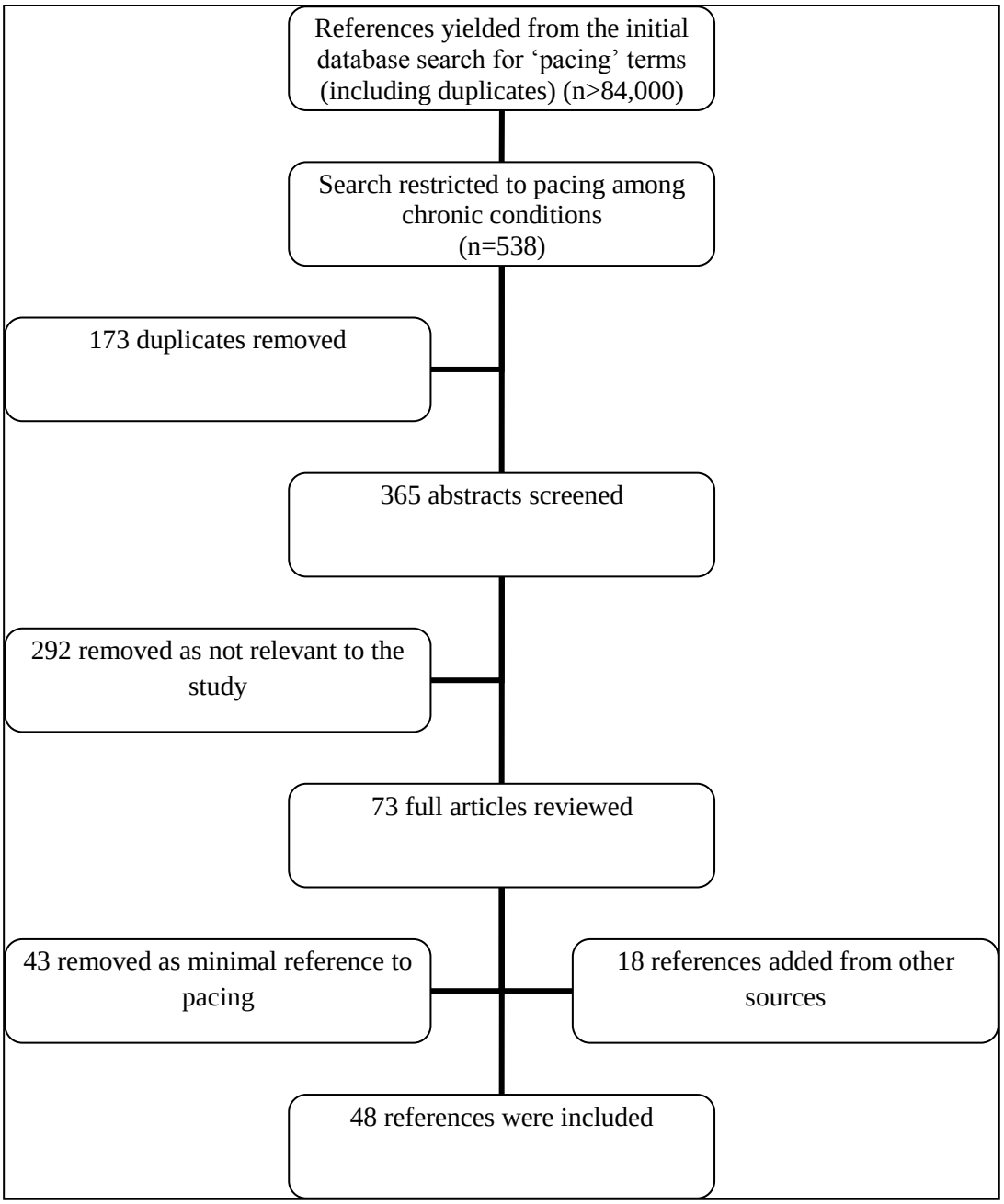


Figure 2.1 Flow diagram of the literature search

2.3 Background to the study

2.3.1 Development of chronic conditions

As stated in Chapter 1, Introduction, the aetiology of conditions such as chronic low back pain, chronic widespread pain, fibromyalgia and chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME) may not always be identified. However, the fear-avoidance model may explain the development of some chronic conditions (Asmundson et al., 1999; Vlaeyen and Linton, 2000). Originally, the fear-avoidance model projected two responses to the fear of pain following an acute episode of back pain: confrontation and avoidance (Lethem et al., 1983). Confrontation involves

the continuation of activities, and the consequential successful rehabilitation. Conversely, avoidance may lead to continued, if not worsening fear (Lethem et al., 1983). This model was extended to recognise the role of pain catastrophizing, or hypervigilance to symptoms (Vlaeyen and Linton, 2000). The result of which includes increased fear of pain or (re)injury, heightened pain reports and altered behaviours, often with no explanatory pathology (Asmundson et al., 1999; Vlaeyen and Linton, 2000). Unchallenged, the continued avoidance of activity results in deconditioning and a decline in physical and cognitive function (Crombez et al., 1999; Vlaeyen and Linton, 2000). Together with disability, activity withdrawal may result in altered mood such as depression (Vlaeyen and Linton, 2000). Thus, a multidimensional cycle of chronic pain and pain behaviours manifests (Vlaeyen and Linton, 2000) *(see Figure 2.2 Fear-avoidance model).*

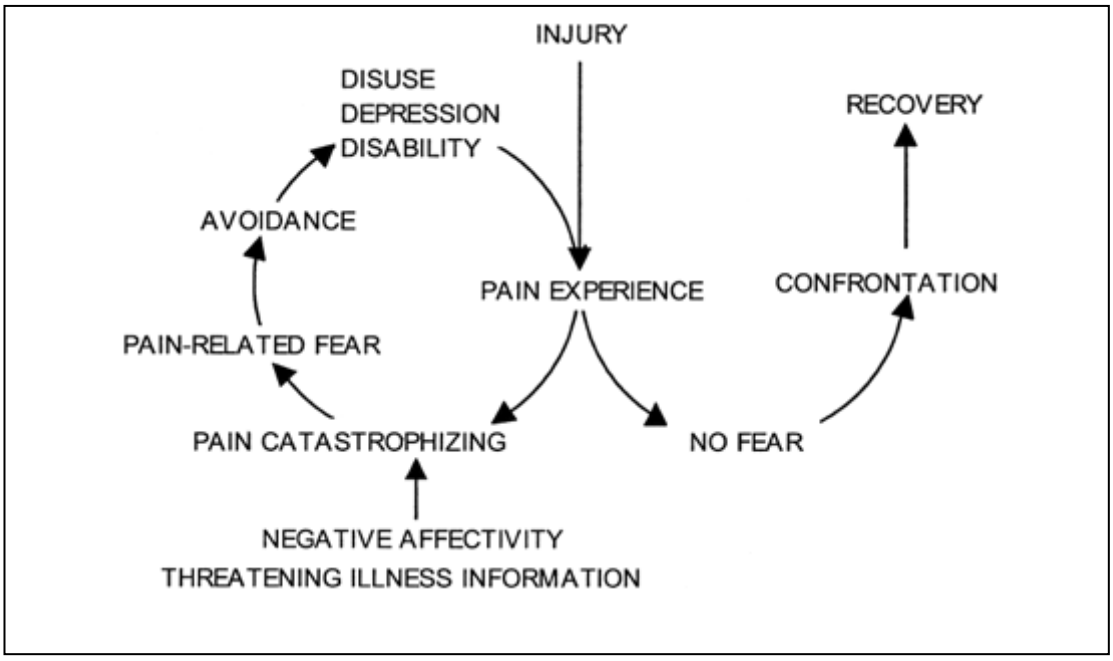


Figure 2.2 Fear-avoidance model (Vlaeyen and Linton, 2000)

The fear-avoidance model is well established in the field of back pain and musculoskeletal pain (Crombez et al., 1999; Vlaeyen and Linton, 2000). However, it is recognised that fear-avoidance is relevant to other chronic conditions, at times in the absence of an initial injury, for example, fibromyalgia (Turk et al., 2004). Indeed, fear-avoidance is significantly associated with pain and disability among patients with fibromyalgia (Roelofs et al., 2004a; Turk et al., 2004). Similarly, the important role of fear-avoidance has been explored among patients with CFS/ME (Silver et al., 2002; Nijs et al., 2004).

The above fear-avoidance model illustrates two distinct responses to the onset of pain: one in which the painful experience is avoided and another where it is confronted. Previous research into the behavioural responses to symptoms of chronic conditions has suggested similar behavioural typologies.

2.3.2 Activity behaviours

There is a body of literature regarding activity behaviours, often categorised as avoidance and persistence (or confronting/overdoing) (McCracken and Samuel, 2007; Cane et al., 2013). Activity may also fluctuate between avoidance and persistence as observed in a 'boom-bust' cycle. Pacing has been described as a pattern of activity (McCracken and Samuel, 2007; Kindermans et al., 2011; Cane et al., 2013), a behaviour (Kindermans et al., 2011; Nielson et al., 2012), and also as a coping strategy (Nijs et al., 2008; Andrews et al., 2012; Cane et al., 2013).

Of the activity behaviours reported in the chronic pain literature, avoidance has been the most widely studied (McCracken and Samuel, 2007; Cane et al., 2013). There are conflicting research findings regarding persistence and a paucity of research relating to pacing (Andrews et al., 2012; Cane et al., 2013).

2.3.2.1 Avoidance

Avoidance refers to the delay or diversion from an activity with the aim of reducing the likelihood of an exacerbation of symptoms (Asmundson et al., 1999; Vlaeyen and Linton, 2000). The avoidance of situations or activities reinforces the fear-avoidance cycle (Vlaeyen and Linton, 2000).

Fear-avoidance has been found to be significantly associated with increased catastrophizing, and fear-avoidance beliefs about physical activity were predictive of increased disability among patients with chronic low back pain (Woby et al., 2004). Similarly, avoidance was associated with increased pain severity, disability, depression and physical impairment among patients with fibromyalgia (Turk et al., 2004; Karsdorp and Vlaeyen, 2009). Furthermore, fear-avoidance was associated with poorer performance (exercise bike assessment), anxiety, depression and disability among patients with CFS/ME (Silver et al., 2002; Nijs et al., 2004). Therefore, avoidance is associated with worse symptoms across different chronic conditions. Due to its

manifestations, it is important to address avoidance behaviour in the management of chronic conditions.

2.3.2.2 Confrontation, persistence and endurance

In contrast to avoidance, confrontation may lead to reduced fear of pain/(re)injury in the fear-avoidance model (Vlaeyen and Linton, 2000). In continuing usual activities, the cycle of deconditioning and its sequelae may be averted. Similarly, task persistence involves the continuation of an activity despite symptoms (Andrews et al., 2012). The author suggests that there may be an overlap between persistence and confrontation since both behaviours involve persevering with activities in the presence of symptoms.

Task persistence has been associated with lower depression, lower disability and lower pain in a sample of older patients with chronic pain (Ersek et al., 2006). It was suggested that patients who persist with tasks divert the focus away from pain, which reduces the impact of pain on activities (Ersek et al., 2006). Likewise, task persistence was significantly associated with reduced disability and physical impairment in zero-order Pearson's correlations among patients with fibromyalgia (Karsdorp and Vlaeyen, 2009). Jensen et al. (1995) describe task persistence as a wellness-focused strategy, and found task persistence correlated significantly with lower depression and pain discomfort.

Conversely, Hasenbring et al. (2010) consider task persistence to be an endurance response. As such, associations between endurance and increased pain among patients with acute and chronic back pain were found (Hasenbring et al., 2009). Although endurance behaviour correlated with lower depression and disability, it was postulated that long-term endurance may lead to increased disability due to an inability to sustain high levels of activity (Hasenbring et al., 2009). Moreover, initial feelings of control through task persistence may lead to overuse, muscular overload, increased symptoms and consequential reductions in activities/enforced rest (Birkholtz et al., 2004a; Hasenbring and Verbunt, 2010; van Koulil et al., 2010; Andrews et al., 2012). Indeed, the avoidance-endurance model suggests that both avoidance and endurance may result in a cycle of chronic pain (Hasenbring et al., 2009).

The avoidance-endurance model posits that at least three responses to pain can lead to the development of chronic pain, namely: fear-avoidance (as above), distress-endurance

and eustress-endurance (Hasenbring et al., 2012). Distress-endurance is associated with thought suppression, emotional distress (anxiety/depression), together with task persistence. Conversely, eustress-endurance is associated with distraction from pain and positive mood despite pain, together with task persistence (Hasenbring and Verbunt, 2010). All three responses were significantly associated with increased back pain at six months follow-up (compared with 'adaptive responders' who balance avoidance with endurance). However, unlike fear-avoidance and distress-endurance, eustress-endurance was not associated with increased disability at follow-up (Hasenbring et al., 2012).

In addition to the above, endurance was associated with both increased and decreased pain in a systematic review and meta-analysis, and showed no significant overall trend among patients with chronic pain (Andrews et al., 2012). However, studies recruiting patients with only fibromyalgia found endurance correlated significantly with worse physical and psychological function (Andrews et al., 2012). At present conflicting findings remain regarding the effects of task persistence. This may in part be due to different studies involving varying samples (for example, fibromyalgia only, or mixed chronic conditions), together with implementing different measures of persistence (Andrews et al., 2012). Furthermore, the author suggests that there may be a range of behaviours within persistence/confrontation from continuing activities to over-exertion. Indeed, Kindermans et al. (2011) categorised persistence into three subthemes: 'task-contingent persistence' (completing usual daily activities), 'excessive persistence' (over-doing activities) and 'pain-contingent persistence' (fluctuating levels of activities driven by symptoms). Interestingly, 'task-contingent persistence' was associated with lower disability ($r=-0.32$, $p<0.001$), whereas 'excessive persistence' was associated with increased depression ($r=0.50$, $p<0.001$) and disability ($r=0.43$, $p<0.001$). Indeed, 'task-contingent persistence' was predictive of lower disability, while 'excessive persistence' was predictive of increased depression and disability when controlling for pain intensity in regression analysis (Kindermans et al., 2011). Therefore, 'task-contingent persistence' may be a beneficial strategy to employ for patients with chronic pain, whereas 'excessive persistence' may be a strategy with limited benefits.

2.3.2.3 Activity fluctuation (boom-bust)

Excessive persistence or over-activity can sometimes activate the boom-bust or overwork-collapse/overactivity-underactivity pattern (Friedberg and Jason, 2001; Birkholtz et al., 2004a). This is a pattern of activity where patients over-do activity, that

is, ‘boom’, usually on a day of reduced symptoms. This over-exertion often leads to increased symptoms, which results in a dramatic reduction in activity as a consequence, that is, ‘bust’ (Birkholtz et al., 2004a; Nijs et al., 2008). This forms a cycle of fluctuations in activity which can result in overall reductions in activity, disuse and deconditioning (Birkholtz et al., 2004a). In this scenario, patients may avoid even low level activities for fear of over-doing activities and thus remain in the ‘under-activity’ pattern (Friedberg and Jason, 2001; Birkholtz et al., 2004a). Interestingly, it has been found that patients with chronic pain who report high levels of avoidance, also report high levels of excessive persistence (Kindermans et al., 2011). The author suggests this association may be reflective of the boom-bust pattern.

2.3.2.4 Pacing behaviour

Pacing behaviour challenges the problems associated with activity avoidance (Andrews et al., 2012) and activity persistence/over-exertion (Hansen et al., 2010; van Koulil et al., 2010; Andrews et al., 2012). In addition, pacing reduces the fluctuations between over-activity and under-activity by developing a more manageable activity-rest pattern (Kavanagh, 1995; Birkholtz et al., 2004a; Gill and Brown, 2009; Hansen et al., 2010). *(Pacing will be described in detail in Section 2.3.4 Activity pacing.)*

2.3.3 The management of chronic conditions

In recognition of the fear-avoidance model, together with the endurance-avoidance model, it is imperative that both psychosocial and physical factors are addressed (Vlaeyen and Linton, 2000; Woby et al., 2004; Hasenbring et al., 2012). A multi-disciplinary approach is therefore advised (Strong, 2002a; McBeth et al., 2011). Specifically, there is growing evidence recommending cognitive behavioural therapy (CBT) and graded exercise therapy (GET) for the management of complex conditions (Schur et al., 2007; Nijs et al., 2008; van Koulil et al., 2010; McBeth et al., 2011; White et al., 2011). Indeed, since both CBT and GET involve gradually increasing activities, they challenge the beliefs that might underpin the fear-avoidance model (Nijs et al., 2004). Conversely, patients with endurance behaviours may gain more benefit from CBT than GET (Hasenbring and Verbunt, 2010).

2.3.3.1 Cognitive behavioural therapy

CBT is the most frequently practiced psychological intervention in the management of pain (Strong and Unruh, 2002). When applied to the fear-avoidance model, CBT aims to address the beliefs and behaviours associated with medical conditions (Strong and Unruh, 2002; Hansen et al., 2010). CBT may involve increasing activity among the inactive, preventing over-activity among the task persistent, improving thoughts/emotions, managing exacerbations of symptoms and adopting coping strategies (Vlaeyen and Linton, 2000; Strong and Unruh, 2002; Hansen et al., 2010). Examples of strategies involved in CBT include positive thinking, relaxation and goal setting, together with activity pacing (Strong and Unruh, 2002; Turner-Stokes et al., 2003; Birkholtz et al., 2004a; Beissner et al., 2009; Lamb et al., 2010; McBeth et al., 2011). Indeed, activity pacing was the most frequently implemented facet of CBT (81% frequency) among physical therapists surveyed regarding the management of chronic pain among older adults (Beissner et al., 2009). This compares to the frequency of implementation of other facets such as relaxation (16%) and distraction (9%) (Beissner et al., 2009).

CBT has been shown to bring about significant improvements in pain, disability, physical function, fear-avoidance and pain self-efficacy among patients with subacute and chronic low back pain in a large scale randomised controlled trial (n=598) (Lamb et al., 2010). Telephone-delivered CBT led to improvements in physical function and self-rated global heath among patients with chronic widespread pain (McBeth et al., 2011). CBT resulted in significantly reduced levels of fatigue ($p<0.001$) and increased physical function ($p=0.0068$) in comparison to standardised specialist medical care in the large scale randomised PACE trial involving 641 patients with CFS/ME (White et al., 2011). However, CBT is not wholly endorsed by patients. Indeed, patients with CFS/ME have reported dissatisfaction with CBT programmes, and increased muscle pains and fatigue when the programme involved gradually increasing activities (Jason et al., 2013).

2.3.3.2 Graded activity and graded exercise therapy

To manage the fear of pain, activity and (re)injury, graded exposure to the avoided activity is advised (Crombez et al., 1999; Griffin et al., 2012). Graded exposure includes a gradual increase in activity despite pain (Vlaeyen and Linton, 2000). The aims of graded activity/GET include reversing the process of deconditioning and encouraging physiological and behavioural changes (Gladwell et al., 2014).

The benefits of GET include improvements in resting blood pressure and heart rate, perceived exertion, work capacity, depression and mental fatigue (Wallman et al., 2004). This was found among patients with CFS/ME undertaking either GET or a relaxation control treatment (n=61) (Wallman et al., 2004). Furthermore, a programme of GET led to significant reductions in fatigue and improvements in physical function in the aforementioned PACE trial (White et al., 2011).

There are conflicting findings and opinions towards GET since it involves exercising despite pain. GET has been shown to have negative consequences in terms of exacerbating symptoms among patients with CFS/ME (Nijs et al., 2008; Larun and Malterud, 2011; Jason et al., 2013; Gladwell et al., 2014). Therefore, GET is advised to be individually tailored to an appropriate intensity and allow for fluctuating symptoms to prevent a relapse (Nijs et al., 2008). Indeed, a focus group of patients with CFS/ME reported a preference towards exercise programmes that were flexible, personalised, self-regulated and enjoyable/leisure-based (Larun and Malterud, 2011).

Activity pacing has been suggested to be a facet of GET since pacing is considered to facilitate flexibility towards exercise, especially following an exacerbation of symptoms (Wallman et al., 2004). Furthermore, pacing has been encouraged during GET to recognise current abilities to prevent over-exertion and hence prevent future relapses (Nijs et al., 2008). Moreover, the terms ‘pacing’ and ‘graded activity’ are sometimes used interchangeably (Nielson et al., 2012).

2.3.4 Activity pacing

Activity pacing is frequently utilised in the management of chronic conditions (Karsdorp and Vlaeyen, 2009; Goudsmit et al., 2012). Activity pacing involves modifying behaviour with the aim of improving activity levels and managing symptoms while reducing relapses and future disability (Nielson et al., 2001; NICE, 2007; Nijs et al., 2008). Activity pacing is thought to have originated from the model of activity-rest cycling, where periods of activity are interspersed with short periods of rest (Birkholtz et al., 2004a). Activity pacing has since been referred to as ‘quota setting’ and simply just ‘pacing’ (Birkholtz et al., 2004a; Gill and Brown, 2009). Pacing is applicable to physical, cognitive, social and work activities (Birkholtz et al., 2004a; NICE, 2007). It is proposed that pacing can operate on a daily, weekly and longer term basis (Strong, 2002b).

Activity pacing has previously been recommended by the Chief Medical Officer's CFS/ME working group and has received anecdotal support from patient groups (Shepherd, 2001; Sharpe, 2002; White et al., 2007). Indeed, 89% of patients with CFS/ME found pacing helpful according to a satisfaction questionnaire (Shepherd, 2001). However, such recommendations are interpreted with caution due to the current paucity of empirical evidence regarding the benefits of pacing (Nielson et al., 2001; NICE, 2007; White et al., 2007; Karsdorp and Vlaeyen, 2009; Goudsmit et al., 2012). Studies that have assessed the benefits of activity pacing have produced conflicting findings. The inconclusive evidence regarding activity pacing may be partly explained by the lack of a comprehensive definition of activity pacing or consensus across the healthcare disciplines (Birkholtz et al., 2004a; Gill and Brown, 2009; Kindermans et al., 2011; Nielson et al., 2012).

Among the varied definitions in the literature, pacing appears to be described as two seemingly opposing strategies: to reduce activities and to increase activities. This notion has been substantiated by a recent review of activity pacing, whereby pacing was suggested to consist of two distinct approaches: energy conservation which aims to reduce symptoms, and operant learning which aims to increase function through quota-contingent activities (Nielson et al., 2012). Indeed, pacing has been described as including both symptom- and quota-contingent strategies (Nielson et al., 2012).

2.3.4.1 Symptom- and quota-contingency

Research regarding activity pacing as a pain-related behaviour may originate from 1976 with work by Fordyce regarding operant conditioning behaviour (Gill and Brown, 2009; Nielson et al., 2012). Operant conditioning behaviour recognises the importance of the outcome of an action as a reinforcing influence on future action. For example, if an activity leads to increased pain, the activity may be subsequently avoided or reduced. Thus, the activity becomes driven by the symptoms, or symptom-contingent (Gill and Brown, 2009; Nielson et al., 2012). Symptom-contingency is considered to be maladaptive due to activity withdrawal, the long-term consequences of which include deconditioning and worsening symptoms on attempting activities (Nielson et al., 2012).

In order to modify this behaviour, pacing via quota-contingent strategies is recommended (Birkholtz et al., 2004a; Gill and Brown, 2009; Nielson et al., 2012). The reinforcing influence of quota-contingency is the achieved quota and not the resulting

symptoms (Gill and Brown, 2009). The quota may be an amount of time or an activity goal, and the quota should be achievable every day to manage both under- and over-activity (Birkholtz et al., 2004a; Gill and Brown, 2009; Nielson et al., 2012). Once a baseline of achievable activity is established, it may be gradually increased over time (Nielson et al., 2012).

Subsequently, the aim of symptom-contingent pacing may be seen to reduce symptoms, while quota-contingent pacing aims to increase function. Therefore, there may be disparate goals of pacing. Following on from this, Nielson et al. (2012) developed a definition of pacing:

> *"the regulation of activity level and/or rate in the service of an adaptive goal or goals."* (p465)

Symptom-contingency may be seen to be adaptive to symptoms, while quota-contingency may fulfil a rehabilitative approach (Nielson et al., 2012). The two different approaches of pacing are discussed in Sections 2.3.4.2 and 2.3.4.3.

2.3.4.2 Activity pacing: an adaptive strategy

Pacing has been described as adaptive pacing therapy (APT), which encourages patients to adjust to their condition and stay within limited amounts of energy by alternating activities and incorporating rest periods (White et al., 2011). APT is in keeping with the 'envelope theory' which depicts working at a sub-maximal level of activity (Sharpe, 2002; White et al., 2007). With particular reference to CFS/ME, the envelope theory is underpinned by the notion that patients have a limited amount of energy (Sharpe, 2002; White et al., 2007). The envelope theory advocates that activities are undertaken within an 'envelope' of perceived exertion in order to experience fewer relapses and less severe symptoms (Jason et al., 2008). Individuals are advised to be aware of 'warning signs' of over-exertion so that they do not breach their envelope (Goudsmit et al., 2012).

According to this theory of pacing, patients are taught energy conservation techniques such as dividing their energy over different activities and stopping activities before the onset of symptoms to avoid an exacerbation of symptoms (White et al., 2007; Nielson et al., 2012). Techniques of energy conservation may involve prioritising activities and switching activities (Goudsmit et al., 2012; Nielson et al., 2012). Symptoms or setbacks

may be avoided by finding a baseline of activity which may involve reducing activities and demands (Nielson et al., 2001; Birkholtz et al., 2004a). Exacerbations of symptoms may be avoided by preplanning and alternating activity with rest breaks (Nijs et al., 2008; Murphy et al., 2010; Nielson et al., 2012). Breaks can include relaxation or undertaking easier activities (Nijs et al., 2008). However, breaks that include rests may be questionable as an illness-focused strategy (Jensen et al., 1995). Resting has been found to be significantly associated with increased depression and pain discomfort ($r=0.32$, $p<0.001$ and 0.43, $p<0.001$ respectively) (Jensen et al., 1995).

Pacing is thought to include breaking down tasks, spreading activities over a period of time, going at a steady or slower speed, and stopping activities in time (Kavanagh, 1995; Nielson et al., 2001; McCracken and Samuel, 2007; NICE, 2007; White et al., 2007). It is the author's opinion that these techniques are consistent with APT and energy conservation.

By implementing an adaptive approach to pacing, a plateau of activity may be attained where patients achieve a consistent level of activity albeit at a sub-maximal level. Indeed, this level of activity may be lower than before commencing pacing (Kindermans et al., 2011). The consequence of this may include reductions in symptoms. However, improvements in function may not be seen (White et al., 2007). It is noteworthy that techniques of energy conservation have been found to have little efficacy (Nielson et al., 2012) and the envelope theory/APT have not been substantiated by research (NICE, 2007; White et al., 2007).

Moreover, it has been questioned whether pacing is a covert avoidance behaviour (Kindermans et al., 2011). Likewise, a concern arising from the envelope theory is that a patient may become trapped in an "envelope of ill health" (White, 2002). Therefore, if pacing is interpreted and practiced according to the strategies listed above, pacing may manifest as avoidance and further disability in some individuals. The envelope theory has since been described as potentially including some increase in the "energy envelope" over time, and there is evidence of improved symptoms in small samples of patients with CFS/ME (Jason et al., 2013). The author suggests that there may be variances within the interpretation of the 'envelope theory', or perhaps the theory is evolving.

2.3.4.3 Activity pacing: a rehabilitative strategy

As a rehabilitative strategy, pacing is described as involving gradual increases in activities (Sharpe, 2002; Birkholtz et al., 2004b; Lamb et al., 2007; Karsdorp and Vlaeyen, 2009; Murphy et al., 2010). Indeed, Nijs et al. (2006) describe pacing in two phases: the stabilisation phase (finding the baseline of activity), followed by a grading phase. The grading phase is a flexible approach to gradually increasing activity while considering inherent fluctuations in symptoms (Nijs et al., 2006). It has been suggested that the grading phase of pacing may contradict APT, and that APT may be more similar to the stabilisation phase of pacing (Nijs et al., 2009).

Similarly, the operant approach of pacing described by Nielson et al. (2012) involves a gradual increase in activities, applying strategies of preplanning, prioritising, alternating activities and using some rest breaks. Although some of these strategies are similar to those involved in the energy conservation approach, the two approaches differ in that operant pacing involves quota-contingent activities as opposed to symptom-contingent activities (Nielson et al., 2012). Furthermore, the aim of pacing through a grading approach is to address the problems of deconditioning such as low tolerance, low confidence and to encourage a general increase in activities (Strong, 2002b).

Activity pacing may involve goal setting and speeding up activities rather than slowing down (Birkholtz et al., 2004b; Nijs et al., 2008). Interestingly, the concept of 'slowing down' as a facet of pacing was least favoured across 49 occupational therapists in a questionnaire survey (20 therapists, 41% of respondents) (Birkholtz et al., 2004b). The agreement of other facets of pacing include: planning (45, 92%) and breaking down activities (44, 90%). Interestingly, the facet of increasing activities was endorsed by 43 (88%) of occupational therapists (Birkholtz et al., 2004b). It should be noted that this survey involved only occupational therapists. Future work should therefore explore opinions on pacing among other health professionals and patients.

2.3.4.4 Other themes of activity pacing

In addition, pacing has been described as an empowering strategy that incorporates problem solving and organisation (Strong, 2002b; Gill and Brown, 2009). Pacing may include acknowledging small goals, a stepwise progression and planned relaxation techniques (Friedberg and Jason, 2001). Pacing may involve monitoring or logging daily activity using an activity diary (Nijs et al., 2008; Murphy et al., 2010; Nielson et

al., 2012). In addition, pacing may incorporate timers to promote time-contingent rather than symptom-contingent activities (Birkholtz et al., 2004b). Pacing may involve alternating activities and positions, negotiating, analysing and preparing for activities (Birkholtz et al., 2004a; Gill and Brown, 2009). Pacing may include being creative and flexible, managing stress and posture awareness (Strong, 2002b; Birkholtz et al., 2004b). Furthermore, pacing may involve delegation and acceptance of activities (Strong, 2002b; Birkholtz et al., 2004b). Moreover, pacing aims to address some cognitions associated with activity behaviours and may increase feelings of self-efficacy (Birkholtz et al., 2004a).

2.3.4.5 Activity pacing for the individual

Since pacing has been described as involving strategies that lead to both increasing and decreasing activities, pacing appears to be an apposite strategy to manage the fluctuating symptoms associated with chronic conditions (Nijs 2008, Hansen 2010, Griffin 2012). Both dimensions of pacing: reducing and increasing activity, may confront the extremes of the overactivity-underactivity pattern of activity (Friedberg and Jason, 2001; Birkholtz et al., 2004a). Specifically, pacing could involve reducing activities on occasions of over-exertion, together with increasing activities during under-exertion to achieve more consistent activity levels and prevent exacerbations of symptoms (Nijs 2008, Hansen 2010, Griffin 2012).

Patients with tendencies towards avoidance behaviour would apply pacing strategies to increase their levels of activities, tolerance and possibly speed (Birkholtz et al., 2004a). Conversely, patients with task persistence behaviours would apply pacing to decrease high levels of activity, such as breaking down tasks (Nielson et al., 2012). Indeed, pacing programmes should be tailored according to individuals' activity behaviour patterns (Kindermans et al., 2011). Therefore, a clinical scale is required that identifies subgroups of patients with different activity behaviours and measures the different facets of pacing.

Goudsmit et al. (2012) suggest that different approaches to pacing suit different conditions. It is suggested that, while quota-contingent pacing may be suitable for chronic pain conditions, symptom-contingent pacing is recommended for patients with CFS/ME (Goudsmit et al., 2012). Indeed, Goudsmit et al. (2012) consider pacing according to the envelope theory and define pacing as:

> *"an approach where patients are encouraged to be as active as possible within the limits imposed by the illness."* (p1140)

This approach is accounted for by the difference in symptoms, pathology and effects of post-exertional malaise in CFS/ME (Goudsmit et al., 2012). Furthermore, it is suggested that some patients with CFS/ME are operating at their maximum level of function and may not demonstrate signs of deconditioning (Shepherd, 2001; Goudsmit et al., 2012). However, this contradicts both the recommendations to promote quota-contingent pacing (to challenge symptom hypervigilance), together with literature that recognises the overlap between conditions of chronic pain and chronic fatigue *(see Chapter 1, Introduction, Section 1.1.4).* Of note, there is a paucity of evidence regarding the benefits of symptom-contingent pacing (Goudsmit et al., 2012).

The envelope theory/APT for CFS/ME focuses on adjusting to the condition and assumes that the condition is irreversible (Sharpe, 2002; Bleijenberg and Knoop, 2011; White et al., 2011). In contrast, CBT and GET assume reversibility in CFS/ME. Indeed, improvements have been seen with both treatments which substantiates evidence of some recovery (Sharpe, 2002; Bleijenberg and Knoop, 2011). Therefore, treatment interventions, and specifically pacing strategies, that promote recovery rather than adaption may be preferable.

2.3.4.6 Activity pacing: a multifaceted construct?

Since diverse descriptions of activity pacing exist, the author suggests that pacing may be multifaceted. Indeed, pacing has been described as a complex behaviour (Birkholtz et al., 2004b). However, this proposal contradicts findings that pacing is unidimensional (Kindermans et al., 2011). This was found on factor analysis of pacing subscale items of the Chronic Pain Coping Inventory (CPCI), Pain and Activity Relations Questionnaire (PARQ) and Patterns of Activity Measure-Pain (POAM-P) (Kindermans et al., 2011). The author suggests that these items reflect similar themes of pacing, namely adaptive strategies involving breaking down tasks, rest breaks and slowing down. No items suggest other rehabilitative themes of pacing such as setting goals or gradually increasing activities. Since there is no consensus on a definition of pacing and pacing has been described with varying goals, the effects of pacing remain unclear. Future research should therefore develop a pacing scale that measures the different facets of pacing in order to assess the effects of pacing on patients' symptoms.

2.3.4.7 Effects of activity pacing

Despite the theoretical benefits of pacing, there is still very little empirical evidence regarding the benefits of this strategy. This in part may be due to diverse descriptions of pacing (as discussed above). Furthermore, pacing is frequently implemented as part of pain management programmes rather than as a lone treatment (Birkholtz et al., 2004b; Nielson et al., 2012). Gill and Brown (2009) undertook a review to analyse the current findings regarding activity pacing as a management strategy for chronic pain. None of the studies identified by Gill and Brown (2009) defined the term 'activity pacing', nor did the studies examine the unique role of activity pacing as a lone treatment strategy (Gill and Brown, 2009).

Andrews et al. (2012) undertook a systematic review and meta-analysis into the effects of activity pacing (together with avoidance and endurance) on function among patients with chronic pain. Systematic reviews and meta-analyses are considered to be top of the hierarchy of evidence for healthcare decision-making (Greenhalgh, 1997). Such reviews synthesise large amounts of information, using specific methods to increase transparency and reduce bias (Cook et al., 1997). Indeed, to increase the rigour of the review by Andrews et al. (2012), the findings were based on two independent researchers' results. The meta-analysis yielded mixed results with overall weak associations between increased pacing and higher levels of psychological functioning, but also higher levels of pain and disability (Andrews et al., 2012). However, these conclusions are limited to a small number of studies: seven studies explored the relationship between psychological function and pacing, four studies explored pain and pacing and nine studies explored physical function and pacing.

The studies included in the systematic review measured pacing according to varying pacing subscales and the pacing subscales measured limited dimensions of pacing. Moreover, the pacing subscales have limited validity. Indeed, it was suggested that a new pacing measure that encompasses a more comprehensive description of pacing would be beneficial (Andrews et al., 2012). Of note, the findings of the systematic review are correlative and not causal. Therefore it is unknown whether increased utility of pacing results in higher levels of psychological function, pain and disability, or whether increased reports of pacing are resultant from better psychological function but more pain and loss of physical function (Andrews et al., 2012). The findings involve patients with chronic pain, but do not include patients with CFS/ME which limits the

generalisability of the findings. The individual studies that have explored pacing are reported below.

Increased pacing has been found to be significantly associated with decreased physical activity among individuals with osteoarthritis ($p<0.001$) (Murphy et al., 2008). Pacing was assessed using only two items from the pacing subscale of the CPCI: breaking down tasks and doing tasks more slowly with rests. Therefore, a limited domain of pacing was assessed (Andrews et al., 2012). Indeed, such items appear more reflective of adaptive pacing therapy than rehabilitative pacing, since no items refer to a gradual increase in activities. The author suggests that the content of the two CPCI pacing items may in part explain why associations were found between pacing and decreased physical activity.

Murphy et al. (2008) classified participants as 'high pacers' and 'low pacers'. In the absence of standardised levels for 'high' and 'low' pacers, participants were split by the median value (Murphy et al., 2008). 'High pacers' generally reported higher pain and fatigue than 'low pacers', and 'high pacers' reported higher levels of pacing as the day progressed as symptoms of pain and fatigue worsened (Murphy et al., 2008). Therefore, pacing may be implemented in response to symptoms, as opposed to being used as a pre-planned method (Andrews et al., 2012). However, dividing 'high' and 'low' pacers by the median value is an unreliable method of analysis that is too dependent on the sample median, loses information and statistical power, and can result in misleading effect sizes and significance levels (MacCallum et al., 2002). The generalisability of this study is further limited by the small sample of 30 female volunteers, with an average age of 64 years, with mild lower limb osteoarthritis.

Following this, Murphy et al. (2010) found a greater reduction in fatigue at 10 weeks using tailored pacing in comparison to general pacing ($p=0.02$). No significant differences in pain were reported ($p=0.35$). The tailored pacing intervention involved addressing individual's fluctuations in activities from accelerometer reports of physical activity. Accelerometers are devices worn on the body to measures human movement, and have been shown to provide valid assessments of physical activity (Verbunt et al., 2001). However, no measure of pacing was implemented by Murphy et al. (2010). Therefore, changes in fatigue may not have been due to changes in pacing. Similarly, the findings are limited by the small sample ($n=32$) of mostly females with lower limb

osteoarthritis. Future work should involve larger samples of males and females with heterogeneous chronic conditions to increase the generalisability of the findings.

The large scale randomised PACE trial compared the effects of standardised specialist medical care with the addition of APT, CBT or GET on symptoms of patients with CFS/ME (White et al., 2011). APT led to some reductions in fatigue and increases in physical function in 42% of 641 participants at 52 weeks post-randomisation. However, these improvements were not statistically different from receiving standardised medical care. Patients reported significantly better fatigue and physical function with CBT or GET when compared to APT (all $p<0.05$). Therefore APT appeared no better than standardised specialist medical care (White et al., 2011), whilst being the least cost-effective (McCrone et al., 2012). Of interest patients were most satisfied with GET (88% satisfaction), followed by APT (85%), then CBT (82%) and standardised care had the lowest satisfaction (50%) (White et al., 2011). This reiterates the anecdotal support for pacing in the absence of empirical evidence.

Randomised controlled trials are considered to be the best research design to evaluate treatment efficacy (Hill and Spittlehouse, 2003). However, the results of the PACE trial are limited to patients with CFS/ME referred to secondary care. Added to this, bias may have arisen from the outcome measures which were all subjective patient-rated outcomes (White et al., 2011). Moreover, no measure of pacing was implemented to assess changes in pacing following APT. Therefore it is unknown whether the changes in fatigue and physical function were related to changes in pacing. The results are further limited to activity pacing being described as APT/the envelope theory. Furthermore, the descriptions of CBT and GET used in the PACE trial include strategies of planned gradual increases in activity, finding a baseline and problem solving which are all suggested facets of pacing. Therefore, the author posits that some of the beneficial findings related to CBT and GET in the PACE trial may be representative of some benefits of pacing if pacing is defined as a rehabilitative strategy. It is essential that future work employs a valid and reliable pacing measure to assess the specific effects of the different facets of pacing.

It was found that avoidance (guarding and asking for assistance) but not pacing explained disability and reduced physical function in hierarchical regression when controlling for demographics, pain and other coping strategies. This was found in a

large sample of 409 patients with fibromyalgia using the CPCI pacing subscale (Karsdorp and Vlaeyen, 2009). However, significant correlations were found between increased pacing and greater disability and physical impairment (both r=0.19, p=0.001).

Increased pacing has been associated with increased pain avoidance (r=0.52, p<0.001), increased activity avoidance (r=0.45, p<0.001) and lower task-contingent persistence (r=-0.49, p<0.001). Furthermore, increased pacing was associated with increased depression (r=0.24, p<0.01) and disability (r=0.34, p<0.001) (Kindermans et al., 2011). Pacing was measured using a scale of combined pacing items from the PARQ, the POAM-P and the CPCI. Of note, these pacing items describe slowing activities, taking rest breaks and breaking down activities. These findings are correlative and not causal and limited to a sample of 132 volunteers in the Netherlands with a range of chronic pain conditions.

Nijs et al. (2009) explored the short-term effects of pacing in a case series study involving patients with CFS/ME. Pacing was instructed as a lone therapy, and consisted of principles of finding a baseline of activity and alternating activity with equal periods of rest. Rest was defined as a low intensity activity or relaxation. This particular treatment included only the 'stabilisation' phase and not the 'grading' phase of pacing. Despite the limited content of pacing instructions, patients reported significantly reduced symptom severity and increased activity ability, together with improved concentration and mood on self-report questionnaires. In contrast, no changes were seen in physical activity in terms of either mean activity levels, peaks of activity or fluctuations in activity. Activity patterns were observed using an accelerometer (Nijs et al., 2009). However, no specific measure of pacing was implemented. Therefore, it is unknown whether there were changes in pacing habits following the intervention. Although the pacing programme showed some self-reported benefits, the results are limited to a small sample of only five female patients.

2.3.4.8 Summary of the effects of pacing

There is a disparity of results regarding the benefits of pacing across different studies, for which there are a number of possible explanations. Since there has been no clear definition of pacing, different studies may be assessing pacing as different constructs. For example, if pacing is described as APT (predominantly avoiding or reducing activities) poor outcomes may be expected. Conversely, if pacing is described as

rehabilitative therapy (including gradually increasing activities) improved outcomes may be observed (Karsdorp and Vlaeyen, 2009; Andrews et al., 2012; Nielson et al., 2012). However, it is noted that some overlap between APT and rehabilitative pacing exists (for example, both may involve planning and incorporating rest breaks).

Since pacing is rarely implemented as a lone treatment, the effects of pacing are unclear. Many previous studies have utilised correlative designs, therefore the cause/effects of pacing are unknown. Additionally, several studies do not implement measures of pacing. Therefore, changes in pacing or associations between pacing and psychometric measures have not been assessed. When pacing measures are used, they are restricted to scales with limited validity. There is currently no standardised measure of activity pacing. Therefore the validity of those studies that have examined the role of activity pacing may be reduced. In view of the aforementioned limitations, definitive conclusions about the efficacy of pacing cannot be determined.

Pacing has been found to be associated with both improved and worsened symptoms. This may be due to the multifaceted nature of pacing, but also according to which measure of pacing was implemented (Nielson et al., 2013). Previous attempts at developing scales include the pacing subscales of the Coping with Rheumatic Stressors questionnaire (CORS) (Van Lankveld et al., 1994), the CPCI (Nielson et al., 2001), the PARQ (McCracken and Samuel, 2007), and the POAM-P (Cane et al., 2013). Of note, the Brief Pain Coping Inventory contains one item regarding pacing activities (McCracken et al., 2005), but offers little additional empirical evidence for pacing because of this (Nielson et al., 2013).

2.3.5 Activity pacing measures

2.3.5.1 Coping with Rheumatic Stressors (CORS) pacing subscale

The CORS measures eight coping strategies, categorised into three domains of the main stressors of rheumatoid arthritis: pain, limitations and dependence (Van Lankveld et al., 1994). Within the domain of coping with pain are the strategies: comforting cognitions, decreasing activity and diverting attention. Within the domain of coping with dependency are the strategies: acceptance and showing consideration. Together with the strategies of optimism and creative solutions, pacing forms a 10-item subscale within the domain of coping with limitations (Van Lankveld et al., 1994). Examples of the pacing subscale items include: *"I avoid hard labour"*, *"I bear my limitations in mind"*,

"I take more time for my activities" and *"I take rest between my activities"*. It is the author's opinion that the items of the CORS pacing subscale coincide with adaptive rather than rehabilitative pacing. Moreover, items may contain themes of avoidance.

The CORS pacing subscale demonstrated high internal consistency (Cronbach's alpha=0.88) and high test-retest reliability (r=0.91) (Van Lankveld et al., 1994). Test-retest reliability was shown in a subgroup of 65 patients with rheumatoid arthritis over a two-week period. However, the actual test-retest analysis was not detailed. Therefore, it is unknown whether robust methods were implemented.

Increased pacing (when measured using the CORS pacing subscale) was positively associated with negative mood, and negatively with cheerful mood on regression analysis while controlling for demographics and functional capacity (both $p<0.01$) (Van Lankveld et al., 1994). This was found in a sample of 112 patients with rheumatoid arthritis. The above findings of worse symptoms may be explained by the pacing subscale items which focus on reducing activities. The 'decreasing activities' subscale of the CORS was similarly found to relate negatively with cheerful mood, and positively with psychological distress and greater disease impact (Van Lankveld et al., 1994; Van Lankveld et al., 2000). Indeed, the content of the items contained within the decreasing activities subscale overlap with those of the pacing subscale, for example, taking rests. Reducing activity is termed a 'maladaptive coping strategy' for the long term management of rheumatoid arthritis (Van Lankveld et al., 2000). Therefore, pacing could be interpreted as maladaptive according to the CORS pacing subscale.

Of the eight coping strategies, pacing and decreasing activities are labelled 'avoidant behaviours', and the remaining six strategies are labelled 'coping cognitions' (Boonen et al., 2004). A retrospective study found both avoidant behaviours were predictive of withdrawal from the labour force among 658 patients with ankylosing spondylitis (Boonen et al., 2001). Furthermore, significant correlations were found between increased pacing (measured using the CORS pacing subscale) and reduced physical function, and greater age among patients with ankylosing spondylitis (Boonen et al., 2004).

The author proposes that some of the items of the 'creative solutions' CORS subscale (planning and finding alternative methods of completing tasks) are possible facets of

pacing. Limitations of the content of the CORS pacing subscale may originate in the methods used to develop the scale leading to the omission of important components of pacing. The CORS has been termed a 'patient-derived questionnaire' (Boonen et al., 2004). Although the eight coping strategies were found on factor analysis of the most frequently applied coping strategies among patients with rheumatoid arthritis, there is no description of the development of the individual subscale items.

The CORS is applicable for rheumatic conditions (Boonen et al., 2004). Of note, rheumatic conditions have a demonstrable underlying disease pathway. Therefore, the results may not be generalised to conditions that cannot be medically explained. The CORS does not instruct a time-scale over which patients complete the questions. This may lead to differences in how patients complete the questionnaire. Moreover, the CORS has not yet been validated in English.

2.3.5.2 Chronic Pain Coping Inventory (CPCI) pacing subscale

Nielson et al. (2001) developed a pacing subscale for the CPCI (Jensen et al., 1995). The CPCI is an established measure of the frequency of implementation of cognitive and behavioural coping strategies within one week. The CPCI contains four subscales which are referred to as 'wellness-focused' coping strategies and include relaxation, task persistence, exercise/stretch and using coping self-statements. There are three illness-focused subscales: guarding, resting and asking for assistance. In addition, the CPCI contains a subscale of using social support (Nielson et al., 2001; Nielson and Jensen, 2004).

The pacing subscale contains six items, for example, *"I focused on going 'slow and steady' instead of on my pain"* (Nielson et al., 2001). Of the six items, five refer to the speed of an activity, three of which include the phrase 'slow and steady'. Aside from the concept of speed, the items contain themes of breaking down tasks, using rest breaks and distracting from pain. Similarly to the CORS, the CPCI pacing subscale items appear to describe more adaptive than rehabilitative pacing. However, it is suggested that the CPCI pacing subscale aims to measure patients' ability to cope with pain with the goal of increasing activity tolerance (Nielson et al., 2013). Therefore, four of the six items refer to pain. The author suggests that this may re-establish pain-contingency as opposed to quota-contingency. This may limit the generalisability of the scale to exclude patients whose main symptom is fatigue and not pain. In addition,

some items may contain more than one concept. For example, *"I was able to do more by just going a little slower and giving myself occasional breaks"* may yield different answers according to those who answer in terms of "doing more", in contrast to those who answer in terms of reducing activities via "going a little slower" and having "occasional breaks".

The CPCI pacing subscale was initially validated on a sample of 110 patients with fibromyalgia (Nielson et al., 2001). The pacing subscale demonstrated high internal consistency (Cronbach's alpha=0.91) indicating that the items may be exploring similar themes. It is stated that Cronbach's alpha should ideally lie between 0.7-0.9 to demonstrate satisfactory internal consistency without the questionnaire items examining the same domain (Loewenthal, 2001). The pacing subscale further demonstrated substantial inter-item correlations (r=0.55-0.74) and item total correlations (r=0.71-0.79). Test-retest reliability was assessed for 96 patients who had pre-admission and admission data. Test-retest reliability was satisfactory ($r=0.60$, $p<0.001$) over a long test-retest period (mean=12.6 weeks). This suggests that the subscale is stable over a moderate duration. Similarly to the CORS, the method of test-retest analysis was not reported, which may undermine the confidence in such findings.

In contrast to the CORS pacing subscale, the CPCI pacing subscale was positively related to three of four CPCI wellness-focused or active coping strategies (relaxing, exercising and using coping self-statements). Additionally, increased pacing was positively related to the CPCI coping strategy of using social support. No significant associations were seen between the pacing subscale and two of the three illness-focused or passive coping strategies of the CPCI: guarding and asking for assistance. Only one item of the pacing subscale demonstrated a significant positive correlation with the resting subscale. This pacing item referred to going slower and taking more breaks (Nielson et al., 2001). Similar findings were replicated on principal component analysis of CPCI data (Nielson and Jensen, 2004). Pacing loaded with exercise, relaxation, coping self-statements and seeking support to form the factor labelled 'active coping'. Guarding and resting formed a factor labelled 'passive coping'. Furthermore, increased pacing correlated with significant reductions in pain and distress six months post-treatment ($p<0.05$) (Nielson and Jensen, 2004).

Task persistence formed a factor on its own, separate to pacing (Nielson and Jensen, 2004). This is similar to findings that the pacing subscale was not significantly associated with task persistence (Nielson et al., 2001). Indeed, the pacing subscale was written to be clearly distinct from the task persistence subscale of the CPCI. It was stated that any increases in activity may occur as a result of pacing, but it is not considered to be a facet of pacing (Nielson et al., 2001). This contrasts previous definitions of activity pacing which have included gradual increases in activity.

Using Pearson's correlations, the CPCI pacing subscale was associated with lower depression ($r=-0.37$, $p<0.001$) (Nielson et al., 2001). However, no significant association was found between pacing and physical impairment. A reverse trend was seen on multiple regression analysis. When demographics, pain and the other CPCI subscales were controlled, pacing did not significantly contribute to the prediction of depression. In contrast, pacing did significantly predict physical impairment ($p=0.02$) (Nielson et al., 2001). It is noted that this association is not causal and therefore increased physical impairment may lead to increased pacing or vice versa.

Conversely, increased pacing (measured using the CPCI pacing subscale) was associated with increased pain ($r=0.23$, $p<0.05$), depression ($r=0.20$, $p<0.05$), and disability ($r=0.27$, $p<0.01$) among participants with chronic pain (Kindermans et al., 2011). In contrast to the findings of Kindermans et al. (2011), increased pacing (measured using the CPCI pacing subscale) was significantly associated with reduced depression and increased self-efficacy (Nielson et al., 2001; Turner et al., 2005). The CPCI pacing subscale appears most frequently in the literature to date. However, this scale generates varying results across the literature.

The limited content of the CPCI pacing subscale may be due to the method of scale development. The pacing items were written based on observations of patients pacing their activities in the clinical setting (Nielson et al., 2001). Since the opinions of other clinicians and patients were not included in the development of the items for the CPCI pacing subscale, it is suggested that important domains of pacing may have been omitted. The pacing subscale focuses on items that involve reducing activity which may explain correlations between pacing and decreased physical activity.

2.3.5.3 Pain and Activity Relations Questionnaire (PARQ) pacing subscale

McCracken and Samuel (2007) developed the PARQ which contains three subscales: avoidance (8 items), pacing (6 items) and confronting (7 items). Each item is rated on a scale of frequency from 0=never to 5=always. Examples of PARQ pacing subscale items include: *"I stop activities before pain becomes too great and return to them later"* and *"I use repeated rest breaks to help me complete activities"*. The content of the items is similar to those of the CPCI pacing subscale insomuch as they refer to breaking down tasks, slowing down and using rest breaks. However, the items of the PARQ pacing subscale have an aim of reducing or preventing pain.

The PARQ pacing subscale demonstrated high internal consistency (Cronbach's α= 0.84). The high internal consistency may be accounted for by three of the six items referring to pacing to reduce pain. Interestingly the pacing subscale of the PARQ was significantly associated with the avoidance subscale ($r=0.51$, $p<0.001$), but not the confronting subscale. In addition, the pacing subscale was positively and significantly associated with a validated measure of avoidance ($r=0.34$, $p<0.001$) and disability ($r=0.23$, $p<0.001$), but negatively with daily uptime ($r=-0.14$, $p<0.05$) (McCracken and Samuel, 2007). The significant associations between the PARQ pacing subscale and avoidance and disability were replicated in the study by Kindermans et al. (2011). Indeed, the wording of the PARQ pacing subscale items may be closely related to avoidance (Kindermans et al., 2011). Furthermore, the PARQ pacing subscale was associated with increased depression and lower task persistence (all $p\leq 0.01$) (Kindermans et al., 2011).

Cluster analysis of the PARQ data from 276 patients with chronic pain identified four typologies of behaviour (McCracken and Samuel, 2007). 'Avoiders' had moderate-high levels of both avoidance and pacing. 'Doers' had the lowest reports of pacing and avoidance, but higher levels of confronting. 'Medium cyclers' demonstrated moderate behaviours of avoidance and pacing but high reports of confronting. Interestingly, pacing was most frequently implemented by the 'extreme cyclers', that is, those who were periodically overactive (McCracken and Samuel, 2007). 'Extreme cyclers' also demonstrated the highest levels of avoidance and confrontation of activity, in keeping with the overactive-underactive cycle. Of note, activity pacing has been suggested as a strategy to reduce the overactive-underactive cycle (Birkholtz et al., 2004a).

The PARQ does not specify a recall period over which patients complete the self-report of their activity which might compromise the reliability of the PARQ. Added to this, to date, there are no data regarding the test-retest reliability or sensitivity to change of the PARQ. The properties of the PARQ have only been assessed among patients with chronic pain and the measure has not been widely used.

The PARQ items are based on the opinions of three clinical psychologists which may limit the content validity of the questionnaire since no other health professionals were involved. For example, physiotherapists and occupational therapists have traditionally played an integral part in facilitating activity pacing. Patients with chronic conditions were not involved in the development of the items. Since patients are experts in the experience of conditions, they are a valuable source of information for scale items (Streiner and Norman, 1995). The future development of pacing scales may therefore benefit from involving both clinicians and patients.

2.3.5.4 Patterns of Activity Measure-Pain (POAM-P) pacing subscale

Since the commencement of the present study, the development of a new scale: the Patterns of Activity Measure-Pain (POAM-P) has been published (Cane et al., 2013). The POAM-P contains three 10-item subscales of avoidance, overdoing (persistence) and pacing. The POAM-P is rated on a 5-point Likert scale of applicability from 0=not at all to 4=always. Examples of pacing items include: *"I do my activities at a slow and steady pace"* and *"When I do an activity I break it into small parts and do one part at a time"*. On observation, the 10 pacing items contain themes of going slow and steady (two items), switching between activity and rest breaks (four items) and breaking down tasks (four items). The items appear somewhat repetitive and limited to more adaptive than rehabilitative pacing strategies. Indeed, the items are comparable to the pacing subscale of the CPCI, which was also developed by Nielson et al. (2001). However, the items of the POAM-P do not have the pain focus of the CPCI pacing subscale.

The original 51 items of the POAM-P were reduced to 30 based on low item mean scores and low item-total correlations. The pacing subscale of the POAM-P had high internal consistency (Cronbach's alpha=0.94). However, as stated in Section 2.3.5.2 an alpha value >0.9 may be indicative of repetition (Loewenthal, 2001). The pacing subscale was positively associated with the avoidance subscale of the POAM-P ($r=0.25$, $p<0.01$), but not significantly associated with the Tampa Scale of Kinesiophobia (a

validated measure of avoidance/fear of movement). The pacing subscale of the POAM-P was negatively associated with the overdoing (task persistence) subscale ($r=-0.48$, $p<0.01$) (Cane et al., 2013). Therefore, there were significant associations between the subscales. This perhaps alludes to relationships between the activity behaviours. Stability analyses of the pacing subscale showed significant correlations over a four-week period ($r=0.65$, $p<0.05$). However, further test-retest assessments are required.

Following interdisciplinary treatment of pacing (together with exercise and education), pacing was not significantly associated with disability (Cane et al., 2013). Since the content of the POAM-P items involve a general reduction in activities, strategies to improve function may not have been assessed. However, pacing was significantly associated with lower depression ($r=-0.35$, $p<0.01$) and anxiety ($r=-0.25$, $p<0.01$), and with increased pain control ($r=0.33$, $p<0.01$). Consequently, pacing was associated with improved symptoms. This coincides with the findings of Nielson et al. (2001) when implementing the CPCI pacing subscale, to which the POAM-P is similar.

Limitations of the study by Cane et al. (2013) include that the original 51 items written for the POAM-P were developed from the clinical observations and opinions of four clinical psychologists. The 51 items were constructed in order to measure avoidance, overdoing and pacing and any differences between them, with each item being theoretically associated with one of those three subscales. Data on the 51 items from 393 participants were analysed statistically to exclude those with skewed distributions and identify those that had the highest item-total correlations with their own subscale. The three resulting subscales conveniently had the same size (10 items). Three drawbacks with this approach are: (a) it assumes a specific model for pain-related activity and the final subscales have minimal overlap of avoidance, overdoing and pacing; (b) if the experience or opinions of the developers are (even unintentionally) biased, this method of subscale development may perpetuate that bias since the solution may to some extent be pre-determined by that bias; and (c) it is based on items that may not reflect the experiences of patients.

In contrast to Cane et al. (2013) where pacing correlated with better symptoms, Kindermans et al. (2011) found that the POAM-P pacing subscale related to worse outcomes among participants with chronic pain. Specifically, pacing was associated with increased pain ($r=0.25$, $p\leq 0.01$), depression ($r=0.18$, $p\leq 0.05$) and disability

(r=0.34, p≤ 0.01). Since the POAM-P is relatively new, it has undergone limited validity testing (Andrews et al., 2012). Future study is required to confirm the three subscales of the POAM-P and validate the scale across a wider population.

2.3.5.5 Summary of the existing pacing subscales

The existing pacing subscales appear to have a number of limitations. For example, limited validation for specific conditions, that is, the CORS is validated for rheumatic conditions and the CPCI, PARQ and POAM-P pacing subscales have been validated for conditions of chronic pain, but not chronic fatigue. Consequently, there is no pacing scale for patients whose predominant symptom is fatigue. The existing pacing subscales are limited by the absence of a clear outline of their development process, and by the content of the scales being driven by homogeneous opinions of pacing.

The existing pacing subscales contain between 6-10 items which appear to describe pacing more in terms of adaptive than rehabilitative strategies (for example, existing scale items do not refer to gradually increasing activities). Indeed, the pacing items focus on avoiding or reducing activity and have limited content validity (Nielson et al., 2013). Some existing pacing subscale items appear to be pain-contingent as opposed to quota-contingent. Since none of the existing subscales include aspects of increasing activities, it is questionable whether they explore the multi-faceted nature of pacing (Andrews et al., 2012; Nielson et al., 2012). Consequently, the full effects of pacing cannot be assessed (Nielson et al., 2013).

2.4 Justification for the study

The term ‘activity pacing’ lacks a clear definition and varying descriptions of pacing exist (Birkholtz et al., 2004a; Gill and Brown, 2009). At present there is no widely used measure of pacing in the clinical setting to assess the effects of pacing. Therefore, conflicting results have been found regarding the benefits activity pacing (Andrews et al., 2012). It is questionable whether existing pacing subscales measure a limited domain of pacing, or perhaps even avoidance behaviours.

Since activity pacing is frequently implemented as a coping strategy for chronic conditions, it is imperative that the effects of pacing are further investigated. Therefore, a comprehensive measure of activity pacing is required that reflects the multifaceted nature of pacing. The aim of this study is to develop a stand-alone pacing scale that can be used more widely among a heterogeneous group of patients with conditions such as chronic low back pain, chronic widespread pain and CFS/ME. The content of the newly developed pacing measure will be driven by consensus of opinions regarding activity pacing to increase the content validity in comparison to existing scales. The use of such a measure would facilitate empirical evidence for what is at present a strategy of unknown benefits.

2.5 Aim of the study

The overall aim of the study is to develop and validate an activity pacing questionnaire (APQ) for chronic pain and/or fatigue.

2.5.1 Objectives

Stage I. To develop the APQ using a consensus technique, the Delphi technique.
Stage II. To assess the psychometric properties of the APQ including the identification of different themes of pacing, together with the reliability and validity of the APQ.
Stage III. To explore the acceptability of the APQ among patients with chronic conditions.

The conceptual framework of the study will be reported in Chapter 3 and the methods of the three-stage study will be described in Chapter 4.

Chapter 3. Conceptual Framework

3.1 Introduction

This chapter introduces conceptual frameworks and their role in research. The conceptual framework of the present study is proposed, with reference to two established models: the health belief model and the theory of planned behaviour. This in turn introduces the format of the study which is detailed in Chapter 4, Research methodology.

3.2 Overview of conceptual frameworks

A conceptual framework is the theory that underpins a study, to include the inter-relationships between relevant concepts (Morse and Field, 1996; Polit et al., 2001). A conceptual framework holds benefits of adding structure and context to a research study (Parahoo, 1997). Furthermore, strategies that are designed to promote public health developed from conceptual or theoretical origins are considered to be more effective than those without such foundations (Glanz and Bishop, 2010).

Conceptual frameworks have also been referred to as 'theoretical frameworks' and 'conceptual models', and these terms are sometimes used interchangeably (Parahoo, 1997; Polit et al., 2001). A theoretical framework may best describe research based upon one specific theory. In comparison, a conceptual framework may be suited to studies based upon a number of concepts or theories (Parahoo, 1997). As highlighted in the literature review, pacing has been described by various concepts. Additionally, previous studies have found varying associations between activity pacing and psychosocial factors, together with interactions between different activity behaviours of pacing, avoidance and task persistence. Therefore, the term 'conceptual framework' is used to describe the underpinning concept of the present study.

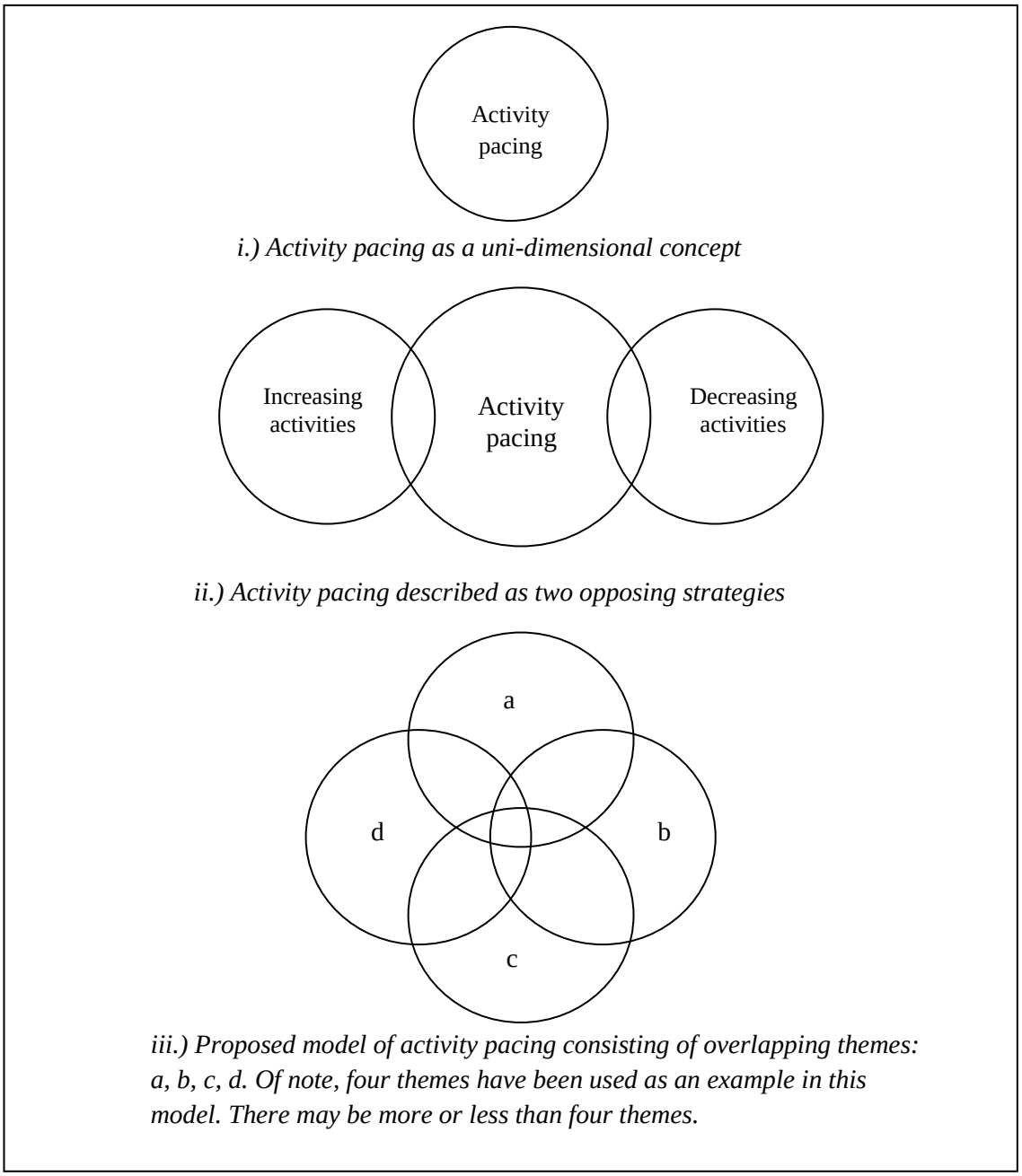
Conceptual models diagrammatise conceptual frameworks to illustrate relationships between the factors under consideration (Parahoo, 1997; Creswell and Plano Clark, 2011). The aim of undertaking research is to build upon existing knowledge and enhance the theory or model (Ritchie, 2003). The conceptual framework will determine the research design that is required to answer the specific research question (Creswell and Plano Clark, 2011). Where little information exists, qualitative rather than

quantitative methods may be more appropriate (Morse and Field, 1996). Indeed, qualitative methods may be implemented to develop an initial conceptual framework which can then be explored quantitatively (Parahoo, 1997). Therefore, the theoretical background of the study may require both qualitative and quantitative research methods (Creswell and Plano Clark, 2011).

3.3 Conceptual framework of the present study

3.3.1 Conceptual model of the themes of pacing

Following the literature review, it was found that there is no clear definition of pacing. Kindermans et al. (2011) found pacing to be unidimensional. Contrary to this, pacing has been described as two seemingly opposing concepts: decreasing activities, for example, the envelope theory/energy conservation/adaptive pacing theory (White et al., 2007; Nielson et al., 2012) and increasing activities, for example, graded activity (Sharpe, 2002; Birkholtz et al., 2004b; Nijs et al., 2006; Nielson et al., 2012). However, within these concepts there may be an overlap of some facets of pacing. It is therefore unknown whether these two opposing concepts may coexist. However, based on current wider literature, the author proposes that pacing may consist of several different themes that are yet to be identified. It is further proposed that these themes may overlap and patients may apply different themes of pacing to different situations *(see Figure 3.1 Different models of themes of activity pacing)*.



i.) Activity pacing as a uni-dimensional concept

ii.) Activity pacing described as two opposing strategies

iii.) Proposed model of activity pacing consisting of overlapping themes: a, b, c, d. Of note, four themes have been used as an example in this model. There may be more or less than four themes.

Figure 3.1 Different models of themes of activity pacing

The aim of Stage I of the study is to develop the model of the themes of pacing by implementing an initial qualitative approach. Stage I will collate the concepts involved in activity pacing and reach a consensus on the items that should be included in an activity pacing questionnaire (APQ). The themes of pacing contained within the APQ will then be identified using factor analysis in Stage II of the study. Therefore, quantitative methods will be employed to further develop the conceptual model.

3.3.2 Conceptual model of pacing as a health behaviour

It was stated in the literature review, that activity pacing has been described as both a strategy for managing chronic conditions, but also as an activity behaviour (Nielson et al., 2012). Furthermore, previous studies have identified associations between pacing and patient demographics, together with physical and psychological factors. Stage II of the present study will implement quantitative methods to investigate if some of the previous associations between pacing and psychosocial factors are replicated using the APQ. This may add evidence with regards to the factors related to the implementation of activity pacing as a health behaviour.

3.3.2.1 Health behaviour models

The implementation of coping strategies, together with individuals' health beliefs and actions are described as health behaviours (Glanz et al., 2002). There are three types of overt health behaviours: preventative health behaviour (actions to avert illness among healthy individuals), illness behaviour (actions undertaken by individuals to evaluate illness and seek suitable treatment) and sick-role behaviour (actions undertaken from a perception of illness, for example, seeking medical help, reducing normal activities and increased dependency) (Glanz et al., 2002). A number of established theoretical models exist to structure studies exploring health behaviours. The most frequently implemented health behaviour models are: the transtheoretical model, the social cognitive theory, the health belief model and the theory of planned behaviour (Glanz and Bishop, 2010).

The transtheoretical model depicts the stages of behavioural change, including: precomtemplation, contemplation, preparation, action and maintenance (Glanz and Bishop, 2010). The social cognitive theory involves behavioural learning and adaptation based on individual's expectations and self-efficacy, environmental factors and reinforcement of behaviours (Rosenstock et al., 1988; Glanz and Bishop, 2010). The transtheoretical model was not selected as a theoretical model for the present study, since it was not the aim of the study to assess the stages of change in pacing behaviours. The social cognitive model was not selected since patients' expectancies, environmental influences, or reinforcing factors were not assessed. Conversely, the health belief model and theory of planned behaviour have greater relevance to the present study and have been selected as possible theoretical models to underpin the study.

3.3.2.2 The health belief model

The health belief model (HBM) has been one of the most widely used models since its inception in the 1950s. It has been the foundation of studies investigating the uptake of medical screening and health care services, and the adherence to medical regimens, together with illness prevention (Janz and Becker, 1984; Polit et al., 2001; Glanz et al., 2002; Glanz and Bishop, 2010). The HBM is a psychosocial model that was developed to be relevant to the implementation of long-term behavioural changes in chronic conditions (Janz and Becker, 1984; Rosenstock et al., 1988). Indeed, the HBM has been found to be predictive of health behaviours including exercising, dieting and smoking (Ogden, 2007). Added to this, the HBM has been implemented for studies exploring illness and sick-role behaviour (Glanz et al., 2002). The HBM is based upon a person's belief towards illness, which is often of greater significance than the symptoms themselves (Glanz and Bishop, 2010). The author suggests that the HBM has relevance to patients with chronic pain and/or fatigue where symptoms may not always be explained medically, and therefore management of the condition involves changing beliefs and behaviours (such as pacing behaviours), rather than directly changing the symptoms.

The HBM is underpinned by the decision to implement health behaviours based on beliefs of the threat of a condition, combined with the beliefs of the benefits of the health behaviour (Rosenstock et al., 1988; Polit et al., 2001). Specifically, the HBM originally consisted of the factors: perceived susceptibility, perceived severity, perceived benefits, perceived barriers and cues to action (Rosenstock et al., 1988; Glanz and Bishop, 2010). 'Perceived susceptibility' includes the beliefs of the likelihood of an illness and re-susceptibility, together with the acceptance of a medical diagnosis (Janz and Becker, 1984; Glanz et al., 2002). The author suggests that both acceptance of the diagnosis and re-susceptibility (for example, a repeat episode/exacerbation of symptoms) have relevance to the present study population. 'Perceived severity' includes the beliefs of how serious the condition is (in terms of pain, disability and even death), together with the effects of the condition (in terms of employment and relationships) (Janz and Becker, 1984; Glanz et al., 2002). 'Perceived benefits' includes the beliefs regarding the potential effectiveness of implementing the action to include health, financial and inter-personal benefits (Glanz et al., 2002). However, 'perceived benefits' may be counterbalanced by 'perceived barriers' such as side effects, emotional impact, cost, inconvenience and time (Janz and Becker, 1984; Glanz et al., 2002).

'Cues to action' have been less frequently studied compared with perceptions of threats and benefits. 'Cues to action' include other prompts, for example, bodily changes or observations of health notifications (Janz and Becker, 1984; Glanz et al., 2002). In addition, demographic factors may impact on decisions to implement health behaviours, such as education level (Glanz et al., 2002). The HBM was extended to include self-efficacy, since the belief that a person can achieve an action will influence whether an action is undertaken (Rosenstock et al., 1988). Furthermore, it has been suggested that the HBM includes 'health motivation' to account for individuals' readiness to consider health changes (Ogden, 2007). Of note, motivation has been suggested to be an important facet in the implementation of pacing (Nielson et al., 2012).

Stage II of the study will explore the health behaviour of whether patients with chronic pain and/or fatigue implement activity pacing as a coping strategy. Although this study does not aim to test the HBM of pacing specifically, the factors of 'perceived susceptibility' and 'perceived severity' will be assessed in the study through data collected from patients' employment demographics and self-report measures of pain and fatigue. 'Perceived barriers' such as cost and inconvenience will not be measured. However, the author suggests that other barriers to implementing activity pacing may arise from self-report measures of anxiety, depression and avoidance. Such factors may inhibit the utility of functional behaviour and coping strategies as illustrated in the fear-avoidance model *(see Chapter 2, Literature Review, Figure 2.2).*

In the present study, 'perceived benefits' will be explored using measures of physical and mental function. The actual health behaviour itself is activity pacing, measured using the APQ. Demographic data will be collected from participants, and it is considered (in light of previous research findings) that demographic factors, such as age and gender may also contribute to implementing pacing strategies. 'Cues to action' will not be measured per se. However, the author suggests that the 'cues to action' in the study may include the attendance of physiotherapy, participation in the study, or the experience of symptoms. Of note, self-efficacy will not be measured in the study. Although self-efficacy may have a role in explaining activity pacing, and has previously been found to be positively associated with pacing (Turner et al., 2005), it is considered that psychosocial factors more pertinent to the present study have been included in the lengthy self-report questionnaire booklet *(see Chapter 6.1, Psychometric study:*

Methods, Section 6.1.2.6). Similarly, 'health motivation' will not be assessed in Stage II of this study.

The HBM has roots as an explanatory model (Glanz and Bishop, 2010). Therefore research enquiries may suit quantitative methods such as Stage II of the study to assess associations between pacing and psychometric measures *(see Figure 3.2 Adaptation of the HBM to show how the present study may sit with this model).*

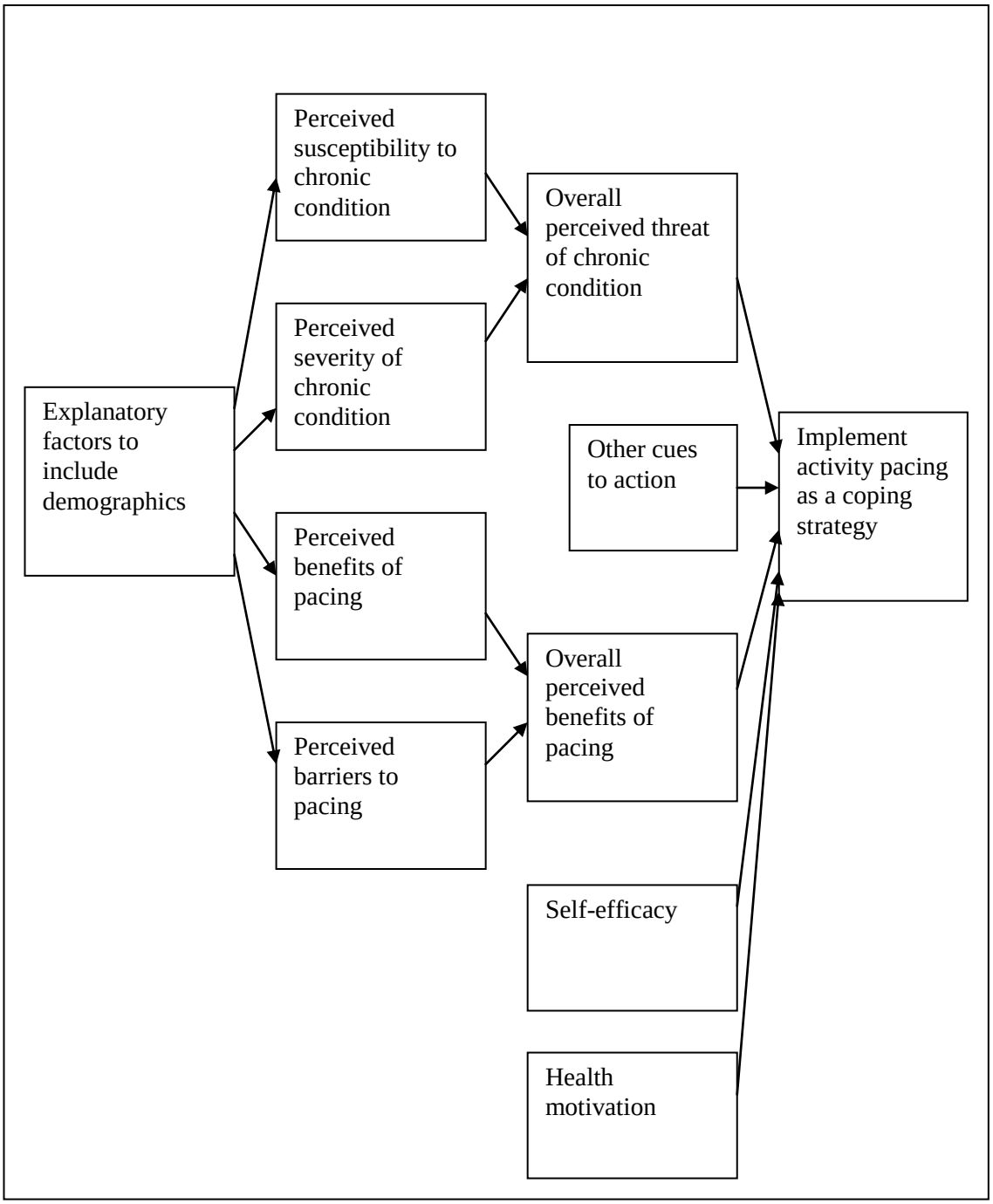


Figure 3.2 Adaptation of the health belief model from Parahoo (1997) p110, and Ogden (2007), p24

It is noteworthy that the present study is exploratory and correlative but not causal in design. Therefore, although the study can be linked to the HBM, it would be speculative to assume that the factors measured in the study are purely influential on the decision to pace activities. Indeed, factors (such as physical and mental function) may be the products of activity pacing. Therefore, the HBM may form an initial correlative framework for the concept of pacing.

3.3.2.3 The theory of planned behaviour

Similarly to the HBM, the theory of planned behaviour (TPB) has relevance to the present study. The TPB underpins the process of behavioural change, and recognises this as a multifaceted process (Glanz and Bishop, 2010). The emphasis is that this model illustrates a process that will involve a sustained change over a period of time (Glanz and Bishop, 2010). The TPB has been used to explore behavioural changes in smoking, health screening and disease prevention, together with evaluating interventions that promote behavioural change (Montaño and Kasprzyk, 2002). The TPB has been frequently implemented to explore exercise behaviour (Bozionelos and Bennett, 1999; Norman et al., 2000). Specifically, the TPB has been found to be predictive of exercise behaviour over a six month period among 87 patients attending health promotion clinics in primary care (Norman et al., 2000).

The TPB is an extension of the theory of reasoned action (TRA) which was originally developed in the 1960's (Ajzen, 1991; Glanz and Bishop, 2010). Both the TPB and the TRA depict models of motivation towards undertaking a behaviour (Montaño and Kasprzyk, 2002). Both models are underpinned by the concept that intention to undertake a behaviour will drive the performance of the behaviour (Polit et al., 2001; Montaño and Kasprzyk, 2002). Behavioural intention has been described as the motivation and effort to undertake a behaviour, with a stronger intention leading to increased likelihood of implementation (Ajzen, 1991). Within the TRA, behavioural intentions are accounted for by attitudes and subjective norms (Polit et al., 2001; Montaño and Kasprzyk, 2002). However, the TRA is limited to a behavioural change for which individuals have full volitional control (Ajzen, 1991). Therefore, the TRA does not allow for uncontrollable factors, such as environmental factors, cost, time or injuries (Norman et al., 2000; Montaño and Kasprzyk, 2002). In the 1980's this limitation was addressed with the addition of 'perceived behavioural control' to the model to form the TPB (Ajzen, 1991) *(see Figure 3.3 for the TPB model)*.

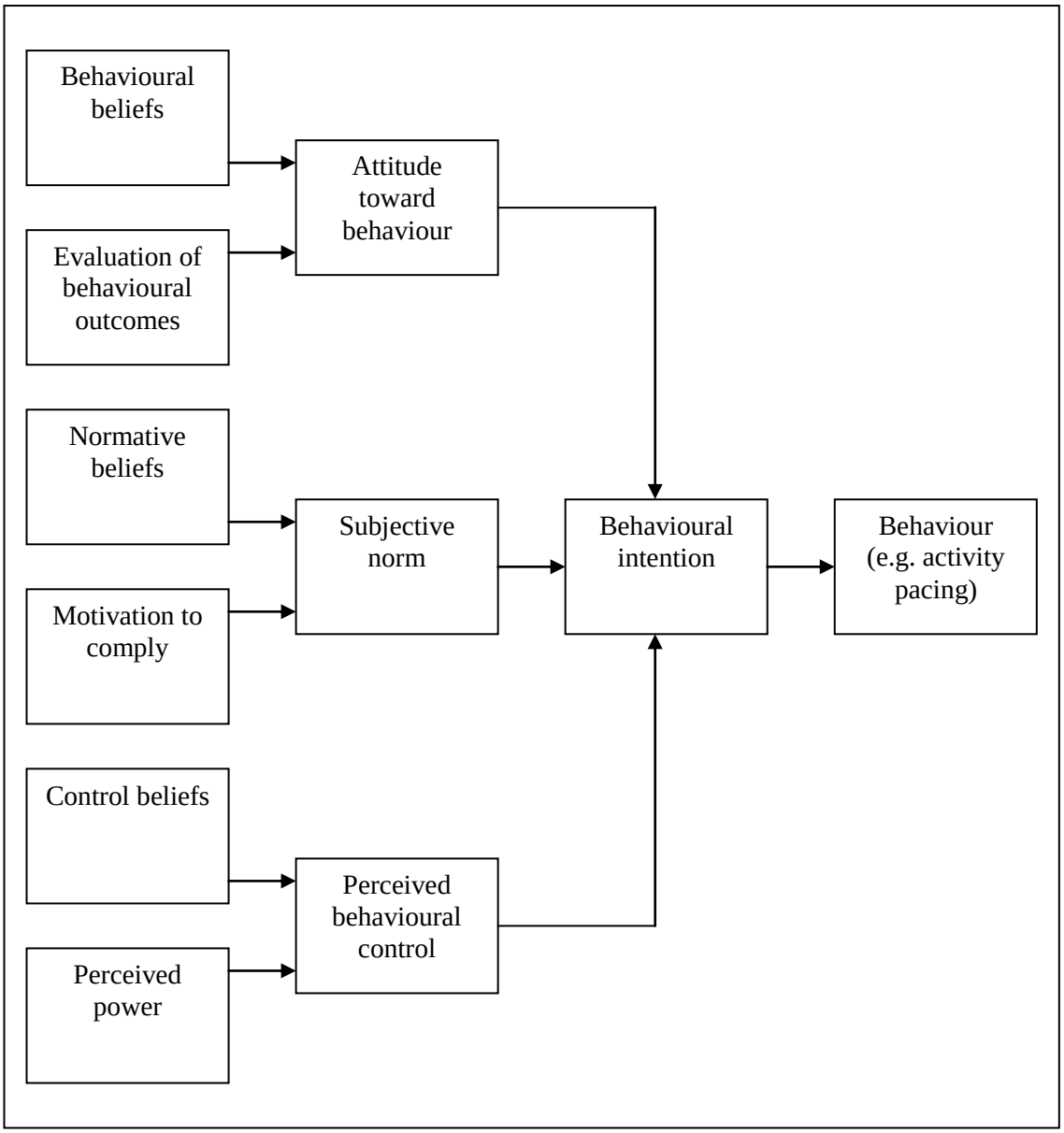


Figure 3.3 The theory of planned behaviour (adapted from Montaño and Kasprzyk, 2002, p68)

In the present study, the behaviour would be activity pacing. The TPB assumes that demographic and health-related factors have a continual influence on cognitions and attitudes rather than acting as specific explanatory factors and are therefore not explicitly portrayed in the model (Montaño and Kasprzyk, 2002). 'Attitude toward behaviour' in the TPB is the individuals' positive or negative opinion towards a behaviour (Ajzen, 1991). 'Attitude toward behaviour' is determined by 'behavioural beliefs' together with 'evaluation of behavioural outcomes'. 'Behavioural beliefs' are beliefs that achievement of the behaviour relates to outcomes or specific attributes. 'Evaluation of behavioural outcomes' is the perceived value of undertaking the behaviour (Montaño and Kasprzyk, 2002). With reference to activity pacing, the

attitude towards pacing will be determined by the belief that pacing can be achieved, and the outcomes that are expected from pacing.

'Subjective norm' (the perception of social approval or disapproval) is driven by a person's beliefs regarding socially accepted behaviours ('normative belief'), together with compliance with behaving within social norms ('motivation to comply') (Montaño and Kasprzyk, 2002). The author suggests that activity pacing may be a socially acceptable behaviour since it is frequently recommended by health professionals. Furthermore, the author suggests that 'motivation to comply' with pacing strategies may vary according to factors such as anxiety or depression, both of which will be measured in Stage II of the study.

'Perceived behavioural control' refers to the control over the decision to implement behaviours. Of note, the term 'perceived behavioural control' was utilised rather than 'actual control' to add psychological rather than physical/practical explanations to the behavioural change (Ajzen, 1991). 'Perceived behavioural control' accounts for the ease or difficulty of executing the task and may be akin to the concept of self-efficacy (Ajzen, 1991). As such, 'perceived behavioural control' may vary according to different activities and circumstances (Ajzen, 1991). 'Perceived behavioural control' comprises obstacles or catalysts to implementing the behaviour, such as internal factors (for example, emotions and abilities), together with external factors (for example, opportunities) (Conner and Armitage, 1998; Ajzen, 1991; Montaño and Kasprzyk, 2002). An important factor included in 'perceived behavioural control' is the influence of past experiences (Bozionelos and Bennett, 1999; Norman et al., 2000). 'Perceived behavioural control' is steered by 'control beliefs' (the likelihood of obstacles/catalysts) and 'perceived power' (the extent of obstacles/catalysts) (Montaño and Kasprzyk, 2002). The greater the 'perceived behavioural control', the higher the implementation of the behaviour (Ajzen, 1991).

The author suggests that possible obstacles/catalysts to implementing pacing may include practicalities such as employment or household responsibilities. However, it is proposed that symptoms themselves, such as pain and fatigue may prove to be obstacles/catalysts.

The TPB facilitates the measurement of behavioural influences by measuring each factor on an individual scale. For example, 'behavioural belief' could be measured using a 7-point scale from unlikely (-3) to likely (+3) (Ajzen, 1991; Montaño and Kasprzyk, 2002). Of note, it is not the intention of the present study to implement this scoring system or to test the TPB of activity pacing. Indeed, the TPB is best applied to prospective study designs since the TPB represents a process over time (Montaño and Kasprzyk, 2002). However, the present study will explore pacing using a cross-sectional design. Established health behaviour models such as the HBM and the TPB provide an underlying framework in which activity pacing may align. Future study may develop a model of pacing using such frameworks.

3.3.3 Conceptual framework of activity pacing

Since the themes of pacing and the associations between pacing and psychosocial factors are unknown, it may be that a new framework may best portray the underpinning theory of the present study. Figure 3.4 summarises the first two stages of the study to include the development of the APQ through a consensus technique and the assessment of the psychometric properties of the APQ. Of note, the double-ended arrows between activity pacing and the physical and psychosocial factors represent the correlative rather than causal study design, where the relationships are interpreted as bi-directional at this point in the research. Conversely, the author suggests that demographic factors in the main (for example, gender, age, ethnicity and marital status) may potentially impact on pacing behaviours and are represented with a unidirectional arrow.

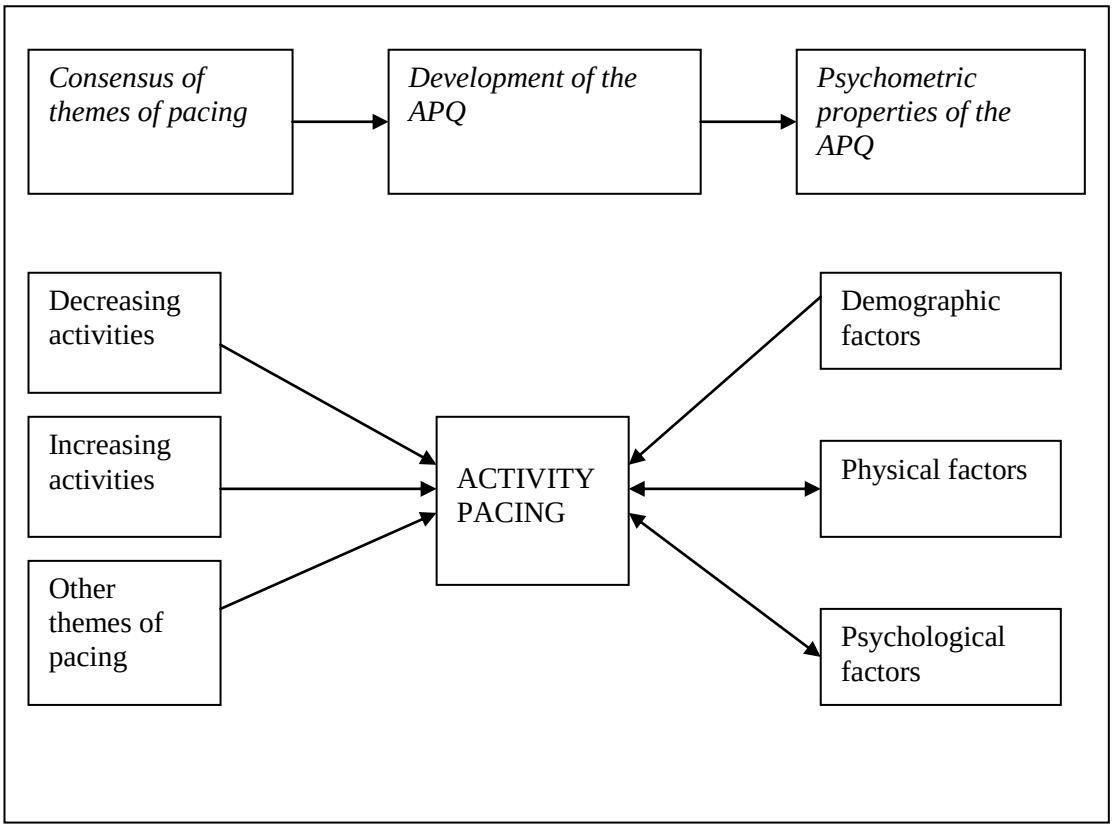


Figure 3.4 Stages 1 and 2 of the present study

The literature review highlighted that together with activity pacing, other activity behaviours included avoidance, persistence, and fluctuating between under- and over-activity (Birkholtz et al., 2004a; Kindermans et al., 2011; Cane et al., 2013). McCracken and Samuel (2007) identified four activity behaviour typologies: 'avoiders', 'medium cyclers', 'doers' and 'extreme cyclers'. Added to this, six activity patterns have been identified: 'pain avoidance', 'activity avoidance', 'task-contingent persistence', 'excessive persistence', 'pain-contingent persistence' and 'pacing' (Kindermans et al., 2011). Although it is not an aim of the present study to clarify the different activity behaviours, it is hypothesised that varying behavioural typologies may emerge. These typologies may become most apparent during Stage III of the study during qualitative interviews with patients regarding the acceptability of the APQ. The author proposes that activity pacing may be associated with avoidance, persistence and fluctuations of activities. If pacing is shown to be multifaceted, different facets of pacing may be applicable to different activity behaviours *(see Figure 3.5 Proposed relationships between activity behaviours).*

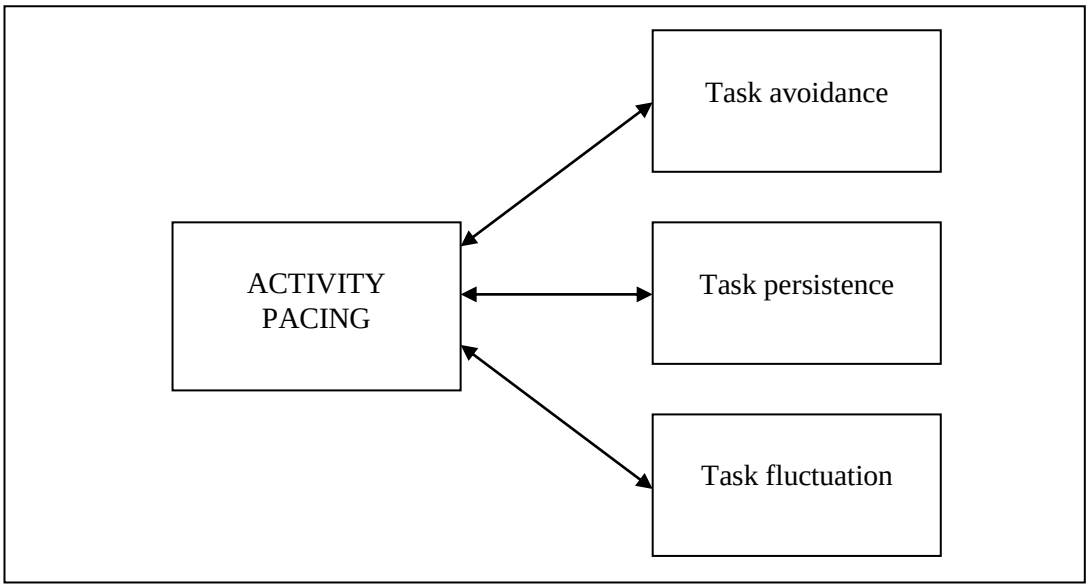


Figure 3.5 Proposed relationships between activity behaviours

Stage III of the study, the acceptability interviews, may also contribute to the behavioural model of activity pacing. Patients with chronic conditions will be invited to discuss their opinions of the APQ, together with their activity behaviours. Therefore, patients will have opportunities to explain their own decisions regarding activity pacing based on their perceived benefits and barriers.

3.4 Summary

The conceptual framework of the study will be used to explore the themes of pacing through the development of the APQ. The APQ will be used to assess the associations between pacing and psychological factors. In undertaking interviews with patients with chronic conditions it is envisaged that different activity behaviours may emerge. Since there is a paucity of evidence regarding activity pacing, a definitive conceptual model regarding this concept is currently absent. It is foreseen that this study may contribute to the development of a conceptual model of activity pacing, to include the themes of pacing, the psychometric properties of pacing, and how pacing relates to other activity behaviours such as avoidance and persistence. Chapter 4, Research methodology, will detail the three stages of the current study and justify the mixed method design.

Chapter 4. Research methodology

4.1 Introduction

This chapter introduces the different types of research methods: quantitative, qualitative and mixed methods, and the debates that surround them. Following on from this, the selection of a mixed method approach for the present study is discussed, and the stages of the study are presented.

4.2 Research methods

4.2.1 Research paradigms

The underpinning paradigm of all research methods include principles of ontology, epistemology and methodology (Doyle et al., 2009; Creswell and Plano Clark, 2011). Ontology refers to the reality of the study which is the basis on which the study is developed (Creswell and Plano Clark, 2011). Epistemology refers to the acquirement of knowledge, including the interaction between researchers and participants (Doyle et al., 2009; Creswell and Plano Clark, 2011). Methodology includes the actual procedure of the study (Creswell and Plano Clark, 2011). Further elements of research paradigms include axiology, which refers to the values of the study (for example, bias potential), together with the rhetoric (language) element of the study (Doyle et al., 2009; Creswell and Plano Clark, 2011). It is with consideration of these elements that the appropriate research method is selected.

4.2.2 Quantitative research

Quantitative research is a long established and accepted method of collecting data in the form of numbers to test a theory in a deductive manner (Doyle et al., 2009; Creswell and Plano Clark, 2011). Quantitative research has historically been considered to be the superlative form of research due to the scientific nature of data collection (Doyle et al., 2009). The ontology of quantitative studies lies in the assessment of a specific hypothesis or relationship between variables (Creswell and Plano Clark, 2011). The epistemology of quantitative research involves minimal interaction between researchers and subjects (Johnson and Onwuegbuzie, 2004; Creswell and Plano Clark, 2011). The methodological stance involves a structured and robust protocol with the aim of reducing bias through transparent methods of sampling, data collection and analysis. Quantitative studies frequently require large sample sizes in order to analyse data with

statistical significance, and for the inference of results to a more general population (Doyle et al., 2009; Creswell and Plano Clark, 2011).

Quantitative research has been referred to as a positivist paradigm where valid and reliable numerical patterns/relationships are deduced from a distance, unaffected by the researcher or external factors (Johnson and Onwuegbuzie, 2004; Doyle et al., 2009). The axiology of quantitative research aims to reduce bias potential, which is reflected in the formal rhetorical approach (Johnson and Onwuegbuzie, 2004; Creswell and Plano Clark, 2011). However, the term postpositivism has evolved which acknowledges the inherent influence of researchers' underlying opinions and methodological preferences, and the inescapable impact of social context (Johnson and Onwuegbuzie, 2004).

Therefore, despite efforts to reduce bias in quantitative research through the implementation of robust protocols, the methods and underlying principles are governed by the research team (Creswell and Plano Clark, 2011). With minimal input from external sources, the conclusions that are drawn from quantitative studies may be biased by the researchers' original hypotheses. A further limitation of quantitative research is the increased generalisation of findings to a greater population is at the cost of detail and relevance to an individual (Creswell and Plano Clark, 2011). Moreover, the conclusions reached from data in the form of numbers may not always be easily explained in words (Creswell and Plano Clark, 2011).

4.2.3 Qualitative research

Qualitative research involves the collection of data in the form of words, achieved through methods such as interviews or focus groups (Creswell and Plano Clark, 2011). In contrast to quantitative research, qualitative research is considered to be a constructivism paradigm, where theories are developed based on the ontological approach of generating multiple ideas or realities (Doyle et al., 2009; Creswell and Plano Clark, 2011). The constructivist paradigm recognises the effect of the researcher on the data due to epistemological stance of high interaction between the researcher and participants to generate detailed observations or opinions (Popay et al., 1998; Creswell and Plano Clark, 2011). Methodologically, it is usual that qualitative research involves a smaller sample, and the participants (often lay people) are considered to be the experts (Popay et al., 1998; Doyle et al., 2009). As such, qualitative studies implement a less formal rhetoric approach (Johnson and Onwuegbuzie, 2004). Such studies are inductive

in nature, and include ethnographic and grounded theory research (Creswell et al., 2004; Doyle et al., 2009). Qualitative methodologies, unlike quantitative methodologies are more flexible, reflexive and follow less formulaic protocols, for example, regarding sample size and data analysis (Popay et al., 1998).

The axiology of qualitative research recognises the effect of both the researcher and the context of the study on the results (Johnson and Onwuegbuzie, 2004). Constructivists consider the immersion of researchers in the study necessary for the richness of the data. However, this subjective influence, the potential for bias and the reduction in standardisation of qualitative methods has been criticised by positivist researchers (Johnson and Onwuegbuzie, 2004; Doyle et al., 2009). Furthermore, qualitative research provides in depth accounts of a small sample, the downside of which is limited generalisability to a larger population (Creswell and Plano Clark, 2011).

4.2.4 Mixed methods research

The recognition of the strengths and limitations of both quantitative and qualitative research methods has led to the emergence of a third research paradigm: mixed methods research or multimethods (Creswell et al., 2004; Johnson and Onwuegbuzie, 2004; Doyle et al., 2009). Mixed methods research collates both numerical data from quantitative methods together with descriptive data from qualitative methods, and is now recognised as a research paradigm in its own right (Creswell and Plano Clark, 2011). Literature regarding mixed methods is thought to hold roots with researchers between 1950 and 1970. However, it was not until the late 1980's that the phenomenon began to gather speed and supporters (Creswell and Plano Clark, 2011). Mixed methods research is considered to be a pragmatist paradigm, involving a plurality of methods and is therefore both inductive and deductive (Johnson and Onwuegbuzie, 2004; Doyle et al., 2009; Creswell and Plano Clark, 2011).

4.2.5 The mixed methods debate

Mixed methods research amalgamates quantitative and qualitative data to answer a complex research question. However, it is debated whether the two established research methods should be combined due to the aforementioned different paradigms (including the ontology, epistemology and methodology), together with the postpositivist and constructivist approaches underpinning quantitative and qualitative research (Barbour, 1998; Doyle et al., 2009; Creswell and Plano Clark, 2011).

Since mixed methods research involves both quantitative and qualitative philosophies and methodologies, the researcher requires multiple competencies to execute both types of recruitment, data collection and data analysis (Doyle et al., 2009). In addition, mixed methods research may be burdensome in terms of timeframes, resources and participants in order to undertake the different methodologies (Johnson and Onwuegbuzie, 2004; Creswell and Plano Clark, 2011).

Despite the philosophical debate regarding mixed method research, the rationale for implementing mixed methods research is justified when one research method would not fulfil the aims of the study (Doyle et al., 2009). Moreover, a mixed methods approach can enhance the understanding of the research question, by observing data from different perspectives (Creswell and Plano Clark, 2011). The corroboration of qualitative and quantitative data facilitates the validation of results and explanation of findings (Doyle et al., 2009). Mixed methods research may potentially reduce bias by widening the researchers' underlying assumptions and opinions in quantitative studies, while increasing the generalisability of qualitative studies. Furthermore, there may be scope to rebalance the researchers' influence in qualitative studies that arises due to the epistemological nature of close interactions between the researcher and participants (Popay et al., 1998). Mixed methods research facilitates the comparison of data collection at each stage of the research process to verify results and highlight anomalies (Creswell et al., 2004). Of particular importance to the present study, one rationale of implementing mixed method research is to develop and assess new clinical measures (Doyle et al., 2009).

4.2.6 Mixed methods designs

Different approaches to mixed methods research include the convergent parallel design, sequential designs: explanatory or exploratory, and the embedded design (Creswell and Plano Clark, 2011). The convergent design involves triangulation via concurrent qualitative and quantitative data collection and comparison of results (Doyle et al., 2009). Sequential designs involve consecutive stages of quantitative followed by qualitative data collection, or qualitative followed by quantitative data collection in explanatory and exploratory sequential designs respectively. This design is appropriate when each stage of the study is reliant on the data generated from the previous stage (Creswell et al., 2004). The exploratory sequential design is also referred to as the instrument development design (Creswell et al., 2004). The embedded design involves a

complementary qualitative or quantitative study in conventional quantitative or qualitative research (Creswell and Plano Clark, 2011).

4.3 Methodological design of the present study

4.3.1 Justification of study design

An exploratory sequential design (instrument development design) was selected for the present study. The purpose of the study was to develop an activity pacing questionnaire (APQ). As highlighted in the literature review, there is no consensus regarding the interpretation of pacing. Therefore, the initial stage of the study required a qualitative approach to generate the content of the questionnaire (Creswell et al., 2004). The second stage of the study involved quantitative data collection and analysis to assess the psychometric properties of the APQ. The present study involved a third stage with a qualitative approach to further explore the findings of the first and second stages of the study. Indeed, mixed methods research holds the advantage of flexibility in terms of structure, where qualitative and quantitative stages can be joined to fulfil the specific aims of the study (Johnson and Onwuegbuzie, 2004).

For the present study, a purely qualitative approach would have led to the construction of a questionnaire, but the psychometric properties of the questionnaire would be unknown. Applying a purely quantitative approach would assess the psychometric properties of the questionnaire, but the content of the questionnaire might be driven by the researchers' personal opinions of activity pacing. Therefore, neither a purely qualitative or quantitative approach was deemed sufficient.

Of relevance to the present study, an exploratory sequential design has been utilised to develop a research protocol for the development and validation of the Volition Exercise Back Pain Questionnaire (Mathy et al., 2011). Similarly to the present study, the first stage of the study involved qualitative data collection (a Delphi technique) to generate scale items. The second and third stages of the study involved quantitative data collection and analyses, including principal component analysis and assessments of validity and reliability (Mathy et al., 2011).

4.3.2 Stages of the present study

Preliminary work:

A literature review was undertaken to highlight the paucity of research regarding activity pacing, including the different interpretations of the term together with the absence of a widely used pacing scale *(see Chapter 2, Literature Review, Section 2.3).*

Stage I: The Delphi technique

The constructivist stage of the study incorporated a consensus technique: the Delphi technique. This involved collating information from an expert panel of patients and clinicians regarding their opinions of activity pacing. From these data, items were developed for the APQ on which participants voted to reach a consensus on the items that should be included in the questionnaire. Hence, the Delphi technique itself involved both qualitative and quantitative data collection and analysis. Data were analysed at each stage of the study in order for the data to contribute to the subsequent stage of the study.

Stage II: Assessing the psychometric properties of the APQ

In order for a scale to have clinical use, it must first be validated. Stage II of the study involved a shift to a postpositivist approach to validate the APQ. Validity refers to how meaningful the results of a psychometric measure are in terms of how trustworthy the measure is deemed (Cook and Beckman, 2006). There are different types of validity.

Content validity refers to the representativeness of the items in a scale to the underlying concepts. This involves qualitative judgements rather than quantitative tests (Walters, 2009). The utility of a Delphi technique involving a wide variety of opinions to reach a consensus on the items of the APQ was envisaged to increase the content validity.

Construct validity refers to how well the scale items can be combined to measure underlying concepts (Walters, 2009). The APQ was expected to have an internal structure consisting of numerical constructs reflecting the underlying concepts within activity pacing. Such constructs can be identified using quantitative methods. Scores on the constructs may then be correlated against scores on similar and dissimilar measures (convergent and discriminant validity), or compared between different groups of

participants to assess whether the results were in line with theoretical expectations (Walters, 2009).

To assess the internal structure and construct validity of the APQ, together with patients' responses to the scale, Stage II of the study involved administering a questionnaire booklet to a sample of patients with chronic pain and/or fatigue. A cross-sectional design was selected for the main part of Stage II, since this involved the collection of data from each participant at one time point (Greenhalgh, 1997). A secondary part of Stage II involved the assessment of reliability of the APQ in terms of showing agreement when measured at two time points. The design used for this part could technically be described as being a prospective cohort study, since it was only planned to assess this type of reliability on a smaller subset of participants. Although randomised controlled studies are considered to be the gold standard of primary research design, such a design was not appropriate for the present study since it was not evaluating the effectiveness of a treatment intervention (Greenhalgh, 1997; Hill and Spittlehouse, 2003). Instead, participants received their usual physiotherapy treatment. Furthermore, Stage II did not involve assessments of causation or prognosis, and therefore neither a cohort or a case-study design were suitable (Greenhalgh, 1997).

The data generated from the questionnaire booklets were used to explore the psychometric properties of the APQ in terms of the underlying themes contained within the scale, the reliability and the validity. Reliability refers to the consistency of a scale across different assessments (Cook and Beckman, 2006). Reliability was assessed via estimations of the internal consistency of the APQ, together with test-retest assessments of the stability of the scale (Cook and Beckman, 2006).

Validity is the degree to which the scores of a scale represent the underlying purpose (Cook and Beckman, 2006). This was explored by assessing correlations between the APQ and existing pacing subscales and validated measures of symptoms commonly presented with chronic conditions (that is, pain, fatigue, anxiety, depression, avoidance and function). Strong correlations would indicate that the APQ identified and measured appropriate constructs (Cook and Beckman, 2006).

Together with assessing the psychometric properties of the APQ, the aim of Stage II was to increase the generalisability of the qualitative data generated in Stage I across a

larger sample. Among the closed-ended questions in the questionnaire booklet, open-ended questions were included to provide patients with the opportunity to explain their quantitative answers using qualitative information.

Stage III: Exploring the acceptability of the APQ

The study involved a third stage in addition to the traditional two-stage exploratory sequential design. Stage III involved qualitative telephone interviews to explore participants' opinions of the APQ, including the layout and the scale itself. Participants were invited to discuss their opinions of what pacing involves to compare these data with both the data originally generated in Stage I, together with the themes of pacing that emerged in Stage II. Therefore, patients were able explain their own answers and potentially some of the findings that were observed following Stage II data analysis (Creswell et al., 2004). Moreover, this stage was beneficial to increase service-user involvement in the development of a clinical measure.

The mixed methods approach utilised in the present study facilitated the collaboration of views from patients and clinicians. This is envisaged to increase the content validity of the questionnaire, that is, the extent to which activity pacing is represented in the questionnaire (Cook and Beckman, 2006). Additionally, involving both patients and clinicians was thought to assist the development of a questionnaire that is relevant and understandable for both patients and clinicians to enhance its clinical use *(see Figure 4.1 Flow diagram of the study design)*.

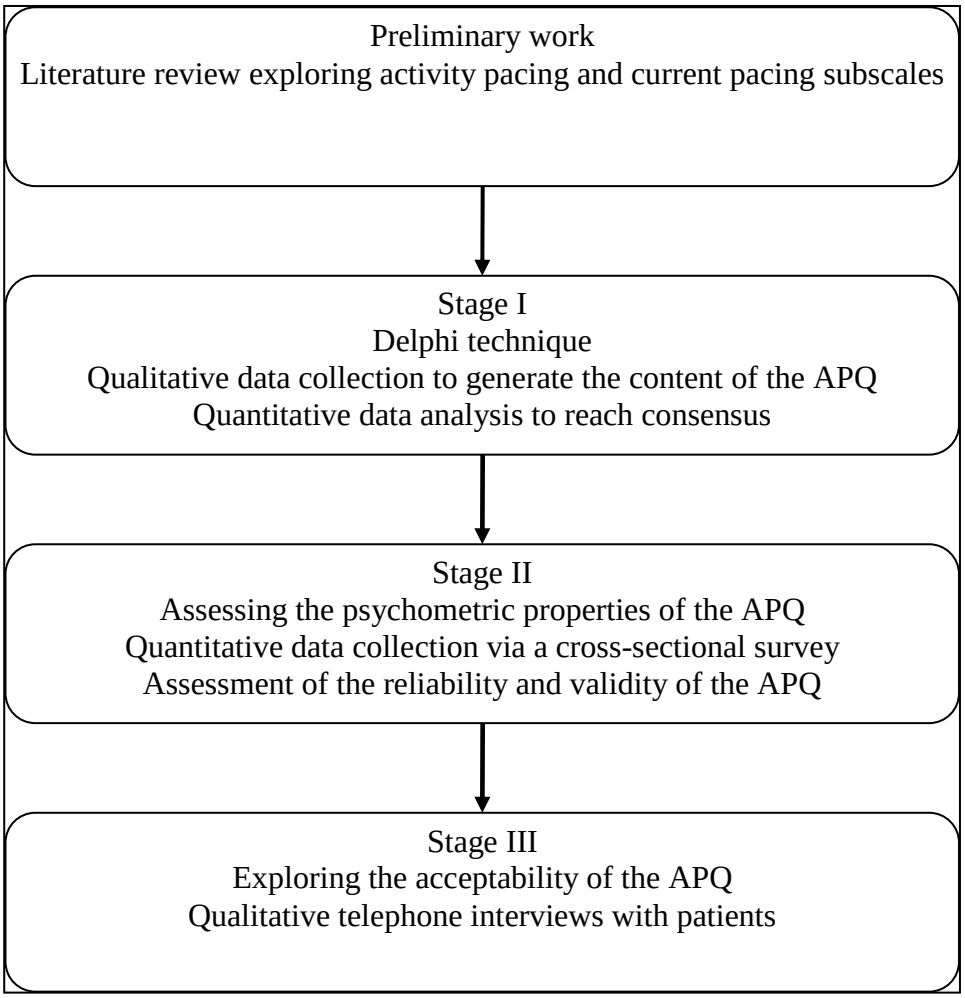


Figure 4.1 Flow diagram of the study design

4.4 Summary

This chapter introduced the different research paradigms, leading to the justification of the exploratory sequential research design that was selected for the study. The three stages of the study, Stage I: the Delphi technique (predominantly qualitative phase), Stage II: Assessing the psychometric properties of the APQ (predominantly quantitative phase) and Stage III: Exploring the acceptability of the APQ (qualitative phase) will be described in more detail in Chapters 5-7, beginning with Chapter 5: The development of the activity pacing questionnaire: A Delphi technique.

Chapter 5. Stage I: The development of the activity pacing questionnaire: A Delphi technique

5.1 Methods

5.1.1 Aim of Stage I

The aim of Stage I of the study was to develop an activity pacing questionnaire (APQ) for chronic pain and/or fatigue using a Delphi technique. This section justifies the methods that were implemented, including the selection of the Delphi technique and the expert panel. This section proceeds to report how the items for the APQ were developed and refined.

5.1.2 Justification of methods

5.1.2.1 Study design

The value of any questionnaire is underpinned by the items that the measure contains. The generation of items is therefore imperative to the development of the questionnaire (Streiner and Norman, 1995). Various methods of item generation were implemented in the existing pacing subscales, for example, using clinical observations, opinions of clinicians or existing literature. However, the author suggests that existing pacing subscales have limited content validity since the items reflect a narrow range of views *(see Chapter 2, Literature Review, Section 2.3.5)*. To generate scale items that capture different domains of a construct, a method is required that collects a broad range of opinions from experts in the field (Streiner and Norman, 1995). To collate a range of opinions, interviews or focus groups may be undertaken (Streiner and Norman, 1995), together with consensus techniques such as the Delphi technique (Keeney et al., 2001).

Interviews may generate a wide scope of opinions, but lack the interactions and discussions that occur using focus groups (Pett et al., 2003). Focus groups usually involve semi-structured meetings of approximately 6-12 participants, facilitated by a group moderator (Streiner and Norman, 1995; Pett et al., 2003). The author suggests that focus groups may be challenged by practicalities such as gathering participants at convenient times and settings, especially if more than one meeting is required. Furthermore, difficulties may arise in reaching a consensus within a focus group due to varying opinions and dominating characters. Such challenges may be overcome by implementing a consensus technique such as the Delphi technique (Parahoo, 1997).

5.1.2.1.1 The Delphi technique

The Delphi technique was developed in the 1950's by Dalkey and colleagues in the RAND (Research ANd Development) Corporation with the purpose of forecasting, such as in the development of new technologies (Murphy et al., 1998b; Vernon, 2009). The Delphi technique is now a recognised consensus method of decision-making that is widely utilised in the health sciences (Hasson et al., 2000; Vernon, 2009). The Delphi technique has been employed to develop clinical guidelines and to predict future models of disease and management (Mullen, 2003). It holds value in achieving a consensus of the most important features of a topic which has previously had little or inconclusive definitions (Jones and Hunter, 1995; Hasson et al., 2000). The Delphi technique is therefore ideal for the development of the APQ since pacing is a construct that has previously failed to reach a 'consensus of definition' (Gill and Brown, 2009).

The Delphi technique is an iterative process in which an expert panel receive 'rounds' of information on which they vote or rank until a level of consensus is reached (Whitman, 1990; Keeney et al., 2001). There are advantages of employing a Delphi technique in comparison to other consensus methods, for example, the nominal group technique. The nominal group technique involves an expert panel meeting face-to-face to debate items related to a specific topic in order to vote to reach a consensus (Jones and Hunter, 1995; Vernon, 2009). In comparison, the Delphi technique assures participant anonymity from the rest of the expert panel, and correspondence occurs via post or e-mail (Whitman, 1990). The Delphi technique allows all participants to express their opinions equally without being influenced by more authoritative or vocally domineering characters in group settings (Jones and Hunter, 1995; Keeney et al., 2001). Therefore, the Delphi technique may reduce the potential for bias that may arise in group settings (Williams and Webb, 1994). The Delphi technique holds additional benefits of low cost, low inconvenience and less locational limitations (Jones and Hunter, 1995; Keeney et al., 2001).

5.1.2.1.2 The 'rounds' of Delphi

There is no standardised method of undertaking a Delphi technique and many different adaptations of the Delphi technique are now in practice (Hasson et al., 2000). A Delphi technique in its most common form consists of sending three rounds of questionnaires (Jones and Hunter, 1995). Round 1 usually involves open-ended questions to generate ideas, and these qualitative data are often reorganised into subcategories (Whitman,

1990; Jones and Hunter, 1995; Keeney et al., 2001). The advantage of an open-ended question in Round 1 is that the researcher does not bias the following rounds with pre-determined concepts (Sinha et al., 2011). In the present study, Round 1 involved collating opinions regarding activity pacing in order to develop items for the APQ.

The data from Round 1 are presented back to the panel on Round 2 to vote or rank, thus producing quantitative data (Jones and Hunter, 1995; Hasson et al., 2000). Round 3 involves repeating the procedure of Round 2 with the addition of showing panellists statistical summaries of Round 2, together with any comments or justification for answers that were provided (Whitman, 1990; Duffield, 1993; Mullen, 2003). Participants are encouraged to reconsider their original answer which may change in light of the Round 2 results (Keeney et al., 2001). This allows for an individual's answer to be swayed by the group which is an important step in achieving consensus (Duffield, 1993; Hasson et al., 2000).

The rounds of Delphi can continue for a fourth round or more (Whitman, 1990). Indeed, the original Classic Delphi consisted of four rounds (Keeney et al., 2001). However, three rounds are more frequently utilised to prevent participant fatigue and high numbers of dropouts due to the repetitive nature of Delphi (Hasson et al., 2000). Furthermore, it is suggested that after three rounds consensus will be reached (Sumsion, 1998). It was envisaged that Round 1 in the present study would have six weeks' duration: three weeks for participants to respond and three weeks for qualitative data analysis. It was planned that Rounds 2 and 3 would have five weeks' duration, allowing three weeks for participant responses and two weeks for data analysis. A three week response period was selected to allow participants sufficient time to complete the questionnaire without losing momentum with proceeding rounds. This timescale was similar to a previous Delphi study whereby participants returned the open-ended question of Round 1 within three weeks, but Rounds 2 and 3 within two weeks (Finger et al., 2006). The Delphi technique of the present study was envisaged to last between four and five months, with the inclusion of telephone reminders.

5.1.2.1.3 Participants: the expert panel

The expert panel selected for a Delphi technique must be appropriate for the research subject. If the subject is specialised or involves an expertise in a specific field, then a homogeneous panel is required (Vernon, 2009). Conversely, if a wide range of opinions

is required, a heterogeneous expert panel is suitable (Keeney et al., 2001). In order to develop the APQ encompassing a range of opinions regarding pacing, a heterogeneous panel were invited to the study. The participants were recruited via purposive sampling, that is, they were purposively selected due to their expertise (Hasson et al., 2000).

The expert panel included clinicians working in the field of chronic pain and/or fatigue who advise activity pacing as a management strategy. Physiotherapists, occupational therapists, nurses and psychologists have been involved in advising pacing as a component of cognitive behavioural therapy in a randomised controlled trial involving patients with low back pain (Lamb et al., 2010). The above types of clinicians were similarly invited to participate in the present study, together with patients with conditions of chronic pain and/or fatigue (see inclusion criteria below). Patients are considered to be a useful source of items, and indeed experts due to their unique experiences (Streiner and Norman, 1995; Baker et al., 2006). It was envisaged that incorporating the opinions and language of clinicians and patients with diverse backgrounds would increase the generalisability and clinical relevance of the APQ.

Inclusion criteria

Clinicians

Healthcare professionals working in the field of chronic pain and/or fatigue in the UK (for example, nurses, physiotherapists, occupational therapists and psychologists). All clinicians were required to have the availability to complete a series of questionnaires.

Patients

Patients were included if they had been referred to the physiotherapy departments of The Pennine Acute Hospitals NHS Trust for the management of a primary presentation of chronic low back pain, chronic widespread pain, fibromyalgia or chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME) (all greater than three months' duration). Patients were eligible to participate if they had been referred to physiotherapy by either a GP or a hospital consultant. Patients were invited to participate before attending physiotherapy so that their responses were based on their own beliefs. Patients were aged 18 or over and required to have a good understanding of the English language.

Exclusion criteria

Patients with a condition of less than three months' duration were excluded. Patients with evidence of a serious underlying pathology (for example, cancer), an inflammatory condition such as rheumatoid arthritis, or neurological conditions, such as a cerebrovascular accident, were not invited to participate. Due to the nature of the questionnaire study, patients who were unable to read and write in English, or complete three rounds of questionnaires were considered ineligible to participate.

5.1.2.1.4 Sample Size

There is no standardised number of participants recommended to be involved in the Delphi technique. Indeed, panel sizes have ranged from 4-3000 experts in health related research (Mullen, 2003). However, the size of the expert panel should be in keeping with the research question and the available resources (Sumsion, 1998). A panel of approximately 30 experts was deemed large enough to gather a wide range of opinions without creating an unwieldy amount of data. Similar sample sizes have been utilised in other Delphi studies. For example, McCarthy et al. (2006) implemented a three-round Delphi technique with 30 panel members (of whom, 28 completed) to reach a consensus on a clinical tool to differentiate subgroups of patients with low back pain.

To generate a panel with approximately 30 members (while allowing for non-responders) it was planned that 50 clinicians and 50 patients would be invited to participate. With regards to recruiting clinicians, a consent rate of 82% was previously attained using a Delphi technique involving primary care practitioners to prioritise a research agenda for low back pain (Henschke et al., 2007). In terms of recruiting patients, a 50% recruitment rate was previously attained in a focus group and two-round Delphi technique to explore patient expectations and satisfaction of a low back pain rehabilitation service (McCarthy et al., 2005). Therefore, recruitment rates of 80% for clinicians and 50% for patients were estimated for the present study. Response rates for the rounds of Delphi have previously ranged from 71% to 97% (McCarthy et al., 2006; Henschke et al., 2007). It was estimated that the present study would attain response rates of a minimum of 70% for Rounds 2 and 3. Figure 5.1.1 shows the estimated response rates for the study. It was envisaged that approximately 20 clinicians and 13 patients would complete the study which was deemed a sufficient sample size (n=33).

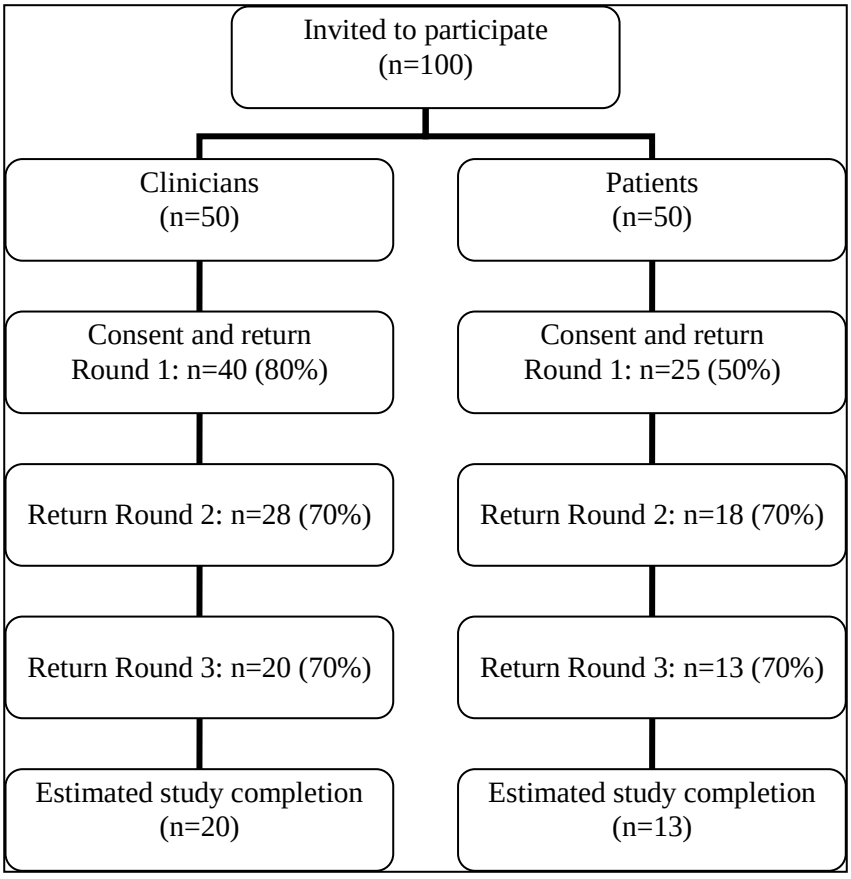


Figure 5.1.1 Estimated recruitment rates for the Delphi technique

5.1.2.2 Scale Development

5.1.2.2.1 Item development

In the present study, Rounds 2 and 3 of Delphi consisted of a list of questions that could be potentially included in the APQ. When considering how many questions should be included in Rounds 2 and 3 it is suggested that the initial item pool should be between one and a half to four times the size of the predicted final amount (DeVellis, 1991; Pett et al., 2003). It was expected that the APQ would contain between 20-30 questions, similar to other widely used and validated questionnaires such as the Roland Morris Disability Questionnaire (n=24 questions) (Roland and Morris, 1983; Turner et al., 2003). It was proposed that approximately 100 questions would be written from the data generated from Round 1. It was anticipated that this number would increase the content validity of the final APQ, without deterring participants from completing Rounds 2 and 3 of Delphi due to the length of the questionnaire (DeVellis, 1991). Indeed, an oversized item pool in the initial stages of questionnaire development may be advantageous, and redundant questions can be removed in later stages of the process (DeVellis, 1991).

When developing scale items, it is advised that each item contains only one concept, the questions are unambiguous, and the use of double negatives is avoided (DeVellis, 1991; Pett et al., 2003). The items should be written in a language as close to the Round 1 statements as possible while endeavouring to ensure that they are understandable in lay persons' terms (DeVellis, 1991; Hasson et al., 2000). It is recommended that each item is ideally no longer than 20 words (Oppenheim, 2000). Indeed, increased item length reduces ease of readability (Flesch, 1948).

The readability of a sentence or a passage may be estimated using a number of tools, for example, the Flesch Reading Ease score (Flesch, 1948). The Flesch Reading Ease score is calculated based on sentence length and word length, where shorter sentences and shorter words correspond to higher scores on a scale of 0-100. A higher score represents greater readability, and a score of 60-70 alludes to 'standard' reading ease (Flesch, 1948). In this way, the Flesch Reading Ease score provides only a basic guide to readability. The score does not reflect whether the passage makes sense, since the same Flesch Reading Ease score would be achieved if the words were rearranged in a random order (Paz et al., 2009). However, the Flesch Reading Ease score has been validated and is frequently used, for example, to assess the readability of healthcare questionnaires and leaflets (Hill and Bird, 2007; Pothier et al., 2008; Paz et al., 2009). Furthermore, it is simple to use and available in Microsoft Word.

5.1.2.2.2 Likert scales

Rounds 2 and 3 of Delphi involved panellists voting to include or exclude each potential APQ item using a 5-point Likert scale. Likert scales are measures of agreement of opinions or behaviours that can be rated on a bipolar linear scale (Oppenheim, 2000; Pett et al., 2003). The Likert scale implemented in the present study was labelled: 0='completely disagree', 1='disagree', 2='neither agree nor disagree', 3='agree' and 4='completely agree'.

The linear scale endeavours to contain answers that have equal intervals between them (Oppenheim, 2000). However, due to subjective interpretations of descriptive adjectives, the intervals between the adjectives cannot be assumed to be equal (Streiner and Norman, 1995). Therefore it could be debated whether the data should be classified as ordinal or interval (Streiner and Norman, 1995). The author suggests that attaching numeric values to the descriptors on the Likert scale may portray clearer steps between

intervals and additionally gives the data some quantitative properties. Streiner and Norman (1995) state that in most cases the data from individual Likert scales are considered to be interval data which enables statistical analysis of the data. Conventionally, the individual items in Likert scales are summated, either as a total score of the questionnaire or as subscales within a questionnaire (Oppenheim, 2000; Pett et al., 2003). Summated scores result in a greater range of scores that can be attained, and where large amounts of values are present, the data are considered to be continuous or interval (Wild and Seber, 2000).

Likert scales have developed from the original 5-point format to include different variations (Pett et al., 2003). The number of intervals on the Likert scale should reflect the ability of the individuals to discriminate between the options (Streiner and Norman, 1995; Pett et al., 2003). If the number is too small, the outcome will contain less detailed information (Streiner and Norman, 1995). For this reason, it was decided that a dichotomised scale with 'agree'/'disagree' options would not be suitable for the study. Dawes (2008) found that 5- and 7-point scales increased reliability and validity in comparison to scales with fewer intervals. However, 5- and 7-point scales derived slightly lower mean scores than the 10-point scale after re-scaling (Dawes, 2008). A 5-point scale was selected for the present study since it is the most frequently implemented Likert scale (Oppenheim, 2000). Furthermore, the author considered this scale able to generate adequate information while maintaining simplicity in a large item pool to encourage completion of the Delphi.

An odd number of intervals in the Likert scale were employed to allow participants to remain ambivalent if they were undecided about an item. It is beneficial to include the 'neither agree nor disagree' middle option so that participants are not forced to include or exclude an item if they are undecided. Forced answers may lead to false results, or in participants ceasing to complete the questionnaire (Pett et al., 2003).

Despite the common use of Likert scales, there are a number of factors that can threaten the reliability and validity of the scale. For example, Streiner and Norman (1995) describe an 'end-aversion bias' where participants avoid choosing the bipolar anchors of the scale. In the present study, a score of either 3='agree' or 4='completely agree', rather than just 4='completely agree' was implemented to represent a vote of inclusion of an item into the APQ to try to reduce this bias. In addition, Likert scales have been

associated with the tendency of participants to give all positive answers ("yea-saying"), or to give answers that are perceived to be socially desirable (Pett et al., 2003; Streiner and Norman, 1995). Some scales incorporate reverse scored questions to try to reduce the effect of these biases. However, reverse scoring can complicate a scale and lead to accidental inaccurate results (Streiner and Norman, 1995; DeVellis, 1991). Since the questionnaire in the present study was predicted to be of substantial length, and the participants included patients with conditions predominated by pain or fatigue, it was decided that reverse scored items would not be included.

5.1.2.2.3 Level of consensus

The items that were retained in the APQ were those attaining consensus of inclusion on Round 3 of Delphi. The level of consensus was pre-determined before commencing the study to reduce researcher bias (Williams and Webb, 1994). There is no definitive level of consensus, however, previous studies incorporating cut-off scores of 50% have been considered too low to differentiate between items to include or exclude (Duffield, 1993). Previous inclusion cut-off scores have comprised of 80% in a study utilising a Delphi technique to categorise physiotherapy interventions (Finger et al., 2006). Alternatively, a consensus level of 75% +/-5% (excluding items with <70%) was implemented in a Delphi technique regarding physiotherapy examinations of non-specific low pack pain (McCarthy et al., 2006). A cut-off value of ≥ 70% was selected for the study as this is a conventional value and considered to be an accurate reflection of the items that have reached consensus (Vernon, 2009).

5.1.2.3 Ethical issues

5.1.2.3.1 Recruitment and consent

Written consent was obtained before participation. Patients were advised that participation would not affect any current or future treatment and that they were free to withdraw from the study at any time.

5.1.2.3.2 Anonymity

In order to maintain confidentiality and anonymity, all participants were identified by unique codes throughout the study. Participants' codes and personal data (including addresses and demographic data) were kept securely on a password protected Microsoft Excel worksheet. The worksheet was stored on two encrypted USB pen-drives and the

paper copies of the questionnaires were kept in a locked filing cabinet in a secure room in The Pennine Acute Hospitals NHS Trust. Participants' questionnaire responses were recorded on a second Microsoft Excel worksheet, on which participants were identified by their unique code to maintain anonymity. The responses made by participants on each round of Delphi remained anonymous to the investigators and to the rest of the panel.

5.1.2.3.3 Ethical approval

Ethical approval was granted by the Oldham Research Ethics Committee (REC ref no. 09/H1011/49, *see Appendix 1*) and the University of Manchester. Permission was granted by The Pennine Acute Hospitals NHS Trust in June 2009.

5.1.3 Methods

5.1.3.1 Participant recruitment

Clinician recruitment

Clinicians were approached through Heads of Physiotherapy Departments in the Greater Manchester region, and two special interest clinical groups: the Physiotherapy Pain Association (PPA) and the Clinical Network Coordinating Centre (CNCC) for CFS/ME in June 2009. Clinicians received an e-mail invitation and they were asked to forward their postal address within four weeks if they wished to participate.

Patient recruitment

Consecutive patients referred to the physiotherapy departments of The Pennine Acute Hospitals NHS Trust with diagnoses of chronic low back pain, chronic widespread pain, fibromyalgia and/or CFS/ME during June-July 2009 were identified. Patients were sent a letter of invitation, together with the study information pack by post since their postal addresses were already known.

5.1.3.2 Developing the APQ: the Delphi technique

5.1.3.2.1 Delphi Round 1

In August 2009, the study information packs and Round 1 of Delphi were sent to a total of 106 potential participants, of whom 54 were clinicians and 52 were patients. The study information pack included the participant information sheet, consent forms, and demographic questions *(see Appendix 2).* Participants were asked to return the signed consent form and demographic questions, together with Round 1 of Delphi within three

weeks. Responses to the demographic questions were checked to ensure that participants met the inclusion criteria.

Round 1 of Delphi involved an open-ended question asking participants to state their opinion of the 10 most important factors involved in activity pacing *(see Appendix 2)*. Requesting a maximum number of answers allowed for the generation of a variety of opinions while aiming to create a fairly succinct list to be interpreted for Round 2 (Hasson et al., 2000). However, space was provided for further comments. Participants were asked to state whether they preferred proceeding rounds to be sent via post or e-mail, and if they agreed to receive a reminder telephone call on Rounds 2 or 3.

Participants who consented were allocated a study code which was then recorded on all of their subsequent questionnaires. If no response was made to Round 1 after three weeks it was assumed that the individual did not wish to proceed in the study and no further communication was made.

5.1.3.2.2 Round 1 data analysis

All of the qualitative data generated from the Round 1 open-ended question were gathered and organised into broad themes of pacing by two members of the research team working independently. The qualitative data were used to develop items that could potentially be included in the APQ. Over 140 items were initially developed to be administered on Round 2. However, within this number there appeared to be some repetition. To prevent participants being overwhelmed by the volume of items, this number was reduced to encourage participant continuation with the questionnaire (Pett et al., 2003). Questions were combined or removed that were either repetitive or contained information that did not arise frequently (Whitman, 1990). Subsequently, 94 questions remained, ordered according to the broad themes of pacing. The questions were assessed for readability using the Flesch Reading Ease score and modified where able, while endeavouring to maintain the original language (Whitman, 1990).

During the development of the potential APQ questions, the term ‘symptom’ was specifically used rather than ‘pain’ or ‘fatigue’ with the aim of developing a questionnaire that was relevant to a heterogeneous group of chronic conditions. This is in comparison to existing pacing subscales that implement the term ‘pain’. Before administering Round 2 to the panel, it was piloted by a physiotherapist, an occupational

therapist and a clerical employee from The Pennine Acute Hospitals NHS Trust. Following the pilot test no changes were deemed necessary to Round 2.

5.1.3.2.3 Delphi Round 2

In November 2009, Round 2 was sent only to participants who responded to Round 1 *(see Appendix 3)*. Participants were advised that the term 'activity' in the APQ referred to physical, mental, emotional and self-care activities. Participants were asked to vote on the 5-point Likert scale the extent to which they thought that each of the 94 items should be included in the APQ. Participants were invited to make additional comments. Allowing participants to justify their answers holds benefits of maintaining participant interest and motivation (Streiner and Norman, 1995).

Participants were asked to return Round 2 within three weeks, and those who consented to telephone reminders were contacted approximately three weeks after sending Round 2 if no response had been made. If Round 2 was not returned following the telephone reminders, it was assumed that the participant did not wish to continue in the study and communication ceased.

5.1.3.2.4 Round 2 data analysis

The results from Round 2 were collated across the expert panel and the percentage scores of votes to include each question were calculated. Missing answers and duplicate answers were omitted from the calculations. All participants' comments were gathered in a comments booklet.

5.1.3.2.5 Delphi Round 3

In February 2010, Round 3 was sent only to panellists who responded to Round 2 in order to achieve consensus *(see Appendix 4)*. Round 3 contained the same 94 items as Round 2, but for each item participants were shown their previous individual scores and the group percentage scores. In addition, participants were sent the comments booklet containing anonymous comments. Round 3 and the comments booklet were piloted by a physiotherapist to ensure clarity of the instructions. Participants were asked to re-rate the items on the same 5-point Likert scale in light of the results and comments from Round 2. Participants were advised that they could keep or change their original answers.

Participants were asked to return Round 3 within three weeks, and telephone reminders were made if no response had been made after 3 weeks. Ten participants requested a copy of the final scores from Round 3 and were sent this information in June 2010 once the final scores had been calculated.

5.1.3.2.6 Round 3 data analysis

The items that were voted to be included and excluded on Rounds 2 and 3 were compared in order to examine the process of reaching consensus. This comparison was made by firstly calculating the percentage agreement between the two rounds, and secondly by estimating the movement in voting between Rounds 2 and 3 using Cohen's kappa statistic of chance-corrected agreement (Cohen, 1960). A kappa value of >0.40 is considered to represent a moderate level of agreement (Landis and Koch, 1977).

For each APQ item, the numbers of participants voting to include/exclude an item on Round 3 were compared by subgroup (patient or type of clinician) using Fisher's exact test. The breakdown of voting preference by subgroup was expected to result in small cell counts, invalidating Pearson's chi-square test. Fisher's exact test is valid, but generalisation depends on the small subgroups being representative samples of the underlying populations.

5.1.3.3 Refining the items of the APQ

The questions that were voted to be included in the APQ by ≥ 70% of the panellists were re-assessed using the Flesch Reading Ease score. Questions that contained more than 20 words or contained complex words were revisited and discussed by the research team. Additionally, the readability of the items was reviewed by The Pennine Acute Hospitals NHS Trust Patient Information Review Group. The research team made amendments to APQ items only when changes led to improvements in readability. Where possible, the original language was maintained so that it reflected the content suggested by participants (Whitman, 1990), together with the terminology that had reached consensus. Finally, the APQ items were rearranged in a random order using a random number generator.

Chapter 5. Stage I: The development of the activity pacing questionnaire: A Delphi technique

5.2 Results

5.2.1 Introduction

Forty-two participants completed the three-round Delphi technique to develop the items for the activity pacing questionnaire (APQ). This section reports the participants' demographics, together with the process of reaching consensus on the APQ items. Furthermore, pertinent comments made by participants are reported.

5.2.2 Participants

5.2.2.1 Response rates

The demographic data of all participants who returned Delphi Round 1 were checked against the inclusion/exclusion criteria. No participants were excluded from the study. Of the 54 clinicians and 52 patients who were invited to participate, 49 clinicians (91%) and 10 patients (19%) consented and completed Round 1. Forty-one of the 49 clinicians (84%), and 4 of the 10 patients (40%) returned Round 2, giving an overall response rate of 76% for this round. Seventeen telephone reminders were made on Round 2 which prompted 5 of the above responses. One clinician withdrew due to their involvement in a different activity management project. One patient withdrew due to other commitments and one clinician was taking extended leave. Forty-two participants responded to Round 3, of whom 38 were clinicians and four were patients. This resulted in a response rate of 93% to Round 3 from the participants responding to Round 2, and 71% from those who responded to Round 1. Seven telephone reminders were made on Round 3 which resulted in six of the above replies. In addition, one clinician withdrew (due to being involved in a different activity management programme) and one clinician was on sick leave *(see Figure 5.2.1 Response rates of the Delphi technique).*

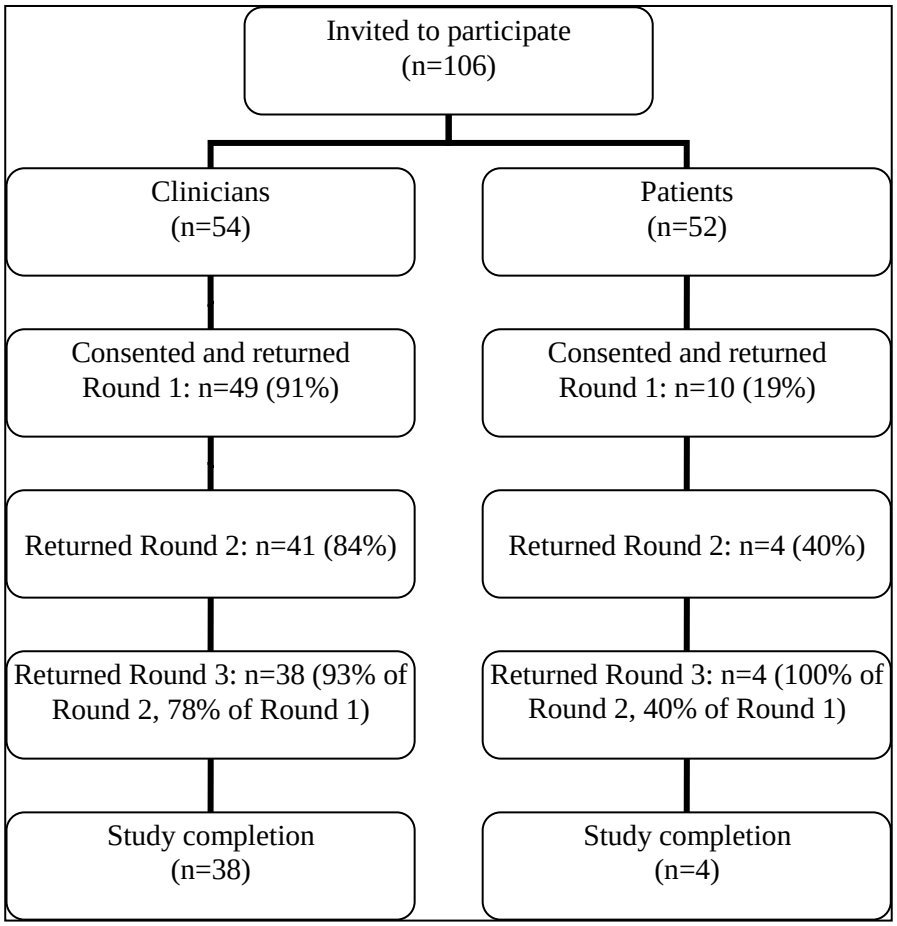


Figure 5.2.1 Response rates of the Delphi technique

5.2.2.2 Participant subgroups

The 59 participants who returned Round 1 included 10 patients, 3 nurses, 33 physiotherapists, 11 occupational therapists, 1 clinical psychologist and 1 rheumatology consultant. The 45 participants who completed Round 2 included 4 patients, 3 nurses, 28 physiotherapists, 9 occupational therapists and 1 clinical psychologist. The subgroups of participants who completed Round 3 are detailed in Section 5.2.2.3.

5.2.2.3 The expert panel

Clinicians

The 38 clinicians who completed Round 3 of Delphi consisted of 3 nurses (all female), 26 physiotherapists (9 males, 17 females) and 9 occupational therapists (all female). Clinicians were recruited from England, Wales and Scotland. The age ranges of clinicians were: nurses=45-50 years (mean=48), physiotherapists=26-54 years (mean=40) and occupational therapists=30-57 years (mean=44). The ranges of clinical experience for clinicians were: nurses=24-29 years (mean=27), physiotherapists=3-31 years (mean=15) and occupational therapists=5-26 years (mean=13).

Patients

Of the four patients who completed all three rounds of Delphi two were male and two were female, with an age range of 24-55 years (mean=45). One patient had a diagnosis of back pain, two patients had back pain and widespread pains and one patient had fibromyalgia and CFS/ME. The duration of conditions ranged between 6 months to 15 years (mean=6 years).

5.2.3 Comparisons between Rounds 2 and 3

5.2.3.1 Comparing responders and non-responders on Round 3

The three participants who responded to Round 2 but not to Round 3 consisted of two physiotherapists aged 51 years (29 years clinical experience) and 30 years (9 years clinical experience), and one clinical psychologist aged 59 years (34 years clinical experience). One of the physiotherapists withdrew from the study owing to their involvement in a different activity management programme. The voting pattern of this participant on Round 2 was compared to votes of the expert panel on Round 3 to examine if there were differences. This participant voted to include 32 questions in the APQ on Round 2. Twelve of these 32 questions were included in the 37 questions that reached consensus on Round 3, leading to a match of 32%. Similarly, 11 questions matched the 34 questions (32%) that the subgroup of physiotherapists had voted to include.

The second physiotherapist who did not return Round 3 voted for 68 questions to be included in the APQ on Round 2. Thirty-four (92%) of these questions matched the 37 questions voted to be included by the panel on Round 3, and 29 questions (85%) matched the 34 questions that the subgroup of physiotherapists voted to include. The clinical psychologist who did not respond to Round 3 voted to include 43 questions on Round 2. Of this number, 26 questions matched the 37 questions (70%) voted to be included by the expert panel on Round 3.

5.2.3.2 Movement of votes between Rounds 2 and 3

On Round 2, 30 items scored ≥ 70% of the votes to be included in the APQ. The same 30 items were voted to be included in the APQ on Round 3 with the addition of Questions: 5, 8, 17, 33, 48, 58 and 89. Twenty-eight of the 37 questions voted to be included in the APQ scored higher percentages of votes on Round 3 than Round 2.

Five questions scored the same percentage of votes on both Rounds 2 and 3, and four questions had fewer votes on Round 3, by no more than 4% of the votes *(see Appendix 5, Table 5.1 Questions voted to be included in the APQ)*.

To examine the process of reaching consensus, the changes that occurred in participants' votes between Rounds 2 and 3 were analysed firstly by looking at the number of votes to include/exclude each item on both rounds. The percentage of agreement of inclusion/exclusion between Rounds 2 and 3 for each of the 37 items that reached consensus ranged from 81% (Questions: 8, 53 and 71) to 100% (Question 68). To investigate this movement in voting between Rounds 2 and 3, Cohen's kappa statistic of chance-corrected agreement was estimated. Thirty of the 37 items had kappa values >0.40 (95% confidence), indicating moderate levels of agreement. For Question 68 there was perfect agreement.

Across the participants, the number of missing answers increased from 34 to 37 between Rounds 2 and 3. Similarly the number of duplicate answers increased from 13 to 15 between Rounds 2 and 3. The number of missing or duplicate answers did not exceed two per APQ item. In Round 3 participants were able to change the answers they gave on Round 2. The number of changed answers on Round 3 ranged between 4 and 64 for individual participants. The total number of changed answers for the full panel on Round 3 was 1027 (mean=25 changed answers per participant).

5.2.4 APQ questions

5.2.4.1 APQ questions reaching consensus

As a result of Round 3, 37 questions were voted to be included in the APQ by ≥ 70% of the 42 participants. Among the subgroups of participants, ≥ 70% of patients voted to include the greatest number of items (67 items), followed by nurses (46 items), then occupational therapists (38 items) and then physiotherapists (34 items).

Fisher's exact test was used to explore if there were differences in how the subgroups voted on the 37 items. Only Question 1: *"I broke down activities into manageable pieces"*, demonstrated a statistically significant difference between the subgroups (p=0.026). Interestingly, 100% of patients, nurses and physiotherapists voted to include Question 1, compared to 67% of occupational therapists. However, such analyses

should be interpreted with caution due to small numbers of participants in some subgroups.

The question that scored the highest percentage of votes on Round 3 was Question 41: *"I did not over-do activities on a 'good' day"*, which was voted to be included by 100% of the panel on Round 3. Interestingly, Question 41 was similar to Question 42: *"I did not under-do activities on a 'bad' day"*, which scored 83% of votes to be included in the APQ. The question that had the lowest votes of inclusion was Question 40: *"I worked at a set speed on each task"*, which scored only 5% of the votes. The top five and bottom five scoring questions are presented in Table 5.2.1. The percentages of votes for all 94 questions are shown in Appendix 5, Table 5.2.

Table 5.2.1 Top five and bottom five scoring questions

Top five scoring questions (to be included in the APQ)	Percentage vote of inclusion
41: I did not over-do activities on a 'good' day	100%
45: I made sure I did some activity every day, even if I had a 'bad' day	98%
63: I changed my activity targets if they were unrealistic	95%
68: I prioritised my activities for each day	95%
1: I broke down activities into manageable pieces	93%
Bottom five scoring questions (to be excluded from the APQ)	
40: I worked at a set speed on each task	5%
51: I tried to maintain a level of activity that I had before the onset of my symptoms	12%
92: I avoided working at levels of discomfort so that I did not increase my symptoms	17%
52: I pushed myself to finish a task	22%
37: I did my activities at a slower speed	22%

5.2.4.2 Reading ease of the APQ questions reaching consensus

The Flesch Reading Ease scores of the 37 questions that reached consensus ranged from 19.0-100.0 (mean=63.1). Question 65: "*I was creative and found new ways of doing*

tasks" had the highest readability. Question 59: "*I used an activity diary to monitor my activity pattern"* had the lowest readability. Twenty-one of the 37 questions (57%) voted to be included in the APQ had a Flesch Reading Ease score of ≥ 60, alluding to standard reading ease (Flesch, 1948).

Revisiting Question 21: *"I alternated the type of activity that I was doing (for example, changing from a physical activity to a cognitive activity)"* and Question 22: *"I was aware of the impact that different types of activities had on me (for example, physical, mental, work, social and emotional activities)"*, which contained 21 and 23 words respectively, led to the exclusion of the examples in the parentheses. The research team agreed that these items were self-explanatory. Furthermore, the APQ instructions provided examples of activities to which the scale refers. The reduction in sentence length of Questions 21 and 22 increased the readability from Flesch Reading Ease scores of 24.3 to 61.3, and 29.0 to 65.7 respectively. In addition, it was decided that Question 62: *"I set activity goals that were meaningful and realistic for me"*, contained two different concepts and was separated into two questions. This increased the Flesch Reading Ease of this question from 'fairly difficult' (57.2) to 'standard' reading ease (66.1). As a result, the APQ contained 38 questions.

The suggestions made by The Pennine Acute Hospitals NHS Trust Patient Information Review Group, led to grammatical amendments of three questions, two of which resulted in lower Flesch Reading Ease scores. Following all of the above minor amendments, the 38 APQ questions maintained the same range of Flesch Reading Ease scores from 19.0 to 100.0 (mean=60.6). However, there was an increase to 24 out of the 38 questions (63%) that had a reading ease score of ≥ 60.0 *(see Appendix 5, Table 5.1 Questions voted to be included in the APQ, with readability scores)*.

The questions that reached consensus appeared to involve a number of different facets, including breaking down activities, spreading activities over the day, gradually increasing levels of activities and setting goals and time limits for activities.

5.2.5 Participants' comments

Participants made comments in Rounds 2 and 3 to voice opinions and justify their voting patterns. Participants queried the terminology of some APQ items, for example, the term 'rest' was queried in Question 7: *"I made sure I had a rest period after being active".* Panel member P97 made the following comment on Round 3:

> *"The term 'rest' needs to be defined, e.g. rest could mean stopping/lying down. The rest may have been as a response to pain if the individual had not previously been pacing." (P97, clinician)*

Question 7 received a further comment from panel member P60 on Round 3:

> *"Disagreement with the Round 2 comment regarding avoidance as the question refers to rest after activity, rather than avoiding activity. It would be useful to know if the rest was planned or forced." (P60, clinician)*

Therefore panel members used the comment booklets to respond to previous comments. Of note, Question 7 did not reach consensus of inclusion into the APQ.

Other comments were made to query whether some of the potential APQ items alluded to avoidance rather than pacing. Indeed, 22 of the 94 potential APQ items received such comments. Of these 22 questions, only five were voted to be included, namely, Question 3: *"I split activities up and did parts throughout the week"*, Question 5: *"I broke tasks up into periods of activity and rest"*, Question 11: *"I had periods of planned rest that did not involve sleeping"*, Question 17: *"I changed activities before I had an increase in my symptoms"*, and Question 53: *"I gradually increased activities that I had previously been avoiding because of my symptoms"*. Of these 22 questions five referred to energy conservation or staying within limits, in keeping with the envelope theory. None of the five questions that referred to the envelope theory reached consensus.

It is noteworthy that while some panellists queried Question 53 in terms of referring to avoidance, other panellists suggested Question 53 referred to 'pacing up' or graded activity. Several comments were made to suggest that 'pacing up' is a separate facet from pacing. For example,

"Some of the comments seem to confuse pacing with "pacing up". Pacing has to be done before pacing up." (P74, clinician)

Of the five questions that received comments querying the concept of 'pacing up', two reached consensus to be included in the APQ. The two questions were Question 53 and Question 54: *"I gradually increased how long I could spend on my activities"*.

Panellists queried whether some of the 94 potential APQ questions referred to other strategies that were separate from pacing. Examples included: relaxation, mindfulness, problem-solving, making lists, using a support network, having a flare-up plan, being assertive, acceptance and reducing feelings of guilt. Comments were made both in support and against the inclusion of these items.

Interestingly, Question 90: *"My symptoms decided how much activity I did each day"*, Question 91: *"I listened to my body and took a break when my symptoms increased"*, and Question 93: *"I stopped an activity before I became too tired"* were suggested to represent 'poor' pacing or the opposite of pacing. One panellist suggested that such items would require reverse scoring. Interestingly, none of these items reached consensus of inclusion. Furthermore, all four questions that referred to the speed of the activity were not voted to be included in the APQ. For example, Question 37: *"I did my activities at a slower speed"* received 22% of votes to be included.

Several panel members suggested additional items that could be included in the APQ. The suggestions included prioritising activities, assessing activity levels, being flexible, negotiating with others and increasing activities from a baseline. However, the suggested items were not added to the APQ since most of these facets had been included in the 94 items developed for the APQ, some of which did not reach consensus of inclusion.

5.2.6 Summary

Forty-two participants completed the three-round Delphi technique to develop the APQ. Consensus was reached on 37 questions, and following the division of one question into two separate questions, the APQ contained 38 items. The expert panel and the methodology of the Delphi technique, together with the findings are discussed in Section 5.3.

Chapter 5. Stage I: The development of the activity pacing questionnaire: A Delphi technique

5.3 Discussion

5.3.1 Introduction

As a result of Stage I, the Delphi technique, the activity pacing questionnaire (APQ) contained 38 questions. This section discusses the methodology of the Delphi technique, together with the expert panel (n=42). The questions that reached consensus will be discussed and compared to items contained in the existing pacing subscales of the Coping with Rheumatic Stressors Questionnaire, the Chronic Pain Coping Inventory, the Pain and Activity Relations Questionnaire and the Patterns of Activity Measure-Pain. Furthermore, this section considers the strengths and limitations of Stage I of the study.

5.3.2 The Delphi technique

The Delphi technique was a valuable method to reach consensus on the questions to include in the APQ. However, despite the wide utility of the Delphi technique in the health sciences, it has been criticised due to the lack of a standardised format (Hasson et al., 2000; Vernon, 2009). Indeed, the credibility of the Delphi may be compromised by the number of modifications of the technique (Keeney et al., 2001). Such lack of standardisation applies to the number of rounds of Delphi, the size of the expert panel, the definition of an expert, the level of anonymity and the analysis of the Round 1 qualitative data (Whitman, 1990; Keeney et al., 2006).

Conversely, one of the benefits of the Delphi technique includes the flexibility of the approach. This enables the methods to adapt to fulfil the objectives of the study (Williams and Webb, 1994; Keeney et al., 2006). The author considers that the Delphi technique implemented in the present study was similar to the Classic Delphi insofar as collecting qualitative data in Round 1 (Keeney et al., 2006). However, the study employed three rounds, and not four as would be expected in the Classic Delphi (Keeney et al., 2001). The Delphi technique was advantageous in collating the opinions of 42 participants who may not have been able to assemble to develop the APQ had other methods been implemented.

5.3.3 Participants

5.3.3.1 Recruitment

The recruitment rate for patients (19%) was noticeably lower than the recruitment rate for clinicians (91%), and lower than the estimated rate *(see Section 5.1 Delphi methods, Figure 5.1.1 Estimated recruitment rates for the Delphi technique)*. This may in part be due to the recruitment process. Clinicians had shown an interest in participating by requesting further information in response to an e-mail invitation before being recruited. In contrast, patients were sent study information packs and Round 1 of Delphi as the first stage of contact. Added to this, the recruitment rates of clinicians may be higher since they had a greater vested interest in the topic and the potential to implement the results of the study, that is, the APQ into clinical practice (Duffield, 1993; Hasson et al., 2000).

The expert panel in the study was recruited via purposive sampling which may introduce bias. However, an attempt was made to reduce this bias by recruiting a larger heterogeneous sample. Indeed, the sample included clinicians working across the UK, therefore holding different experiences and training (Jackson et al., 2009). Time constraints limited additional patients being recruited from outside The Pennine Acute Hospitals NHS Trust to prevent losing momentum with those who had already consented.

5.3.3.2 Sample Size

There is no specific number of participants that is recommended to be involved in a Delphi technique (Hasson et al., 2000; Vernon, 2009). The sample should be representative of the population from which it was taken, whilst corresponding to the available resources (Whitman, 1990; Sumsion, 1998). A sample size of approximately 30 was envisaged with the aim of including heterogeneous opinions of pacing in order to increase the content of the APQ. The expert panel who actually completed all three rounds of Delphi (n=42) was larger than predicted. The representativeness of the sample will be discussed below *(see Sections 5.3.3.3 and 5.3.3.4)*.

The reliability of a consensus method may be reduced when panels contain fewer than six participants, and increases over this number (Murphy et al., 1998b; Mullen, 2003). However, increasing the panel size beyond twelve may not necessarily increase the reliability of the consensus method any further, and reliability is dependant on dropout

rates (Murphy et al., 1998b). To optimise reliability, it is recommended that Delphi studies involve panels of ≤ 20 members (Mullen, 2003; Baker et al., 2006). Conversely, while homogeneous samples may warrant smaller sample sizes, heterogeneous samples (such as that involved in the present study) require larger sample sizes (Baker et al., 2006).

The Delphi technique has increasingly involved larger panels to include participants with a range of experiences, in comparison to more traditional small samples of stereotypical 'experts' (Whitman, 1990). As such, sample sizes between 10-50 are considered suitable (Whitman, 1990). Moreover, expert panels containing ≥ 50 participants have been involved in previous Delphi studies (McCarthy et al., 2005; Henschke et al., 2007). Larger sample sizes are advantageous to gather diverse information and opinions (Whitman, 1990). This in turn may result in improved content validity (Hasson et al., 2000). Nevertheless, a sample that is too large (previous samples have included >1000 participants) may become difficult to manage due to the large amounts of data (Vernon, 2009). Additionally, larger samples require more time between the rounds to analyse the data (Whitman, 1990; Hasson et al., 2000). This was found in the present study, whereby the study was expected to last 4-5 months, but in reality had 10 months' duration.

5.3.3.3 Response rates

With a greater sample size, the number of dropouts may increase (Mullen, 2003). With high attrition rates there is a chance of bias. This increases if the participants who drop out carry different characteristics to those who complete the study (Oppenheim, 2000; Mullen, 2003; Keeney et al., 2006). A response rate of ≥ 70% is suggested for each round in order to maintain rigour (Mullen, 2003). In the present study, the response rates to Rounds 2 and 3 among clinicians were 84% and 93% respectively. This was higher than the estimated 70% response rate. In contrast, the response rate of patients on Round 2 was only 40%, but 100% on Round 3.

These findings are in keeping with previous studies employing the Delphi technique, where lower response rates have been attained among patients in comparison to clinicians. For example, response rates between 71%-74% were found among clinicians, in comparison to a response rate of 55% among patients with low back pain (McCarthy et al., 2005; Henschke et al., 2007). Added to this, it is the author's opinion

that patients may have been dissuaded from completing a long questionnaire due to symptoms of pain and/or fatigue. Furthermore, the high dropout rate among patients may be accounted for by possible effects of 'marginalisation' of patients (Baker et al., 2006). That is, patients may have felt that their views were less significant, or that they had less understanding of some of the terminology (Baker et al., 2006). In the present study, patients were recruited before attending physiotherapy and may not have been exposed to the concept of activity pacing.

In comparison, the high response rate and comments made by clinicians demonstrated that activity pacing is an area of clinical interest and uncertainty, and the development of a pacing measure was beneficial. Therefore, higher response rates may be explained. To overcome the disparity between clinicians' and patients' response rates, it is suggested that other methods or triangulating the results may increase service-user involvement (Baker et al., 2006). Indeed, patients will be involved in Stage III, the acceptability interviews, to confirm the understanding of the APQ items and address if any concepts have been omitted or are redundant.

Conversely, the only dropouts between Rounds 2 and 3 were clinicians: two physiotherapists and one clinical psychologist. In order to estimate the effect that these dropouts had on reaching consensus, the percentage of agreement between the questions voted to be included on Round 2 by the clinicians who dropped out and the panel's votes on Round 3 were calculated. One physiotherapist who withdrew demonstrated a 32% agreement with the questions that were voted to be included in the APQ. Despite this low match of inclusion, it was noted that some of the facets that this physiotherapist suggested on Round 1 (for example, prioritising activities, gradually increasing activities and being assertive) were voted to be included on Round 3.

The second physiotherapist who dropped out of Round 3 had a higher percentage of agreement (92%) between the questions they voted to include on Round 2 and those voted by the panel on Round 3. However, this high match rate may be explained by the large number of questions that this participant voted to include (n=68). The clinical psychologist who did not respond to Round 3 voted to include a smaller number of questions on Round 2 (n=43), which coincided with a lower level of agreement (70%) with the panel on Round 3. Since the three participants who did not respond to Round 3 had varying rates of agreement with the panel, the effect of their departure on

consensus is unknown. It is considered that panellists who have less popular opinions may be more likely to drop out of the Delphi rounds, thus the level of consensus may be exaggerated (Sinha et al., 2011). However, between Rounds 2 and 3 there were only three dropouts of 45 participants (7%). Therefore, the author suggests that the impact on consensus may be smaller than had there been a greater rate of attrition between the final two rounds of Delphi, or indeed had a smaller sample participated.

Methods to reduce the number of dropouts include giving participants reminders and also incorporating face-to-face meetings in Round 1 to build rapport with participants (Keeney et al., 2006). It was beyond the scope of the study to meet every panellist since the clinicians were spread across the UK. It might have been possible to meet patients, but this may have led to the researcher influencing patients' answers. Furthermore, the author suggests that meeting panellists may discourage participation in the study due to inconvenience and loss of anonymity. Instead, telephone reminders were made, which were successful in increasing the response rates on Rounds 2 and 3. However, this was at the cost of delaying subsequent rounds of Delphi.

Overall, it is considered that the Delphi study demonstrated rigour as response rates of >70% were achieved for the panel as a whole. Specifically, response rates of 76% and 93% were attained on Rounds 2 and 3 respectively. In addition, 71% of the panel who responded to Round 1 completed Round 3. The panel that completed Round 3 reflected those who completed Round 1 in terms of subgroup sizes, with largest subgroup of physiotherapists, followed by occupational therapists, then patients and then nurses. Unfortunately, the panel that completed Round 3 did not include the clinical psychologist or rheumatology consultant who completed Round 1. The small number of patients who completed Round 3 is less representative of the wide population of patients with chronic conditions of pain and/or fatigue.

5.3.3.4 The expert panel

The expert panel is of great importance in the Delphi technique, since the panel will drive the results (Keeney et al., 2006). The utilisation of an expert panel is considered to be both advantageous and disadvantageous to the Delphi technique. The advantages of involving experts include recruiting individuals with an expertise to highlight the important features of a subject. Expertise is thought to increase content validity

(Hasson et al., 2000). The author considers that the panel demonstrated wide ranging expertise which may increase the content validity of the APQ.

However, the panel that completed the Delphi rounds comprised of uneven proportions of clinicians and patients which may compromise the generalisability of the study. The sample was heavily weighted towards physiotherapists, with the second largest subgroup consisting of occupational therapists. Nevertheless, the author considers that physiotherapists and occupational therapists are the principal clinicians who implement strategies such as activity pacing as part of rehabilitation programmes. Indeed, the ratio of clinicians in the panel (physiotherapists=62%, occupational therapists=21%, nurses=7%, and patients=10%) is not dissimilar to the ratio of clinicians involved in instructing pacing in a large randomised trial (physiotherapists=81%, occupational therapists=9%, psychologists=6%, and nurses=4%) (Lamb et al., 2010).

Although the panel contained a smaller proportion of patients than clinicians, to the authors' knowledge, this is the first study that has engaged both clinicians and patients in a Delphi technique to develop a pacing questionnaire. Indeed, the opinions of the 10 patients who completed Round 1 were incorporated into the development of the APQ items, and patients' votes accounted for 10% of the final votes on Round 3. Involving patients during scale development is beneficial to help to reach consensus on items that are understandable to a lay person.

In comparison, existing pacing subscales have utilised the opinions or observations of either homogeneous groups of clinicians or patients, but not both to develop scale items (Van Lankveld et al., 1994; Nielson et al., 2001; McCracken and Samuel, 2007; Cane et al., 2013). The involvement of clinicians with different professional backgrounds, together with patients resulted in a heterogeneous expert panel being employed in the present study. Heterogeneous expert panels are suitable for fields of research with previous ambiguity, and heterogeneous panels reduce consensus being driven by previously established opinions (Murphy et al., 1998b; Vernon, 2009). Moreover, the author suggests that utilising opinions and language of clinicians and patients may increase the clinical relevance of the APQ, in contrast to scales that are based on researchers' opinions.

Although heterogeneous panels can be advantageous over homogeneous panels, problems may arise if heterogeneity leads to conflict and consensus is not reached due to multiple diverse opinions (Murphy et al., 1998b). However, in the present study, 37 questions were voted to be included in the APQ by ≥ 70% of participants despite the heterogeneity of the panel. This is similar to a previous three-round Delphi technique in which consensus was reached on the 10 most important research areas for low back pain among a heterogeneous panel of chiropractors, general practitioners and physiotherapists (Henschke et al., 2007).

Conversely, the expert panel may be disadvantageous as the selection of experts may be seen to introduce bias into a non-random sample (Keeney et al., 2001). Indeed, the panel were recruited into the present study using purposive sampling as per convention in the Delphi technique. Purposive sampling is required to ensure that participants with an expertise are recruited (Hasson et al., 2000). Since purposive sampling was utilised, it is not intended that the results are fully representative of the population (Hasson et al., 2000; Mullen, 2003; Keeney et al., 2006). The author believes that purposive sampling was appropriate for the qualitative aspect of the Delphi technique as opposed to the quantitative aspect. Moreover, the expert panel may be better judged on the quality of the expertise as opposed to the representativeness (Baker et al., 2006).

5.3.3.5 Definition of an 'expert'

At present, there is no standardised definition of an 'expert' in the Delphi technique (Baker et al., 2006). Indeed, the definition of an expert may be considered arbitrary (Williams and Webb, 1994; Sinha et al., 2011). Many different descriptions of an 'expert' exist and this term is no longer limited to individuals with stereotypical high prestige or qualifications. Instead, more current definitions of an 'expert' include individuals with unique experience or knowledge in an area, to include service-users (Whitman, 1990; Baker et al., 2006).

In order for experts' opinions to be meaningful, they must represent the population from which they were selected and must have knowledge in the chosen area (Baker et al., 2006; Sumsion, 1998). The experts involved in the present study included clinicians (mean clinical experience=18 years) and patients (mean duration of chronic pain and/or fatigue=6 years). However, it is questioned whether expertise can be judged on the number of years of experience alone (Baker et al., 2006). Added to this,

the neutrality of the panel members may be questionable since those who complete the Delphi technique may be more reflective of those with a vested interest in the topic, as opposed to being experts in the field (Keeney et al., 2001). Moreover, the panel may be biased by those who hold strong opinions regarding the topic (Hasson et al., 2000). Indeed, participants' knowledge will naturally sway or bias their views (Keeney et al., 2001). Therefore, panellists are required to be open-minded to other opinions.

The author proposes that the expertise of the panel may be best determined by the content of the APQ. On face validity the items that reached consensus of inclusion into the APQ appear to contain a number of facets of pacing which are in keeping with the literature regarding pacing *(see Chapter 2, Literature review, Section 2.3.4)*. The content of the APQ will be further explored in Stages II and III of the study using factor analysis and acceptability interviews *(see Chapters 6 and 7).*

5.3.3.6 Comparing the subgroups of participants

Of the four subgroups of participants, patients voted the greatest number of items to be included (n=67). This is almost double the number of items that were voted to be included by the subgroup of physiotherapists who voted for the least number of items (n=34). There are a number of reasons that are proposed to explain this finding. Firstly, it is postulated that patients may not have had specific guidance in pacing to channel their opinions. Secondly, patients may have a tendency to give mainly positive answers, that is, give biased answers by 'yea-saying' (Streiner and Norman, 1995). Therefore, patients may give positive answers to avoid an 'incorrect' rejection of an item. However, 21 of the 27 items that the subgroup of patients voted to exclude on Round 3 matched the items that were excluded by the full panel. Therefore, the subgroup of patients demonstrated some discriminatory abilities between items to include and exclude that were similar to clinicians. Although the four subgroups of panellists voted differently across the 94 questions, it was found that only one question of the 37 that were voted to be included showed a difference between the subgroups using Fisher's exact test. Of note, the subgroup that voted differently on this item was comprised of clinicians (occupational therapists) and not patients. However, such analyses should be interpreted with caution due to small numbers of participants in some of the subgroups (specifically, n=4 patients, n=3 nurses).

Of the 57 questions that did not achieve ≥ 70% of the votes, only six questions (11%) showed a statistically significant difference in voting between subgroups of the panel. Therefore, a total of only 7 out of the 94 questions (7%) showed a statistically significant difference between the voting patterns of the four subgroups. Hence, using a heterogeneous sample in the study did not demonstrate vastly divergent opinions that may have threatened reaching consensus.

The smallest subgroup within the panel consisted of nurses (n=3). In order for an APQ item to be included by this subgroup with ≥ 70% consensus, all three nurses had to give a positive vote, so effectively, 100% consensus was required. The subgroup of nurses voted for a total of 46 questions to be included in the APQ. The two largest subgroups: the physiotherapists and the occupational therapists, reached consensus on the fewest number of items. This may allude to larger numbers of participants demonstrating more specific patterns of voting. This may contribute to the lower levels of reliability observed when smaller sample sizes are implemented in consensus methods (Murphy et al., 1998b).

5.3.4 Methodology of the Delphi

5.3.4.1 Round 1 of Delphi

There is no specific guidance regarding the analysis of the open-ended data generated in Round 1 of Delphi (Whitman, 1990; Sumsion, 1998). Furthermore, difficulties arise in analysing vast amounts of data from Round 1 when the sample is large (Hasson et al., 2000). The number of participants who responded to Round 1 in the study was 59, and many participants gave more than 10 answers which resulted in a large amount of qualitative data to analyse. However, the advantage of this large amount of data may be observed in the increased content validity of the APQ. An open-ended Round 1 is beneficial to the Delphi technique as opposed to ranking items on a pre-determined list to reduce researcher influence, together with increasing participants' motivation to complete the rounds (Whitman, 1990).

The initial qualitative data may be explored using content analysis, and by forming subgroups of similar items (Jones and Hunter, 1995; Hasson et al., 2000). Content analysis involves coding the data according to similar concepts, and counting the frequency of occurrence of each concept (Morse and Field, 1996; Spencer et al., 2003). Although a computerised method of content analysis or specific coding of the data was

not performed in the present study, all of the data were categorised into subgroups of common broad themes. This was performed independently by two researchers, and these themes were compared and discussed. The two researchers worked collaboratively to re-phrase all of the items listed under each broad theme to develop potential questions for the APQ.

Unlike other Delphi studies, it was not the intention of Stage I of this study to rigorously identify specific themes within the data. Rather, the purpose of the Round 1 qualitative data analysis was to develop potential APQ items on which to vote in Rounds 2 and 3. The identification of specific themes of pacing occurs in Stage II, the psychometric study. Furthermore, the identification of broad themes and development of APQ items required a longer time period than initially envisaged. Undertaking full content analysis of the qualitative data may have slowed this process further, potentially leading to higher attrition rates.

To limit researcher influence of the development of the APQ questions, the items were written in a manner that maintained participants' original language whilst ensuring readability to a lay person (DeVellis, 1991; Hasson et al., 2000). Participants had the opportunity to comment if they felt the APQ items had misinterpreted the answers they gave on Round 1. No additional information was added in the development of the items (Whitman, 1990; Sumsion, 1998). However, there was a reduction in data at this stage. Over 140 questions were initially developed from Round 1. Repeated information or infrequently occurring data were removed (Whitman, 1990). This may introduce bias since it is considered that panellists should decide which items remain (Hasson et al., 2000). Conversely, too many items may "cloud consensus", or obscure the results (Hasson et al., 2000). Reducing the number of items may have facilitated higher response rates to Rounds 2 and 3 (Pett et al., 2003), which may have reduced bias that arises from high dropout rates (Oppenheim, 2000; Mullen, 2003).

5.3.4.2 Rounds 2 and 3: reaching consensus

Rounds 2 and 3 of Delphi involved voting on the questions developed in Round 1 to either include or exclude each item from the APQ. In order to reach consensus on Round 3, participants were provided with further information to encourage informed decision-making (Duffield, 1993). In Round 3 participants were shown the group scores for each question, together with comments made by other participants in order

to reconsider their original answer. Since participants remained anonymous throughout the study, any changes in voting were not biased by the status or dominance of an individual (Murphy et al., 1998b; Mullen, 2003). Nevertheless, despite anonymity, participants may have followed the votes of the majority rather than being influenced by further evidence-based reasoning (Whitman, 1990). However, the threat of panellists 'conforming' with the group is similar to that observed in any situation that aims for a group agreement (Whitman, 1990).

It might be argued that the rounds of Delphi continue until full consensus is reached or by the 'law of diminishing returns' (Keeney et al., 2006). This might occur when all panellists are in agreement, or when there is no further movement in votes. The number of changed votes between Rounds 2 and 3 had a mean of 25 (of 94 items) per person which demonstrated that panellists did reconsider their votes on Round 3. However, statistical analysis demonstrated that there was a moderate level of agreement between the voting patterns on Rounds 2 and 3 for 81% of the 37 questions voted to be included in the APQ. In addition, 89% of the questions voted to be included in the APQ scored the same or a higher percentage of votes to be included on Round 3. Although the rounds of Delphi can continue up to four rounds or more, the number of rounds is governed by time restrictions of the study, together with participant attrition and fatigue (Keeney et al., 2006). Three rounds were considered appropriate for the study given the resources available, and more importantly, since there appeared to be a convergence of opinions towards the 37 questions that had been voted into the APQ.

5.3.4.3 Missing answers

There was a slight increase in missing and duplicate answers on Round 3 compared to Round 2. This may be due to human error or fatigue in completing the third round of an extensive questionnaire (Whitman, 1990; Hasson et al., 2000). The maximum number of missing or duplicate answers for an individual APQ item was two. Of the nine questions that had either two missing or duplicate answers, four of these were voted to be included in the APQ. Therefore, the missing or duplicate answers did not necessarily reflect unpopular items. Indeed, the APQ item that had the lowest percentage of votes of inclusion, Question 40: *"I worked at a set speed on each task"*, had no missing or duplicate answers.

5.3.4.4 Readability of the APQ questions

The 37 questions that reached consensus to be included in the APQ on Round 3 were assessed for readability twice using the Flesch Reading Ease scale. Together with this, advice from The Pennine Acute Hospitals NHS Trust Patient Information Review Group led to some modifications of a few items. Modifications included reducing the sentence length and minor grammatical changes. These modifications were undertaken only where improvements were seen in readability, while maintaining the content of the item on which consensus had been reached.

After splitting Question 62 into two separate questions, the APQ contained 38 questions. Of these 38 questions, 24 had a Flesch Reading Ease score of >60.0 *(see Appendix 5, Table 5.1 Questions voted to be included in the APQ, with readability scores)*. This suggests that 63% of the questions have a standard reading ease. However, this does not necessarily indicate that 37% of the questions are difficult to read. Since Flesch Reading Ease scores are calculated by the number of syllables, some questions had low readability scores as a result of containing the four-syllable word 'activity'. For example, Question 20: *"I used an activity diary to monitor my activity pattern"* had the lowest Flesch Reading Ease score of 19.0 although conceptually it is a simple and readable statement. As discussed previously, the Flesch Reading Ease score provides a rough guide to assessing one aspect of readability (Paz et al., 2009).

5.3.5 Facets of pacing

5.3.5.1 Facets of pacing in the APQ

As a result of the consensus technique, the APQ appears to contain a number of different facets, such as balancing activity with rest, and undertaking consistent amounts of activity. This is in concordance with existing literature that has described pacing as a strategy to use rest breaks to reduce an exacerbation of symptoms, and to avoid the underactivity-overactivity cycle that commonly presents in chronic conditions (Birkholtz et al., 2004a; Gill and Brown, 2009). Furthermore, the APQ contains items regarding alternating activities/positions, planning, prioritising and setting goals, which is consistent with the literature (Sharpe, 2002; Birkholtz et al., 2004b; Nijs et al., 2008).

5.3.5.2 Comparison of the APQ with existing pacing subscales

In comparison to existing pacing subscales, the APQ appears to contain a wider number of facets. Existing pacing subscales appear to measure pacing as an adaptive strategy, whereas the APQ may contain concepts that describe pacing as a rehabilitative strategy, for example, by including quota-contingent items and items that refer to gradually increasing activities.

The pacing subscale of the Coping with Rheumatic Stressors (CORS) questionnaire (Van Lankveld et al., 1994) contains only 10 items which focus on reducing activities, for example, slowing and stopping activities, and avoiding or delegating heavy tasks. However, similarities are seen between some of the CORS items and the APQ items, for example, the CORS pacing item: *"I bear my limitations in mind"*, is similar to APQ Question 83: *"I accepted that I have some limitations due to my symptoms"*. The CORS pacing item: *"I disperse activities over the day"*, is similar to APQ Question 23: *"I spread different types of activities across the day".* Interestingly, a number of APQ questions are similar to those contained in the CORS subscale of 'seeking creative solutions'. For example, the CORS item: *"I try to find new ways of getting things done",* is similar to APQ Question 65: *"I was creative and found new ways of doing tasks"*. Furthermore, the CORS item: *"I think about planning my activities",* resembles APQ Questions 70 and 71 regarding planning *(see Appendix 5, Table 5.1 Questions voted to be included in the APQ, with readability scores)*. Finding creative solutions may be a facet of activity pacing, and previous literature has alluded to this concept (Friedberg and Jason, 2001; Birkholtz et al., 2004b; Gill and Brown, 2009).

The six items contained in the Chronic Pain Coping Inventory (CPCI) pacing subscale (Nielson et al., 2001) refer to breaking down tasks, slowing down, working at a steady speed and using breaks. Similarly to the CPCI pacing subscale, the APQ contains items that refer to breaking down tasks and using breaks. However, the APQ does not contain items that refer to slowing down or going at a steady speed. Indeed, the item that scored the lowest votes (5%) was Question 40: *"I worked at a set speed on each task"*. The APQ items are more in keeping with the findings from a national survey among 49 occupational therapists, whereby the concept of slowing down was least favoured (Birkholtz et al., 2004b).

Four of the six items of the CPCI pacing subscale contain phrases such as, *"despite my pain"*, or, *"distract myself from my pain"*. Although the aim of the CPCI is to measure patients' ability to cope with pain (Nielson et al., 2013), it is the author's opinion that such questions may reinstate a pain-contingent approach. Conversely, the expert panel voted to exclude 14 potential APQ items that made reference to symptoms. The three APQ items referring to symptoms that reached consensus are APQ Question 17: *"I changed activities before I had an increase in my symptoms",* APQ Question 53: *"I gradually increased activities that I had previously been avoiding because of my symptoms"*, and APQ Question 83: *"I accepted that I have some limitations due to my symptoms"*. However, the author proposes that the aims of these items are to change activities, to gradually increase activities and to accept activity levels. Furthermore, the questions in the APQ that refer to symptoms account for only three of 38 questions (8%) of the APQ questions, in comparison to four of the six questions (66%) of the CPCI pacing subscale that refer to pain. Moreover, the APQ contains four questions that refer to quota-contingent strategies, for example, APQ Question 71: *"I planned in advance how long I would spend on each activity"*. This is important since quota-contingent behaviours have been recommended over symptom-contingent behaviours (Birkholtz et al., 2004a; Gill and Brown, 2009).

The Pain and Activity Relations Questionnaire (PARQ) pacing subscale contains six items (McCracken and Samuel, 2007). Of these six items, only two appear similar to the questions voted to be included in the APQ, namely PARQ pacing subscale items: *"I use repeated rest breaks to help me complete activities"* and *"I split tasks into parts and do them one step at a time"*. Three items contained within the PARQ pacing subscale are pain-focused. Again, this is dissimilar from the APQ, since many symptom-contingent questions did not reach consensus of inclusion. For example, APQ Question 92: *"I avoided working at levels of discomfort so that I did not increase my symptoms"* attained 17% of votes and was therefore excluded.

The Patterns of Activity Measure-Pain (POAM-P) pacing subscale contains 10 items, of which four items refer to breaking down tasks, four refer to taking breaks and two refer to going 'slow and steady' (Cane et al., 2013). The author proposes that this pacing subscale appears to be an extension of the CPCI pacing subscale, and it was developed by one of the same researchers. Similarly to the CPCI pacing subscale, the POAM-P pacing subscale measures limited themes of pacing. However, in contrast to

the CPCI pacing subscale, the POAM-P pacing subscale makes no reference to pain. Therefore, the newly developed POAM-P pacing subscale may demonstrate a shift in focus away from symptom-contingent activities, which is more akin to the APQ.

The existing pacing subscales do not include additional facets that were voted to be included in the APQ such as setting goals, gradually increasing activities, not over-doing or under-doing activities, assessing activity levels, using activity diaries and accepting activity levels. These facets have previously been suggested as components of pacing in the literature (Friedberg and Jason, 2001; Sharpe, 2002; Birkholtz et al., 2004a; Gill and Brown, 2009; Nielson et al., 2012). Additionally, the APQ contains novel items, such as having a flare-up plan, being assertive and using support. Due to the different facets of pacing contained within the APQ, it appears that this scale may reflect the proposed multifaceted nature of pacing.

5.3.6 Participants' comments

The comments made by the expert panel on Rounds 2 and 3 highlighted interesting concepts for discussion between the rounds. The concept of utilising rest breaks evoked a number of comments querying whether the rest was pre-planned, occurred as a consequence of over-exertion (therefore in the absence of pacing), or whether it was used as a means of avoidance. Interestingly, of the eight questions that contained the term 'rest', four were voted to be included in the APQ. Of note, these four questions refer to either breaking up activities with rest breaks or using planned rests.

Some of the potential APQ questions were highlighted as alluding to avoidance, and panellists commented that avoidance behaviour was different to pacing. Of the 22 questions that generated comments querying avoidance behaviour, only five were voted to be included. It is the author's opinion that these five items refer to using planned rest breaks, splitting up activities, changing activities and gradually increasing activities that have previously been avoided by the individual. The author considers these strategies to encourage regular activity, as opposed to avoiding activity. Therefore, such items refer to strategies that appear to follow more rehabilitative pacing than adaptive pacing.

It is noteworthy that five other potential APQ items that were highlighted as alluding to avoidance referred to energy conservation (in keeping with the envelope theory and

adaptive pacing therapy). These five items were not voted to be included in the APQ. However, two different items that refer to 'energy' were voted to be included. These questions refer to energy management as opposed to energy conservation: APQ Question 27: *"I spread out the activities that require a high amount of energy"* and APQ Question 28: *"I switched between activities that use high and low amounts of energy" (see Appendix 5, Table 5.2 Round 3 votes for all potential 94 questions of the APQ).*

In addition, the concept of 'pacing up' or 'grading activities' led to comments from panellists. Two of the five items that generated comments regarding 'pacing up' were voted to be included. This finding is in agreement with previous literature in which grading up, or gradually increasing activities has been suggested as a facet of pacing (Birkholtz et al., 2004a; Gill and Brown, 2009). However, this is in disagreement with Nielson et al. (2001) who stated that gradually increasing activities may be resultant, but not a facet of pacing.

Several panellists queried how to manage items that reflected 'poor' pacing, with regards to voting to exclude such items or voting to include the items under the premise of reverse scoring. Interestingly, all of the potential APQ items were developed based on the responses to the Round 1 open-ended question which asked for the 10 most important factors involved in activity pacing, and not the factors that are considered to be 'poor pacing'. All items were purposefully written in a manner so that they would not be reverse scored to reduce incorrect answers due to confusion. Of note, items that were highlighted as reflecting 'poor pacing' were voted to be excluded from the APQ.

A small number of panellists suggested that it might be difficult to develop a generic questionnaire for both chronic pain and fatigue. Some participants proposed that different subgroups of patients may answer APQ items dissimilarly, for example, Question 94: *"I stopped an activity before I became too tired"*. With regards to avoidance behaviour, panellist P60 commented:

> *"…avoidance is rare in CFS, it is more common in pain. Only a small percentage of patients become avoidant in CFS, often it is about reducing their high energy levels of engagement." (P60, clinician)*

However, there is an overlap in the symptoms and presentations of chronic conditions of pain and fatigue (Clauw and Crofford, 2003). Furthermore, rehabilitation approaches are advised that manage patients holistically to include diverse symptoms of pain and fatigue (Aggarwal et al., 2006). Moreover, it was intended that the APQ would be developed for a heterogeneous patient group so that it could be implemented more widely than existing pacing subscales.

The author considers that although panellists did not engage in formal discussions as would be experienced in the nominal group technique, the utility of the comments booklet enabled interactions between participants which facilitated reaching consensus, for example,

> *"Revisiting my own answers (after reading how others had answered) raised an awareness that sometimes the questions seemed to be seeking to identify the knowledge base; at others they could be helpful in identifying a lack of knowledge, both important for clinicians." (P98, clinician)*

The original 94 APQ items reflected the variety of opinions regarding activity pacing. Items that some participants considered to reflect good pacing, others considered to reflect poor pacing. Some panellists suggested that pacing involved concepts such as relaxation and planning, while others disagreed. Indeed, the conflict between pacing to reduce symptoms (such as adaptive pacing therapy) or to increase activities (such as rehabilitative pacing) was highlighted by panellist P74:

> *"It seems that there is a tension between pacing to manage/reduce symptoms, and pacing in order to optimise function." (P74, clinician)*

This diversity of opinions may explain in part why there is currently no standardised definition of activity pacing (Birkholtz et al., 2004a; Gill and Brown, 2009). This confirms the necessity of a consensus method to develop the APQ.

5.3.7 Strengths, limitations and rigour of the Delphi study

5.3.7.1 Strengths and limitations

One of the major strengths of this stage of the study was the implementation of the Delphi technique. This allowed for a large heterogeneous panel from across the UK to participate which is anticipated to increase the content validity of the scale (Hasson et al., 2000). Aside from wide locational advantages, the Delphi is beneficial as it allows

panellists to take time to consider their answers which is not possible in group settings (Sumsion, 1998). To maintain rigour of the Delphi, >70% response rate is advised for the subsequent rounds of Delphi (Sumsion, 1998). Over 70% response rates were attained on both Rounds 2 and 3 of the study, thus reducing this potential for bias.

It is suggested that the effect of bias was reduced by maintaining participant anonymity throughout the study. Maintaining anonymity had the advantage of allowing panellists to answer honestly without feeling judged by other panel members (Williams and Webb, 1994). Furthermore, each answer given by an individual panellist had equal weighting (Keeney et al., 2001). However, it is considered that the level of anonymity of the Delphi technique may in fact be termed 'quasi-anonymity' since the panellists are known to the researcher, and some panellists may even know each other in their field of work or interest (Keeney et al., 2001). Indeed, quasi-anonymity may be compromised if participants work in the same department or converse about the study (Keeney et al., 2006). Although the data were analysed via panellists' study codes, the researcher was aware of participants' identities, therefore again, full anonymity was not achieved. Quasi-anonymity is required for the Delphi technique to allow the researcher to follow up subsequent rounds (Keeney et al., 2006).

Further efforts to reduce bias include determining the consensus level before commencing the study (Keeney et al., 2006). This aims to reduce researcher influence on the study (Williams and Webb, 1994). Similarly, the number of rounds was pre-determined. However, maintaining the pre-determined number of rounds may not always be appropriate if it appears that consensus has not been reached. To explore the level of consensus, the convergence of answers can be demonstrated through the variance between voting on the subsequent rounds (Hasson et al., 2000). Cohen's kappa statistic found good agreement between the votes on Rounds 2 and 3 which adequately confirmed consensus had been attained in the present study. Furthermore, it was considered that the APQ would be further developed in Stage II, assessing the psychometric properties of the APQ.

Participants' language was maintained as closely as possible to reduce bias but also increase the clinical utility of the APQ. Added to this, the APQ items were assessed twice for readability and advice was sought from a patient information guidance group. It may be considered that the output of the Delphi technique has both face validity

since experts nominated the original data, but also concurrent validity since the expert panel members agreed with each other (Williams and Webb, 1994). In addition, concurrent validity may be demonstrated if the findings of the consensus technique are in keeping with the current literature (Murphy et al., 1998b). Indeed, the items contained within the APQ appear to represent a number of facets of pacing that have been described in the literature.

There may inevitably be a number of potential limitations in the present study. The Delphi technique collects both quantitative and qualitative data. However, the interpretation of these data is not prescriptive (Keeney et al., 2001). Researcher bias may have been introduced during the development of items from the qualitative data generated in Round 1 (Sumsion, 1998). However, all of the diverse data gathered in Round 1 were attempted to be represented equally on Rounds 2 and 3. Bias may have been introduced by the phrasing of the open-ended question on Round 1 which determined the data initially generated (Hasson et al., 2000). However, the open-ended question introduces less bias than other forms of Delphi in which Round 1 involves ranking a pre-determined list (Hasson et al., 2000).

There was a higher dropout of patients in comparison to clinicians. The effect of the disproportionate dropout rates is unknown. However, the expert panel consisted of a heterogeneous group, and this is the first panel of clinicians and patients (known to the author) that has engaged in the development of an activity pacing questionnaire.

The Delphi technique has been criticised because it does not facilitate group discussions (Keeney et al., 2001), and it may be argued that panellists state opinions without any justification (Hasson et al., 2000). Therefore, panellists are potentially less accountable for their answers (Vernon, 2009). In the present study, panellists were invited to make comments and several panellists used this facility to explain their answers. The Delphi technique, like other surveys, may yield answers that participants deem ‘socially desirable’, or answers that are predicted to be favourable to the researcher (Keeney et al., 2001). Furthermore, participants may vote with the majority, following assumptions that they were previously wrong, as opposed to readjusting their belief or understanding (Keeney et al., 2006).

The Delphi technique had a longer duration than anticipated. This was due to the larger panel size, leading to a vast amount data to analyse, together with allowing participants longer to return the Delphi rounds. Indeed, the Delphi technique is a time-consuming method in contrast to a single questionnaire (Keeney et al., 2006). The impact of the longer duration of Delphi may present as a loss of motivation and increased attrition (Vernon, 2009). However, a single questionnaire does not undertake a process of reaching group consensus (Keeney et al., 2006).

It is of note that although consensus was reached on 37 questions for the APQ, it cannot be assumed that the 'correct' decisions were made (Hasson et al., 2000; Vernon, 2009). Indeed, an alternative panel voting on the same questions may have reached a different outcome (Hasson et al., 2000). Furthermore, it cannot be assumed that all of the different views regarding activity pacing have been explored. A different sample containing other health professionals and patients may have proposed other facets, leading to consensus on different items (Murphy et al., 1998b).

Similarly, a different open-ended question on Round 1, or a separate research team may have developed alternative items. Therefore the reliability (or repeatability) of the Delphi technique is questioned (Keeney et al., 2001). The validity of the Delphi technique may also be debated. Conversely, content validity is assumed if the expert panel are representative of the target population (Keeney et al., 2001). This is indeed the case in the present study, since both patients and clinicians in the field of chronic conditions were represented.

5.3.7.2 Rigour from a qualitative perspective

Judging the Delphi technique according to quantitative methods may be inappropriate (Keeney et al., 2001). Since the Delphi technique collects both quantitative and qualitative data it may be that more constructivist (qualitative) criteria are met as opposed to postpositivist (quantitative) (Hasson et al., 2000; Keeney et al., 2001). Therefore, the Delphi technique may be more appropriately critiqued using four subcategories of qualitative rigour: truth value (representativeness), applicability (generalisability), consistency, and neutrality (the recognition of bias) (Sandelowski, 1986; Hasson et al., 2000). With regards to the Delphi technique, the author considers that the methods demonstrated representativeness of the panel, since the opinions of the panel were used to develop the APQ items, and the items that reached consensus were

determined by the panel. Indeed, representativeness may be enhanced through respondent validation (Sandelowski, 1986). The author believes that panellists had the opportunity to validate their answers through voting whether to include or exclude an item and by making comments on Rounds 2 and 3.

The applicability of the Delphi technique refers to the transferability of the findings to the sample that was represented. This sample is not intended to be statistically representative (Sandelowski, 1986). Therefore, the purposive sample may not be appraised as a random sample might be assessed in quantitative studies (Mullen, 2003). By stating the demographics of the sample, the applicability of the sample can be inferred. The applicability of the APQ will be further explored in Stage II, the psychometric study, when it will be administered to a larger group of patients with chronic conditions.

The author proposes that the consistency (repeatability) of the Delphi technique may be increased in comparison to other constructivist research methods due to the nature of the iterative rounds. Indeed, an adequate level of consistency was shown between the voting patterns on Rounds 2 and 3. Consistency may also be enhanced if there is a clear audit trail (Sandelowski, 1986). An audit of the study may be retraced using the documentation of all participants' answers to the three rounds. Furthermore, a previous study demonstrated consistency of the Delphi technique by inviting two different panels (n=16 and 34) to determine nursing competencies. The two panels showed high agreement in findings of 93% of the items (Duffield, 1993). However, the two samples involved in the study by Duffield (1993) comprised of homogeneous panels of nurses working in similar fields which may explain some comparable opinions.

Neutrality refers to the recognition of bias (Sandelowski, 1986). It is recognised that the Delphi technique has the potential for researcher bias (Vernon, 2009). Researchers determined the open-ended Round 1 question and selected the expert panel (Vernon, 2009). In addition, the author analysed the data on each round, presented these data back to the panel and made reminder calls as necessary.

5.3.8 Conclusion

The Delphi technique was an appropriate method to implement in the development of the APQ since pacing has previously yielded diverse opinions. The content of the APQ is in keeping with descriptions of pacing that exist in current literature, but demonstrates more facets of pacing in comparison to existing pacing subscales. This is the first study, to which the author is aware, that has involved a heterogeneous panel of clinicians and patients in the development of an activity pacing questionnaire. Stages II and III of the study will further increase service-user involvement with the aim of addressing the lower recruitment rates of patients in the Delphi study.

5.3.9 Summary

A stand-alone, comprehensive activity pacing questionnaire has been developed in Stage I, the Delphi technique. Following three rounds of Delphi, consensus was reached across a panel of clinicians and patients regarding the questions to be contained within the APQ. The APQ consists of 38 questions that appear to contain different broad themes, such as, breaking down tasks, spreading activities and gradually increasing activities. However, the number of specific themes, and the number of items contained within each theme is unknown.

The next stage of the study will assess the psychometric properties of the APQ, to include the exploration into the presence of these themes of pacing, together with the reliability and validity of the APQ.

Chapter 6. Stage II: Assessing the Psychometric Properties of the Activity Pacing Questionnaire (APQ)

6.1 Methods

6.1.1 Aims of Stage II

As a result of Stage I, the Delphi technique, the Activity Pacing Questionnaire (APQ) contained 38 questions which appeared to contain a number of different themes of pacing (for example, breaking down tasks and gradually increasing activities). The purpose of Stage II, the psychometric study, was to further develop and test the psychometric properties of the APQ. This included the identification of underlying pacing themes of the APQ and assessing the reliability and validity of the scale.

6.1.2 Justification of methods

6.1.2.1 Study design

In order to explore the psychometric properties of the APQ, Stage II of the study had a quantitative, cross-sectional design, collecting data from self-report questionnaires. Patients attending physiotherapy for the management of chronic conditions were invited to complete the APQ together with two existing pacing subscales, and validated measures of pain, fatigue, anxiety, depression, avoidance and physical and mental function. Statistical analyses were undertaken with regards to the demographics of the sample. Exploratory factor analysis was utilised to explore the presence of themes of pacing in the APQ. Reliability of the APQ was assessed via estimations of internal consistency and test-retest measures of agreement. Convergence validity was assessed via correlations with the existing pacing subscales, and associations between the APQ themes and symptoms of chronic conditions.

6.1.2.2 Participants

Patients with chronic low back pain, chronic widespread pain and chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME) were invited to participate in Stage II, the psychometric study. This sample was considered to be representative of patients with persistent symptoms of pain and fatigue who are commonly advised to pace their activities to manage their condition. Furthermore, patients with different chronic conditions were included with the aim of validating the APQ across a heterogeneous group of conditions to increase the generalisability and clinical utility of the scale.

A consecutive sample of patients was invited to participate with the aim of reducing selection bias. The sample included both current and retrospective patients. The benefits of inviting current and retrospective patients included increasing the available sample size. Added to this, involving retrospective and current patients enabled comparisons to be made between patients at different stages of their treatment (that is, pre- or post-intervention). Furthermore, it is envisaged that the APQ will be used in the future to assess the changes in pacing that occur with treatment. In addition, current patients attending rehabilitation groups designed specifically for chronic conditions were invited to participate. The rehabilitation groups facilitate the implementation of coping strategies such as pacing, and patients can choose to attend a group following the attendance of individual treatment sessions. The aim of recruiting patients who had received individual and group treatment was to enable comparisons to be made between patients who had received different levels of instruction regarding pacing.

A sample of current patients who completed the APQ was invited to participate in the test-retest arm of the study. This was a convenience sample for pragmatic reasons since it was proposed that current patients may have a higher response rate due to their status as either awaiting treatment or currently attending treatment.

Inclusion criteria

Patients were invited to participate if they were attending physiotherapy in The Pennine Acute Hospitals NHS Trust for the management of a primary presentation of chronic low back pain, chronic widespread pain or CFS/ME (of over three months' duration) currently or previously within the last two years (that is, discharged from physiotherapy from September 2009 onwards). Patients were eligible to participate if they had been referred to physiotherapy by either a GP or a hospital consultant and had attended a minimum of one appointment. Patients were aged 18 or over, and were required to have a good understanding of the English language.

Exclusion criteria

Patients with a condition for less than three months' duration were excluded. Patients with evidence of a serious underlying pathology (for example, cancer), an inflammatory condition (such as rheumatoid arthritis), or a neurological condition (such as a cerebrovascular accident) were not invited to participate. Due to the nature of the

questionnaire design study, patients who were unable to read and write in English were considered ineligible to participate.

6.1.2.3 Sample size

A sample of 300 participants was estimated to be sufficient for factor analysis of the APQ (Tabachnick and Fidell, 2001). Furthermore, this sample size appeared realistic from the number of patients referred to the physiotherapy department. It was envisaged that approximately 600 patients would be approached in order to recruit 300 patients for data analysis. Test-retest reliability of the APQ was estimated using an intraclass correlation coefficient (ICC). A subgroup of 60 current patients was approached for the test-retest analysis in order to estimate an ICC of 0.90 with a 95% confidence interval of +/- 0.1 (Machin et al., 2009).

6.1.2.4 Data collection

The questionnaire booklet included demographic questions regarding age, gender, condition, duration of symptoms and employment status. The scales in the questionnaire booklet included the APQ, and the pacing subscales of the Chronic Pain Coping Inventory (CPCI) (Nielson et al., 2001) and the Pain and Activity Relations Questionnaire (PARQ) (McCracken and Samuel, 2007) to explore associations between the pacing scales. In addition, the pacing subscales of the CPCI and PARQ have not previously been validated for a heterogeneous group of patients with conditions of chronic pain and/or fatigue. There is currently a paucity of test-retest reliability data for the existing pacing subscales. Therefore both existing pacing subscales were included in the test-retest arm of the present study.

Of note, the pacing subscale of the Coping with Rheumatic Stressors Questionnaire (Van Lankveld et al., 1994) was omitted from the questionnaire booklet since it was developed in Dutch and developed specifically for rheumatoid arthritis. The Patterns of Activity Measures-Pain pacing subscale (Cane et al., 2013) was published after the psychometric study was undertaken and was therefore not included in the questionnaire booklet.

6.1.2.5 Pacing scales

A five-point Likert scale was selected as the scoring system for the APQ. The Likert scale is one of the most frequently implemented scoring systems (Pett et al., 2003).

Furthermore, the five-point Likert scale was in keeping with the scale utilised in Rounds 2 and 3 of the Delphi technique of Stage I, which appeared to be acceptable to participants. As stated in Stage I, the five-point Likert scale holds the benefits of producing data that are considered to be quantitative for analysis, together with producing data that have shown to be as reliable as larger scales with more than five intervals (Streiner and Norman, 1995; Wild and Seber, 2000; Dawes, 2008) *(see Appendix 6, Questionnaire booklet. The APQ is entitled 'The new activity pacing questionnaire')*. In comparison to the six options of the 0-5 rating scale implemented in the PARQ pacing subscale, a 0-4 scale with a central option was selected for the APQ. This was purposely selected to allow participants to give a mid-point answer, to reduce being forced to give potentially inaccurate positive or negative answers (Pett et al., 2003). The PARQ pacing subscale labels only the anchors 0='never' and 5='always' *(see Appendix 6, Questionnaire booklet. The PARQ pacing subscale is entitled 'Pacing Scale 2')*. Conversely, each point on the APQ Likert scale was labelled (0='never did this', 1='rarely did this', 2='occasionally did this', 3='frequently did this' and 4='always did this') with the aim of increasing the ease of completion. In contrast, each item of the CPCI pacing subscale is rated in terms of a number of days (0-7 days). The author considered that a Likert scale may be more acceptable for participants *(see Appendix 6, Questionnaire booklet. The CPCI pacing subscale is entitled 'Pacing scale 1')*.

Unlike the pacing subscales of the CPCI and PARQ where minimal instructions are provided, instructions were written for the APQ to direct patients to consider their answers in terms of all of their activities. Since pacing can relate to all different activities patients were advised to consider not only physical activities, and examples were given such as walking, working, reading, socialising and household tasks.

Both the APQ and the CPCI pacing subscale invite patients to consider their answers as a reflection of the last seven days. It has been debated whether a seven day time frame is sufficient to be fully representative of patients' behaviour since their answers may be affected by specific events or seasons (Oppenheim, 2000). Conversely, due to problems of memory recall, a time frame of no more than a few days may be more appropriate to reduce inaccuracies (Oppenheim, 2000). However, for the context of the scale, it was considered that a seven day recall period would be reflective of patients' typical activities across the week, to include both work and leisure activities. Furthermore, it was envisaged that the seven day time frame would be more representative of patients'

symptoms as opposed to capturing a few 'good' or 'bad' days. Of note, many validated scales implement a seven-day recall period *(see Section 6.1.2.6)*. Interestingly, the PARQ pacing subscale does not give a recall period over which patients rate their answers.

Following the APQ and each of the two existing pacing subscales, there was a five-point Likert scale for patients to indicate how easy they found the scales to complete. Together with this, there was space for patients to write comments about the individual pacing scales. The aim of this was to compare the acceptability of the three pacing scales.

6.1.2.6 Validated Measures

The questionnaire booklet included validated measures of the symptoms commonly reported by patients with chronic pain and/or fatigue, together with some of the symptoms associated with the fear-avoidance model *(see Chapter 2, Literature Review, Section 2.3.1)*. The measures included:

1.) Eleven-point Numerical Rating Scale (NRS) to measure current and usual pain (Jensen et al., 1994)

2.) Chalder Fatigue Questionnaire (CFQ) (Chalder et al., 1993)

3.) Hospital Anxiety and Depression Scale (HADS) (Zigmond and Snaith, 1983)

4.) Short version of the Pain Anxiety Symptoms Scale (PASS-20) to measure pain related fear and avoidance (McCracken and Dhingra, 2002)

5.) Short-Form 12 (SF-12) to measure mental and physical function (Ware et al., 1996)

1.) Eleven-point Numerical Rating Scale (NRS)

Commonly used measures of pain include: visual analogue scales (100mm horizontal line, with bipolar anchors: 'no pain' and 'worst imaginable pain'), numerical rating scales (numbers written on a line, for example, 0-10), verbal rating scales (verbal descriptors of pain) and the faces pain scale (faces depicting varying levels of pain) (Ferreira-Valente et al., 2011). The 11-point visual numerical rating scale (NRS) was selected for the present study due to demonstrating superior sensitivity in comparison to other pain scales (Chanques et al., 2010; Ferreira-Valente et al., 2011). Although Chanques et al. (2010) found the visual NRS had high sensitivity (96.6%), it had lower specificity (63.4%). However, the specificity of the NRS remained higher than the visual analogue scale (horizontal scale=53.6%, vertical scale=56.1%) (Chanques et al., 2010).

Further advantages of the NRS in comparison to other pain rating scales include acceptability, ease of use in both written and verbal form, together with significantly higher success rates of completion by patients (Chanques et al., 2010; Ferreira-Valente et al., 2011). Moreover, the NRS provides data that can be analysed using parametric statistics in comparison to the categorical data provided by the verbal rating scale and the faces pain scale (Ferreira-Valente et al., 2011).

Together with different formats of pain rating scales, the scales can vary in the number of intervals, for example, from 4 to 101 points (Jensen et al., 1994). An 11-point NRS was selected for the present study. An 11-point rating scale has previously demonstrated similar sensitivity to a 101-point scale amongst a sample of 124 patients with chronic pain (Jensen et al., 1994). Indeed, patients frequently applied intervals of five and 10 to the 101-point scale, and therefore potentially used only 21 or 11 points on the scale (Jensen et al., 1994). Of note, scales with six or fewer intervals were less sensitive to change pre- to post-treatment (Jensen et al., 1994). This may be relevant to the test-retest arm of the study since a second measure of pain will be administered. However, the findings of Jensen et al. (1994) were estimated by administering only the 101-point scale and re-scaling it to form 21, 11, 6, 4, 3 and 2-point scales. It cannot be assumed that patients would answer the individual scales identically to the re-scaled 101-point scale. Despite this, the 11-point scale is the most frequently used NRS scale, and holds benefits of ease of completion together with responsiveness (Bolton et al., 2010).

Jensen et al. (1994) implemented pain scales that measured worst pain, least pain, current pain, average pain and usual pain. The present study implemented only two pain measures: current and usual pain. Two measures were deemed adequate to reflect different aspects of pain, while reducing the burden of the questionnaire, since pain was only one dimension of chronic conditions that was measured. ‘Current pain’ was selected since pain was measured at two different time points for those participants involved in the test-retest analysis, during which time changes may have occurred in symptoms. ‘Usual pain’ was selected to address the natural daily variations in symptoms that may not be reflected by ‘current pain’ (Bolton, 1999). Indeed, the measure of usual/average pain has been found to be an accurate reflection of patients’ pain experiences in relation to the actual average of repeated measures of pain (Bolton, 1999). This was especially important for participants not involved in the test-retest analysis in the present study.

Added to this, current pain ratings can be influenced by factors such as emotions on that specific day (Gendreau et al., 2003).

In the present study, patients were invited to rate their pain over a one-week recall period, similar to the studies by both Jensen et al. (1994) and Bolton et al. (1999). However, the recall of pain may be affected by factors such as memory bias. For instance, ratings of usual pain may be biased by current pain and worst pain (Gendreau et al., 2003). The author considers that all self-reported scales may be affected by such variations due to the subjective nature of questionnaires.

2.) Chalder Fatigue Questionnaire

The Chalder fatigue questionnaire measures the severity of fatigue, on a scale of 'better than usual', 'no more than usual', 'worse than usual' and 'much worse than usual' (Chalder et al., 1993). This scale can be scored either on a continuous Likert scale (0-3) or on a bimodal scale (0,0,1,1) (Chalder et al., 1993). The scale consists of 11 questions, with a 2-factor solution: physical fatigue (7 items) and mental fatigue (4 items) (Chalder et al., 1993). The scale has good reliability (Cronbach's alpha=0.89), and concurrent validity in terms of sensitivity and specificity with the Revised Clinical Interview Schedule Fatigue question (Chalder et al., 1993).

The scale was originally developed using a sample of patients in a General Practice setting, but it was designed for use in both the hospital and out-patient settings (Chalder et al., 1993). Although the Chalder fatigue questionnaire was designed for patients with CFS/ME, it purposefully does not include questions referring to the specific symptoms of CFS/ME. Furthermore, the Chalder fatigue questionnaire has been validated across a wide range of patients (Dittner et al., 2004). The scale has been used in studies exploring chronic widespread pain in general practice (Rohrbeck et al., 2007), and stress and fatigue in general practice (Kocalevent et al., 2011).

Other scales that measure fatigue include the Fatigue Severity Scale (Krupp et al., 1989). This scale contains nine questions rated on a 7-point Likert scale. However, this scale was developed for neurological conditions, for example, multiple sclerosis (Dittner et al., 2004). The Chalder fatigue questionnaire was selected for the present study, due to its relevance to the sample, the brevity of both the scale and the scoring system, together with the items contained in the scale. The Chalder fatigue questionnaire contains items

relating to physical and cognitive abilities, using rest breaks and initiating activities, which are pertinent to the concept of pacing.

The 4-point Likert scale was utilised in the present study due to the wider range of scores that can be attained (0-33) as opposed to the bimodal scoring system. Furthermore, the Likert scale is commonly utilised, for example, in the large scale PACE trial (White et al., 2011). The scores were summated to give two subtotal scores for physical and mental fatigue for analysis, as recommended (Chalder et al., 1993). Where no specific guidance exists with regards to managing missing data, a conventional allowance of 10% missing data was applied to sum the physical and mental subscales in order to maximise the amount of data for analysis. Of note, higher scores indicate more fatigue.

3.) Hospital Anxiety and Depression Scale (HADS)

The Hospital Anxiety and Depression Scale (HADS) is a widely used measure that was developed to be used in non-psychiatric hospital settings to assess symptoms of anxiety and depression associated with somatic conditions (Zigmond and Snaith, 1983; Bjelland et al., 2002). The HADS is a generic scale and has been translated into over 30 different languages (Zigmond and Snaith, 1983; Bjelland et al., 2002). The HADS has been used in previous studies exploring groups of patients with chronic low back pain (Woby et al., 2008), chronic widespread pain and fibromyalgia (Arnold et al., 2007) and CFS/ME (Morriss et al., 1998; White et al., 2011).

The HADS contains two subscales: HADS-A, which measures potential anxiety and HADS-D which measures potential depression. Patients are asked to complete the HADS in view of their symptoms over the past week and to answer each question on a 4-point scale (0-3). The subscales both contain seven questions and have a range of scores from 0-21 where higher scores indicate a greater level of potential anxiety/depression (Zigmond and Snaith, 1983). Both subscales have approximate sensitivities and specificities of 0.80 when a score of 8 and above is used to indicate the presence of potential anxiety or depression (Bjelland et al., 2002). This cut-off is in keeping with initial suggestions by Zigmond and Snaith (1983) to incorporate a cut-off score of 8/9 to reduce false negatives.

Acceptable internal consistency has been found for both subscales (Cronbach's alpha: HADS-A=0.83, HADS-D=0.82) (Bjelland et al., 2002). Exploration into the reliability of

the HADS has found acceptable item-total correlations of both subscales, together with test-retest reliability scores indicative of scale stability (Herrmann, 1997).

Alternative scales of depression include the Beck Depression Inventory, with which the HADS has moderate-strong correlations, suggesting the HADS has good concurrent validity (Bjelland et al., 2002). However, the HADS has been shown to be acceptable for patients with mild cases of depression, whereas the Beck Depression Inventory enquires into suicidal thoughts (Herrmann, 1997). The HADS was selected for the study due to its brevity in comparison to the 21-items of the Beck Depression Inventory (Beck et al., 1961). Similarly, the HADS anxiety subscale was selected in preference over the State-Trait Anxiety Inventory which contains 20 items regarding 'state' (current anxiety) and 20 items regarding 'trait', ("anxiety proneness") (Julian, 2011). The brevity of the HADS is advantageous in the present study to encourage participants to complete the questionnaire booklet containing a number of scales. Furthermore, the HADS has been shown to be acceptable for use in general hospital outpatients departments (Zigmond and Snaith, 1983), and holds the benefit of a simple scoring system (Herrmann, 1997).

To maximise the data, one missing answer per subscale was permitted in the present study, and an estimate for the depression and anxiety subscales was based on the six present answers (GL.Assessment, 2014). If there was more than one missing answer, the subtotal score was omitted from the analyses.

4.) Pain Anxiety Symptoms Scale (short-form version: PASS-20)

The PASS-20 is a measure of pain-related fear and anxiety and contains four subscales: cognitive anxiety, escape and avoidance, fearful thoughts, and physiological anxiety (McCracken and Dhingra, 2002). Patients with chronic conditions frequently experience fear, anxiety and avoidance which can manifest in their approach to activities. Of specific interest to the study was the subscale 'escape and avoidance', to explore if associations between pacing and avoidance that have previously been found in the literature were replicated in the present study *(see Chapter 2, Literature review, Section 2.3.4.7).*

The PASS-20 is the short form version of the original 40-item Pain Anxiety Symptoms Scale (McCracken et al., 1992). The PASS-20 was developed with the aim of increasing the utility of the scale in the clinical setting due to its brevity. The PASS-20 contains five questions per subscale and each item is rated on a 6-point Likert scale (0=never to

5=always) where higher scores indicate higher levels of fear and anxiety (McCracken and Dhingra, 2002). Validation of the PASS-20 with a sample of 282 patients with chronic pain showed the shortened version maintained good levels of internal consistency for each subscale (Cronbach's alpha=0.75-0.86), together with similar correlations with scales of pain, depression, and disability as the 40-item version. Furthermore, the PASS-20 showed high correlations with the original PASS, indicating good convergence validity (McCracken and Dhingra, 2002). The 4-factor solution, internal consistency and construct validity of the PASS-20 was confirmed in a sample of patients with chronic low back pain and fibromyalgia (Roelofs et al., 2004b).

The PASS-20 was selected for the present study in preference to the Fear-Avoidance Beliefs Questionnaire (FABQ) since the FABQ contains questions referring specifically to back pain for which it was developed (Waddell et al., 1993). The items contained in the PASS were developed as a general measure of fear/anxiety and avoidance for different pain conditions (Crombez et al., 1999). Additionally, the PASS contains cognitive items together with physical items. This is in keeping with the APQ in which patients are asked to consider activity pacing in relation to all different types of activities: physical, cognitive and activities of daily living. The PASS was originally developed for use among patients with various chronic pain conditions, but it has since been used to explore the experience of pain among patients with CFS/ME (Marshall et al., 2010).

Following correspondence with the developer of the PASS-20, it was advised that one missing answer per subscale could be permitted, and a total for each subscale should be calculated based on the mean of the four scores that were present.

5.) Short Form-12 (SF-12)

The Short-form 12 (SF-12) is a generic health survey containing physical and mental component summaries. The SF-12 is a shortened version of the Medical Outcomes Study 36-Item Short-Form Health Survey (SF-36) (Ware and Sherbourne, 1992). The shortened version was developed to encourage more widespread use due to its brevity (Ware et al., 1996). The items that were selected for the SF-12 physical and mental components were shown to be predictive of the physical and mental components of the SF-36 (R^2=0.91 and 0.92 respectively) across a large sample (n=2,474). Furthermore, the SF-12 was shown to be reliable over a two-week recall period amongst a UK sample of 187 participants

(product moment correlations for physical component summary=0.86 and mental component summary=0.77) (Ware et al., 1996).

Since the SF-12 contains only one third of the questions of the SF-36, large study sample sizes (n>500) are recommended (Ware et al., 1996). However, high correlations between the scores for the physical and the mental component summary of the SF-12 and SF-36 were confirmed in a study involving a smaller sample (n=259) (Jenkinson et al., 1997). This sample size is similar to the intended sample of 300 patients for the present study.

The SF-12 contains items referring to each of the eight components in the SF-36, that is: physical functioning, role limitations due to physical problems, bodily pain, general health, vitality, social functioning, role limitations due to emotional problems and mental health. The SF-12 has lower correlations with the eight-factor format of the SF-36 in comparison to the two factor solution of physical and mental component summaries, and it is recommended that the two components are used for analysis in the SF-12 (Ware et al., 1996). Of note, the data analysed in the present study were based on the physical component and mental component summaries calculated using the SF-12 software, which adjusts the subtotal scores around missing answers. Specifically, the SF-12 version 2 with a one-week recall was implemented in the present study. The one-week recall period was selected to be in keeping with the recall of the APQ, pain scales and HADS. The physical and mental component summaries were scored on a scale of 0-100 where higher scores reflected better function (Hoffman and Dukes, 2008).

The SF-12 has been utilised in research studies involving patients with fibromyalgia/chronic widespread pain (Hoffman and Dukes, 2008), chronic low back pain (Luo et al., 2003), and CFS/ME (Sullivan et al., 2009). The SF-12 is advantageous over other measures of generic health status such as the EuroQol Group's EQ-5D (EuroQol, 1990) as it has been found to be more sensitive, and is less affected by the ceiling effect apparent in the EQ-5D due to the smaller range of scores available in this scale (Johnson and Coons, 1998).

6.) General comments and further contact

In addition to the above scales, patients were invited to write general comments. There was a check box for participants to tick if they consented to receiving a telephone call to discuss any of their answers and to follow up missing data.

6.1.2.7 Ethical issues

6.1.2.7.1 Recruitment and consent

Written consent was obtained before participation, and patients were advised that participation would not affect any current or future physiotherapy treatment. The patient administration system was checked for deceased patients before recruitment.

6.1.2.7.2 Anonymity

In order to maintain patient confidentiality and anonymity, patients were identified by unique codes throughout the study. Patients' codes and personal data (including addresses, and demographic data) were kept securely on a password protected Microsoft Excel worksheet. The worksheet was stored on two encrypted USB pen-drives and the paper copies of the questionnaires were kept in a locked filing cabinet in The Pennine Acute Hospitals NHS Trust. The participants' questionnaire responses were recorded in a separate SPSS data file, on which patients were identified only by their unique code in order to maintain anonymity of their responses.

6.1.2.7.3 Ethical approval

Ethical approval for Stage II, the psychometric study, was granted in July 2011 by the NRES Committee North West-GM North (REC Ref No. 11/NW/0295) *(see Appendix 7)*. Approval from The Pennine Acute Hospitals NHS Trust was received in August 2011. In addition, the study was lodged with the University of Manchester. Approval to analyse anonymous data from the non-responders to assess the representativeness of the responders was confirmed by the Pennine Acute Hospitals NHS Trust *(see Appendix 7. Email confirmation to use anonymous data from the non-responders).*

6.1.3 Methods

6.1.3.1 Piloting the questionnaire booklet

Before commencing recruitment for the study, the questionnaire booklet was piloted to test the ease of completion and the length of time needed to complete the booklet. Three of the eight current patients who were invited to pilot the questionnaire consented and returned a completed booklet. From the responses to the pilot, no changes were deemed necessary. Since no amendments were made, the three patients were asked if their data could be used in the full data analysis, and a second consent form was sent to the patients.

6.1.3.2 Participant recruitment

A sample of eligible retrospective patients was identified from discharged physiotherapy notes in The Pennine Acute Hospitals NHS Trust. Recruitment of retrospective patients commenced in August 2011 and ceased in August 2012. A consecutive sequence of patients who had been referred to the out-patient physiotherapy departments in The Pennine Acute Hospitals NHS Trust were recruited via the post between October 2011 and August 2012.

Both retrospective and current patients were invited to participate in the study by receiving a study pack in the post containing the study information sheet, a consent form and the booklet of questionnaires (T1) *(see Appendix 6)*. Patients were asked to complete the questionnaire booklet and consent form and return them in a pre-paid envelope within 3 weeks. To increase the return rate, reminder packs (T1R) were sent to patients if no contact had been made after three weeks. If no response to T1R was received within approximately three weeks, it was assumed that the patient did not wish to participate in the study and no further contact was attempted. The number of reminder packs and non-responders were documented to maintain accurate data regarding response rates, and to enable an analysis of the representativeness of the sample.

In addition, current patients were invited to participate (if they had not already done so) if they attended a rehabilitation group specifically for the management of chronic conditions. The number of patients in the group, together with the number who collected a study pack was recorded for the purposes of calculating recruitment rates.

A sample of current patients who returned the first booklet of questionnaires (T1) were sent a second, smaller booklet of questionnaires (T2) 1-2 weeks after returning the first booklet *(see Appendix 8)*. The second booklet contained only the APQ, the pacing subscales of the CPCI and PARQ, the NRS for current and usual pain and the Chalder fatigue questionnaire in order to gain test-retest data. Test-retest questionnaires were sent until complete data were available for 60 patients. A test-retest period of 1-2 weeks was implemented to reduce the effect of patients remembering their answers while avoiding external changes that may occur over longer periods (Pett et al., 2003).

6.1.3.3 Data entry

Patients' demographic details were entered onto a Microsoft Excel spreadsheet together with their unique study codes. The data from the questionnaire booklets were entered into an SPSS data file. This was performed twice for a 10% sample of the questionnaire booklets (n=32) for cross-checking purposes. The cross-check showed a 0.2% rate of errors. Following on from this, an exploration of accuracy of data entry was performed using a 10% random sample from the SPSS data file. The questionnaire responses were cross-checked against the fields in SPSS. The rate of errors was 0.14% (that is, 7 errors across 4,995 variables). Since no two errors occurred on the same scale, it was considered that this accuracy check did not highlight specific problems with data entry. The corrections were applied to the data file before analysis.

6.1.3.4 Statistical analysis

6.1.3.4.1 Descriptive and comparative statistics

Descriptive statistics were employed with regards to the demographics of the participants, for example, age, gender, condition, duration of symptoms, physiotherapy intervention (individual only, or individual and group treatment) and response rates. Characteristics of retrospective patients and current patients were compared, as were characteristics of the test-retest subgroup and those not in the subgroup using appropriate two-group tests, such as Pearson's chi-square test for nominal variables, the Mann-Whitney U test for ordinal or skewed interval variables, and unpaired t-tests for interval variables with approximately symmetrical distributions. It was expected that comparisons involving variables such as ethnicity, marital status and employment status may involve some small groups due to the lower frequency of certain characteristics in the population. In situations where Pearson's chi-square test became invalid due to small expected cell counts, Fisher's exact test (Bland, 1995) was used for nominal variables to allow a comparison to be made between the two groups.

6.1.3.4.2 Plan for development of final version of APQ

The presence of underlying themes in the APQ was assessed using exploratory factor analysis. This and related techniques were used to identify potentially redundant items and produce a final version for analysis largely following the detailed methods of Pett et al. (2003).

For the factor analysis procedure in SPSS, the default option of listwise deletion of missing values was chosen. This means that data from any participant with one or more missing values over the items selected would be excluded from the analysis. The other two options offered by SPSS were not used. Tabachnick and Fidell (2001) warn that substitution of a missing value by the sample mean for that variable, reduces the variance of the variable and consequently its correlation with other variables. They also comment that the other option, pairwise estimation of correlations (where each correlation is estimated separately using all cases with non-missing values on the two variables concerned) can lead to eigenvalues (an eigenvalue is the variance explained by a factor) that are either negative or inflated. Both options may produce distorted results. The number of missing values per item and the extent of the problem were assessed during the running of a preliminary factor analysis, making listwise deletion particularly appropriate. Another advantage of running factor analysis with listwise deletion of missing values was that the author was able to perform the analyses herself.

The first step involved a principal components analysis of all 38 items in the APQ to determine whether partial correlations within the full set of items were sufficiently strong to justify using exploratory factor analysis. This was assessed using the Kaiser-Meyer-Olkin measure of sampling adequacy (KMO), which takes values in the range from 0 to 1. Pett et al. (2003) suggest that KMO >0.70 is recommended for factor analysis to be worthwhile. The KMO may also be estimated for individual items, and Pett et al. (2003) comment that the same interpretation be applied for the items: any items with KMO <0.70 were considered for exclusion.

APQ items with substantial numbers of missing values were also considered for exclusion. Items with mean scores assessed as being very high or low were also considered for exclusion on the grounds that the question may not have been sensitive to the full range of available values (DeVellis, 1991). The principal component loadings were also studied as correlations between items and the components. Items with a loading <0.32 on all components were considered for removal, as were items that only loaded on a single component and were the only item to do so (Tabachnick and Fidell, 2001).

For each item considered for exclusion, correlations with other items were examined, as was feedback from participants in the form of comments written on the questionnaire. If

the correlations were low and comments about the item were negative, the item was excluded.

Principal components analysis was re-run for the remaining items with a Varimax rotation, and the overall and individual item KMO values were examined to check they were still above 0.70. The number of factors present was assessed by looking at the number of principal components with eigenvalues greater than or very close to 1.00, a value which indicates that a component accounts for as much of the total variance of an individual item (Tabachnick and Fidell, 2001). Solutions for different numbers of factors were examined to find one that produced rotated components that made most sense clinically and intuitively (Pett et al., 2003).

Principal components analysis was not used as the final factor extraction technique. Pett et al. (2003) point out its usefulness in summarising a multivariable dataset in a set of uncorrelated linear components accounting for decreasing amounts of variance, but question its tendency to overestimate the linear patterns and query the usefulness of rotating the already uncorrelated components. They note that it does not separate the common variance between items from errors in measurement. Following the advice of Pett et al. (2003), principal axis factoring was used to extract factors, as this has the same number of factors as the principal components solution but with better estimates of correlations based only on common variance. Once the number of factors was determined using principal components analysis, principal axis factoring was used to extract that number of factors. The results of principal axis factoring with two methods of factor rotation were compared for a consistent solution, an orthogonal Varimax rotation producing uncorrelated factors and an oblique Oblimin rotation producing correlated factors. Items with a loading <0.32 on all rotated factors were considered for removal, as were items that only loaded on a single rotated factor and were the only item to do so (Tabachnick and Fidell, 2001).

Reliability of the rotated factors was assessed using inter-item correlations, item total correlations and Cronbach's alpha (Pett et al., 2003). Correlations were checked for negative signs to determine whether any items should be reverse-coded (Pett et al., 2003). High levels of internal consistency are suggestive of homogeneous items in a scale, whereas lower levels are suggestive of the presence of potentially multiple concepts in a scale (Cook and Beckman, 2006). For each factor, inter-item correlations were examined

as were the meanings of the related items. The effect on Cronbach's alpha of removing either of the items with highest inter-item correlations was examined to see if there was an indication that an item should be removed. If Cronbach's alpha is noticeably increased when an item is deleted, that item should be considered for removal from the factor; if alpha is noticeably reduced when an item is deleted, then the item should be retained (Pett et al., 2003). Items that loaded strongly on more than one factor were studied to see where their content fitted most logically, and the effect on Cronbach's alpha of removing that item from each factor was assessed (Pett et al., 2003).

Once any further items had been removed, principal axis factoring was re-run, again comparing a Varimax rotation with an Oblimin rotation, and the reliability analysis was repeated. Results were compared with those of the previous run. When a final consistent solution was achieved, the meanings of the items loading most strongly on each APQ factor were considered to determine a common theme for the factor (Pett et al., 2003).

6.1.3.4.3 Calculating APQ factor scores

Scores were calculated per participant for each APQ factor to show participants' level of response for the factor. Rather than using the factor scores estimated from multiple correlations between items and factors, the method of factor-based scales was used (Pett et al., 2003). In this approach, participants' responses on the items making up a factor are combined together, either as a simple unweighted sum or mean. Pett et al. (2003) report this simplifies interpretation and facilitates comparisons between studies. Since the APQ factors contained different numbers of items, mean scores were estimated over the items associated with each factor. This has the advantage that the score on a factor can be related back to the original Likert scale (0 to 4 in this study) because it takes the same range of values. For example, APQ factor 5 was associated with APQ items 22, 23 and 24. Thus the score for factor 5 was calculated as:

Factor 5=(APQ22 + APQ23 + APQ24)/3
(where, for example, APQ22 was the score on APQ item 22)

APQ factor scores were initially calculated for participants with complete data on all items within a factor. It was decided beforehand to also calculate scores allowing for one missing value across the items within a factor. Allowing one missing answer per factor is an approach that is used in validated scales such as the HADS (Zigmond and

Snaith, 1983; GL.Assessment, 2014), the PASS-20 (McCracken and Dhingra, 2002; McCracken, 2013), and the Falls Efficacy Scale (FES) and the Falls Efficacy Scale-International Version (FES-I) (Hauer et al., 2010). When one value was missing for an APQ factor, the factor score was calculated as the mean across the valid items. For example, if the response to APQ22 was missing, then the score for factor 5 would be:

$$\text{Factor 5} = (\text{APQ23} + \text{APQ24})/2$$

This is numerically equivalent to replacing the missing item by the mean across the other items:

$$\text{APQ22'} = (\text{APQ23} + \text{APQ24})/2$$

$$\begin{aligned}\text{Factor 5} &= (\text{APQ22'} + \text{APQ23} + \text{APQ24})/3 \\ &= ((\text{APQ23} + \text{APQ24})/2 + \text{APQ23} + \text{APQ24})/3 \\ &= (3*\text{APQ23}/2 + 3*\text{APQ24}/2)/3 \\ &= (\text{APQ23} + \text{APQ24})/2\end{aligned}$$

This approach makes the assumption that the patient would have responded proportionately on the missing item based on responses to the other items. If responses to two items, e.g. APQ22 and APQ23 were missing, however, the score for APQ factor 5 would be treated as being missing. Allowing one missing value per factor was expected to increase the number of patients with factor scores when the APQ was applied in clinical practice. Moreover, this scoring method was considered to be simple to implement, therefore allowing clinicians to easily assess patients' pacing habits, and to potentially use the APQ factor scores to inform treatment.

Distributions of the factor scores for complete data and allowing one missing value were summarised using descriptive statistics, and Pearson's correlations between the scores were estimated. The numbers with missing values on the different factors were monitored and results for the two approaches were compared. Associations between factor scores and interval level characteristics of participants, such as age, were examined using Pearson's correlation. Associations with categorical characteristics, such as main condition, were examined by comparing mean factors scores between categorical groups using either unpaired t-tests (two groups) or one-way analysis of variance (ANOVA) (more than two groups). Small groups were excluded from these analyses to avoid distorting the results due to having an increased variance around

imprecisely estimated means in the small groups. However, in a sensitivity analysis, the analyses were also run including the small groups to assess if there were any differences in the statistical significance of the findings when the small groups were retained.

6.1.3.4.4 Validity

Convergence validity of the APQ factors was assessed against the existing pacing subscales of the CPCI and the PARQ. Associations of the APQ factors were explored with the validated measures of pain, fatigue, anxiety, depression, avoidance, and mental and physical function to assess the properties of the APQ. Convergence correlations and associations with the other measures were assessed using Pearson's correlation or Kendall's correlation as appropriate. Associations of the APQ factors with socio-demographic data were analysed, to include participants' conditions, duration of symptoms, employment status and type of physiotherapy treatment (individual or group).

6.1.3.4.5 Test-retest reliability

Reliability was further explored using test-retest analyses. Reliability refers to the consistency of a measure (Cook and Beckman, 2006). It is essential that a clinical measure is reliable so that when repeated measures are made, the changes that are reported are due to changes in the patients' presentation and not due to error in the measure (Shrout and Fleiss, 1979; Rankin and Stokes, 1998). Test-retest reliability of the APQ, and pacing subscales of the CPCI and PARQ were estimated using Pearson's correlations, intraclass correlations and the Bland and Altman method. Pearson's correlation coefficients provide estimations of the strength of correlations between two sets of measures (Rankin and Stokes, 1998). However, estimations of correlations such as Pearson's correlation do not explore the level of agreement between two sets of measures, and it is possible to have high levels of correlation with low levels of agreement (Bland and Altman, 1986; Rankin and Stokes, 1998). It is recommended to implement both intraclass correlations and the Bland and Altman method to explore the reliability of clinical measures that generate continuous data (Rankin and Stokes, 1998). Of note, it was considered that the APQ generated continuous data due to the scores of the themes being calculated from the sum of the items rated on the five-point Likert scale.

Pearson's correlation coefficient (r) reflects the magnitude of the association between the measures at T1 and T2 (Bland and Altman, 1986). Pearson's correlation coefficients have values between -1 and 1, where -1 indicates a perfect negative association, 0

indicates no association and 1 indicates a perfect positive association. Cohen (1992) gives the interpretation of r as an effect size: r=0.10 as small, r=0.30 as medium and r=0.50 as large. Since r^2 is a measure of the variance of one variable accounted for by the other, these correspond to 1%, 9% and 25% of variance explained.

Intraclass correlations estimate reliability via a calculation of the variance of interest divided by the sum of variance of interest and error (Shrout and Fleiss, 1979; Rankin and Stokes, 1998). Intraclass correlations can be calculated using different formulae, appropriate to fixed and random effects specific to a study design (Shrout and Fleiss, 1979; Rankin and Stokes, 1998). In the present study, there were single measures at T1 and T2, in a two-way mixed analysis of variance, where the test-retest time point was considered to be a fixed effect, but the patients were considered to be a random effect (Shrout and Fleiss, 1979). An intraclass correlation >0.75 is said to have an excellent level of reliability and a correlation of between 0.4-0.75 is said to have fair to good reliability (Fleiss, 1986).

The Bland and Altman method visually illustrates the level of agreement between the measures (Bland and Altman, 1986). The Bland and Altman method plots the difference of the two scores for each participant on the y-axis against the mean of the two scores for the participant on the x-axis. The plot can be used to identify any cases where the difference between the two scores is relatively large or small, and explore whether the difference itself is related to the mean score (ideally, it should not be). Horizontal lines may be added to indicate the mean of the differences d (the line y=d) and 95% limits of agreement (at y=d–2s and y=d+2s where s is the standard deviation of the differences) (Bland and Altman, 1986). The limits of agreement may be assessed to decide whether the precision of the differences is clinically or practically acceptable. A sample size of >50 is recommended for purposeful Bland and Altman plots (Rankin and Stokes, 1998).

Chapter 6. Stage II: Assessing the Psychometric Properties of the Activity Pacing Questionnaire (APQ)

6.2 Results

6.2.1 Introduction

Three hundred and eleven questionnaire booklets containing the activity pacing questionnaire (APQ) were suitable for analysis following administration to patients with chronic conditions. This section begins by reporting the demographics of the sample, including comparisons between retrospective and current patients, patients receiving individual treatment versus group treatment and responders versus non-responders. It then reports the results of exploratory factor analysis of the APQ which was conducted to explore the presence of pacing themes. This section continues to report correlations between the APQ themes and two existing pacing subscales, validated measures of pain, fatigue, anxiety, depression, avoidance and function. Finally, test-retest reliability of the APQ is reported.

6.2.2 Recruitment rates

6.2.2.1 Retrospective patients

Of the 802 initial questionnaire booklets and 689 reminder booklets that were sent to retrospective patients, 155 patients were recruited (recruitment rates=12.6% for the initial booklet, 7.8% for the reminder booklets, 19.3% overall). Eight patients did not meet the inclusion criteria, resulting in 147 eligible retrospective patients. The reasons for exclusion included: one patient reported a two months history of the condition, two patients suffered with inflammatory conditions (rheumatoid arthritis and systemic lupus erythematosus), one patient reported true sciatica (pain down to the foot), two patients required spinal surgery, a patient who had suffered a stroke, and a patient who based her answers on her condition of carpal tunnel syndrome rather than chronic low back pain, chronic widespread pain or chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME) *(see Figure 6.2.1 Flow diagram of the recruitment rates for retrospective patients)*.

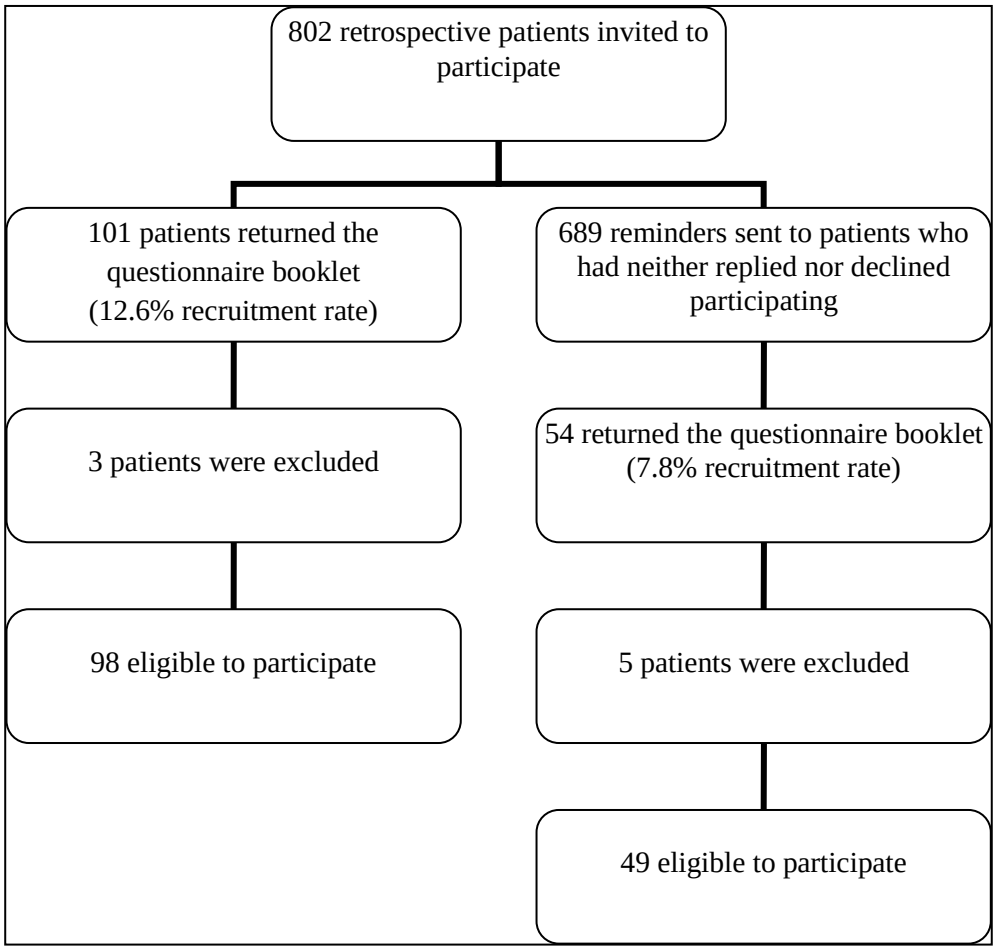


Figure 6.2.1 Flow diagram of the recruitment rates for retrospective patients

6.2.2.2 Current patients

Of the 714 questionnaire booklets sent to current patients in the post before they had commenced physiotherapy, 141 patients were recruited (recruitment rate=19.7%) and 134 met the inclusion criteria. No reminder booklets were sent as it was the aim to recruit current patients before they had attended physiotherapy. The reasons for exclusion of the seven patients were: two patients recalled a two months history of the condition, one patient reported a low muscle tone disorder, one patient struggled with the English language, one patient's condition had resolved, one patient reported true sciatica to the foot and one patient reported hip pain only.

One hundred and five questionnaires were administered to patients attending a rehabilitation group specifically designed for the management of chronic conditions. Thirty two patients were recruited (recruitment rate=30.5%), of whom 29 were eligible to participate. The reasons for exclusion of the three patients were: one patient suffered migraines and hip problems as their main condition, one patient suffered with Crohn's

disease and palindromic arthritis as their main condition and one patient suffered with neck pain only.

6.2.2.3 Patients involved in the pilot questionnaire booklet

Three patients attending a rehabilitation group for chronic conditions completed the pilot questionnaire booklet. Since no changes were required to the questionnaire booklet, the three patients were asked if their answers could be incorporated into the full data set, to which one patient consented. During data analysis this patient's data have been included in the 30 current patients who were recruited from a rehabilitation group. Therefore, in total there were 164 prospective patients (individual and group) who were eligible to participate. The overall response rate for current patients was 21.2%.

6.2.2.4 Test-retest sample

Of the 111 test-retest questionnaire booklets that were sent to current patients treated individually, 51 patients returned the completed booklet (return rate=45.9%). Of the 26 patients attending group treatment, 18 returned their completed test-retest booklet (return rate=69.2%). In total, 69 test-retest booklets were returned (overall return rate=50.4%) *(see Figure 6.2.2 Flow diagram of the recruitment rates for current patients)*.

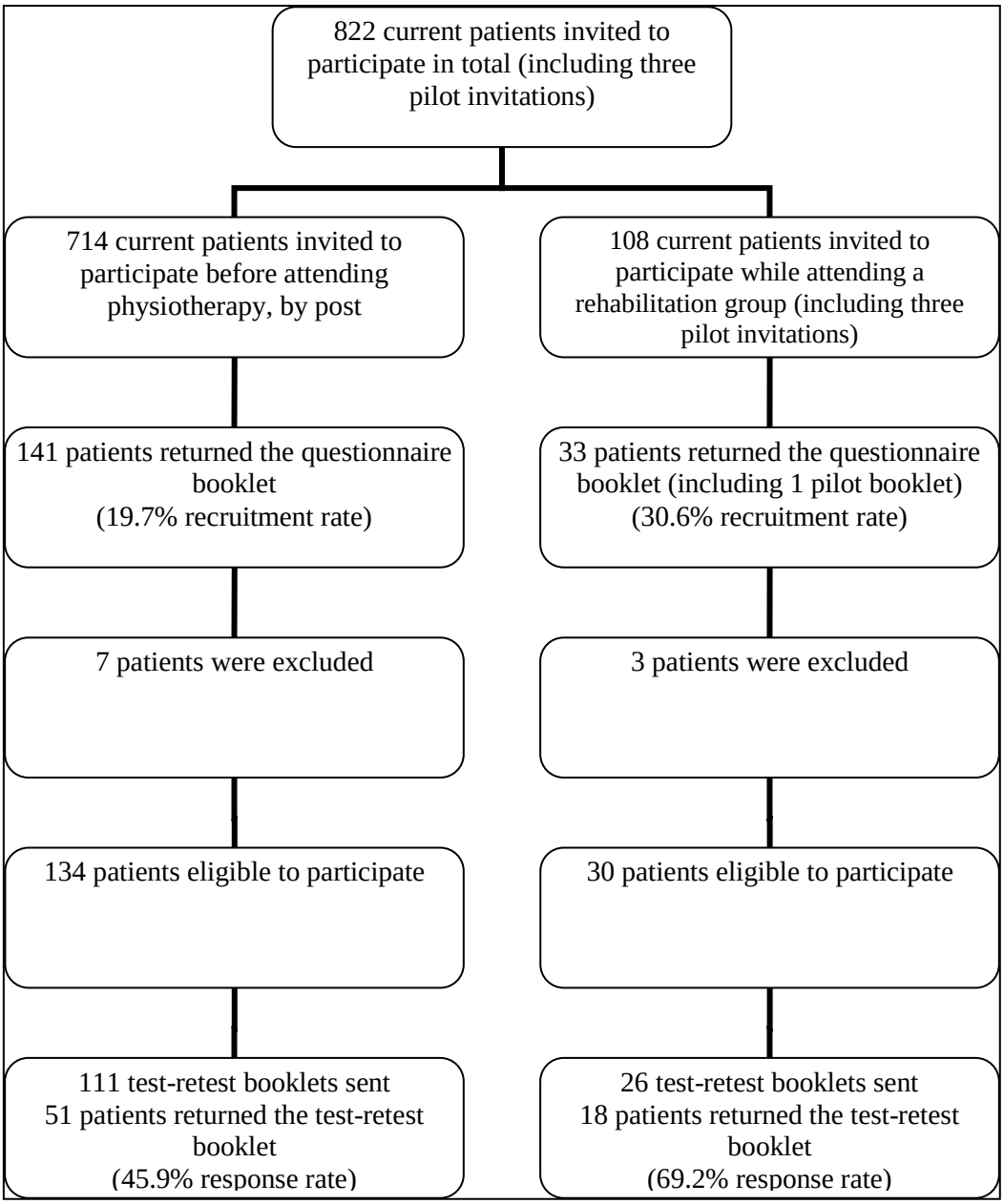


Figure 6.2.2 Flow diagram of the recruitment rates for current patients

6.2.3 Participant characteristics

6.2.3.1 All retrospective versus all current patients

Demographic characteristics

More female patients participated in the study compared to male patients among both retrospective patients (females=70.7%) and current patients (65.9%). There was no significant difference in male and female percentages between the retrospective and current patient groups (p=0.355) *(see Appendix 9, Table 6.1 Demographic characteristics of all patients).*

There was a higher mean age of retrospective patients (48.1 years) compared with current patients (43.7 years) and this difference was significant (p=0.007) *(see Appendix 9, Table 6.1 Demographic characteristics of all patients).* The distribution of ages for retrospective patients was approximately Normal with a mean value similar to the median. However, there was a positive skew (0.34) that is more extreme than ±0.29 and therefore considered significantly different from zero for this sample size (Pett, 1997). There was a small positive kurtosis (0.09) that is no more extreme than ±0.58, and therefore not considered significantly different from zero (Pett, 1997). The distribution of ages for current patients showed an approximately Normal distribution with a mean similar to the median, an insignificant small positive skewness, but a significant negative kurtosis *(see below: Table 6.2.1 Distribution of the continuous data for participants' demographic and clinical characteristics)*. Of note, it is suggested that the unpaired t-test may be used in samples where the mean is a suitable estimate for the centre of the distribution; and those that do not have an approximately Normal distribution, but where the total sample size is ≥40 (Moore and McCabe, 1993).

Table 6.2.1 Distribution of the continuous data for participants' demographic and clinical characteristics

Characteristic	Patients	Mean (SD)	Range	1st quartile	Median	3rd quartile	Skew	Kurt
Age (in years)	Retro n=147	48.10 (13.67)	19.00-91.00	38.00	48.00	57.00	0.34	0.09
	Current n=164	43.72 (14.58)	18.00-76.00	31.25	45.00	55.00	0.16	-0.85
Duration of condition (in years)	Retro n=127	7.26 (8.08)	0.50-50.00	2.25	4.50	10.00	2.69	9.13
	Current n=139	6.81 (8.94)	0.25-48.00	1.25	3.00	10.00	2.30	5.63
Current pain [a]	Retro n=141	4.72 (2.85)	0.00-9.00	2.00	5.00	7.00	-0.23	-1.20
	Current n=158	6.30 (2.58)	0.00-10.00	5.00	7.00	8.00	-0.74	0.50
Usual pain [a]	Retro n=141	4.90 (2.66)	0.00-10.00	3.00	5.00	7.00	-0.32	-0.88
	Current n=161	6.28 (2.42)	0.00-10.00	5.00	7.00	8.00	-0.56	0.03
Physical fatigue [b]	Retro n=142	10.80 (4.84)	0.00-21.00	7.00	10.00	14.00	0.50	-0.46
	Current n=161	12.20 (4.85)	0.00-21.00	8.00	12.00	16.00	-0.04	-0.64
Mental fatigue [b]	Retro n=142	5.73 (2.68)	0.00-12.00	4.00	5.00	8.00	0.61	0.02
	Current n=162	6.02 (2.90)	0.00-12.00	4.00	5.00	8.00	0.41	-0.61

Retro=Retrospective patients, SD=Standard deviation, Skew=Skewness, Kurt=Kurtosis
[a] Current and usual pain were measured using two Numerical Rating Scales (0-10); [b] Physical and mental fatigue were measured using the Chalder Fatigue Questionnaire.

Most patients were 'married/living as married', with a greater percentage among retrospective patients in comparison to current patients. The majority of both retrospective and current patient groups were of white ethnicity. There were significantly more patients of Asian/Asian British origin among current patients than retrospective patients (p=0.003). The 'other' ethnic groups that were given included: East African, Asian, Jewish, Iranian, Kurdish British and Arabian. Among both retrospective and current patient groups, most patients were working full-time *(see Appendix 9, Table 6.1 Demographic characteristics of all patients)*. Of note, the analyses of marital status, ethnicity and employment status involved some small groups (n<5), and were therefore analysed using Fisher's exact test. Where analyses involved small groups, the interpretation of the results should be treated with caution.

Clinical characteristics

Back pain was the most commonly reported condition among both retrospective and current patients. There were no significant differences between retrospective and current patients in terms of the percentages of patients who had back pain (p=0.115), CFS (p=0.253) or 'other' condition (p=0.389). However, there were statistically significant differences between the two groups in terms of reports of chronic widespread pain (retrospective 29.9% v current 41.7%, p=0.031), fibromyalgia (retrospective 18.4% v current 10.4%, p=0.046) and ME (retrospective 8.2% v current 2.5%, p=0.023). Many patients reported more than one condition, but most patients stated that back pain was their main condition. There was no significant difference between retrospective and current patients in terms of the main condition that was reported (p=0.439) *(see Appendix 9, Table 6.2 Clinical characteristics of all patients)*. However, these analyses involved some small groups, and the results should be interpreted with caution.

The 'other conditions' that patients reported included: osteoarthritis, pelvis pain, endometriosis, irritable bowel syndrome, reflux oesophagitis, coeliac disease, kidney problems, leg pain and specific regional pain such as knee pain, neck pain and shoulder pain. The above patients reported conditions that were required to meet the inclusion criteria and it was considered that none of the above 'other conditions' fulfilled the exclusion criteria.

Retrospective patients had a longer duration of their condition (median 4.5 years) in comparison to current patients (median 3 years), and this difference was statistically significant different (p=0.024) *(see Appendix 9, Table 6.2 Clinical characteristics of all patients)*. For both retrospective and current patients there was a strong positive skewness in duration of the condition *(see Table 6.2.1 Distribution of the continuous data for participants' demographic and clinical characteristics)*.

Of the retrospective patients, 135 (92.5%) reported pain and 158 (96.9%) of the current patients reported pain. There was no significant difference between the presence of pain between retrospective and current patients (p=0.077) *(see Appendix 9, Table 6.3 Patients' symptoms, part I)*.

Retrospective patients reported a lower mean level of current pain (mean=4.7) in comparison to current patients (mean=6.3). This difference was statistically significant (p<0.001) *(see Appendix 9, Table 6.3 Patients' symptoms, part I)*. The distribution of current pain for retrospective patients showed the mean and median were similar and had a small negative skewness, but a strong negative kurtosis. The distribution for current patients showed a similar mean and median, an insignificant kurtosis, but a strong negative skewness *(see Table 6.2.1 Distribution of the continuous data for participants' demographic and clinical characteristics)*. The negative skew indicates that a greater number of current patients reported higher levels of pain with relatively few reporting lower levels of pain. The distribution of usual pain of both retrospective and current patients had approximately Normal distributions, and similarly to current pain, there was a statistically significant difference between the usual pain reported by retrospective and current patients (p<0.001) *(see Table 6.2.1 Distribution of the continuous data for participants' demographic and clinical characteristics and Appendix 9, Table 6.3 Patients' symptoms, part 1)*.

The distribution of physical fatigue for both retrospective and current patients was approximately Normal. Retrospective patients had a lower mean level of physical fatigue (10.8) compared to current patients (12.2). This difference was statistically significant (p=0.012). The distribution of mental fatigue showed similar means to the respective medians, but with a positive skewness. Retrospective patients had a slightly lower mean level of mental fatigue (5.7) in comparison to current patients (6.0). This difference was not statistically significant (p=0.374) *(see Table 6.2.1 Distribution of the continuous data for participants' demographic and clinical characteristics and Appendix 9, Table 6.3 Patients' symptoms, part 1)*.

In comparison to current patients, retrospective patients had significantly lower levels of anxiety (retrospective mean=8.4 v current mean 10.1, p=0.004), depression (6.4 v 8.6, p<0.001), cognitive anxiety (14.1 v 17.2, p<0.001), escape and avoidance (12.1 v 14.8, p<0.001), fearful thoughts (8.4 v 11.9, p<0.001), physiological anxiety (7.5 v 10.4, p=0.001), and higher levels of physical function (39.6 v 37.0, p=0.039) and mental function (45.6 v 39.2, p<0.001) *(see Appendix 9, Table 6.3 Patients' symptoms, parts 1 and 2)*.

Therefore, among the total sample there were some similarities and differences between retrospective and current patients. Retrospective and current patients were similar in terms of gender, marital status and employment. However, retrospective patients were older, and a smaller proportion reported an Asian or Asian/British ethnicity. Retrospective and current patients were similar in the proportion of patients reporting back pain, CFS and 'other' condition; and back pain was reported to be the main condition in both groups. Conversely, there were higher reports of fibromyalgia and ME among retrospective patients, while there were higher reports of chronic widespread pain among current patients. Retrospective patients reported a longer duration of their condition. Retrospective and current patients were similar in terms of reporting the presence of pain and in mental fatigue. Interestingly, retrospective patients reported lower current and usual pain, lower physical fatigue, anxiety, depression, pain-related fear and avoidance, and increased physical and mental function.

The next stage of the analysis compared the patients who were treated individually with those treated in a rehabilitation group. In order to do this, the patients were first separated into the subgroups of retrospective or current patient status.

6.2.3.2 Retrospective and current patients: individual treatment versus rehabilitation group treatment

Demographic characteristics

There were more females than males treated both individually and in a rehabilitation group among retrospective and current patients. There was no significant difference in terms of gender between those treated individually or in a group among retrospective or current patients (p=0.466 and p=0.917 respectively) *(see Appendix 9, Tables 6.4 and 6.5 Retrospective and current patients' demographic characteristics: individual versus group rehabilitation).*

Retrospective patients attending group treatment (mean age=45.1 years) were younger than retrospective patients receiving individual treatment (mean age=50.1 years). This difference was statistically significant (p=0.029). Unexplainably, current patients attending group treatment (mean age 50.0 years) were older than current patients receiving individual treatment (42.3 years). This difference in age was also statistically significant (p=0.009).

Most retrospective and current patients were 'married/living as married' among those who received individual or group treatment. There was no statistically significant difference in marital status between the two types of treatment (p=0.740 and p=0.247 retrospective and current patients respectively). Most patients were of white ethnicity, and there was no difference in ethnicity between patients treated individually or in a group among retrospective or current patients (p=0.549 and p=0.594 respectively). Similarly, there was no statistical difference between the employment status of patients treated individually or in a group among retrospective or current patients (p=0.342 and p=0.969). Of note, the most frequently reported employment status was working full-time (45.4% of retrospective patients, 35.2% of current patients). Analyses of marital status, employment and ethnicity involved some small groups, and should therefore be interpreted with caution.

Clinical characteristics

Of the retrospective patients there were statistically significant differences between those who were treated individually compared to those treated in a group who reported low back pain (individual 77.5% v group 56.9%, p=0.008), fibromyalgia (9.0% v 32.8%, p<0.001) and CFS (4.5% v 34.5%, p<0.001). There were no significant differences between retrospective patients treated individually or in the group in terms of chronic widespread pain (p=0.331), ME (p=0.063) or 'other condition' (p=0.957). Most retrospective patients reported back pain as their main condition (63.0%), but this was reported to a greater extent among the patients who were treated individually (69.1%) in comparison to those treated in a group (52.2%). This difference was statistically significant (p=0.014) *(see Appendix 9, Table 6.6 Retrospective patients' clinical characteristics: individual versus group rehabilitation).*

Among the current patients there were no significant differences between patients treated individually or in a group who reported back pain (p=0.383), chronic widespread pain (p=0.843), fibromyalgia (p=0.741), CFS (p>0.999), ME (p>0.999) or 'other condition' (p=0.317). Back pain was the most frequently reported main condition among patients treated both individually (70.0%) and in a group (55.2%). There was no significant difference between the main condition reported by current patients treated individually and in a group (p=0.373) *(see Appendix 9, Table 6.7 Current patients' clinical characteristics: individual versus group rehabilitation).* The analyses involving

the conditions that patients reported involved some small groups and the findings should therefore be interpreted with caution.

Retrospective patients treated individually had a higher median duration of their condition (5 years) compared to those treated in a group (4 years), but this difference was not significant (p=0.885). Conversely, current patients treated individually had a lower median duration of the condition (3 years) in comparison to those treated in the group (4.5 years), but again, this difference was not statistically significant (p=0.972) *(see Appendix 9, Tables 6.6 and 6.7 Retrospective and current patients' clinical characteristics: individual versus group rehabilitation).*

Of the retrospective patients, there was no significant difference in the presence of pain between patients treated individually (89.8%) and those treated in a group (96.6%, p=0.201). Furthermore, there was no significant difference between retrospective patients treated individually and in a group in terms of current pain (p=0.466) or usual pain (p=0.474). Among current patients there was no significant difference in terms of the presence of pain between patients treated individually (96.2%) or in a group (100.0%, p=0.585). Current patients treated in a group reported lower current pain (mean=5.4) in comparison to the patients treated individually (mean=6.5) and this difference was statistically significant (p=0.033). There was no significant difference between usual pain ratings of patients treated individually and those treated in a group setting (p=0.974) *(see Appendix 9, Tables 6.8 and 6.9 Retrospective and current patients' symptoms, individual versus group rehabilitation, part 1)*.

Of the retrospective patients there was no significant difference in physical or mental fatigue between those treated individually and those treated in a group (p=0.844 and p=0.173 respectively). Conversely, among current patients there was a significant difference in physical fatigue between those treated individually and those treated in a group (individual mean=12.6 v group mean=10.5, p=0.033). However, there was no significant difference in mental fatigue (p=0.153).

Of the retrospective patients, there were no statistically significant differences between the level of anxiety or depression between patients treated individually or in a group (p=0.458 and p=0.251 respectively). Similarly there was no significant difference between retrospective patients treated individually or in a group in terms of avoidance

(all PASS subscales), or physical or mental function. Of the current patients, there were no significant differences between patients who were treated individually and those treated in a group in terms of anxiety or depression (p=0.121 and p=0.125 respectively), physical and mental function and all subgroups of the PASS with the exception of cognitive anxiety (individual mean=17.6 v group mean=15.4, p=0.033) *(see Appendix 9, Tables 6.8 and 6.9 Retrospective and current patients' symptoms: individual versus group rehabilitation, parts 1 and 2).*

In summary, both retrospective and current patients treated individually compared to attending a rehabilitation group were similar in terms of gender, marital status, ethnicity and employment status. Retrospective patients treated in a group were significantly younger than retrospective patients treated individually, while the reverse was true for the current patients. Retrospective patients treated individually and in a group were similar in terms of the presence of chronic widespread pain, ME and an 'other' condition. Current patients attending either individual or group treatment were similar in terms of the presence of all of the listed conditions. Of the retrospective patients, back pain was cited as the main condition whether patients were treated individually or in a group, but this was to a significantly lesser extent among those patients treated in a group. This difference did not apply among current patients.

There were no significant differences between patients treated individually and in a group whether retrospective or current in terms of the duration of the condition, the presence of pain or usual pain. However, current patients attending a group reported significantly lower current pain than current patients treated individually. Both retrospective and current patients showed no differences between those treated individually or in a group regarding mental fatigue, anxiety and depression, physical and mental function and all PASS avoidance subscales with the exception of cognitive anxiety. Current patients treated individually reported significantly higher levels of cognitive anxiety, together with higher levels of physical fatigue.

Therefore, some differences existed between patients treated individually and in a rehabilitation group and these differences varied between retrospective patients and current patients. The next stage of data analysis assessed the representativeness of the patients who participated in the study in comparison to those who did not respond.

6.2.3.3 Responders versus non-responders

Of the responders, more patients were female (68.4%) than male. Of the non-responders, again more patients were female (59.9%) than male but to a lesser extent and this difference in proportions was statistically significant (p=0.005). Patients who responded to the study were significantly older (mean age=45.9 years, median age=46 years) than the non-responders (mean age=42.4 years, median age=42 years, p<0.001) *(see Appendix 9, Table 6.10 Demographic and clinical characteristics: total responders versus non-responders).*

There were significant differences between responders and non-responders in terms of the presence of back pain (responders 74.2% v non-responders 91.9%), chronic widespread pain (38.9% v 4.1%), fibromyalgia (14.0% v 6.3%), CFS (14.9% v 3.5%) and ME (6.4% v 1.3%) (all p<0.001). Patients who responded to the study had a significantly longer duration of their condition (responders median=4 years v non-responders median=1.2 years, p<0.001). The details regarding treatments for retrospective responders and non-responders were known. Responders were more likely to have attended a rehabilitation group (38.7% v 19.6%, p<0.001) and completed their treatment (64.3% v 49.3%, p=0.001) than non-responders *(see Appendix 9, Table 6.11 Retrospective patients' treatment type and treatment completion: responders versus non-responders).*

In brief, patients who participated in the study were significantly older, more likely to be female and to have had their condition for a longer duration than those who did not participate. A significantly smaller proportion of responders had back pain, whereas those who responded had significantly higher reports of chronic widespread pain, fibromyalgia, CFS and ME in comparison to the non-responders. Furthermore, a greater proportion of retrospective responders attended a rehabilitation group and completed their treatment compared to the non-responders.

Following the analysis of the representativeness of the participants, the focus of data analysis moves to examining the properties of the APQ. This begins with the exploratory factor analysis of the APQ.

6.2.4 Exploratory factor analysis of the APQ

Principal components analysis was first performed using all 38 APQ items. The Kaiser-Meyer-Olkin measure of sampling adequacy (KMO) was estimated in order to assess whether there were sufficient correlations between the APQ items to justify using exploratory factor analysis (Pett et al., 2003). The overall KMO for the 38 items in the APQ was 0.928. A KMO value >0.70 is recommended to undertake factor analysis, with values >0.80 rated as high (Pett et al., 2003). The KMO for individual APQ items were mainly approximated around 0.90, with the lowest value at 0.747. The initial principal components analysis proposed an eight factor solution of the APQ. The eight components with eigenvalues >1, accounted for 66.1% of the total variance *(see Appendix 10, Table 6.12 for the mean scores and number of missing answers for each of the 38 APQ items and Table 6.13 for the component loadings).*

6.2.4.1 Removing redundant questions

It is not uncommon that there is a reduction in number of items during factor analysis in order to develop a succinct scale containing logical subscales (Pett et al., 2003). The above initial analysis was based on only 228 complete cases from 311 returned questionnaires. To increase the number with complete data for factor analysis, APQ items with high numbers of missing answers were removed. Accordingly, APQ17: *"I made sure I had a flare up plan"* was removed due to the greatest number of missing answers (n=19). Of interest, one participant (RN373) made a comment that they did not understand the term 'flare up plan'.

Furthermore, APQ20: *"I did not under-do activities on a 'bad' day"* was removed due 17 missing answers. Eight patients wrote comments expressing their confusion regarding the wording of APQ20, with particular focus on the presence of a double-negative. Similarly, APQ34: *"I did not over-do activities on a 'good' day"* was removed due to 17 missing answers. Six patients wrote comments in reference to confusing phrasing of APQ34, specifically the inference of "I did not" on the 0-4 rating scale. One further patient commented that they had not had a 'good day' for three weeks. Of note, the APQ instructs that answers are rated as a reflection over the previous seven days. APQ37: *"I assessed my activity levels"* which also had 17 missing answers was maintained at this stage as it did not contain a double negative, and had a strong factor loading with similar items.

APQ items with very low or high mean scores were removed. The range of available answers for a single APQ item is 0-4, and therefore the mean score is two. If an item had a very small or very large mean, it may have indicated that the question was either under-used or over-used and may not have been sensitive to the full range of values (DeVellis, 1991). As a result, APQ32: *"I used an activity diary to monitor my activity pattern"* was removed as it had a noticeably low mean score (mean=0.47). It was considered that APQ32 was infrequently implemented as a pacing strategy.

After removing APQ32, APQ2: *"I was aware of the effect that different types of activities had on me"* was the only item to load onto component 4, and APQ2 was therefore removed (Pett et al., 2003). Of interest, one patient wrote a comment that APQ2 did not make sense. APQ26: *"I used support from others to help me with my activities"* and APQ27: *"I did not feel guilty when I stopped an activity"* were removed due to low correlations with other items and consequently small contributions to the components. Moreover, APQ27 was the only item to load onto component 6. Interestingly, APQ27 generated comments from three patients highlighting the confusion caused by the use of negative phrasing. Although no specific comments were made in relation to APQ26, one patient (PN531) made the following general comment:

> *"Some questions about tasks and activities do not accommodate single parents. I feel pain all the time, most of the time severe but I still have to push myself to do things for the sake of my children and their well being." (PN531)*

It was considered that APQ26 regarding asking for support may not always be appropriate for patients. After removing the above seven questions, the number of complete cases increased from 228 to 244 (KMO=0.936).

6.2.4.2 Number of factors

Principal components analysis was re-run for the remaining 31 items with a Varimax rotation. Five components had eigenvalues >1, but a sixth had an eigenvalue of 0.997, which was considered close enough to 1 to warrant exploring both a five and six factor solution. However, the items in the rotated six factor solution did not appear to load as logically as the five factor solution. Therefore, the five factor solution was retained with all eigenvalues >1, which explained 62.8% of the total variance in terms of the principal components solution.

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To explore the most suitable factor solution principal axis factoring was utilised with Varimax and Oblimin rotations. Both rotations produced a similar solution for all but one item. APQ28: *"I set activity goals that were realistic for me"* loaded onto factor 1 in the Varimax rotation, together with the item from which it was divided following the Delphi technique, APQ25: *"I set activity goals that were meaningful to me"*. However, this was not the case in the Oblimin solution. Therefore, the Varimax rotation appeared to be most suitable. None of the remaining 31 items had low loadings on all rotated factors and no item loaded in isolation on a single factor. The percentage of variance explained under principal axis factoring was 55.7%, the drop reflecting the exclusion of variance due to measurement error (Pett et al., 2003).

6.2.5 Reliability of the APQ

6.2.5.1 Inter-item correlations, item total correlations and Cronbach's alpha

An initial exploration of the reliability of the 31-item APQ was made using estimations of inter-item correlations, corrected item total correlations and Cronbach's alpha. Inter-item correlations estimate the level of association between items in a factor and it is recommended that this is <0.80 so that two items are not identical (Pett et al., 2003). Corrected item total correlations estimate the association between an item and the scale score without that item. Corrected item total correlations between an approximate range of 0.4-0.7 are considered moderately high (Pett et al., 2003). Cronbach's alpha is an estimation of the internal consistency of a scale, that is, the amount of variance in a scale for which can be accounted (Pett et al., 2003). Cronbach's alpha can range from 0 to 1 and it is suggested that alpha=0.70-0.80 is "respectable" and between 0.80-0.90 is "very good" (DeVellis, 1991). The higher alpha coefficient is suggestive of greater homogeneity of items. However, alpha values >0.90 are considered to be indicative of repetitive items, which possibly requires item reduction (DeVellis, 1991).

Cronbach's alpha for all 31 APQ items was 0.95, which is higher than the recommended 0.90. However, the coefficient of alpha increases with an increased number of items (Pett et al., 2003). Cronbach's alpha was estimated for each of the APQ factors together with inter-item correlations and corrected item total correlations.

APQ factor 1 (20.6% of variance explained)

Cronbach's alpha for APQ factor 1 was 0.932, which is higher than the recommended 0.90. However, APQ factor 1 was the largest factor (n=12) *(see Appendix 11, Table 6.14*

APQ factor 1 corrected item total correlations, Cronbach's alpha if item deleted, mean and standard deviation).

There were no negative inter-item correlations in APQ factor 1, and therefore no items required reverse scoring *(see Appendix 11, Table 6.15 APQ factor 1 inter-item correlations).* The highest inter-item correlation was between APQ13: *"I broke tasks up into periods of activity and rest"* and APQ15: *"I divided each day up into periods of activity and rest"* respectively (r=0.71). These items generated a comment from a patient regarding their similarity. Although, APQ13 and 15 are similar in terms of incorporating rests, they contain two important concepts of breaking up a task and breaking up the day. Removing APQ13 led to a reduction of Cronbach's alpha from 0.932 to 0.922 and removing APQ15 reduced alpha to 0.925. Therefore, removing either item did not reduce alpha to <0.90. Since the inter-item correlation between APQ13 and 15 was <0.80, both items were retained.

The items with the lowest inter-item correlation were APQ8: *"I alternated the type of activity that I was doing"* and APQ11: *"I accepted that I have some limitations due to my symptoms"* (r=0.35). However, both items were retained as low inter-item correlations do not necessary reduce the overall reliability of a scale (Pett et al., 2003). APQ13 had the highest item total correlation (r=0.82) and APQ11 had the lowest item total correlation (0.55). There was no effect on alpha by removing APQ11. Additionally, APQ11 did not have multiple loadings onto different factors, and was therefore retained.

Interestingly, APQ33: *"I broke down activities into manageable pieces"* loaded onto factor 2 (0.575) more than factor 1 (0.446). However, it was queried whether this item might be more suitable in factor 1. Cronbach's alpha was estimated for factor 1 containing APQ33, leading to a slight increase in terms of alpha (0.934) for factor 1 but a decrease in alpha for factor 2 (0.900). In addition, moving APQ33 to factor 1 led to a reduction in the minimum and maximum inter-item correlations and item total correlations. It was concluded that APQ33 would remain in factor 2.

APQ factor 2 (12.3% of variance explained)

There were no negative inter-item correlations requiring reverse scoring of any items in APQ factor 2 *(see Appendix 11, Tables 6.16 and 6.17 APQ factor 2 corrected item total*

correlations, Cronbach's alpha if item deleted, mean and standard deviation, and inter-item correlations). The highest inter-item correlation was between APQ25 and APQ28: *"I set activity goals that were meaningful to me"* and "*I set activity goals that were realistic for me"* respectively (r=0.68). Of note, APQ25 and APQ28 were originally 1 item that was split into two following the Delphi technique. APQ25 had a lower mean, lower item-total correlation and lower factor loading in comparison to APQ28. Therefore, it was justified that APQ25 would be removed from APQ factor 2 due to repetition. The effect of removing APQ25 was a reduction in alpha from 0.911 to a more acceptable 0.900.

APQ factor 3 (8.1% of variance explained)

There were no negative inter-item correlations for APQ factor 3 *(see Appendix 11, Tables 6.18 and 6.19 APQ factor 3).* Cronbach's alpha for APQ factor 3 was 0.828 which is considered to be very good (DeVellis, 1991). Of interest, removing APQ3: *"I prioritised my activities for each day"* would increase alpha to 0.836. However, as a small subscale containing only three items and an acceptable alpha coefficient, all items were retained.

APQ factor 4 (7.6% of variance explained)

There were no negative inter-item correlations in APQ factor 4 *(see Appendix 11, Tables 6.20 and 6.21 APQ factor 4).* APQ factor 4 had an acceptable Cronbach's alpha (0.774) and there was no indication to remove any items from this factor.

APQ factor 5 (7.2% of variance explained)

There were no negative inter-item correlations in APQ factor 5, and all questions remained positively scored *(see Appendix 11, Tables 6.22 and 6.23 APQ factor 5).* Cronbach's alpha for APQ factor 5 (0.724) was satisfactory and the effect of removing any of the three items caused a reduction in Cronbach's alpha. All items were therefore retained.

Following the exploration of the items contained within the five factors, only APQ25 was removed *(see Appendix 11, Table 6.24 Summary of the items removed from the APQ).* Accordingly, the APQ contained 30 items and this led to an increase from 244 complete cases for the 31-item APQ to 245 complete cases *(see Appendix 12, Table 6.25 for mean and standard deviation of each of the 30 items).* The remaining 30 items

had scores fairly close to the mean. The minimum mean score for an item was for APQ31: *"I planned in advance how long I would spend on each activity"* (mean=1.29). Of interest, APQ31 generated one patient comment:

> *"I'm not sure how much 'advance planning' I do when considering activities. I tend to be guided by how I feel on a particular day or by how many other activities I need to complete. For me, it's tied in with prioritising what I do as well as available energy". (RN262)*

The maximum mean score was for APQ11: *"I accepted that I have some limitations due to my symptoms"* (mean=2.76).

Exploratory factor analysis was repeated for the 30 items, and KMO=0.935 (Chi square for Barlett's test=4479.46, df=435, $p<0.001$). Five factors had eigenvalues >1 on principal axis factoring, with a sixth factor with an eigenvalue=0.990. Principal axis factoring with Varimax rotation with five factors found an identical loading matrix to the 31-item scale for all but one item, APQ18: *"I was creative and found new ways of doing tasks"* which loaded on factor 2 in the 31-item scale, but factor 1 in the 30-item scale. The six factor solution did not give rise to any items that loaded most heavily on the sixth factor, and therefore the five factor solution was accepted.

The five factor solution accounted for 63.2% of the variance (which was a slight increase from 62.8% for the 31-item analysis) in terms of the initial eigenvalues through principal components analysis. Under principal axis factoring, the percentage of variance explained was 55.9%, virtually the same as the 55.7% for the 31-item analysis. APQ factor 1 appeared to be the most important factor, explaining the highest percentage of the variance (21.2%), whilst APQ factor 5 appeared to be the least important factor, accounting for the lowest percentage of the variance (6.5%) *(see Appendix 12, Table 6.26 for the five factor solution for the 30-item APQ)*. Table 6.2.2 below shows the five factors of the 30-item APQ, the percentages of variance explained and Cronbach's alpha for each factor, together with the theme names and the items contained within each theme.

Table 6.2.2 The five factors of the 30-item APQ (together with percentages of variance explained, Cronbach's alpha and the items contained within each theme)

Factor	APQ	APQ item	% variance explained	Cronbach's alpha
1 Activity limitation	5	I took a short rest from an activity so that I could complete the activity later	21.2%	0.933
	6	I had periods of planned rest that did not involve sleeping		
	7	I changed activities before I had an increase in my symptoms		
	8	I alternated the type of activity that I was doing		
	9	I split activities up and did parts throughout the week		
	10	I planned my activities around events that were important to me		
	11	I accepted that I have some limitations due to my symptoms		
	12	I spent less time on some activities so that I could do them every day		
	13	I broke tasks up into periods of activity and rest		
	15	I divided each day up into periods of activity and rest		
	16	I spread out the activities that require a high amount of energy		
	18	I was creative and found new ways of doing tasks		
	19	I spread different types of activities across the day		
2 Activity planning	28	I set activity goals that were realistic for me	12.0%	0.894
	29	I switched between activities that use a high amount of energy and activities that use a low amount of energy		
	31	I planned in advance how long I would spend on each activity		
	33	I broke down activities into manageable pieces		
	35	I set realistic time limits for specific tasks so that I did not over-do things		
	36	I developed a routine so that I had a balance between being active and inactive		
	37	I assessed my activity levels		
3 Activity progression	1	I gradually increased activities that I had been avoiding because of my symptoms	8.4%	0.828
	3	I prioritised my activities for each day		
	4	I gradually increased how long I could spend on my activities		
4 Activity consistency	14	I kept to a consistent level of activity every day	7.8%	0.774
	21	I did a variety of different activities		
	30	I made sure I did some activity every day, even if I had a 'bad' day		
	38	I did a similar amount of activity on 'good' and 'bad' days		
5 Activity acceptance	22	I was able to say 'no' if I was unable to do an activity	6.5%	0.724
	23	I changed my activity targets if they were unrealistic		
	24	I did my activities without putting pressure on myself to complete them		

6.2.5.2 APQ factor themes

The items in factor 1 contained concepts such as using rests, modifying activities, reducing activities, and spreading/alternating activities, and appear to come under a theme of 'Activity limitation'. The items contained within APQ factor 2 contain concepts such as planning, setting goals and having a routine. As a result, this factor has been named 'Activity planning'. APQ factor 3 contained items referring to gradually increasing activities and prioritising activities. Hence, this theme was named 'Activity progression'. The concepts contained within APQ factor 4 involve having consistent levels of activity and having similar levels of activities on good and bad days. APQ factor 4 was named 'Activity consistency'. The items in APQ factor 5 contained concepts such as 'saying no', changing targets and reducing pressure on oneself. APQ factor 5 appears to have a theme of 'Activity acceptance'.

6.2.6 Comparisons between the APQ factors

6.2.6.1 Distribution of the APQ factor scores

The scores for the five factors of the APQ were calculated firstly allowing for only complete data sets. A second calculation was made allowing for one missing answer per factor in a data set. For example, if APQ24 was missing for a participant, the score for factor 5 was calculated as:

Factor 5=(APQ22 + APQ23)/2

This resulted in an increased number of participants with factor scores that could be included in analyses (that is, an increase by 23 for factor 1, 14 for factor 2, 10 for factor 3, 12 for factor 4 and 5 for factor 5). Allowing for one missing item per factor, the number of participants with a score for each factor ranged from 294 to 304, with 287 out of 311 participants having a score for each of the five factors. Of note, the scores for the data sets with one missing answer were similar to the complete data sets, with the largest difference in mean score being only 0.05 for factor 2. Due to the increased data that could be analysed, permitting one missing answer per factor was selected and will thereafter be advised when scoring the APQ *(see Table 6.2.3 for the descriptive data and Appendix 12, Figures 6.1 to 6.5 Histograms showing the distribution of scoring for the five APQ factors).*

Table 6.2.3 Descriptive statistics for APQ factor scores for participants with complete data and with one missing value within each factor

APQ factor		Mean	SD	Range	1st quartile	Median	3rd quartile	Skewness	Kurtosis
Factor 1	Complete (n=271)	1.96	1.00	0.00-4.00	1.23	2.00	2.77	-0.15	-0.79
	1 missing (n=294)	1.96	1.00	0.00-4.00	1.23	2.04	2.77	-0.19	-0.79
Factor 2	Complete (n=282)	1.68	1.03	0.00-4.00	0.86	1.71	2.57	-0.05	-0.89
	1 missing (n=296)	1.73	1.04	0.00-4.00	1.00	1.71	2.57	-0.07	-0.92
Factor 3	Complete (n=293)	1.87	1.13	0.00-4.00	1.00	2.00	2.67	-0.08	-0.94
	1 missing (n=303)	1.88	1.13	0.00-4.00	1.00	2.00	2.67	-0.09	-0.91
Factor 4	Complete (n=292)	2.17	1.01	0.00-4.00	1.50	2.25	3.00	-0.44	-0.47
	1 missing (n=304)	2.16	1.00	0.00-4.00	1.50	2.25	3.00	-0.42	-0.47
Factor 5	Complete (n=299)	2.36	1.07	0.00-4.00	1.67	2.33	3.00	-0.43	-0.41
	1 missing (n=304)	2.35	1.07	0.00-4.00	1.67	2.33	3.00	-0.42	-0.40

Table 6.2.3 shows that APQ factor 5: Activity acceptance had the highest mean (2.35), indicating more agreement with that factor, whereas APQ factor 2: Activity planning had the lowest mean (1.73), indicating less agreement. For each APQ factor the means were similar to the respective medians, which is especially evident in APQ factors 2 and 5. APQ factors 4 and 5 were negatively skewed (for this size of sample, a sample skewness more extreme than ±0.29 would be considered significantly different from 0) with a sample skewness of -0.42 (Pett, 1997). APQ factors 1, 2 and 3 had high negative kurtoses (values more extreme than ±0.58 would be considered significantly different from 0) (Pett, 1997). Together with observation of the histograms in Appendix 12, Figures 6.1-6.5, the distribution of the five APQ factors appear to be approximately Normal, but with a spike at the score of zero, with factor 2 having the most apparent spike at zero. A score of zero for a factor corresponds to a participant completely disagreeing with each item in the factor.

6.2.6.2 Correlations between APQ factors

All five APQ factors correlated with each other significantly ($p<0.001$) *(see Appendix 12, Table 6.27 Pearson's correlations between the APQ factors)*. Correlations between scores were also very similar whether complete data was used or whether one missing

value was allowed. Allowing for one missing value, the strongest correlation was between Activity limitation and Activity planning (r=0.76, p<0.001). The smallest correlation was between Activity consistency and Activity acceptance (r=0.35, p<0.001).

6.2.7 Validity

6.2.7.1 Convergent validity of the APQ against two existing pacing subscales

All five APQ factors correlated significantly with the six items of the Chronic Pain Coping Inventory (CPCI) pacing subscale (p≤ 0.001). The highest correlation was between Activity limitation and CPCI pacing subscale item 3: *"I broke up tasks into manageable pieces so I could still get a lot done despite my pain"* (r=0.58, p<0.001). The lowest correlation was between Activity consistency and CPCI pacing subscale item 1: *"I was able to do more by just going a little slower and giving myself occasional breaks"* (r=0.21, p=0.001). Unexpectedly, Activity progression had low but significant correlations with the CPCI pacing subscale *(see Appendix 13, Table 6.28 Correlations between the APQ factors and the CPCI pacing subscale items).*

All five APQ factors correlated significantly with the six items of the Pain and Activity Relations Questionnaire (PARQ) pacing subscale (p≤ 0.002). The highest correlation was between Activity limitation and PARQ pacing subscale item 2: *"I use repeated rest breaks to help me complete activities"* (r=0.69, p<0.001). The lowest correlation was between Activity consistency and PARQ pacing subscale item 2 (r=0.18, p=0.002). Again, unexpectedly, weaker correlations (although still significant) were found between Activity progression and all six PARQ pacing subscale items *(see Appendix 13, Table 6.29 Correlations between the APQ factors and the PARQ pacing subscale items).*

6.2.7.2 Internal consistency of the CPCI and PARQ pacing subscales

The CPCI pacing subscale had an internal consistency of Cronbach's alpha=0.93 with only 226 valid cases having responses for each of the six items. This compared poorly with the APQ where 287 participants had scores on all of the five factors. Of note, each item in this scale has a possible range of 0-7 days (mean=3.5). For all 6 items in the CPCI pacing subscale, participants' mean scores were lower than 3.5 (mean=2.87-3.26) *(see Appendix 13, Table 6.30 Mean score and standard deviation of the items in the CPCI pacing subscale).*

The PARQ pacing subscale had an internal consistency of Cronbach's alpha=0.91 with 290 valid cases having responses for each of the six items. Each item has a possible range of 0-5 (mean=2.5). The participants' mean scores for each item were higher than 2.5 (mean=2.54-3.02) *(see Appendix 13, Table 6.31 Mean score and standard deviation of the items in the PARQ pacing subscale).*

6.2.7.3 Ease of completion of the APQ, CPCI pacing subscale and the PARQ pacing subscale

In order to compare the ease of completion of the APQ with the CPCI and PARQ pacing subscales, participants were invited to rate each scale on a 0-4 NRS scale, where 0=very difficult to complete and 4=very easy to complete. Participants found the PARQ pacing subscale the easiest to complete and the CPCI pacing subscale the most difficult to complete. The CPCI pacing subscale had the most number of missing answers per item. Although the APQ contained the greatest number of items, it had the lowest average number of missing answers *(see Table 6.2.4 Ease of completion of the APQ, CPCI and PARQ pacing subscales).*

Table 6.2.4 Ease of completion of the APQ, and CPCI and PARQ pacing subscales

	APQ	CPCI pacing subscale	PARQ pacing subscale
Number of questions (range of possible answers)	38 (0-4)	6 (0-7)	6 (0-5)
Ease of completion NRS(0-4): mean(SD)	2.23 (1.02)	2.01 (1.08)	2.41 (0.98)
Ease of completion NRS median (range)	2.00 (0-4)	2.00 (0-4)	2.00 (0-4)
Number of missing answers per item, range (mean)	6-17 (11.39)	49-68 (54.83)	11-17 (14.33)

6.2.7.4 Associations between the APQ and validated measures

Activity limitation, Activity planning, Activity progression and Activity acceptance all correlated positively and significantly with current pain. Therefore, higher scores on these APQ factors correlated with increased current pain. There was a small negative correlation between Activity consistency and current pain, but this was not significant (r=-0.08, p=0.199). Activity limitation, Activity progression and Activity acceptance correlated positively and significantly with usual pain ($p<0.05$). Similarly to current

pain, there was a negative correlation between Activity consistency and usual pain, but this was not statistically significant (r=-0.05, p=0.435) *(see Appendix 14, Table 6.32 Correlations between APQ factors and validated measures).*

Activity consistency correlated negatively with physical and mental fatigue (r=-0.30, p<0.001 and r=-0.22, p<0.001 respectively). Therefore, higher Activity consistency scores were associated with lower fatigue. Of interest, negative relationships were found between Activity planning and Activity progression and fatigue, but not to levels of significance.

There was a significant correlation between increased Activity limitation and increased anxiety (r=0.12, p=0.045). Conversely, Activity consistency correlated significantly with lower anxiety (r=-0.15, p=0.009). Activity limitation correlated significantly with increased depression (r=0.13, p=0.025). However, Activity consistency correlated significantly with lower depression (r=-0.29, p<0.001). There were weak associations between Activity planning and Activity progression and lower depression, but these were not statistically significant.

In terms of fear-avoidance, Activity limitation correlated significantly with increased cognitive anxiety (r=0.14, p=0.023), escape and avoidance (r=0.25, p<0.001), fearful thoughts (r=0.21, p=0.001) and physiological anxiety (r=0.19, p=0.002). Activity planning correlated significantly with increased escape and avoidance (r=0.15, p=0.015). Activity progression was not significantly associated with fear-avoidance. Activity consistency correlated significantly with reduced fear-avoidance on all four subscales (r=-0.20, p=0.001; r=-0.15, p=0.011; r=-0.18, p=0.002; r=-0.25, p<0.001). Activity acceptance correlated weakly but significantly with increased cognitive anxiety (r=0.12, p=0.038) and escape and avoidance (r=0.19, p=0.001).

Activity limitation correlated significantly with lower physical function (r=-0.34, p<0.001). No significant correlation was found between Activity limitation and mental function. Activity planning correlated significantly with reduced physical function (r=-0.12, p=0.035). Similarly, a negative correlation was found between Activity progression and physical function but this was not statistically significant (r=-0.11, p=0.056). Activity consistency correlated significantly with both increased physical function (r=0.17, p=0.003) and mental function (r=0.28, p<0.001). Activity acceptance

correlated significantly with lower physical function (r=-0.14, p=0.013). There was an insignificant association between Activity acceptance and lower mental function.

6.2.7.5 Associations between the APQ and participants' demographics

There were no significant correlations between any of the five APQ factors and the duration of participants' conditions. Participant's age was significantly associated with only Activity limitation and Activity acceptance (r=0.14, p=0.021; r=0.16, p=0.006 respectively). There were no statistically significant differences between how male and female patients scored on the APQ factors, although female patients scored slightly higher for all APQ factors, with the exception of Activity limitation *(see Appendix 15, Table 6.33 Associations between the APQ factors and participant demographics)*.

Comparing the APQ scores between the retrospective and current patients, retrospective patients scored slightly higher on all APQ factors, except for Activity acceptance. However, these differences were not statistically significant *(see Appendix 15, Table 6.34 Comparisons of APQ factor scores between retrospective and current patients)*.

In order to further compare patients at different stages of treatment, current patients were separated into those who were attending a rehabilitation group and therefore receiving current treatment, with those who had been sent the questionnaire booklet in the post, therefore pre-treatment. Patients attending a rehabilitation group had higher mean scores for all APQ factors. However, this difference was only significant for Activity planning and Activity progression (t=-3.01, df=75.6, p=0.004; t=-2.91, df=58.9, p=0.005 respectively) *(see Appendix 15, Table 6.35 Comparisons of APQ factor scores between current patients pre-treatment and those attending a rehabilitation group)*. Of interest, all patients treated in a group had higher APQ scores than those treated individually, whether retrospective or current patient status.

In terms of participants' ethnicity, there were small numbers of all categories other than white *(see Appendix 15, Table 6.36 Frequency of the different ethnic groups)*. Therefore, the APQ factor scores across different ethnicities were not explored. Among the different marital status groups, the groups with small numbers with complete data sets (that is, n=8 separated, and n=6 widowed) were excluded to allow a comparison between the APQ factor scores to be explored using ANOVA. There were no statistically significant differences between APQ factor scores across the different

marital status, even when the two groups with smaller numbers were removed from the analysis *(see Appendix 15, Table 6.37 Comparisons of APQ factor scores across marital status)*. Of note, removing the small groups from the analysis did not affect the statistical significance of the results.

Among the different employment status groups, the groups with small numbers with complete data sets (that is: n=5 working full-time at home, n=6 student and n=3 semi-retired) were excluded to allow a comparison between the APQ factor scores to be explored using ANOVA *(see Appendix 15, Table 6.38 Frequency of categories of employment status)*. Patients who were 'not working due to their condition' had the highest mean scores of Activity limitation and Activity progression. The lowest mean score for both factors was reported by those who were 'unemployed but seeking work'. This difference in mean scores for Activity limitation and Activity progression was statistically significant (F=4.08, df=5, 250, p=0.001 and F=4.42, df=5, 75.94, p=0.001 respectively). The same pattern was seen for Activity planning. However, this difference was not statistically significant. Patients who had the highest mean score of Activity consistency were those working part-time. The group with the lowest mean score were those 'not working due to other reasons'. This difference was not significant. The group with the highest mean score of Activity acceptance were those 'not working due to their condition'. The group with the lowest score were those working full-time. This difference was not statistically significant *(see Appendix 15, Table 6.39 Comparisons of APQ factor scores across employment status)*.

6.2.7.6 Associations between the APQ and participants' conditions

Patients without back pain scored higher on APQ factors: Activity limitation, Activity planning and Activity progression. However, this difference was only significant for Activity limitation (t=2.47, df=292, p=0.014). Patients with chronic widespread pain reported higher scores for Activity limitation, Activity planning, Activity progression and Activity acceptance. This was statistically significant for Activity limitation, Activity planning and Activity progression (t=-3.03, df=292, p=0.003; t=-2.52, df=293, p=0.012; t=-2.56, df=300, p=0.011 respectively). Patients with fibromyalgia reported higher scores for all five APQ factors in comparison to patients without fibromyalgia. However, this difference was only significant for Activity progression (t=-2.09, df=300, p=0.037). Patients with CFS scored higher on all factors of the APQ with the exception of Activity consistency. However, this difference was only significant for Activity

limitation, Activity planning and Activity progression (t=-3.28, df=292, p=0.001; t=-2.49, df=72.6, p=0.015; t=-3.40, df=67.3, p=0.001). Patients with ME scored higher on all five APQ factors in comparison to patients without ME. This difference was significant for Activity limitation and Activity progression (t=-2.89, df=292, p=0.004; t=-2.10, df=300, p=0.036 respectively). Patients who reported they had another condition (in addition to the above chronic conditions) had lower scores for all five APQ factors. However, these differences were not statistically significant *(see Appendix 15, Tables 6.40-6.45 Comparisons of APQ factor scores between patients with and without specific chronic conditions).*

Patients with ME had the highest mean scores for all APQ factors with the exception of Activity planning, for which patients with CFS had the highest score. Conversely, patients with an 'other condition' gave the lowest scores for all APQ factors.

Since patients were able to report the presence of more than one condition, they were asked to indicate their main condition. Of note, ME and 'other condition' were excluded from this analysis due to small numbers of patients. Excluding ME and 'other condition' did not affect the statistical significance of the results *(see Appendix 15, Table 6.46 Comparisons of APQ factor scores between patients' main conditions)*.

Patients who reported CFS as their main condition had the highest mean score of Activity limitation, while patients with back pain had the lowest mean score. The difference in scores across patients' main conditions for Activity limitation was statistically significant (F=4.78, df=3,237, p=0.003) *(see Figure 6.2.3 Bar chart of mean Activity limitation scores).*

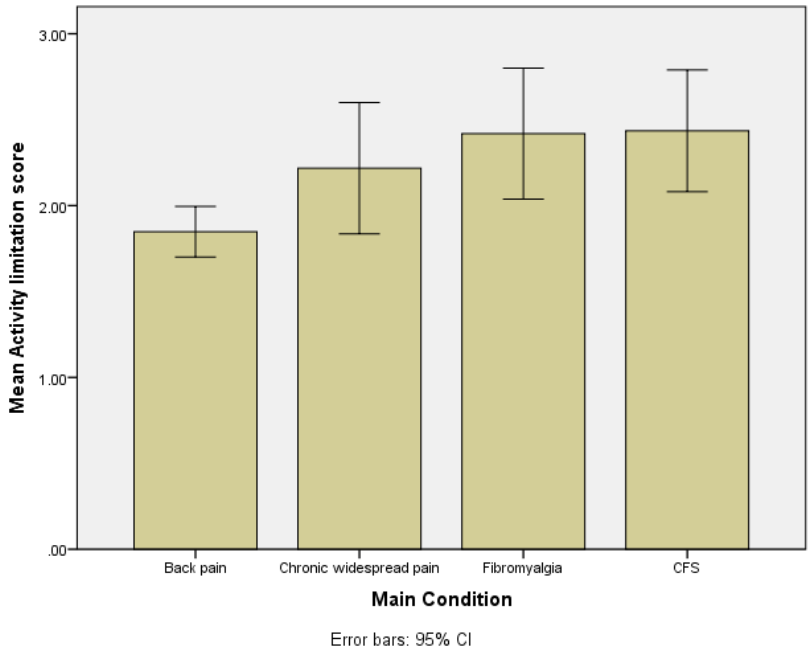

Figure 6.2.3 Bar chart of mean Activity limitation scores across patients' main conditions

Patients with fibromyalgia as their main condition had the highest mean score of Activity planning, in comparison to patients with back pain as their main condition who had the lowest mean score. This difference was statistically significant (F=3.89, df=3, 55.2, p=0.014) *(see Figure 6.2.4 Bar chart of mean Activity planning scores).*

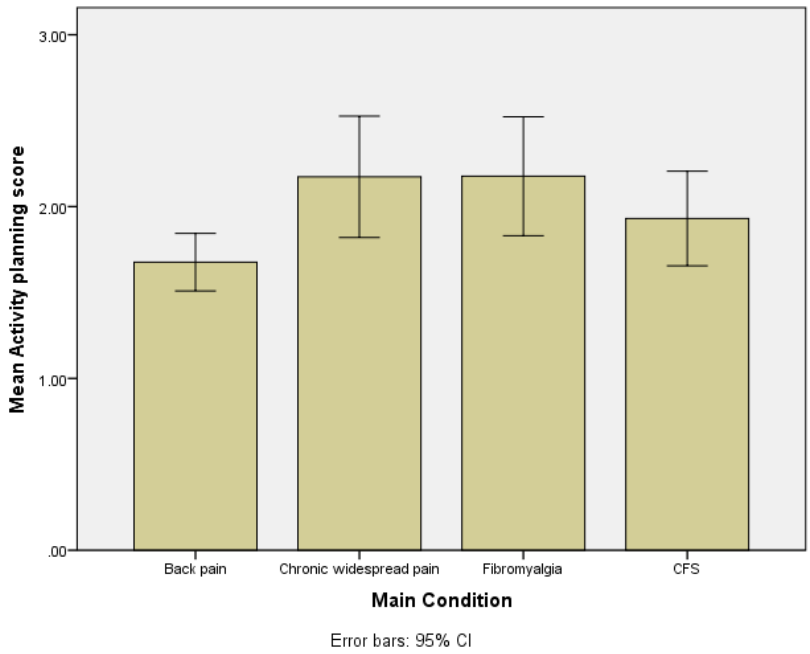

Figure 6.2.4 Bar chart of mean Activity planning scores across patients' main conditions

Patients with CFS as their main condition had the highest mean score of Activity progression, and patients with back pain as their main condition had the lowest mean score. This difference was not statistically significant *(see Figure 6.2.5 Bar chart of mean Activity progression scores).*

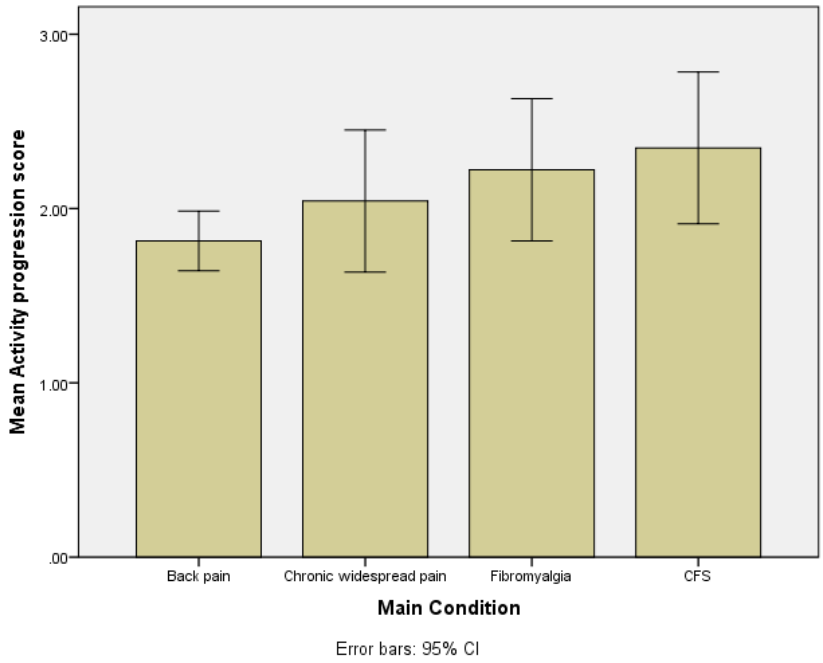

Figure 6.2.5 Bar chart of mean Activity progression scores across patients' main conditions

Patients with a main condition of chronic widespread pain had the highest mean score of Activity consistency, and patients with CFS as their main condition had the lowest mean score. This difference was not statistically significant *(see Figure 6.2.6 Bar chart of mean Activity consistency scores).*

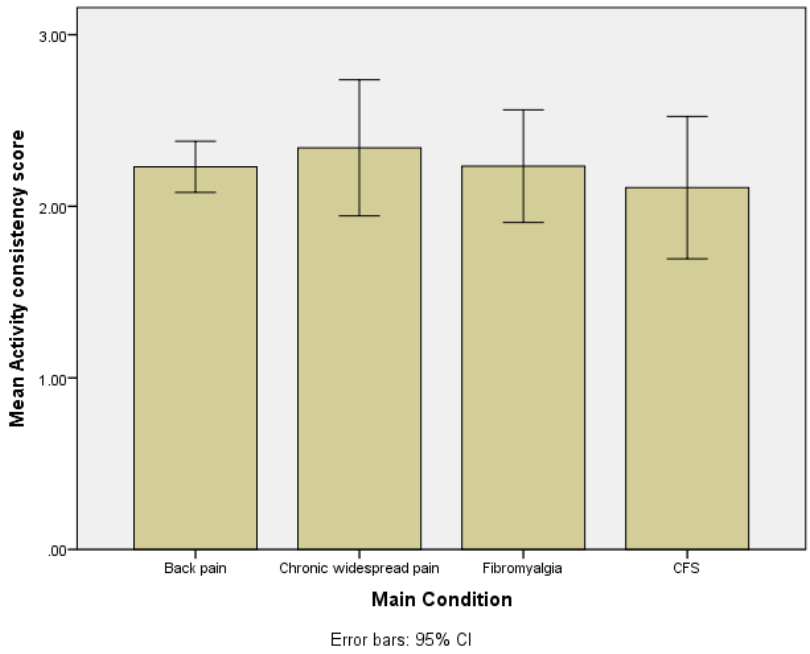

Figure 6.2.6 Bar chart of mean Activity consistency scores across patients' main conditions

Patients with fibromyalgia as their main condition had the highest mean score of Activity acceptance, while those with back pain as their main condition had the lowest mean scores. This difference was not statistically significant *(see Figure 6.2.7 Bar chart of mean Activity acceptance scores across patients' main conditions)*.

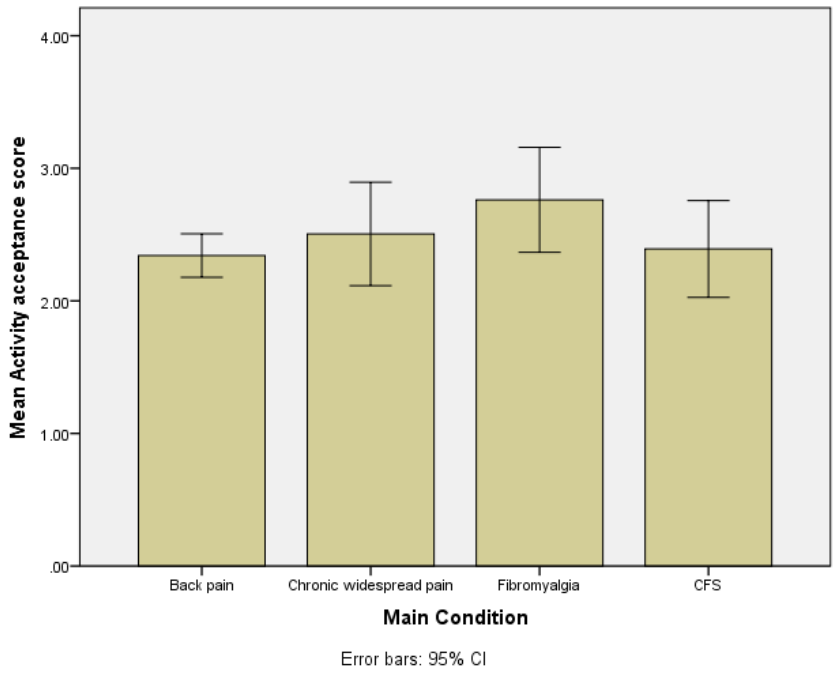

Figure 6.2.7 Bar chart of mean Activity acceptance scores across patients' main conditions

6.2.8 Test-retest reliability of the APQ

The mean test-retest period was 29.6 days (SD=13.3, min-max=8-81 days). Sixty-nine current patients returned test-retest questionnaire booklets (return rate=50.4%).

6.2.8.1 Exploring the representativeness of the test-retest group

Among the current patients, there were no significant differences between the patients involved and not involved in the test-retest arm of the study in terms of gender, marital status and employment. There were no significant differences in terms of the presence of back pain, chronic widespread pain, fibromyalgia, CFS or ME. Of note, the above analyses included some small groups, and these findings should therefore be interpreted with caution. There were no significant differences between the two groups in terms of the presence of pain, or current or usual pain. Furthermore, there was no significant difference between the test-retest and non test-retest groups in terms of mental fatigue *(see Appendix 16, Tables 6.47-6.49 Comparisons of demographic characteristics, clinical characteristics and patients' symptoms between patients involved and not involved in the test-retest study).*

Current patients involved in the test-retest study (mean age=47.9 years) were significantly older than those not involved (mean age=40.7 years, t=-3.18, df=162, p=0.002). Patients involved in the test-retest sample had a longer duration of their condition (mean=8.3 years) than those not involved in the test-retest (mean=5.8 years). This difference was almost significant (p=0.057).

There was a significant difference between current patients involved and not involved in the test-retest study in terms of ethnicity, with a greater proportion of patients involved in the test-retest study of white ethnicity (88.4% v 77.7%, Fisher's exact p=0.018). There was a significant difference between the main condition that patients reported, with a smaller proportion of patients reporting back pain as their main condition (55.7% v 75.6%) and more patients reporting chronic widespread pain (18.0% v 14.1%), fibromyalgia (11.5% v 3.8%) and CFS (13.1% v 2.6%) in the test-retest group compared to the non test-retest group (Fisher's exact p=0.009). However, the above analyses of ethnicity and main condition included some small groups, and these findings should therefore be interpreted with caution. The test-retest group reported significantly lower physical fatigue compared to those not involved in the test-retest study (11.3 v 12.9, t=2.13, df=159, p=0.035).

To summarise, the sample size of 69 participants involved in the test-retest arm of the study was adequate to assess the test-retest reliability of the APQ. This subgroup of current patients was similar to the full group of current patients in terms of gender, marital status, employment status, and the presence of back pain, chronic widespread pain, fibromyalgia, CFS and ME. Furthermore, the test-retest group reported similar levels of current and usual pain, together with mental fatigue. However, the test-retest group showed some differences in terms of older age, predominantly white ethnicity and the main condition that was reported. Additionally, participants involved in the test-retest study reported significantly lower levels of physical fatigue.

6.2.8.2 Change in APQ factor scores over the test-retest period

The mean scores for all APQ factors except Activity acceptance increased from the initial measure (T1) to the second measure (T2). The increases in mean scores for each factor were all marginal, the largest change in mean score being for Activity consistency (T1 mean=2.21, T2 mean=2.39, T1-T2=-0.18). A negative score indicates an increase over the test-retest period.

The internal consistency of the five factors remained very stable for all APQ factors. The biggest change in Cronbach's alpha was for Activity acceptance, where an increase of 0.05 was noted *(see Appendix 17, Table 6.50 APQ Mean scores and internal consistency over the test-retest period).*

6.2.8.3 Test-retest methods

Test-retest reliability was explored via three methods: Pearson's correlations, intraclass correlations and the Bland and Altman method.

Pearson's correlation

Pearson's correlations for the five APQ factors ranged from r=0.50 (Activity consistency) to r=0.79 (Activity limitation), all significant at $p<0.001$ which are interpreted a large effect size (Cohen, 1992) *(see Appendix 17, Table 6.51 Pearson's correlations for all APQ factors across the test-retest period).*

Intraclass correlations (ICC)

Activity limitation had an excellent reliability with the highest intraclass correlation of all the APQ factors (ICC=0.79, p<0.001). Of note, this factor has the greatest number of items and highest Cronbach's alpha. Interestingly, this factor had the fewest complete data sets for analysis (n=64 out of 69). Activity consistency had the lowest intraclass correlation (ICC=0.50, p<0.001). However, this is still considered to be a fair to good level of reliability (Fleiss, 1986). Of note, this is not the factor with the lowest number of items (that is, Activity progression) *(see Appendix 17, Table 6.52 Intraclass correlations of the APQ factors).*

Bland and Altman method

To explore the level of agreement between the APQ factor scores at T1 and T2, the Bland and Altman method was used. There were data for 64-68 patients for each APQ factor, which is adequate for a purposeful analysis (Rankin and Stokes, 1998) *(see Appendix 17, Table 6.53 Summary data for Bland and Altman plots).*

The mean difference between T1 and T2 for Activity limitation was close to zero (-0.07), and Activity limitation had the smallest standard deviation of the difference (0.63), both of which are indicative of good agreement (Rankin and Stokes, 1998). Furthermore, all but two measures were within +/- 2 standard deviations of the mean difference of scores for Activity limitation on T1 and T2 with most clustered near the mean. Therefore, it is considered that these data are Normally distributed. Agreement is considered good for the test-retest reliability of Activity limitation. This complements the intraclass correlation for Activity limitation which was the highest of all APQ factors *(see Figure 6.2.8 Bland and Altman plot of Activity limitation).*

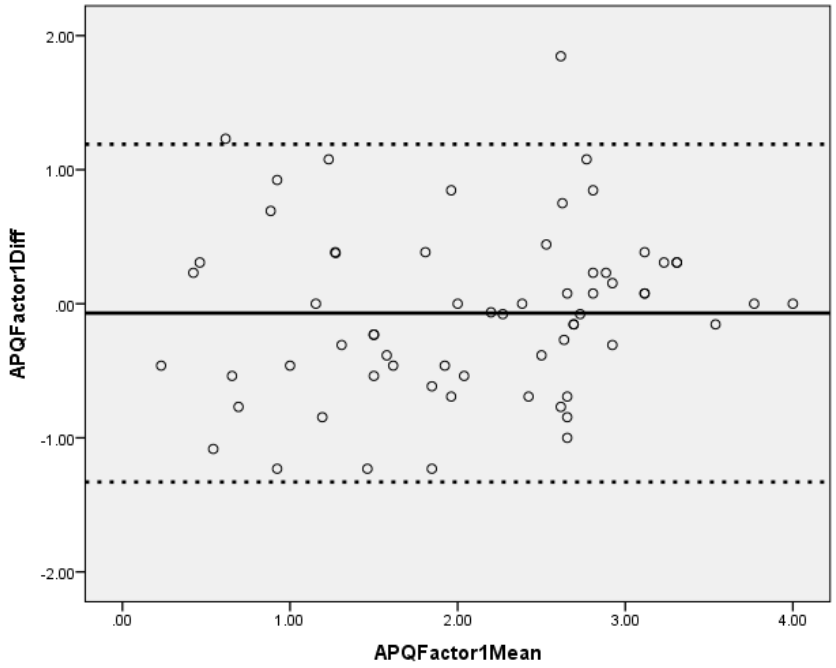

Figure 6.2.8 Bland and Altman plot of Activity limitation (APQ factor 1)

Activity planning had a mean difference between T1 and T2 which was close to zero (-0.06), and a small standard deviation of differences (0.82), indicating mostly good agreement. The data were predominantly located within two standard deviations of the mean, except for five measures. Ideally, to be considered Normally distributed, less than four measures would be advised as outliers. It appears there may be less agreement between T1 and T2 in comparison to Activity limitation, but the agreement is still good *(see Figure 6.2.9 Bland and Altman plot of Activity planning).*

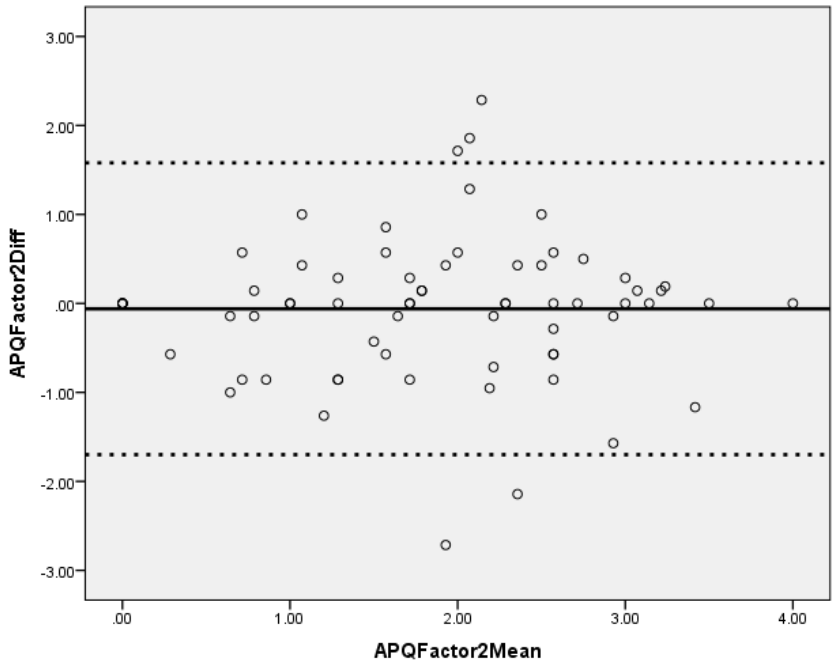

Figure 6.2.9 Bland and Altman plot of Activity planning (APQ factor 2)

Activity progression had a slightly larger mean difference between T1 and T2 (-0.10), and slightly larger standard deviation of the difference (0.93). However, most data were within 2 standard deviations of the mean with the exception of four outliers. Activity progression is considered to have satisfactory agreement across the test-retest period *(see Figure 6.2.10 Bland and Altman plot of Activity progression).*

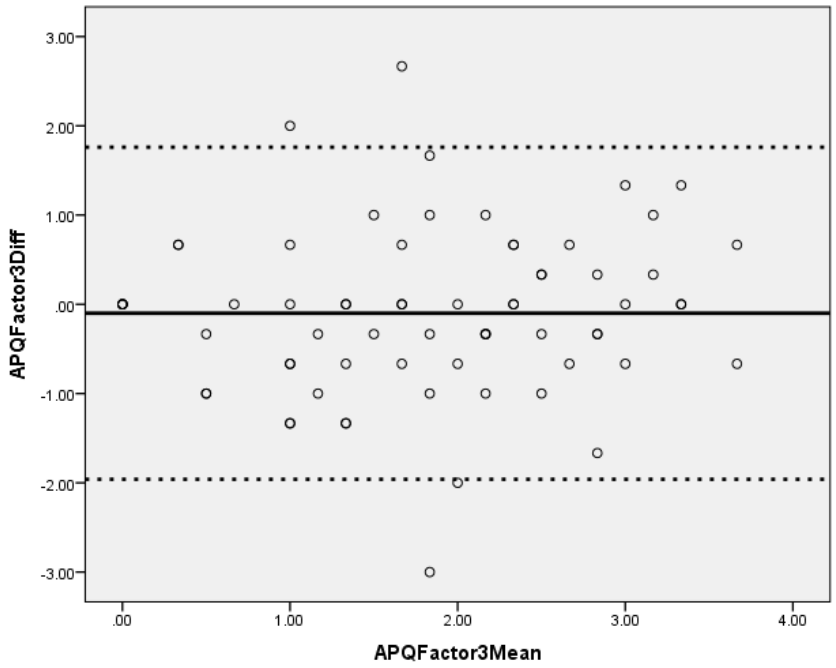

Figure 6.2.10 Bland and Altman plot of Activity progression (APQ factor 3)

Activity consistency had the largest mean difference (-0.18) and joint largest standard deviation (0.93) indicating less agreement than the other factors. The Bland and Altman plot shows five outliers. Of note, Activity consistency had the lowest intraclass correlation of all of the APQ factors (ICC=0.50, $p<0.001$) *(see Figure 6.2.11 Bland and Altman plot of Activity consistency).*

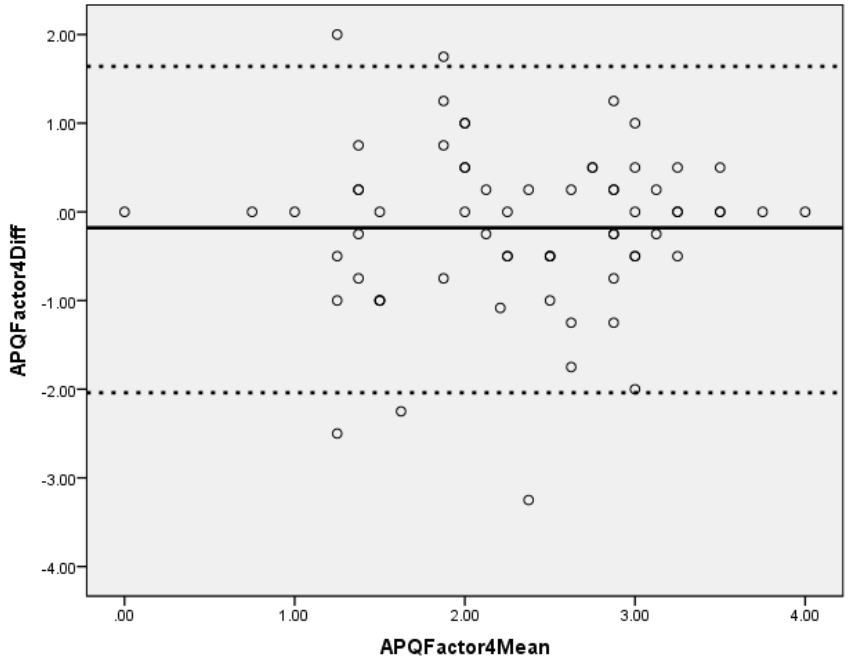

Figure 6.2.11 Bland and Altman plot of Activity consistency (APQ factor 4)

Activity acceptance had the smallest mean difference between T1 and T2 (0.06), and a small standard deviation (0.89), indicating satisfactory agreement. There were four outliers outside the range of the mean +/- two standard deviations *(see Figure 6.2.12 Bland and Altman plot of Activity acceptance).*

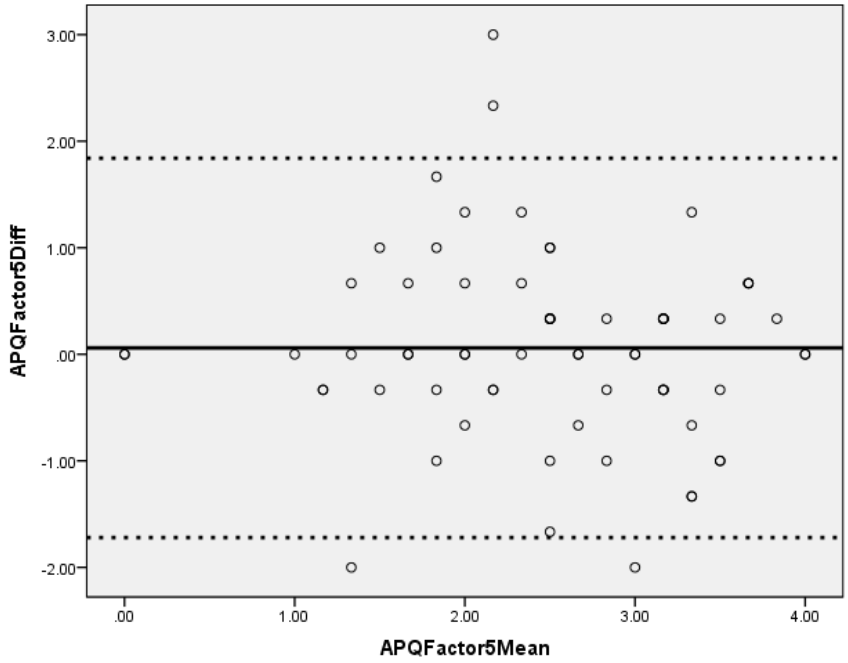

Figure 6.2.12 Bland and Altman plot of Activity acceptance (APQ Factor 5)

6.2.8.4 Test-retest of the CPCI and PARQ pacing subscales

The mean scores of the CPCI and PARQ pacing subscales for the test-retest subgroup both increased between T1 and T2 (T1=3.23, T2=3.61; T1=2.74, T2=2.89 respectively). Therefore, patients reported that they were pacing more according to these subscales at T2. This increase was observed to a greater extent in the CPCI pacing subscale. The internal consistency remained very high for both scales. There was a reduction in Cronbach's alpha for the CPCI pacing subscale (T1 α=0.95, T2 α=0.91), and a marginal increase for the PARQ pacing subscale (T1 α=0.89, T2 α=0.90) *(see Appendix 18, Table 6.54 Mean scores and internal consistency of the CPCI and PARQ pacing subscales at T1 and T2).*

As an exploration of test-retest reliability, Pearson's correlations of the CPCI pacing subscale showed that all six questions were significantly correlated at T1 and T2, but to a lesser extent than the APQ five factors (r=0.27, p=0.044 to r=0.46, p<0.001) *(see Appendix 18, Table 6.55 Pearson's correlations between T1 and T2 for the CPCI pacing subscale).* The intraclass correlations of the six items of the CPCI pacing subscale, together with the total CPCI pacing subscale score (allowing for one missing answer) were all significant but demonstrated low to fair correlations (ICC range from 0.27, p=0.021 to 0.48, p<0.001). Of note, the intraclass correlations for the CPCI were all lower than the intraclass correlations for the APQ five factors *(see Appendix 18, Table 6.56 Intraclass correlations of the CPCI pacing subscale items).*

Pearson's correlations for the six items of the PARQ pacing subscale showed good test-retest reliability with greater correlations between T1 and T2 than the CPCI pacing subscale, but generally less than the APQ (r=0.38, p=0.002 to r=0.60, p<0.001) *(see Appendix 18, Table 6.57 Pearson's correlations between T1 and T2 for the PARQ pacing subscale).* The intraclass correlations of the six items of the PARQ pacing subscale were all significant, and all but item 1 had a fair to good correlation over the test-retest period. PARQ pacing subscale item 1: *"I stop activities before the pain becomes too great and I return to them later"* had the lowest intraclass correlation (ICC=0.38, p<0.001). PARQ pacing subscale item 6: *"I pace myself to get things done"* had the highest intraclass correlation of the six items (ICC=0.60, p<0.001) *(see Appendix 18, Table 6.58 Intraclass correlations of the PARQ pacing subscale items).*

6.2.8.5 Test-retest of the validated measures

Pearson's correlations and intraclass correlations estimated that the measures of current pain and usual pain had high reliability across the test-retest period. The Chalder fatigue questionnaire mental subscale had higher reliability than the physical subscale. All correlations were statistically significant *(see Appendix 19, Table 6.59 Pearson's correlations and intraclass correlations of the pain and fatigue scales over the test-retest period).*

There was a small decrease in the mean rating of current pain and usual pain (0.36 and 0.35 respectively). A positive change in pain (T1-T2) indicates a reduction in pain. However, this reduction in either current or usual pain was not significant (p=0.175 and 0.117 respectively). Therefore, patients reported little change in terms pain over this period *(see Appendix 19, Table 6.60 Change in pain scores over the test-retest period).*

6.2.8.6 Associations between change in symptoms and change in pacing

Pearson's correlations were estimated to explore if there were associations between changes in pain and changes in APQ, CPCI and PARQ pacing subscale scores. No significant correlations were seen between changes in either current or usual pain and changes in any APQ factors. Since no significant changes in either current or usual pain were found between T1 and T2, the absence of correlations with the APQ factors adds evidence to further support the test-retest reliability of the APQ (as previously observed in the marginal change in mean scores for the APQ factors). Similarly, no significant correlations were found between change in current and usual pain and the CPCI and PARQ pacing subscales over the test-retest period *(see Appendix 19, Table 6.61 Pearson's correlations between change in pain and change in APQ factors, CPCI pacing subscale and PARQ pacing subscale scores).*

Furthermore, the test-retest questionnaire booklet contained a question to capture participants' self-reported changes in their condition. This question read: *"If your condition has noticeably changed since completing the first questionnaire booklet, please try to describe these changes in the space below".* The answers were coded as 0=worse, 1=no change and 2=better for statistical analysis. In total, 12 patients reported they felt worse, 40 patients felt the same and 11 patients reported some improvements, a fairly balanced outcome. A one-way ANOVA was implemented to explore if there were associations between patients' self-reported change and changes in pain, fatigue, APQ

factor scores, and CPCI and PARQ pacing subscale scores. There were no significant associations between patients' self-reported change and changes in usual pain. However, there was a significant association between patients' self-reported change and changes in current pain (F=10.54, df=2, 59, p<0.001). The 10 patients who reported their condition had worsened showed an increase in current pain (mean=-1.00). The 39 patients whose condition was reported to be the same also reported an increase in pain but to a lesser extent (mean=-0.23). The 11 patients who reported improvements in their condition reported a large reduction in pain (mean=2.64). Of note, the number of participants' data available for this and subsequent ANOVA was fewer than the total numbers in the self-reported categories of change due to missing data *(see Appendix 20, Table 6.62 One-way ANOVA between participants' self-reported change in condition and change in pain and fatigue).*

The association between self-reported change and change in physical fatigue was not quite significant (F=2.99, df=2, 59, p=0.058). However, the association between self-reported change and change in mental fatigue was significant (F=3.39, df=2, 60, p=0.041). Interestingly, the 11 participants who reported their symptoms were worse showed no difference in mental fatigue (mean=0.00). The 39 participants whose condition remained the same showed a small mean reduction in mental fatigue between T1 and T2 (mean=0.15). The 11 participants who reported improvements in their condition also had a reduction in mental fatigue (mean=2.27).

There were no significant associations between patients' self-reported change in condition and change in APQ factor scores, PARQ and CPCI pacing subscale scores with the exception of CPCI pacing subscale item 6: *"By going at a reasonable pace (not too fast or too slow) pain had less effect on what I was doing"* (F=3.35, df=2, 48, p=0.044). The seven patients who reported a decline in their condition, reported an increased frequency of this item (mean=-1.29 days). The 32 patients who reported no change in their condition showed a reduction in this item (mean=0.34 days). The patients who reported some improvements in their condition had an overall increase in the frequency of this item (mean=-2.20 days) *(see Appendix 20, Tables 6.63-6.65 One-way ANOVA between participants' self-reported change in condition and change in APQ factor scores and CPCI and PARQ pacing subscale scores).*

Therefore, participants' self-reported change in condition was most associated with changes in current pain and mental fatigue. This may represent a subtle change in the health status of participants from the T1 to T2. However, pacing did not appear to be associated with patients' self-reported change in condition over the test-retest period with the exception of one CPCI pacing subscale item.

The results of Stage II, the psychometric study moves forward to report the qualitative data that were collected in the questionnaire booklets.

6.2.9 Written comments

6.2.9.1 Comments regarding the APQ

Five patients commented that they found the APQ too long, and 12 patients commented that they found some questions repetitive. Twenty-six patients commented that some questions were confusing, particularly in terms of the use of double negatives as reported earlier. Regarding specific questions, one patient (RN238) queried the meaning of APQ24: *"I did my activities without putting pressure on myself to complete them".* Regarding APQ25, one patient (PB133, pre-treatment) asked the meaning of the term 'activity goals'.

One patient commented that there were not enough instructions to complete the APQ, whereas two patients commented that there were sufficient instructions. Two patients commented that relating the APQ to all different activities (physical, mental and social activities) made the items too broad, for example,

> *"Because of the very wide range of 'activities' the answers above are probably a little vague. It isn't easy to see how socialising and reading relate to back pain." (RB213)*

Six patients commented that the APQ was difficult to complete. Separate to this, four patients commented that they were unable to pace their activities due to their daily responsibilities, for example,

> *"You cannot pace yourself at work because of back pain, you have just got to get on with it or someone else will do it and you end up unemployed." (RC341)*

Four patients commented that the APQ was not adequately specific. Sixteen patients commented that the APQ was not relevant since they did not undertake the actions in the questions, or they did not have symptoms. Of interest, one patient made the following comment:

> *"The new activity pacing questionnaire felt too long-winded trying to encompass all issues associated with chronic conditions some parts not relevant to all people." (PC068)*

In contrast one patient commented that the APQ was relevant, but at present unachievable:

> *"It was difficult because what the questionnaire highlights to me is what I know I should do but paradoxically fail to do because of my condition! I am aware of what I need to do to control my condition, but feel I rarely succeed in doing what I need to do!!" (RN167)*

Twelve patients made comments regarding the seven day recall period of the APQ. Of interest, all 12 patients suggested that seven days was not long enough to give a true reflection due to fluctuations in their condition, being on holiday or work commitments. Two general comments were made at the end of the questionnaire booklet in reference to completing any scale on different occasions, for example,

> *"These past 7 days I have been in quite a lot of pain, but some weeks this can be less and some weeks a lot more-so unless you get me to fill in a similar questionnaire each week/month, you still will not get and accurate picture of how my illness affects me." (RN314)*

It is noteworthy that no patients commented that they struggled to remember their activities over the past seven days and would prefer a shorter recall period for the APQ. Three patients commented that the APQ 0-4 rating scale was confusing. To balance this, three patients found the five options a good range. Fifteen patients made comments that the APQ was easy to complete, to include the layout, the relevance and the scale.

6.2.9.2 Comments regarding the CPCI pacing subscale

Seven patients commented that they found the CPCI pacing subscale easy to complete. However, one of the seven patients commented:

> *"Easy to complete because NOT at all relevant to my behaviours and management of my condition." (RC068)*

However, eleven patients commented that they found the CPCI pacing subscale difficult to complete. Twenty-six patients made comments regarding the lack of relevance of the CPCI pacing subscale to their condition. Twenty-five patients commented that they found the questionnaire difficult to answer or irrelevant due to the pain focus of the questions, for example,

> *"..I am not in any pain so the questions do not apply to me." (RB096)*

Of note, the questions in the CPCI pacing subscale refer to 'pain' whereas the APQ purposefully refers to 'symptoms'. Two patients commented in reference to the pain focus of the CPCI pacing subscale, for example,

> *"Pain is something I've got used to and rarely bars me from doing any task. The main issue for me is fatigue, absolute fatigue, and this isn't covered by the pacing scale above." (RN167)*

Interestingly, in the test-retest booklet, one patient changed the word 'pain' to 'fatigue' on the CPCI pacing subscale in order to provide answers. In contrast, two patients commented that they found the CPCI relevant to their condition. However, of these two patients, one patient reported that they tried to ignore the pain and the other patient made the following comment:

> *"I employ all the strategies and tactics described in this section all the time, and thought the question about number of days I'd used them to be an incorrect one to ask. More appropriate, I think, would be to ask about what percentage of each day the tactics were used." (RN262)*

Nine further comments were given in relation to the difficulty of the CPCI rating scale in terms of the number of days that they had done an activity, for example,

> *"Not sure what scale I was referring to i.e. 7 days or always. Questions did not address the wider variations needed in activity levels as the new [APQ] one did." (RN095)*

> *"I can't measure some of these in 'days' e.g. sometimes I would just go slow and steady for a couple of hours….This questionnaire just confused me in general." (PC129)*

Moreover, many patients did not answer as a number from 0-7, and instead wrote words such as "all of the time" or "most of the time". Indeed, one patient made the following comment:

> *"Question 6 – the answer is for 'how many days'. It seems it should be on a scale of 'unlikely ----------highly likely" (PW048)*

It is noteworthy that the CPCI pacing subscale had the greatest number of missing answers of the three pacing scales. Fifteen patients commented that the questions in the CPCI pacing subscale did not make sense, were vague or misleading. Unlike the APQ, the CPCI pacing subscale does not instruct to which activities the questions refer.

Seven patients commented that they found the CPCI pacing subscale to be repetitive, for example,

> *"Not very relevant. It feels like the same questions being asked 6 times." (PF009)*

Four questions in the CPCI pacing subscale refer to going slower, of which three questions use the term 'slow and steady'. Six patients made comments in reference to not being able to go slower with their activities, for example,

> *"Questions are not specific enough to apply to me or my activities. To me, not all activities can be done at a slow or steady pace." (PG017)*

Similarly to the APQ, patients made comments referring to the difficulty of answering the CPCI over a seven-day recall period. Seven patients reported that their condition or activities change each week and so completing the scale on a different week would yield different answers. However, one patient reported difficulties remembering their week:

> *"Can't remember how I was each day. I think a diary would be useful for the week prior to completing this. When you feel good, you forget the pain." (PW026)*

6.2.9.3 Comments regarding the PARQ pacing subscale

Unlike the APQ and CPCI pacing subscale, the PARQ pacing subscale does not give a length of time over which to recall the answers. There were no comments highlighting the absence of a recall period. Ten patients commented that the PARQ pacing subscale was easy to use, of whom two patients commented that it was easier than the CPCI pacing subscale. Four patients commented that the PARQ pacing subscale was relevant to them. However, one of these patients answered five of the six items of the PARQ pacing subscale with scores of '0' and one question as '1' (on a 0-5 rating scale, where 0=never). Furthermore, one patient made the following comment:

> *"I would do all of the above depending how I feel except number 1 as this would feel too much like giving in." (RN348)*

Thirteen patients made comments that referred to the PARQ pacing subscale not being relevant to them, due to either their pain or their approach to activities, for example,

> *"Again the questions assume back ache increases with activity-in my case activity (regular, moderate) is actually often good for my condition and alleviates pain. Sitting down aggravates my condition and unfortunately my life consists of too much sitting." (RN022)*

Four patients found the PARQ pacing subscale difficult to complete, in terms of being confusing or lacking information. Similarly to the CPCI, the PARQ pacing subscale does not define the activities to which the questions refer. One patient commented:

> *"When I completed this task, I meant just activities which I am doing in fitness club." (PN122)*

Therefore, the answers may not have been in terms of all activities as requested for the APQ. With regards to the PARQ scale (which contains only word anchors at 0=never and 5=always) one patient made the following comment:

> *"There is a slight grey area from 1-4" (RN209)*

The PARQ pacing subscale received one comment referring to repetitive questions. However, five patients commented that the questions and the grading system were easy to understand.

6.2.9.4 General comments

One patient commented that the whole questionnaire booklet was too general. However, scales selected for the study questionnaire booklet were not condition specific so that they were relevant to a number of chronic conditions. Interestingly, patients commented on some difficulties completing not only the pacing scales, but also validated measures such as the HADS, the Chalder fatigue questionnaire and the SF-12.

Two patients commented that following the completion of the questionnaire they realised that they were implementing pacing as a coping strategy, for example,

> *"Until doing the questionnaire I didn't realise or think that I was 'pacing' myself, but broken down in questions it was easy to see that I do this without realising it. I know my limits and what I can and can't do." (PF006)*

Some patients commented favourably with regards to being involved in research in this field, for example,

> *"Great to be consulted on such questionnaires…What I do like is covering 'pain' not only in a physical sense but also in an 'emotional' and 'mental' sense. Thanks for asking." (RN167)*

Interestingly, under the APQ two patients commented that they would prefer one-to-one questioning.

6.2.10 Summary

To summarise, the exploratory analysis of the APQ found a five factor solution with a reduction in APQ items from 38 to 30. The five factors demonstrated high levels of reliability in terms of inter-item correlations, item total correlations and Cronbach's alpha. With regards to validity, the five APQ factors were all significantly associated with the existing pacing subscales of the CPCI and PARQ. However, the APQ demonstrated higher levels of reliability than existing pacing subscales, together with relative ease of completion. Furthermore, significant associations were found between the APQ factors and validated measures of symptoms of chronic conditions. Of note, increased scores of Activity limitation correlated significantly with increased pain, anxiety, depression and avoidance, and reduced physical function. Similar associations were found between Activity planning, Activity progression and Activity acceptance and worse symptoms. Conversely, higher scores of Activity consistency showed correlations with improved symptoms, that is, reduced physical and mental fatigue, anxiety and depression and avoidance, but increased physical and mental function.

There were no significant correlations between any of the five APQ factors and participants' gender, marital status or duration of condition. In addition, there were no significant differences in the five APQ factor scores between retrospective and current patients. Participant's age was significantly correlated only with Activity limitation and Activity acceptance. In terms of employment status, significant differences in APQ factor scores were found only for Activity limitation and Activity progression, in which both found that participants who were not working (due to the condition) had the highest mean and those who were unemployed (but seeking work) had the lowest mean. With regards to the main condition that participants reported, there were significant differences in the APQ factor scores for Activity limitation and Activity planning. Participants with CFS had the highest mean score for Activity limitation, while participants with low back pain had the lowest mean score. The same pattern was seen for Activity progression, but this difference was not quite significant. Participants with fibromyalgia had the highest mean for Activity planning, and those with back pain had the lowest, and this difference was significant. Interestingly, participants with back pain reported the lowest mean scores for all APQ factors, with the exception of Activity consistency, for which participants with CFS had the lowest mean.

With both intraclass correlations and Bland and Altman plots taken into consideration, all five APQ factors had adequate test-retest reliability, with Activity limitation demonstrating the highest level of test-retest reliability and Activity consistency having the lowest. The internal consistency of the five factors remained stable across the 30-day test-retest period, and there was a small increase in mean scores for all APQ factors except Activity acceptance.

The CPCI pacing subscale demonstrated lower test-retest reliability than the PARQ pacing subscale, both of which were lower than the test-retest reliability of the APQ. The internal consistency of the CPCI and PARQ pacing subscales remained stable over the test-retest period. No changes in any pacing scores were significantly associated with the marginal changes in pain levels between the test-retest measures, again adding evidence to suggest stability of the pacing scales.

Chapter 6. Stage II: Assessing the Psychometric Properties of the Activity Pacing Questionnaire (APQ)

6.3 Discussion

6.3.1 Introduction

In Stage II, the psychometric study, 311 questionnaire booklets and 69 test-retest booklets were analysed. This section discusses the sample who participated and the psychometric properties of the activity pacing questionnaire (APQ) to include the themes of pacing that emerged through exploratory factor analysis. Together with this, the reliability and validity of the APQ and two existing pacing subscales of the Chronic Pain Coping Inventory (CPCI) and the Pain and Activity Relations Questionnaire (PARQ) are discussed. Additionally, this section considers the strengths and weaknesses of this stage of the study.

6.3.2 Participants

The target sample sizes of 300 participants for the first questionnaire, and 60 participants for the test-retest booklet were achieved. Both retrospective and current patients who had been referred for physiotherapy were recruited into the psychometric study. The benefits of this were twofold: to allow comparisons to be made between patients at different stages of treatment and to increase the number of accessible patients invited to participate.

6.3.2.1 Comparisons between retrospective patients and current patients

The recruitment rate was higher for current patients than retrospective patients. The author proposes that this may be due to a perception of greater relevance of the study for current patients who were awaiting or attending physiotherapy at the time of the study. The highest recruitment rate was achieved from patients currently attending a rehabilitation group. A possible explanation for this may be due to an increased frequency of attendance and increased rapport with the physiotherapists.

The subgroups of retrospective and current patients were similar in terms of both being dominated by female participants. This may be due to females having a higher prevalence of widespread pain (Wolfe et al., 1995; Clauw and Crofford, 2003), fibromyalgia (Wolfe et al., 1995; Clauw and Crofford, 2003; Berger et al., 2007) and

chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME) (Afari and Buchwald, 2003). Previous studies have found a similar prevalence of back pain among men and women (Andersson, 1999), but also a higher prevalence of back pain among women (Macfarlane et al., 2006; Chenot et al., 2008).

In addition, historically women are considered to seek medical help more frequently than men (Hunt et al., 2011). However, only an inconsistent and weak overall trend towards more females than males seeking medical help for back pain was found in a review of 15 studies (Hunt et al., 2011). An earlier study suggested that it was both greater functional loss associated with low back pain, together with other bodily pains among women that was explanatory of the increased utility of the healthcare services as opposed to being female per se (Chenot et al., 2008). Alternatively, more females than males have been found to present in secondary care on multiple occasions with "unexplained medical conditions" such as fibromyalgia (Reid et al., 2002). Of the referrals into the physiotherapy department during the recruitment period of the present study (August 2011 to August 2012), 59.7% were female. This greater proportion of female referrals may partly explain the higher percentage of females who responded to the study (68.2%). However, of the males invited to participate, 18.1% responded, in comparison to 24.2% of females who responded. Indeed, lower response rates to clinical studies are generally seen among men (Patel et al., 2003).

The most common employment status among retrospective and current participants who participated in the psychometric study was working full-time. It is speculative to suggest that this group are more functionally active and possibly of a higher education, and therefore returned the questionnaire booklets with greatest frequency. However, low education level and low employment status are considered to be factors associated with lower response rates (Patel et al., 2003).

There were some statistically significant differences between retrospective and current patients. Retrospective patients were significantly older than current patients (mean difference=4.4 years). This may in part be due to retrospective patients having attended physiotherapy up to two years prior to being invited to participate. However, the author suggests that the difference could be due to younger current patients being referred to physiotherapy. There was a greater proportion of Asian/Asian British current patients who participated in the study in comparison to retrospective patients. It is speculative to

suggest that there is an increasing use and awareness of physiotherapy to manage chronic conditions among Asian/Asian British groups. Furthermore, there could be an increase in the younger Asian generations who are literate in the English language. Of note, due to the presence of some small groups in the analysis (for example, Asian/Asian British retrospective patients n=1) the findings should be interpreted with caution.

Among both retrospective and current patients, back pain was the most commonly reported condition, with fewest reports for ME. This is consistent with previous epidemiological studies *(see Chapter 1, Introduction)*. Although the term CFS/ME is now recommended (Sharpe, 2002), the questionnaire booklet in this study provided separate options for 'CFS' and 'ME' to suit patients' preferences. Interestingly, some patients ticked both CFS and ME and commented that the terms were interchangeable. However, many participants did use the terms 'CFS' and 'ME' separately, with a greater number of participants reporting 'CFS' than 'ME'.

Retrospective patients reported a significantly longer duration of their condition than current patients (mean difference=5.3 months). This may in part be due to timing, since retrospective patients were recruited from those who had attended physiotherapy up to two years previously. Due to the nature of chronic conditions, it was expected that retrospective patients may continue to experience symptoms after being discharged from physiotherapy. However, retrospective patients were envisaged to manage their symptoms better than those who had not yet attended physiotherapy or had just commenced physiotherapy, that is, current patients. This may explain the significantly higher reports of pain among current patients. Additionally, current patients may have reported more pain since their symptoms were forefront due to their ongoing treatment.

Similarly, current patients reported significantly higher levels of physical fatigue, symptoms of anxiety and depression, and pain-related fear and avoidance, but lower physical and mental function than retrospective patients. Of interest, both retrospective and current patients had mean scores above the threshold (≥ 8) on the Hospital Anxiety and Depression Scale (HADS) anxiety subscale to indicate the potential presence of anxiety (Zigmond and Snaith, 1983; Bjelland et al., 2002). Current patients had a significantly higher mean score on the HADS anxiety subscale (10.1) than retrospective patients (8.4). Current patients had a mean score above the threshold (8.6) on the HADS

depression subscale to suggest the potential presence of depression. Interestingly, both retrospective and current patients reported better mental function than physical function.

6.3.2.2 Comparisons between patients attending individual and rehabilitation group treatment

There was no consistent relationship between age and whether participants attended individual or group treatment. Retrospective patients attending individual treatment were significantly older than those attending group treatment, but the reverse was true for current patients. In terms of ethnicity there were no differences between the proportions of different ethnic groups attending individual or group treatment. Of note, this analysis involved some small groups and should therefore be interpreted with caution.

Retrospective and current patients showed no significant differences in the duration of their condition between those attending individual or group treatment. However, among current patients, those attending group treatments reported significantly lower levels of current pain and physical fatigue than those attending individual treatments. This difference was not found among retrospective patients. This may be because some current patients in the 'individual treatment' subgroup were awaiting treatment, and therefore had not been advised regarding management techniques.

6.3.2.3 Comparisons between responders and non-responders

Patients who responded to the psychometric study showed some significant differences in comparison to those who did not respond. Responders (retrospective and current patients) were more likely to be female, older and reported a longer duration of their condition. This is similar to a previous study in which there were improved response rates by older females (with chronic widespread pain) to a postal questionnaire (McBeth et al., 2002). The author suggests that those participants who recalled a longer duration may have increased knowledge of coping strategies such as pacing, or a sense of greater vested interest in the study. Inexplicably, responders reported higher incidences of chronic widespread pain, fibromyalgia and CFS/ME, but lower incidences of low back pain than the non-responders. Moreover, patients who completed their treatment, or attended group treatment were more likely to respond. The author suggests that such patients may have had a better understanding of physiotherapy and more engagement

with services, and therefore felt more inclined to participate. Hence, the sample may be biased towards patients who had a positive experience of physiotherapy. Since there were some differences between responders and non-responders, the generalisability of the results may be limited. With these differences in mind, the results from the psychometric study were analysed and interpreted.

6.3.3 Psychometric properties of the pacing scales

6.3.3.1 Exploratory factor analysis of the APQ

As a result of exploratory factor analysis of the APQ, there was a reduction in the number of items from 38 to 30 on the basis of multiple missing answers, low mean scores, low contribution to the factors, low inter-item correlations and negative comments from participants regarding specific items. Such comments included the appearance of double negatives or unfamiliar terminology in items. For example, APQ17: *"I made sure I had a flare up plan"* was removed due to 19 missing answers but also attracted a comment querying the meaning of a 'flare up plan'. Of note, during Stage I, the Delphi technique, this question received comments querying whether having a flare up plan was a different concept to pacing. In comparison to the existing pacing subscales, no other scales contain this concept. The reduction in the number of APQ items was beneficial to reduce the burden of the questionnaire.

6.3.3.2 Themes of pacing

The remaining 30 questions formed a five factor solution, namely, factor 1: Activity limitation, factor 2: Activity planning, factor 3: Activity progression, factor 4: Activity consistency and factor 5: Activity acceptance.

Activity limitation contains items referring to breaking down tasks, using rest breaks and alternating activities. These concepts of pacing appear to be the most historically referenced themes of pacing (Birkholtz et al., 2004a). Activity limitation may have the closest links with 'adaptive pacing therapy' which has been described as limiting activities and using rest and relaxation to manage energy expenditure to prevent an exacerbation of symptoms (White et al., 2007). Energy management and symptom regulation through achieving a balance between activity and rest has been further cited as a concept of pacing (Nijs et al., 2006). Moreover, the concepts of limiting activities appear in the existing pacing subscales (Van Lankveld et al., 1994; Nielson et al., 2001; McCracken and Samuel, 2007; Cane et al., 2013).

Activity planning includes items that relate to scheduling activities and setting goals. Setting goals has previously been described as a facet of pacing (Nijs et al., 2006). However, setting goals has not previously been included in existing pacing subscales. Activity planning contains items that refer to having a quota-contingent approach to activities, for example, APQ35: *"I set realistic time limits for specific tasks so that I did not over-do things"*, and APQ31: *"I planned in advance how long I would spend on each activity"*. Quota-contingency is recommended over symptom-contingency, since symptom-contingency may be related to avoidance behaviours where patients reduce or stop activities for fear of increasing their symptoms (Birkholtz et al., 2004a) *(see Chapter 2, Literature Review, Section 2.3.4.1)*. Interestingly, 'planning activity' received the highest level of agreement (92%) among 49 occupational therapists surveyed regarding the facets of activity pacing (Birkholtz et al., 2004b).

Activity progression includes concepts of gradually increasing activities. Although the concept of progressing activities was deliberated in Stage I, the Delphi technique, the two APQ items that include the phrase 'gradually increase' loaded together to form APQ factor 3. This opposes literature describing an increase in activities as a result of pacing (Nielson et al., 2001), but agrees with literature describing an increase in activities as a facet of pacing (Shepherd, 2001; Birkholtz et al., 2004a; Gill and Brown, 2009). Indeed, gradually increasing activities reached 88% agreement as a facet of pacing in a survey among occupational therapists (Birkholtz et al., 2004b).

Activity consistency contains items that refer to achieving similar amounts of activity each day. This would facilitate the management of both over-exertion and under-exertion. This is concordant with previous literature that describes pacing as a strategy to reduce the underactivity-overactivity cycle of activity to manage chronic conditions (Birkholtz et al., 2004a). This concept is not included in existing pacing subscales.

Activity acceptance contains items referring to modifying activity targets and being assertive, for example, APQ22: *"I was able to say 'no' if I was unable to do an activity"*, and APQ24: *"I did my activities without putting pressure on myself to complete them"*. This theme may relate to having an awareness of symptoms or abilities, which may share similarities with adaptive pacing therapy (White et al., 2007). Alternatively, acceptance has been referenced as a feature of pacing in the recognition of activity capabilities which may lead to planning activities (Strong, 2002b). The items

contained within Activity acceptance involve changing activity targets, and possibly new concepts of being assertive and reducing self-imposed pressure. This may be similar to the concept of delegating tasks which has been suggested as a facet of pacing (Birkholtz et al., 2004b).

In comparison to previous pacing literature, there may be concepts of pacing that were removed from the APQ during factor analysis. For example, APQ32: *"I used an activity diary to monitor my activity pattern"* was removed due to a notably low mean score. Therefore this scale item was infrequently used. However, the use of an activity diary has been cited as a facet of adaptive pacing therapy (White et al., 2007).

Conversely, pacing concepts that are novel to the APQ (in comparison to existing pacing subscales) that were retained following factor analysis include being creative and finding new approaches to tasks. Being creative has been stated as a facet of pacing (Birkholtz et al., 2004b) and may coincide with the concept of problem solving which has been described in the pacing literature (Gill and Brown, 2009).

Overall, following factor analysis the APQ maintained 30 items that include a number of different facets and as a result, five different themes of pacing emerged. This challenges the previous finding that pacing is unidimensional (Kindermans et al., 2011). Kindermans et al. (2011) reached this conclusion following exploratory factor analysis of the combined pacing items of the Patterns of Activity Measure-Pain (POAM-P), the PARQ and the CPCI, which on face value appear to describe pacing in terms of slowing down, taking rest breaks and breaking down activities. Such items are similar to the APQ factors Activity limitation and Activity planning only. Therefore, the APQ appears more comprehensive and multifaceted than existing pacing subscales.

6.3.3.3 Principal axis factoring

Following principal axis factoring, it was apparent that items associated with a factor were sometimes numerically consecutive in the questionnaire booklet. Of note, the items of the APQ were arranged in a statistically random sequence. Therefore, the factor loadings of consecutive numbers occurred either by chance, or by participants answering neighbouring questions similarly (Streiner and Norman, 1995).

On face value, the majority of APQ items within each factor appear to be related to the same underlying concept. However, a few potential anomalies were detected. For example, APQ33: *"I broke down activities into manageable pieces"* loaded predominantly onto Activity planning, but had a lesser loading on Activity limitation. It is thought that APQ33 could similarly sit with other questions relating to breaking down activities in Activity limitation, such as APQ13: *"I broke tasks up into periods of activity and rest".* The author suggests that the word 'manageable' in APQ33 has loaded onto Activity planning due to similarities with other questions referring to setting 'realistic' goals or time limits. Conversely, APQ10: "*I planned my activities around events that were important to me"* loaded onto Activity limitation, but appears to be relevant to Activity planning. Likewise, APQ18: *"I was creative and found new ways of doing tasks"* initially loaded onto Activity planning during exploratory factor analysis of the 38-item APQ. However, following the removal of redundant questions, APQ18 loaded onto Activity limitation. There appears to be greatest similarities between Activity limitation and Activity planning in terms of the content of the items. Indeed, the highest correlation between two APQ factors was seen between Activity limitation and planning ($r=0.76$, $p<0.001$).

APQ3: *"I prioritised my activities for each day"* loaded predominantly onto Activity progression. This item sits with other items referring to gradually increasing activities. The author suggests that prioritisation may facilitate gradually increasing activities. However, the author also suggests that prioritising may be a facet of Activity planning.

The final potential anomaly is APQ11: *"I accepted that I have some limitations due to my symptoms"* which loaded onto Activity limitation. Due to containing the concept of limiting activities, this item may have loaded appropriately. However, the author suggests that APQ11 may also be related to Activity acceptance.

Despite possible anomalies of a small number of item loadings, on balance, the principal axis factoring solution is meaningful, and appears to be clinically logical and relevant to existing literature regarding activity pacing *(see Chapter 2, Literature review, Section 2.3.4).*

6.3.3.4 Reliability of the APQ

All five APQ factors demonstrated good reliability via high internal consistency, moderately high item total correlations and satisfactory inter-item correlations. All inter-item correlations were positive, therefore no questions required reverse scoring. Of note, all questions were worded so that no reverse scoring was required to increase the ease of completion. Additionally, all inter-item correlations were <0.80, which suggests that no two items in the APQ were repeated (Pett et al., 2003).

Activity limitation demonstrated the highest internal consistency of the five factors (Cronbach's alpha=0.933). It is recommended that alpha is no higher than 0.90 so that the items are not perceived to be repetitive (DeVellis, 1991). However, alpha is increased with a greater number of items, and Activity limitation is indeed the largest factor (n=13). Thirteen items are not considered too large for a subscale. Pett et al. (2003) advise that each subscale should contain the minimum number of items whilst maintaining maximum reliability, and suggest 10-15 items per subscale.

Activity planning had the second highest level of internal consistency (Cronbach's alpha=0.894), which coincides with the second largest number of items (n=7). This follows the removal of APQ25: "*I set activity goals that were meaningful for me".* It was considered that APQ25 was repetitive of APQ28: "*I set activity goals that were realistic for me"* from which it was divided in Stage I, the Delphi technique. Interestingly, Activity planning had the lowest mean score of the five factors, indicating that participants implemented this strategy the least. This may be due to the items referring to setting activity goals and planning activities which are strategies that are advised during treatment, and some current patients had not yet attended physiotherapy. However, this small subgroup of pre-treatment participants may not account entirely for the lower mean score for Activity planning. The lower mean score may be due to some items referring to having a quota-contingent approach. The author suggests that participants (pre- or post-treatment) may apply symptom-contingent approaches to their activities. This will be explored in Stage III, the acceptability interviews with patients.

Despite containing only three items, Activity progression maintained a very good level of internal consistency (Cronbach's alpha=0.828) (DeVellis, 1991). This factor had the second lowest mean. Gradually increasing activities may be a strategy that occurs once a stable baseline of manageable activity has been achieved. Therefore, some patients

may not have been at this stage. Furthermore, the author suggests that some patients may not feel able to increase their activities due to a deterioration of the condition or other external factors.

Activity consistency demonstrated satisfactory internal consistency (Cronbach's alpha=0.774) and had the second highest mean. Patients therefore reported implementing strategies to try to undertake similar amounts of activities every day. It is noteworthy that the lowest correlation between two APQ factors was between Activity consistency and Activity acceptance ($r=0.35$, $p<0.001$). This may be due to Activity consistency containing concepts of similarity, in comparison to concepts of readjusting activity levels in Activity acceptance.

Activity acceptance had the lowest level of internal consistency (Cronbach's alpha=0.724) and the joint smallest number of items with factor 3 (n=3). However, Activity acceptance demonstrated the highest mean score of the five factors. The author suggests that the high scores may be reflective of concepts advised during physiotherapy, together with personality traits of responders to the study.

All five APQ factors had approximately Normal distribution of scores, with a spike at zero. This may indicate a group of patients who ticked zero for a number of items if they felt that the strategies were not applicable.

6.3.3.5 Convergent validity of the APQ and the pacing subscales of the CPCI and PARQ

All five APQ factors demonstrated significant convergent validity against the existing pacing subscales of the CPCI and PARQ ($p\leq 0.002$). Positive associations were expected between Activity limitation and the existing pacing subscales of the CPCI and PARQ due to similar concepts of breaking down tasks and using rest breaks. Indeed, the highest correlation was between Activity limitation and PARQ pacing subscale item 2: *"I use repeated rest breaks to help me complete activities"* ($r=0.69$, $p<0.001$). The highest correlation between the APQ and the CPCI pacing subscale was between Activity limitation and CPCI pacing subscale item 3: "*I broke up tasks into manageable pieces so I could still get a lot done despite my pain"* ($r=0.58$, $p<0.001$).

It was less expected that Activity progression would correlate significantly with existing pacing subscales. Activity progression contains items referring to gradually increasing activities, in comparison to the pacing subscales of the CPCI and PARQ, which on initial observation appeared to focus on slowing down and limiting activities. However, Activity progression had generally low, but significant correlations with the existing subscales. The highest correlation between Activity progression and any of the CPCI pacing subscale items was also with item 3 ($r=0.45$, $p<0.001$). On closer observation of CPCI pacing subscale item 3, the phrase *"get a lot done"*, rather than, *"I broke up tasks"* might have led to the association with Activity progression. The highest correlation between Activity progression and the PARQ pacing subscale was with PARQ pacing subscale item 6: *"I pace myself to get things done"* ($r=0.45$, $p<0.001$). The association between Activity progression and this item may be on the basis of *'getting things done'*.

It is of interest that the lowest correlations between the CPCI and PARQ pacing subscales and all of the APQ factors were observed with Activity consistency. The lowest correlation between Activity consistency was with CPCI pacing subscale item 1: *"I was able to do more by just going a little slower and giving myself occasional breaks"* ($r=0.21$, $p=0.001$). The correlation was statistically significant for the current large sample size, but the percentage of variance explained, $R^2=4\%$, was low. The author suggests that the two phrases in the CPCI pacing item *"do more"* and *"going a little slower"* may portray disparate concepts, in contrast to maintaining consistency as in the APQ factor. The lowest correlation between Activity consistency and the PARQ pacing subscale was with PARQ pacing subscale item 2: *"I use repeated rest breaks to help me to complete activities"* ($r=0.18$, $p=0.002$). Similarly to CPCI pacing item 1, it may be considered that PARQ pacing item 2 contains both concepts of resting, but also completing activities which may be less well associated with the concept of consistency.

Despite some unexpected correlations between the APQ factors and the CPCI and PARQ pacing subscales, it is considered that correlations with the existing subscales may add evidence of validity of the APQ. Concurrent validity refers to correlations between a new scale completed simultaneously with other validated scales of the same concept (Oppenheim, 2000). In the absence of a gold standard pacing measure, the author considers that correlations between the APQ and existing pacing subscales are suggestive that the APQ is measuring some facets of pacing. However, on face value, it

is considered that the APQ contains more of the different facets of pacing, to include gradually increasing activities, which is more overtly represented in the APQ.

6.3.3.6 Internal consistency of the CPCI and PARQ pacing subscales

The CPCI pacing subscale demonstrated high internal consistency in the present study (Cronbach's alpha=0.93). This is similar to the level of internal consistency found in previous literature of the CPCI pacing subscale (Cronbach's alpha=0.91) among a sample of 110 patients with fibromyalgia (Nielson et al., 2001). The sample was predominantly female (89.1%) to a greater extent than the present study (68.2%), with a mean age (45.3 years) very similar to the present study (45.8 years). However, a level of internal consistency >0.90 may be indicative of repetition (DeVellis, 1991). Indeed, high alpha value for the CPCI pacing subscale may be suggestive of repetition since it cannot be explained by a large number of items (n=6). In contrast, a more recent study found the internal consistency of the CPCI pacing subscale to be lower (Cronbach's alpha=0.78) (Kindermans et al., 2011). This reduction in internal consistency may be due to a more diverse sample involving 132 participants with chronic pain at various body sites.

The internal consistency of the PARQ pacing subscale was higher in the present study (Cronbach's alpha=0.91) than previously found in a sample of 276 patients with chronic pain, but not specifically chronic widespread pain, fibromyalgia or CFS/ME (Cronbach's alpha=0.84) (McCracken and Samuel, 2007). Similarly to the present study, 65.6% of the sample was female, and the mean age was 46.6 years (McCracken and Samuel, 2007). The lower alpha value estimated by McCracken and Samuel (2007) may be due to differences in the sample, in which patients with various chronic conditions participated. The author suggests that within this group some participants may have conditions that have not been classified as medically unexplained leading to a different sense of heterogeneity in comparison to the present study. More similar to the study by McCracken and Samuel (2007), the internal consistency of the PARQ pacing subscale has been found as Cronbach's alpha=0.87 (Kindermans et al., 2011).

6.3.3.7 Ease of completion of the APQ, and the CPCI and PARQ pacing subscales

In terms of ease of completion, the PARQ pacing subscale had the greatest ease of completion on the 0-4 numerical rating scale (NRS=2.41), followed by the APQ

(NRS=2.23), and then the CPCI pacing subscale (NRS=2.01). These ratings may be explained in part by participants' comments. Some participants found the APQ long as it contained over six times as many items than the CPCI and PARQ pacing subscales (APQ n=38, CPCI n=6, PARQ n=6). Despite the small number of items in the CPCI pacing subscale, it was rated the most difficult to complete. Several participants commented regarding difficulties of the seven-day rating scale of the CPCI. The author suggests that completing the Likert scales of the APQ and PARQ may be preferable since circling an answer may be less labour intensive than thinking of a number. Furthermore, participants may be more familiar with the Likert scale format since it is one of the most common forms of scale (DeVellis, 1991).

In comparison to the APQ and CPCI pacing subscale, the PARQ pacing subscale does not involve a timeframe over which participants answer. Of interest, a few participants commented that a week (as per the APQ and CPCI pacing subscale) may not be long enough to give a true reflection of their symptoms, and that a 'good' or a 'bad' week would yield different answers. The advantage of omitting a timeframe is that participants can reflect on their usual habits without feeling they are providing an unrepresentative snapshot of their behaviours. On the contrary, answering in terms of a timeframe facilitates the measurement of change, which is pertinent to behaviours that are likely to vary over time (DeVellis, 1991). The author believes that activity pacing is likely to vary, according to receiving treatment, together with changes in the condition. Therefore, a specific timeframe was deemed necessary for the APQ. Moreover, it is envisaged that the APQ will be used at different time points, for example, pre- and post-treatment. In the absence of a recommended timescale, the timeframe was selected according to the underlying concept. The author considered that a period of a week was suitable to allow participants the opportunity to undertake work, leisure, exercise and social activities, without having to recall a time period that was too cognitively draining and more prone to recall bias.

Interestingly, the APQ had the lowest mean number of missing answers per item (mean=11.39) in comparison to the pacing subscales of the CPCI and PARQ (mean=54.83 and 14.33 respectively). The CPCI pacing subscale received not only blank answers but also word answers, for example, 'sometimes' instead of reporting the number of days. The number of missing answers may reflect an aspect of the acceptability of the questions. The APQ may contain more acceptable questions since

they were developed from Round 1 of the Delphi which included 10 patients' suggestions. The original language was maintained as closely as possible, and efforts were made to maximise the readability of the questions.

It might be argued that the higher completion rate of the APQ was due to the order that the scales were presented in the questionnaire booklet since the APQ was presented first. Therefore, the APQ may have been most thoroughly completed due to lower effects of fatigue or repetition of pacing scale items. Contrary to this argument, if the order affected patient completion of the scale alone, it would be expected that the CPCI pacing subscale (presented second) would be better completed than the PARQ pacing subscale (presented third). However, the reverse was true. A previous study found that the order of scales in a questionnaire does not significantly affect the rate of completion, or the scores on different scales (Dunn et al., 2003). This was found in a sample of 259 patients with back pain who completed four validated scales in a questionnaire booklet arranged in two different orders. Therefore, rearranging the order of the pacing scales in the present study may not have necessarily changed the completion rates or the ease of completion. Furthermore, participants have the option of choosing which scale to answer first in a postal questionnaire (Dunn et al., 2003). Consequently, the author considers the APQ and PARQ pacing subscale to have greater ease of completion than the CPCI pacing subscale.

6.3.3.8 Validity of the APQ: associations with validated measures

Associations between pacing and pain

There were significant associations between increased current pain and increased Activity limitation (r=0.20, p=0.001), Activity planning (r=0.12, p=0.046), Activity progression (r=0.14, p=0.020) and Activity acceptance (r=0.16, p=0.006). Since the study design was correlative and not causal it is uncertain whether high levels of pain led to increased implementation of these strategies, or if implementing these pacing strategies led to higher reports of current pain. The author suggests that perhaps patients who experience high levels of pain may be more inclined to implement the strategies involved in Activity limitation and Activity planning, therefore, utilising more rest breaks and breaking down/alternating activities.

Interestingly, a systematic review and meta-analysis of activity pacing and other activity behaviours found a relationship between increased pacing and increased pain (Andrews

et al., 2012). Similarly, this pattern was not causal, and it was proposed that patients who report high levels of pain are more likely to implement pacing strategies (Andrews et al., 2012). The sample included English-speaking patients with chronic pain. However, this pattern was only seen in three out of four available studies measuring associations between pacing and pain, and the combined correlation of the four studies showed a weak correlation (r=0.09, 95% CI=0.168-0.200) (Andrews et al., 2012).

Rather unexpected was the finding in the present study of the significant association between increased Activity progression and increased pain. It was initially considered that participants might commence progressing activities when pain became manageable, and therefore lower levels of current pain were expected to be associated with Activity progression. The author suggests that perhaps instead, participants who progress their activities are experiencing natural increases in symptoms related to increased exertion. Furthermore, one item of Activity progression involves increasing activities that have been avoided due to symptoms, which may explain why increased pain was associated with this theme. Alternatively, patients who progress their activities could potentially have task persistence behaviours, whereby they continue activities, possibly to levels of exacerbation of symptoms. Existing literature reports mixed findings with regards to task persistence being associated with both increased and decreased pain (Karsdorp and Vlaeyen, 2009; Andrews et al., 2012).

In terms of the association between Activity acceptance and current pain, it appears logical that patients who report higher levels of current pain implement more strategies associated with Activity acceptance, such as saying ‘no’ to activities or changing activity targets. However, acceptance has previously been found to correlate with decreased pain (McCracken et al., 2004). This association was found between the Chronic Pain Acceptance Questionnaire (CPAQ) and a 10-point numerical rating scale of current pain. It was suggested that acceptance is a beneficial coping strategy, associated with continuing functional activity despite pain (McCracken et al., 2004). Of note, the CPAQ items refer to controlling and accepting pain. In comparison, Activity acceptance refers to the acceptance of activity.

There were significant associations between usual pain and Activity limitation, Activity progression and Activity acceptance ($p<0.05$). Unlike current pain, usual pain was not

significantly associated with Activity planning. Therefore, usual pain appeared to measure a different facet of pain, and it was valuable to include both measures of pain.

The above associations between increased pacing and increased pain concur with correlative findings from a questionnaire study among 409 patients with fibromyalgia, using the CPCI pacing subscale ($r=0.10$, $p<0.05$) (Karsdorp and Vlaeyen, 2009). Similarly, pacing was associated with increased pain when measured using both the CPCI and POAM-P pacing subscales among a sample of 132 participants with varying sites of chronic pain ($r=0.23$, $p\leq 0.05$, and $r=0.25$, $p\leq 0.01$ respectively) (Kindermans et al., 2011). As previously stated, the author considers that existing pacing subscales are most similar to the APQ factors Activity limitation and Activity planning.

Contrary to the present study, pacing was previously found to be significantly associated with reduced pain severity, when measured using the CPCI pacing subscale (Nielson and Jensen, 2004). This disparity of findings may be due to a number of reasons. The association apparent in the study by Nielson and Jensen (2004) was between changes in pacing and changes in pain at different time intervals. The present study did not assess changes in the measures pre- to post-treatment, which may have yielded different results. The participants involved in the study by Nielson and Jensen (2004) undertook intensive multidisciplinary treatment involving attending therapy for five days per week for four weeks. The therapy involved exercise therapy, cognitive-behavioural therapy, together with other complimentary therapies. It is not described how pacing was advised, or the impact of the other aspects of treatment. Additionally, the sample involved a homogeneous group of 198 patients with fibromyalgia, with a much higher proportion of females (92%) than the present study.

Similarly, Murphy et al. (2010) found that there was a reduction in pain following two sessions (1.5 hour treatment time) of general or tailored pacing as a lone therapy. Pacing techniques included increased regularity of rest breaks, spreading activities, and planning (to avoid fluctuations in activities), therefore appearing similar to APQ factors Activity limitation, Activity planning and Activity consistency. These reductions were significant when unadjusted, but insignificant when adjusted for age and gender. The results of the pilot study by Murphy et al. (2010) may have limited relevance to the present study. The small sample involved 25 patients with osteoarthritis of the hip or knee, conditions that have not been classified as medically unexplained. Furthermore,

patients gave a self-report of pacing six times a day as opposed to implementing a pacing scale. The self reports complimented objective data from a wrist worn accelerometer. However, no control group was utilised in the study with which to compare the effects of pacing.

Interestingly, the present study found very small but insignificant correlations between Activity consistency and decreased current pain ($r=-0.08$, $p=0.199$) and usual pain ($r=-0.05$, $p=0.435$). Therefore, Activity consistency may be the preferable APQ theme to implement with regards to lower reports of pain. This is an encouraging finding, which if substantiated by further evidence will justify why consistent activities are advised as a management strategy for chronic conditions.

In keeping with the above association between decreased pain and Activity consistency, are the findings from a randomised controlled trial involving 137 patients with fibromyalgia (van Koulil et al., 2010). Participants were stratified into two groups: those who avoided activities, and those who persisted in activities. Participants who persisted with activities received treatment involving activity pacing, to include regulating activities, varying activity with rest, setting goals and then gradually increasing activities. These strategies appear similar to those in the APQ, including Activity consistency. The study by van Koulil et al. (2010) found significant improvements from pre- to post-treatment in terms of pain. Pacing formed part of a tailored treatment of cognitive behavioural therapy and exercise (van Koulil et al., 2010). However, no measure of pacing was implemented and since pacing was not implemented as a lone therapy, it cannot be assumed that improvements occurred as a result of pacing alone.

Associations between pacing and fatigue

Activity consistency was the only APQ factor that correlated significantly with fatigue. Activity consistency correlated with reduced physical fatigue ($r=-0.30$, $p<0.001$) and mental fatigue ($r=-0.22$, $p<0.001$). It is suggested that the items contained within Activity consistency such as doing similar levels of activity every day might have been undertaken by those participants with lower levels of fatigue. Conversely, being consistent with activities may be less physically and mentally tiring than having an inconsistent (boom-bust) approach to activities.

These findings are similar to the aforementioned study by van Koulil et al. (2010) where significant improvements in fatigue were measured pre- to post-treatment. Furthermore, Murphy et al. (2010) found that a tailored pacing programme led to significant reductions in the impact of fatigue in comparison to general pacing advice. Indeed, tailored pacing led to improvements in fatigue, whereas general pacing resulted in worsening fatigue. It was observed that tailored pacing led to more reductions in fluctuations in activity than general pacing (Murphy et al., 2010). The author suggests that the concept of reducing fluctuations is most transferable to APQ factor 4: Activity consistency. This might explain why similar associations between Activity consistency and reduced fatigue were observed in the present study. However, the limitations of this inference of the study by Murphy et al. (2010) were stated above to include the small sample of patients with osteoarthritis of the hip or knee.

The large scale randomised PACE trial found that pacing was no more effective at reducing fatigue than standard medical care (White et al., 2011). This was found among 641 patients with CFS/ME attending 10 treatment sessions being advised about pacing. However, pacing was defined as adaptive pacing therapy. The author considers that some of the concepts of adaptive pacing therapy might be similar to APQ factors: Activity limitation, Activity planning and Activity acceptance. However, unlike the APQ, adaptive pacing therapy has a symptom-contingent focus with the aim of energy conservation. In agreement with the findings of White et al. (2011), no significant correlations were found between Activity limitation, Activity planning and Activity acceptance and improved fatigue in the present study. Of note, adaptive pacing therapy did lead to small reductions in fatigue in the PACE trial. However, these reductions were not significant in comparison to standard medical care. White et al. (2011) stated that this may have been due to the larger measured improvements following standard care than expected. The study by White et al. (2011) is limited by the omission of a pacing measure. It is unknown whether participants randomised to the adaptive pacing therapy group actually did change their pacing habits following treatment.

Associations between pacing and anxiety

Activity limitation was significantly associated with greater anxiety ($r=0.12$, $p=0.045$). Conversely, Activity consistency was significantly associated with reduced anxiety ($r=-0.15$, $p=0.009$). The author suggests that participants who have higher levels of anxiety may implement more limitations on activity to reduce predicted symptoms. In

comparison, participants who have a regular amount of activity may be less anxious due to less fluctuating symptoms.

The association between Activity consistency and reduced anxiety is similar to the findings of van Koulil et al. (2010), where significant improvements were found in anxiety pre- to post-treatment (involving pacing). In addition, pacing has been shown to correlate with reduced anxiety using the pacing subscale of the POAM-P ($r=-0.25$, $p<0.01$) (Cane et al., 2013). This was found in a sample of 164 participants with chronic pain who attended a pain management programme including pacing (Cane et al., 2013). Pacing was instructed to be a time-contingent rather than a pain-contingent strategy. However, the specific facets of pacing that were instructed were not reported. The pacing subscale of the POAM-P contains 10 items that have very high internal consistency (Cronbach's alpha=0.94). The items appear somewhat repetitive, with a focus on breaking down activities, using rest breaks and going slow and steady. Of note, Nielson was a co-author of the development of the POAM-P and the pacing subscale of the POAM-P appears similar in content to the pacing subscale previously developed for the CPCI by Nielson et al. (2001). The pacing subscale of the POAM-P is most similar to APQ factors: Activity limitation and Activity planning. Despite this, Activity limitation was significantly associated with increased anxiety, and no significant association was found between anxiety and Activity planning in the present study.

Associations between pacing and depression

Similarly to the associations between pacing and anxiety, increased depression was significantly associated with increased Activity limitation ($r=0.13$, $p=0.025$), but decreased Activity consistency ($r=-0.29$, $p<0.001$). The author suggests that Activity limitation may be associated with depression due to the potential reduction in participants' usual activities. In contrast, continuing regular activities may maintain usual function such as employment, daily tasks and socialising, therefore associated with better mood. This concurs with significant improvements in negative mood pre- to post-treatment following tailored treatment involving pacing (van Koulil et al., 2010).

The association between Activity consistency and lower depression in the present study replicates the association previously found between increased pacing (using the CPCI pacing subscale) and lower levels of depression ($r=-0.37$, $p<0.001$) (Nielson et al., 2001). Furthermore, a significant association was found between pacing and reduced

depression using the POAM-P pacing subscale (r=-0.35, p<0.01) (Cane et al., 2013). Of note, both the CPCI pacing subscale and the POAM-P pacing subscale are considered to be most similar to Activity limitation and Activity planning. However, the APQ found that increased Activity limitation was associated with increased depression. No significant association was found between depression and Activity planning in the present study. Therefore, perhaps more similar to the present study are the significant associations between the pacing subscales of the POAM-P, PARQ and CPCI with increased depression (r=0.18, p≤ 0.05; r=0.25, p≤ 0.01; r=0.20, p≤ 0.05 respectively) (Kindermans et al., 2011).

In addition, pacing was associated with increased depression when measured using the Coping with Rheumatic Stressors (CORS) pacing subscale (r=0.20, p=0.001) (Van Lankveld et al., 1994). This was found among a sample of 112 patients with rheumatoid arthritis. This 10-item pacing subscale includes statements referring to avoiding, delegating, and limiting activities. It is considered that this pacing subscale is most similar to APQ factors: Activity limitation, Activity planning and Activity acceptance.

Associations between pacing and avoidance

Activity limitation correlated with increased avoidance on all four subscales of the Pain Anxiety Symptoms Scale (PASS), that is, cognitive anxiety, escape and avoidance, fearful thoughts, and physiological anxiety (r=0.14, p=0.23; r=0.25, p<0.001; r=0.21, p=0.001; r=0.19, p=0.002 respectively). Significant correlations were found between Activity planning and increased escape and avoidance only (r=0.15, p=0.015). These findings are concordant with those of McCracken and Samuel (2007), where the PARQ pacing subscale was shown to be associated with increased avoidance (r=0.34, p<0.001). Similarly to the present study, McCracken and Samuel (2007) measured avoidance using the PASS. It is considered that of all of the APQ factors, Activity limitation and Activity planning may be most similar to the PARQ pacing subscale which is why similar findings were observed. However, unlike the present study, the sample included participants with diagnoses of chronic pain conditions, but not chronic fatigue (McCracken and Samuel, 2007).

Significant associations between increased pacing and increased avoidance were replicated between each of the pacing subscales of the POAM-P, PARQ and CPCI with three measures of avoidance: the POAM-P avoidance subscale, the PARQ avoidance

subscale and the Behavioural Responses to Illness Questionnaire limiting subscale (considered akin to avoidance) (Kindermans et al., 2011). Unlike the present study, the 132 participants with chronic pain involved in the study by Kindermans et al. (2011) were recruited from a newspaper advertisement and not a clinical environment.

McCracken and Samuel (2007) found that decreased acceptance correlated with increased avoidance. Conversely, in the present study increased Activity acceptance correlated significantly with increased avoidance on three of four PASS subscales. McCracken and Samuel (2007) measured acceptance of pain using the Chronic Pain Acceptance Questionnaire (McCracken et al., 2004). In contrast, the APQ factor Activity acceptance involves accepting activity levels as opposed to pain.

Interestingly, it has been found that higher levels of avoidance (measured using the PASS) are associated with passive coping strategies, such as resting and limiting activity (akin to APQ factor 1: Activity limitation). In contrast, active coping (for example, continuing activities) is associated with reduced pain-related avoidance (Strahl et al., 2000). The author proposes that active coping strategies would be most similar to the APQ factors: Activity progression and Activity consistency. No significant associations were found between avoidance and Activity progression in the present study. However, Activity consistency correlated significantly with reduced avoidance on all four subscales of the PASS (all $p<0.02$). This may be due to items referring to undertaking activities on both 'good' and 'bad' days, therefore challenging the avoidance of activities.

Of note, the findings from the present study substantiate proposals put forward in a review of pacing undertaken by Nielson et al. (2012). It was suggested that activity pacing strategies that limit activities to reduce symptoms may reinforce fear-avoidance beliefs. In contrast, activity pacing strategies that encourage increased activity and function would not be associated with avoidance (Nielson et al., 2012).

Moreover, pacing has been shown to be unrelated to avoidance (Cane et al., 2013). This was found using the POAM-P pacing subscale. This pacing subscale was found to be relatively independent from the other two subscales: avoidance and overdoing. The questionnaire study involved 393 participants with chronic pain. Again, this sample did not include participants with chronic fatigue as in the present study.

Associations between pacing and physical function

Activity limitation correlated significantly with reduced physical function (r=-0.34, p<0.001). The author suggests that taking rests and breaking down tasks may lead to an overall reduction in level of function. Similarly, Activity planning correlated with reduced physical function (r=-0.12, p=0.035). This association is weaker, but may still be evident due to the overlap in content with Activity limitation. These associations are similar to previous findings between the PARQ pacing subscale and reduced daily uptime (time spent standing or walking) (r=-0.14, p<0.05) (McCracken and Samuel, 2007). In addition, the PARQ pacing subscale previously correlated with increased physical disability (r=0.23, p<0.001) (McCracken and Samuel, 2007).

Murphy et al. (2008) found that pacing was significantly associated with lower physical activity on linear regression (p<0.001). Pacing was determined by two modified questions from the CPCI pacing subscale which are most similar to APQ factors Activity limitation and Activity planning. Similarly, the present study found that Activity limitation and Activity planning correlated with lower physical function. As concluded by Murphy et al. (2008), the concept of going slower and taking rests would logically seem to correlate with lower physical activity. Unlike the present study (which implemented the Short-Form 12, SF-12), physical activity was measured by Murphy et al. (2008) using an accelerometer.

Although disability was not measured in the present study per se, disability may be related to some questions of the SF-12 physical component subscale (for example, the impact of the condition on climbing stairs or undertaking housework). Previously, a weak association was found between increased pacing and increased disability in a systematic review and meta-analysis of nine studies (r=0.112, 95% CI=0.005-0.215) (Andrews et al., 2012). Andrews et al. (2012) suggested that perhaps patients who are more disabled are more likely to pace their activities. This weak association is similar to the correlation coefficients found in the present study between decreased physical function and Activity limitation (r=-0.340, p<0.001), Activity planning (r=-0.12, p=0.035), Activity progression (r=-0.11, p=0.056) and Activity acceptance (r=-0.14, p=0.013).

As previously stated, the author suggests that the pacing subscales of the POAM-P, the PARQ and the CPCI are most similar to the content of APQ factors: Activity limitation

and planning. Concordant with the associations between Activity limitation and planning with reduced physical function, the pacing subscales of the POAM-P, PARQ and CPCI were significantly associated with increased disability ($r=0.34$, $p\leq0.01$; $r=0.23$, $p\leq0.01$; $r=0.27$, $p\leq0.01$ respectively) (Kindermans et al., 2011). Furthermore, Karsdorp and Vlaeyen (2009) found pacing was significantly associated with increased disability ($r=0.19$, $p=0.001$) and increased physical impairment ($r=0.19$, $p=0.001$). However, on hierarchical regression, pacing did not explain variance in disability or physical impairment when pain and pain catastrophizing were controlled. Pacing was measured using the CPCI pacing subscale in a questionnaire completed by 409 patients with fibromyalgia (Karsdorp and Vlaeyen, 2009).

The PACE trial (as previously described) found that adaptive pacing therapy was not significantly more effective at increasing physical function than standard care alone (White et al., 2011). However, the PACE trial did find some small improvements in function with adaptive pacing therapy. These improvements were smaller than those observed with cognitive behavioural therapy and graded exercise therapy. As stated previously, adaptive pacing therapy may have limited transferability to the APQ due to differing approaches to pacing.

Less expected was the correlation between Activity progression and reduced physical function. However, this correlation just failed to be statistically significant ($r=-0.11$, $p=0.056$), and the effect size was small. It was initially considered that gradually increasing activity would correlate with increased physical function. This may be an anomalous finding, or indeed a relationship that requires further investigation using a causal study design.

In contrast, Activity consistency correlated significantly with improved physical function ($r=0.17$, $p=0.003$). Therefore, it is suggested that achieving similar amounts of activity every day is related to overall better physical function than perhaps a 'boom-bust' pattern of activity. These findings are similar to the improvements in functional disability observed among participants with fibromyalgia attending a 10-week treatment programme including pacing (van Koulil et al., 2010).

The significant association between Activity acceptance and reduced physical function ($r=-0.14$, $p=0.013$) may be explained due to the items contained within this factor

referring to saying ‘no’ to activities, changing activity targets and not completing activities. This contrasts previous findings where decreased acceptance correlated with increased disability (McCracken et al., 2004; McCracken and Samuel, 2007).

Associations between pacing and mental function

Activity consistency was the only APQ factor that had significant associations with the SF-12 mental function subscale. Activity consistency correlated with improved mental function ($r=0.28$, $p<0.001$). Since the association was not causal, it is unclear whether participants with higher mental function consciously implement more consistent activities, or whether increased mental function is the result of consistent activities in the absence of a potentially tiring fluctuating pattern of activities.

Andrews et al. (2012) did not explore mental function per se in the systematic review and meta-analysis. However, a weak combined correlation of seven studies found that increased pacing was associated with improved psychological function ($r=-0.143$, 95% CI=-0.0265 to -0.016). This is similar to the correlation found in the present study between Activity consistency and lower reports of anxiety, depression, fear avoidance and improved mental function. Andrews et al. (2012) suggest that those patients with improved psychological function are perhaps more capable of implementing coping strategies such as pacing to manage their condition (Andrews et al., 2012).

Interestingly, the systematic review undertaken by Andrews et al. (2012) highlighted an association between task persistence and improved physical and psychological function. The measure of task persistence was the CPCI task persistence subscale. This was considered to be more descriptive of continuing activities, as opposed to persisting with activities to the point of symptom exacerbation (Andrews et al., 2012). The author suggests that the concept of continuing activities is most similar to the APQ factor Activity consistency. Similar to the findings highlighted by Andrews et al. (2012), the present study found correlations between increased Activity consistency and improved physical and mental function measured by the SF-12. Furthermore, ‘task-contingent persistence’, but not ‘excessive persistence’ has been found to be associated with lower reports of disability (Kindermans et al., 2011).

To summarise, the correlations between the APQ and validated measures of symptoms of chronic conditions show some comparable results with previous literature, alluding to

construct validity of the APQ. However, some divergent findings arose, which may be due to the different samples, different research methods and varying pacing scales (when indeed a measure of pacing was implemented). Observations of previous literature have highlighted that there are no consistent patterns between pacing and the symptoms of chronic conditions. Hence, at present the empirical evidence of pacing is somewhat lacking despite the frequent utility of this coping strategy (NICE, 2007; Kindermans et al., 2011).

Most frequently, Activity limitation, Activity planning, Activity progression and Activity acceptance correlated with increased pain, anxiety, depression, avoidance and reduced physical function. These findings were more commonly in agreement with previous studies that have postulated that the utility of pacing may not be underpinned by empirical benefits. It is of note that Activity limitation and Activity planning in particular are most similar to existing pacing subscales.

Conversely, Activity consistency was associated with reduced symptoms of chronic conditions. Moreover, Activity consistency was found to have the weakest correlations with the existing pacing subscales of the PARQ and the CPCI compared with the other four APQ factors. This possibly alludes to differences between Activity consistency and existing pacing subscales. Of interest, existing literature refers to pacing as promoting consistent levels of activities, yet 'consistency' does not appear to be measured in existing pacing subscales.

6.3.3.9 Associations between APQ factors and patient demographics

None of the five APQ factors were significantly associated with the duration of the condition in the present study. However, participants' age was significantly associated with Activity limitation and Activity acceptance. The author suggests that with increasing age there may be natural increases in limitations and acceptance of modifications to activities. This is similar to the association between increasing age and pacing when pacing was measured using the CORS pacing subscale (Boonen et al., 2004). The author considers that the CORS pacing subscale may be most similar in content to the themes of Activity limitation and Activity acceptance due to the inclusion of CORS items, such as *"I bear my limitations in mind"*, and *"I tell myself not everything has to be done at once"*. There were no significant differences between male and female participants in terms of APQ scores. This is dissimilar to a previous study

where male participants reported increased pacing, together with increased avoidance and lower over-doing behaviours (Cane et al., 2013). This difference may be due to the sample of patients (chronic pain, but not chronic fatigue), a higher proportion of females (73.8%), and a different pacing scale in comparison to the present study.

There were no significant differences between APQ factor scores of retrospective and current patients. Since all retrospective patients had attended physiotherapy, in comparison to some current patients awaiting physiotherapy, it was expected that retrospective patients may report a greater utility of pacing. However, some retrospective patients may have only attended one treatment session or stopped attending physiotherapy before pacing had been practiced. Furthermore, it might be expected that current patients attending a group may pace to a greater extent than those who attended a group two years ago.

To facilitate a more representative comparison in patients' pacing behaviours, current patients were analysed according to those attending a group versus those awaiting treatment. Current patients attending a group reported significantly higher Activity planning (pre-treatment mean=1.61 v group treatment mean=2.60, p=0.004) and Activity progression (pre-treatment mean=1.70 v group treatment mean=2.24, p=0.005). Patients attending a rehabilitation group had a higher mean score for Activity consistency but this difference was not quite statistically significant (t=-1.91, p=0.059). Therefore, patients appeared to be instructed pacing strategies while attending rehabilitation groups, and the APQ showed capacity to detect these changes.

It is noteworthy that all patients treated in a rehabilitation group scored higher than those treated individually, whether retrospective or current patients. This may be due to specific pacing instructions and opportunities to practice pacing while attending a rehabilitation group. However, it may be questioned whether an increase in strategies such as Activity limitation are beneficial to the management of chronic conditions if there are significant correlations with worsening symptoms. Future longitudinal studies are required to explore these effects.

There were significant differences between the mean APQ factor scores according to the employment status of participants for Activity limitation and Activity progression. In both instances, participants who were 'not working due to their condition' had the

highest scores and participants who were ‘unemployed but seeking work’ had the lowest scores. It is speculated that those participants who are not working apply the most limitations to their activities and this may be due to perceived symptom severity. However, the explanation for higher levels of Activity progression is unclear, unless perhaps this group of patients have the lowest baseline levels of activity and are therefore able to progress activities more than other already active groups. It is suggested that perhaps participants who are seeking work apply less limitations to their activities while searching for employment. This group of patients may therefore feel that they are increasing their activities, and are therefore unable to progress activities further. Hence, low Activity progression scores may be seen for participants who were seeking work. Furthermore, participants seeking work may not be able to increase activities such as hobbies or sports since their current focus is returning to work.

There were some significant differences in APQ scores across the different conditions. Participants with chronic widespread pain scored significantly higher on Activity limitation, Activity planning and Activity progression than those without chronic widespread pain. Interestingly, patients with fibromyalgia had significantly higher scores on Activity progression than those without fibromyalgia. Therefore the group of patients with widespread pain reported higher limitations on their activities, but also reported progressing their activities. It is noteworthy that these findings show subtle differences between patients reporting chronic widespread pain and fibromyalgia.

Similar subtle differences were seen between participants who reported CFS and those who reported ME. Participants with CFS scored significantly higher than those without CFS on Activity limitation, Activity planning and Activity progression. Participants with ME scored significantly higher than those without ME on Activity limitation and Activity progression. These subtle differences between CFS and ME, together with chronic widespread pain and fibromyalgia are of interest as the above diagnoses are often used interchangeably in the clinical setting. Indeed, there is a significant overlap in presentation of conditions such as chronic widespread pain, fibromyalgia and CFS/ME where no medical explanation can be found (Wessely et al., 1999; Clauw and Crofford, 2003; Aggarwal et al., 2006; Schur et al., 2007). However, if the above differences between conditions are found to be important, this might have clinical and research implications. These findings may be incidental. Alternatively, these findings might suggest heterogeneity across a sample of chronic conditions considered to have

many shared characteristics. Therefore, it might be important to subcategorise chronic conditions in future research.

Overall, participants with ME reported the highest APQ scores for all factors except Activity planning, for which patients with CFS gave the highest score. It is unclear whether patients with CFS/ME implement more pacing strategies than those with chronic low back pain or widespread pain due to a greater impact of the condition on daily activities, or due to receiving more extensive instructions of pacing. Since differences in pacing habits exist, it may be advisable to tailor pacing treatments to the needs of each individual. Indeed, recent exploration into tailored treatment interventions have found benefits of individualised pacing programmes (Murphy et al., 2010; Goudsmit et al., 2012). With further validation, the APQ may prove to be a useful tool to promote tailored treatment for the management of chronic conditions.

6.3.3.10 Test-retest reliability

6.3.3.10.1 Demographics

The mean test-retest period (29.62 days) was longer than initially envisaged (14 days) due to practicalities such as posting the questionnaires, logging returned questionnaires and patient availability.

With regards to the representativeness of the 69 current patients involved in the test-retest group in comparison to the current patients not involved in the test-retest study, there were no significant differences in terms of gender, marital status, employment, the presence of back pain, chronic widespread pain, fibromyalgia and CFS/ME, pain severity and mental fatigue. There were some significant differences in terms of age (test-retest group were older) and ethnicity (test-retest group had a greater proportion of white ethnicity), main condition (test-retest group had a smaller proportion with low back pain) and physical function (test-retest group had lower physical function). The explanation for these differences is uncertain, and some differences may be chance findings. Furthermore, the analyses of marital status, ethnicity, employment status and condition involved some small groups, and the findings should be interpreted with caution. However, it is speculated that older participants may feel more able to participate in the test-retest study due to increased time availability, or greater relevance to their condition. Furthermore, participants with lower physical function may feel more affected by the condition and therefore have a greater interest in the research.

Of note, the test-retest sample was recruited from current patients only, and not retrospective patients. Therefore it cannot be assumed that the sample is representative of retrospective patients. This method of recruitment was selected to increase recruitment rates due to higher relevance of the study to those patients currently attending physiotherapy. Moreover, the purpose of the test-retest data was to assess the reliability of the APQ and not to repeat the comparison between current and retrospective patients.

6.3.3.10.2 Change in pacing scale scores over the test-retest period

All APQ factors showed modest increases over the test-retest period, with the exception of Activity acceptance. The largest increase was seen in Activity consistency. The author suggests that over the test-retest period participants may have been instructed regarding some of the strategies of pacing, with particular focus on regulating activities. It might be that the theme of Activity acceptance requires a longer duration to demonstrate increases. Generally, the changes in APQ scores were small (0.07-0.18 on the 0-4-point Likert scale). Since the effect sizes for the APQ have not been determined, the clinical significance of these changes is unknown. The small change may be due to the mean test-retest period of less than one month, during which time participants may have attended physiotherapy only a few times, or may have still been awaiting physiotherapy. However, the test-retest study was designed to test the stability of the APQ and not to look for changes with treatment per se. Indeed, the internal consistency of all five factors of the APQ remained very stable over the test-retest period. The scores of both pacing subscales of the CPCI and PARQ increased over the test-retest period. Similarly, the internal consistency for both subscales remained stable over the test-retest period.

6.3.3.10.3 Test-retest reliability of the pacing scales

All five factors of the APQ demonstrated moderate to good test-retest reliability when estimated using Pearson's correlations, intra-class correlations and the Bland and Altman approach. Activity limitation appeared to have the highest test-retest reliability (intra-class correlation, ICC=0.79, $p<0.001$) and Activity consistency had the lowest reliability (ICC=0.50, $p<0.001$). The APQ demonstrated generally higher test-retest reliability than the existing pacing subscales of the CPCI (ICC range for the six items: 0.27 to 0.48, $p<0.05$) and PARQ (ICC range for the six items: 0.38 to 0.68, $p<0.001$).

No existing test-retest data have been retrieved for the PARQ pacing subscale. There are existing test-retest reliability data for the CPCI pacing subscale (0.60, $p<0.001$) (Nielson et al., 2001). However, the method of estimating test-retest reliability was not stated. It is noteworthy, that in comparison to the test-retest period of the present study (mean=29.6 days, SD=13.3 days), the test-retest period of the study by Nielson et al. (2001) was much greater, and with wider variation (mean=12.6 weeks, SD=8.13 weeks). The present study found the test-retest reliability of the CPCI subscale to be much lower than previously found. The difference in test-retest reliability may be due to the different sample involved, the different method of estimating test-retest reliability and the different test-retest time period. Contrary to the present findings, it might be expected that a shorter time period may increase test-retest reliability (Nielson et al., 2001). This would be expected due to less variation in condition or external factors.

Beneficial to the present study was the implementation of three methods to explore test-retest reliability. It appeared that the three methods: Pearson's correlations, intra-class correlations and the Bland and Altman approach were in agreement. Pearson's correlations, although widely used in this context by researchers, measure the degree of linear association and not agreement (Rankin and Stokes, 1998). If all individual test and retest measurements were to differ by the same clinically important constant, then the linear association would be perfect but the agreement would be minimal. Limitations of intra-class correlations include being affected by increased natural variance with heterogeneous samples. This in turn increases the intra-class ratio resulting in higher levels of intra-class correlations, and possibly exaggerated levels of reliability (Rankin and Stokes, 1998). In the present study a heterogeneous sample was purposefully recruited. However, it may be argued that it is advantageous to implement a scale that is sensitive to natural variance as this will be more reflective of reliability across different populations (Rankin and Stokes, 1998). To reduce such possible exaggeration in reliability, the Bland and Altman method was implemented. The Bland and Altman method is not considered to be affected by factors such as sample heterogeneity (Rankin and Stokes, 1998).

6.3.3.10.4 Test-retest reliability of the validated measures

The measures of usual and current pain showed good reliability over the test-retest period, more so than the Chalder fatigue questionnaire. Some written comments in the questionnaire booklet indicated difficulties completing the Chalder fatigue

questionnaire due to confusion over the scale anchors. This may have increased the variability of scores. The Chalder fatigue questionnaire mental subscale demonstrated higher reliability than the physical fatigue subscale. The author speculates that there may be less variability of mental fatigue than physical fatigue for the present sample of patients. Mental fatigue may be more problematic to patients with CFS/ME, chronic widespread pain and fibromyalgia, in comparison to the larger proportion of patients who reported back pain as their main condition.

6.3.3.10.5 Associations between change in pain and change in pacing scales

There were no significant changes in pain reports over the test-retest period, indicating a level of stability in the condition over this time. Therefore, despite a longer test-retest period than initially planned, minimal changes in pain were reported. The study collected data from patients with chronic conditions which are likely to vary less than acute conditions over the same period. Furthermore, the test-retest period was not a pre- to post-treatment measure. Indeed, several participants commented that they were still awaiting physiotherapy.

Since pain reports did not change significantly over the test-retest period, similarly to APQ scores, it was expected that there would be no associations between change in pain and change in APQ scores. The author suggests that this adds further evidence to the stability of the APQ. Similarly, no significant associations were found between change in pain and change in CPCI and PARQ pacing subscale scores.

6.3.4 Participants' comments

Participants wrote comments in the questionnaire booklet regarding the length and repetition of the APQ. Additionally, specific questions were highlighted as being confusing. Of interest, increased questionnaire length, repetition and complexity may reduce response rates (Edwards et al., 2002; Rolstad et al., 2011). One aim of Stage II, the psychometric study, was to remove redundant questions. Following factor analysis the number of items was reduced from 38 to 30. Interestingly, questions that participants reported as being confusing were frequently those that had been removed.

With regards to the CPCI pacing subscale, participants commented that the scale was less easy to use. Frequently, participants answered this scale incorrectly by writing a word answer, as opposed to stating a number of days. Furthermore, the pain-focused

questions were not deemed applicable for all participants, for example, those who experienced fatigue more than pain, or those who were pain-free at the time of completing the scale. Other participants found the term 'slow and steady' (utilised in three of six of the CPCI pacing items) to be irrelevant. With reference to the PARQ pacing subscale, participants found the scale easier to use than the CPCI pacing subscale and the brevity preferable to the APQ. However, similar problems as the CPCI pacing subscale arose regarding the pain-focused questions. In contrast, the APQ items were purposefully written with the word 'symptom' not 'pain'.

Participants wrote additional comments regarding the validated scales, such as difficulties with the Chalder fatigue questionnaire scale and the HADS. One participant highlighted that the minimum score on one HADS anxiety scale item was "only occasionally", whereas the answer "not at all" was required. Therefore, it appears that validated scales may also contain flaws.

6.3.5 Strengths and limitations of the study

A major strength of Stage II, the psychometric study, was that the target sample size was achieved (n>300). Despite recruiting to target, the recruitment rates were lower (12.6%-30.6%) than predicted (50%). This response rate is much lower than that achieved in a postal questionnaire among patients with chronic widespread pain (75%) (McBeth et al., 2002). Indeed, the response rate of the present study was lower than the conventionally accepted rate of 60%-70% for survey design studies (Swinscow and Campbell, 2002; Owen-Smith et al., 2008). A mean response rate of 60% for postal studies reported in medical journals during 1991 has been found (Asch et al., 1997), while more recently, mean response rates between 45%-53% for postal surveys in other areas have been found (Baruch and Holtom, 2008; Owen-Smith et al., 2008; Shih and Fan, 2009). Despite the low recruitment rate of the present study, the findings may still be generalisable, depending on the extent of bias within the sample (Swinscow and Campbell, 2002). Bias was explored in the present study through the comparison between responders and non-responders, and both differences and similarities were found. Attempts were made to address the low recruitment rate in the present study by sending reminder booklets, personally addressing letters and including pre-paid return envelopes (Edwards et al., 2002), together with engaging physiotherapists working on site in the study. This led to increased labour, materials and a longer test-retest period

than envisaged. However, as a result, recruiting to target permitted meaningful analyses of the psychometric properties of the APQ.

The sample included a heterogeneous group of patients with different chronic conditions. It was intended that the APQ would be developed for wider use than the existing pacing subscales by validating it in a sample of patients with chronic pain and/or chronic fatigue. In an attempt to reduce bias during the recruitment process, consecutive sampling was implemented since random sampling was not possible. Consecutive sampling is the optimal method for continuous recruitment of all accessible subjects over a set time period (Polit and Beck, 2013). Despite being a non-probability method of sampling, bias may be reduced with an increased time period (Polit and Beck, 2013). Indeed, for the present study, retrospective patients were recruited from those who attended physiotherapy up to two years prior to the study, and current patients were recruited over a one-year period. Furthermore, all accessible patients were invited to participate from three hospital sites in an attempt to reduce bias, and therefore undertake meaningful statistical analyses with increased generalisability of the results.

Although the sample size of 311 increases the generalisability of the results, the results can not be assumed to be representative of all patients with chronic pain and/or chronic fatigue. However, this sample is larger than the studies by Nielson et al. (2001) to develop the CPCI pacing subscale (n=110), and McCracken and Samuel (2007) to develop the PARQ pacing subscale (n=276). Of note, it was beyond the scope of the present study to check every participant against the specific diagnostic criteria of fibromyalgia or CFS/ME *(see Chapter 1, Introduction, Section 1.1)*. Instead, participants were invited to participate based on their referral from a GP or consultant and confirmed by the self-report of their condition in the questionnaire booklet.

There may be biases associated with the recruitment process. Non-English speaking patients were excluded from the study. In addition, there may be a self-selection bias among participants where those who respond to the study carry different characteristics to those who do not respond (Bland, 1995). Indeed, there were some differences between the responders and non-responders to the study, together with differences between current patients involved in the test-retest arm of the study and those who were not. In the present study, responders were more likely to have completed their physiotherapy treatment or attended a rehabilitation group.

The study may be limited due to collecting data from self-report questionnaires only, with no objective measures. Problems associated with questionnaires include social desirability, that is, participants giving answers that they deem to be 'correct' (Streiner and Norman, 1995; Oppenheim, 2000). For example, some participants who had attended physiotherapy may have felt obliged to give answers that were instructed during their treatment. However, the subject of activity pacing is considered to be less controversial or sensitive than other questionnaires. Therefore, social desirability may have less impact on the results. Further distortion on the results may occur through 'yea-saying' where predominantly positive answers are given (Streiner and Norman, 1995). However, the APQ factor scores remained approximate to the mean score on the Likert scale, as opposed to the upper boundary as would be expected with 'yea-saying'. There was no evidence of end-aversion bias where the minimum and maximum values on the scale are avoided, since participants utilised the full 0-4 Likert scale of the APQ.

Together with this, potential bias may arise from the involvement of the author in the study methods. The author was responsible for undertaking the recruitment process, data collection, data entry and statistical analysis. However, this may also strengthen the study in terms of a consistent and methodical approach to recruitment and data entry. Indeed, data were entered into two SPSS data files for a 10% sample to undertake a cross-check of errors. The rate of errors was 0.2%. An additional 10% random sample was checked for accuracy against the original questionnaire responses. This yielded only a 0.14% rate of errors. Therefore, the author considers that the process of data entry had good accuracy.

Despite the findings of interesting associations between the different themes of pacing contained within the APQ and symptoms of chronic conditions, it is of note that the associations are correlative and not causal. Therefore, the effects of the themes of pacing on symptoms remain unknown.

6.3.6 Summary

Stage II, the psychometric study, found the APQ to form a five factor solution. The five factors that emerged have been labelled: Activity limitation, Activity planning, Activity progression, Activity consistency and Activity acceptance. All five factors demonstrated high internal consistency, good test-retest reliability, and validity against two existing pacing subscales and validated measures of pain, fatigue, anxiety, depression, avoidance and function. In comparison to existing pacing subscales, the APQ appears to contain more themes of pacing, demonstrates moderate ease of completion and has greater reliability. Activity consistency has emerged as being the most beneficial theme of pacing in terms of associations with improved symptoms. However, further validation of the APQ is required and longitudinal studies would allow causal relationships between pacing and symptoms of chronic conditions to be assessed. The next stage of the present study explores the acceptability of the APQ among a sample of participants who completed the scale.

Chapter 7. Stage III: Exploring the Acceptability of the Activity Pacing Questionnaire (APQ)

7.1 Methods

7.1.1 Aims of Stage III

Stage II, the psychometric study, found that the APQ consisted of a number of different themes of pacing and that the questionnaire demonstrated high levels of reliability and validity. In order for the APQ to be clinically useful, the questionnaire must not only be valid and reliable, but additionally, it must be acceptable to patients. To explore the acceptability of the APQ, patients involved in Stage II were invited to discuss their opinions of the questionnaire via telephone interviews. This included discussion into the format, content and instructions of the APQ, and the pacing subscales of the Chronic Pain Coping Inventory (CPCI) and Pain and Activity Relations Questionnaire (PARQ). The aim of this stage of the study was not only to explore the acceptability of the pacing scales, but additionally to explore patients' opinions of the concept of pacing. This included discussing the themes of pacing that emerged in the APQ, together with any facets of pacing that may not have been included in the questionnaire. The interviews also aimed to discuss factors that may influence the implementation of pacing, including other coping strategies or behaviours. The benefits of this were to explore patients' opinions of pacing, and to further increase service-user involvement in the development of the APQ.

7.1.2 Justification of methods

7.1.2.1 Study design

Stage III, the acceptability study, employed a qualitative design, collecting data from interviews with patients with chronic low back pain, chronic widespread pain and chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME). Methods of collecting qualitative data include undertaking focus groups and individual interviews. Focus groups generate ideas from discussions between participants, frequently involving homogenous samples (Morse and Field, 1996). Focus groups are efficient in collecting data from larger groups of people simultaneously. However, focus groups may lead to problems of organisation and accessibility of the meetings and transcription of multiple voices in a discussion (Morse and Field, 1996). Moreover, focus groups can prove challenging in terms of mediating discussions and allowing each individual to participate equally (Ayres, 2007). By comparison, individual interviews maintain attention on a

single participant's opinion (Ritchie, 2003). Individual interviews via the telephone were selected for the present study to enable in-depth discussions with participants regarding their opinion of the APQ. Furthermore, participants completed the APQ in Stage II by providing personally applicable answers, and not answers that were the product of group discussions. Although some non-verbal information may have been lost over the telephone, this was at the gain of increasing recruitment due to reducing inconvenience, cost and potential accessibility issues (Lewis, 2003; Johnson et al., 2009).

Telephone interviews may be structured, semi-structured or unstructured. Structured interviews are more suitable for quantitative surveys than qualitative research due to the nature of set questions requiring limited answers (Ayres, 2007). Semi-structured interviews are implemented when most of the questions regarding the topic are known, while allowing participants to expand on their answers (Morse and Field, 1996). In contrast, unstructured interviews are suitable when little is known about the topic and exploratory questions are developed from participants' answers (Arthur and Nazroo, 2003). As such, unstructured interviews may be divergent across different participants, whereas semi-structured interviews follow a similar format of open-ended questions, with variations in probing questions according to individual participants (Arthur and Nazroo, 2003; Ayres, 2007). Semi-structured interviews were selected for the present study since it was the aim of the study to ask specific questions based on the findings of Stage II, the psychometric study, and to explore the acceptability of the APQ, together with the concept of activity pacing.

7.1.2.2 Participants

A purposive sample of patients who completed Stage II was invited to participate in Stage III due to their previous experience of completing the APQ. Purposive sampling is a non-random method of sampling and is commonly implemented in qualitative studies to select participants who are representative of a group, or hold certain characteristics or knowledge (Morse and Field, 1996; Ritchie et al., 2003a). Furthermore, purposive samples are often used in studies where there is underlying theory *a priori* (Curtis et al., 2000). This was indeed the case for the acceptability study where specific questions for the qualitative interviews were prepared based on the three pacing scales, together with the themes of pacing that had emerged from the psychometric study. The purposive sample invited to participate in the acceptability study was selected with the aim of representing the patients who participated in the psychometric study, together with

representing patients who are commonly advised to pace their activities. Therefore, the sampling technique of the acceptability study selected patients purposefully to represent the heterogeneity that occurred more naturally during recruitment for the psychometric study. In recruiting patients with different chronic conditions, it was envisaged that the sample would increase the generalisability of the results (Curtis et al., 2000).

Specifically, the sample included patients who had been referred to the physiotherapy departments of The Pennine Acute Hospitals NHS Trust with primary diagnoses of chronic low back pain, chronic widespread pain and/or CFS/ME (of over three months' duration). Participants were recruited in a reverse chronological order, beginning with those who completed the psychometric study most recently. The purposive sample included both retrospective patients (discharged from physiotherapy from September 2009 onwards) and current patients. This aligned with the sample recruited for the psychometric study, and allowed comparisons between patients at different stages of treatment. The method of recruitment for the psychometric study and the inclusion and exclusion criteria are reported in full in Section 6.1, Psychometric study methods.

7.1.2.3 Sample size

Due to the nature of detailed data collection involved in qualitative studies, it is usual that the sample size is small (Morse and Field, 1996; Ritchie et al., 2003a). The sample size involved in qualitative studies is reflective of the research question, and can be as little as one, for example, as in case study methods (Pope et al., 2000). Unlike quantitative studies, there are no calculations to justify the sample size. Indeed, the sample size may evolve according to the information generated from data collection (Morse and Field, 1996; Ritchie et al., 2003a). That is, poor quality interviews may require an increased sample size, whereas good quality interviews may reach a point of saturation, or diminishing returns, where no new information is added with an increased sample size (Morse and Field, 1996; Ritchie et al., 2003a). Additionally, the sample size may be driven by the available time and resources due to the labour-intensive nature of qualitative data gathering and analysis (Ritchie et al., 2003a).

For the purpose of Stage III, the acceptability study, patients who consented to telephone contact in their returned questionnaire booklets from Stage II were invited to participate. It was envisaged that patients would be invited to participate until 20-30 patients had been recruited, or data saturation had been achieved (Morse and Field, 1996; Pope et al.,

2000; Johnson et al., 2009). A similar sample size (n=26) was used in a study exploring patients' hospital experiences regarding chest pain treatment via semi-structured interviews, and produced sufficient data for meaningful analysis (Johnson et al., 2009). Of the 311 patients who completed the psychometric study, approximately 60% (n=180) consented to receiving a telephone call. The psychometric study had a recruitment rate of approximately 20%. However, it was thought that the recruitment rate for the acceptability study would be >20% since patients had already consented to the questionnaire study and for telephone contact. Therefore, it was considered that 20-30 patients was an achievable sample size.

7.1.2.4 Data collection

The semi-structured telephone interviews comprised of a series of open-ended questions following the same script for every patient (Arthur and Nazroo, 2003). The benefit of semi-structured interviews includes the use of specific questions to address one concept at a time (Morse and Field, 1996). The questions that were included in the interview were designed to facilitate discussions regarding the concept of pacing, the content and phrasing of the questions included in the APQ, together with the ease of completion of the questionnaire, including the use of the 5-point Likert scale. The telephone interviews were digitally recorded and transcribed promptly for ongoing data analysis and awareness of data saturation. In addition, fieldnotes were made during the interview to document any contextual issues that would not have been digitally recorded, together with any prompts for data analysis (Morse and Field, 1996; Arthur and Nazroo, 2003).

7.1.2.5 Data analysis

Qualitative data analysis involves the organisation, reduction, generation of concepts and interpretation of often large volumes of qualitative data (Spencer et al., 2003). Qualitative analysis is an iterative process whereby data are revisited as concepts are generated to refine, or 'distil' concepts (Spencer et al., 2003). Qualitative data can be analysed following various methods and differ according to the nature of the data and the method of data collection (Spencer et al., 2003). Methods of qualitative data analysis include thematic analysis, content analysis and framework analysis.

Thematic analysis involves the identification of themes that emerge across the qualitative data. The researcher is immersed in all of the data in order to develop their own interpretation of the data, leading to the formation of the themes. Thematic analysis

involves an iterative process of repeatedly reading the information across the texts and then coding the themes (Morse and Field, 1996).

Content analysis involves coding the data according to concepts contained within each section of a text. Initially, broad concepts or categories are identified, which are frequently divided into sub-categories (Morse and Field, 1996). Content analysis involves counting the incidence of each concept across the different texts, with consideration of contextual features from which the data originated (Spencer et al., 2003). Thematic and content analyses involve predominantly inductive processes: developing themes during data analysis (Pope et al., 2000). It is the interpretation of these themes and the interactions between the themes from which new theories are developed (Spencer et al., 2003). The above methods of analysis were deemed less suitable for the present study since a more deductive method was required to explore the specific themes of pacing, together with the acceptability of the APQ. However, a method of analysis was required that also allowed inductive analysis to facilitate the emergence of new themes from the telephone interviews.

Framework analysis was selected for the purpose of Stage III, the acceptability study. Framework analysis is a matrix method which holds its roots in social policy-making in the 1980s (Ritchie et al., 2003b; Ward et al., 2013). Framework analysis is a step-wise and iterative method, and the framework matrix involves charting qualitative data into themes and subthemes in order to synthesise concepts from the data (Ritchie et al., 2003b). Framework analysis is now frequently utilised to inform health policy and practice, and it encourages creativity, flexibility and transparency (Ritchie and Spencer, 1994; Pope et al., 2000; Johnson et al., 2009; Ward et al., 2013). Due to the transparent and structured nature of framework analysis, it is considered to be more comprehensive and easier to replicate in comparison to other forms of qualitative data analysis (Hall et al., 2009). Framework analysis is apposite when the purpose of the qualitative data is to answer specific questions, often complementing quantitative data (Pope et al., 2000). Framework analysis is therefore suitable for analysing data from semi-structured interviews (Ward et al., 2013). In answering predetermined questions, themes may be generated before commencing data analysis. As such, framework analysis is considered to be a more deductive process than other forms of qualitative data analysis (Pope et al., 2000). Therefore, framework analysis may appear to have limited capability to generate new theories (Ward et al., 2013). However, some new concepts will arise from

interviewees' responses, thereby incorporating inductive analyses (Hall et al., 2009). Since framework analysis involves both inductive and deductive processes it was considered to be the most ideal method of analysis for the acceptability study.

Framework analysis was selected for the present study with the additional pragmatic benefits of lesser time requirements, together with the practicality of following a five-stage systematic method (Johnson et al., 2009). The five stages include: familiarisation with the data, identifying a thematic framework, indexing, sorting or charting the data using headings and subheadings, and mapping/interpreting the data with reference to the aims of the study (Ritchie and Spencer, 1994; Pope et al., 2000; Ritchie et al., 2003b) *(see Figure 7.1.1 Outline of the five stages of framework analysis).*

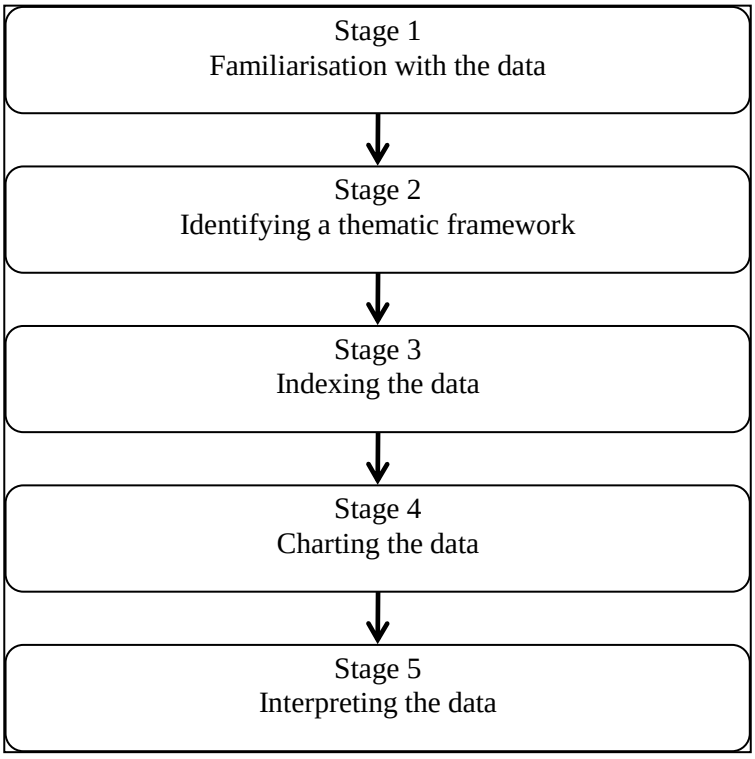

Figure 7.1.1 Outline of the five stages of framework analysis

Stage 1, familiarisation with the data, involves immersion in the data (Ritchie and Spencer, 1994). In the present study, familiarisation involved reading the interview transcripts and any relevant fieldnotes. Familiarisation facilitates the development of themes from ideas that emerge from, and recur in the data (Pope et al., 2000; Ritchie et al., 2003b). Stage 2 involves identifying a thematic framework of all themes or concepts contained within the data (Ritchie and Spencer, 1994). These themes will arise from both the ideas initially hypothesised (from the nature of the semi-structured interview

questions), together with new concepts that emerge from the interviewees' responses (Pope et al., 2000). Similar themes may be classified together under main themes, with subdivisions to develop the thematic framework (Ritchie et al., 2003b).

Stage 3 requires indexing the themes in the transcripts using codes. It may be that a body of text refers to more than one theme, and will be indexed by all relevant codes (Pope et al., 2000). As indexing proceeds, it may appear that different themes co-occur on multiple occasions. This may be suggestive of associations between themes which are recorded (Ritchie et al., 2003b). Stage 4, charting the data, involves the reorganisation of data according to the indexing system into themes. This process facilitates the closer evaluation of each theme and summaries may be synthesised from the grouped data to assist the reduction in the amount of data (Pope et al., 2000; Ritchie et al., 2003b).

Stage 5 involves the interpretation of the themes and mapping the concepts that have arisen, with reference to the original hypotheses. Relationships between themes are explored, and attempts to explain concordant and discordant data are attempted (Pope et al., 2000). Patterns between the responses made by different subgroups of participants may also be evident (Ritchie et al., 2003b). During the processes of coding, indexing and charting, the patients' original language is maintained as closely as possible (Ritchie et al., 2003b). However, as the themes are developed and interpreted, the concepts may need to be renamed and reported using theoretical language (Spencer et al., 2003).

Framework analysis is an iterative process in which there is movement forwards and backwards throughout the five stages. This will assist the refinement of the matrix and ensure that all data have been included within the relevant themes and that all themes and subthemes have been identified (Ritchie et al., 2003b). The process of returning to the raw data and comparing it with the emerging themes may be referred to as the constant comparison method. The constant comparison method is thought to assist the validation of the analysis. This method has been utilised in qualitative studies as a method of data analysis in its own right (Eborall et al., 2012), or as part of thematic analysis (Bee et al., 2010), or framework analysis (Lovell et al., 2008).

Data analysis of the qualitative interviews commences as the data are transcribed. This facilitates the development of subsequent interviews to probe issues that have been raised by previous interviewees. In this way, new hypotheses can be explored to observe

agreement or disagreement between interviewees (Pope et al., 2000). Furthermore, the concurrent processes of data collection and analysis facilitates the detection of data saturation when no new concepts emerge (Morse and Field, 1996; Ritchie et al., 2003b).

To facilitate the navigation through large amounts of qualitative data, together with increasing the systematic organisation of data into themes and retrieval of data, computer programs are frequently employed (Pope et al., 2000; Spencer et al., 2003). The NVivo9 program was selected for this study. NVivo9 facilitates the re-organisation of the uploaded transcripts so that once indexed, the data can be presented according to themes for interpretation.

7.1.2.6 Rigour in qualitative research

Since qualitative research presents with diverse and flexible approaches, it has been criticised for a lack of rigour, certainly in terms of the critique applied to quantitative studies (Ryan-Nicholls and Will, 2009). Amidst debates regarding the method of assessing rigour, criteria have been developed that are apposite to philosophy of qualitative research (Murphy et al., 1998a). That is, criteria that recognises the ontology, epistemology, axiology and the methodology of qualitative research, for example, regarding sampling and bias. Rigour may be subcategorised into the truth value (or representativeness) of the findings, the applicability (or generalisability), the consistency and neutrality (or the recognition of bias) (Sandelowski, 1986).

7.1.2.6.1 Truth value (representativeness)

In terms of the truth value, or representativeness of the findings, each interview is considered to be representative of an individual's opinion, rather than seeking to validate a specific theory (Sandelowski, 1986; Ryan-Nicholls and Will, 2009). However, the interviews themselves may be affected by situation, date, or experiences for each individual (Sandelowski, 1986). Therefore, it is possible that different 'realities' may exist, in keeping with the ontological stance of qualitative studies.

Respondent validation of the findings has been suggested as a method of increasing the representativeness of the outcome of qualitative studies (Sandelowski, 1986). Furthermore, respondent validation may be seen to increase the corroboration of the findings (Barbour, 2001). However, respondent validation may cause difficulties if participants carry different interpretations of the results to either one another, or the

researcher (Murphy et al., 1998a; Ryan-Nicholls and Will, 2009). Moreover, participants may not be able to separate their own beliefs from general conclusions that are collectively drawn from the group (Barbour, 2001). On a practical level, asking respondents to validate the findings increases the burdensomeness of participation (Barbour, 2001). For the purpose of the present study, participants were asked to verify their own interview transcript, but not the analysis of all transcripts.

The validity of the qualitative analysis may be enhanced if the findings can be related to previous theories or findings (Sandelowski, 1986). Indeed, the findings from the telephone interviews were intended to be related to the conceptual models discussed in Chapter 3, Conceptual Framework. However, it was not the intention of the interviews to prove/disprove these theories. The qualitative data were used to discuss the data collected in Stages I and II through a sequential process, as opposed to a method of triangulation. Triangulation involves simultaneous pooling or a comparison of different data that have been collected to answer the same research question (Murphy et al., 1998a). The data may have been collected from different samples, via varying methods or researchers, or even regarding different theoretical models (Murphy et al., 1998a). However, triangulation itself presents some difficulties in combining different types of data (Barbour, 2001). Moreover, triangulation may lead to high quality data counterbalancing poorer quality data when corroborating the findings (Mays and Pope, 2000).

7.1.2.6.2 Applicability

Due to nature of sampling and smaller sample sizes involved in qualitative research, a reduction in applicability (or generalisability) of the findings is foreseen. Although a sample does not aim to be statistically representative, the sample is considered to represent the group from which it was recruited (Sandelowski, 1986). The demographics of the participants in the present study will be disclosed for transparency of the interpretation of findings. In doing so, the relevance of the study to other populations may be assessed. Relevance of the study may also be considered in terms of new findings that emerge, or where findings confirm or refute current knowledge (Mays and Pope, 2000).

An advantage of qualitative studies is that data collection often occurs in natural surroundings, and therefore the findings may be transposed to usual environments rather than clinical environments (Sandelowski, 1986). Indeed, during the present qualitative

stage of the study, participants remained in their own environments since data collection occurred via the telephone.

The term ‘transferability’ may be more reflective of the interpretation of ‘applicability’ (or external validity) to describe the potential for findings to be transferred to different situations (Murphy et al., 1998a). To further increase rigour, deviant cases or unusual findings are reported to increase the awareness of the limits of generalisability of the findings (Sandelowski, 1986; Murphy et al., 1998a; Ryan-Nicholls and Will, 2009).

7.1.2.6.3 Consistency

The nature of qualitative research involves enquiries into individuals’ experiences which will inherently yield a variety of responses across the sample. Indeed, each interaction with a participant may vary at different time points (Murphy et al., 1998a). Whilst the diversity of data is celebrated in qualitative research, it may be perceived as a threat to the consistency (or reliability) of repeated findings (Sandelowski, 1986). Although reliability in the sense of quantitative research is not attempted, consistency of qualitative work may be increased by presenting a clear audit trail of the data collection and analysis so that the process can be repeated (Sandelowski, 1986). The five stages of framework analysis lend themselves to producing a repeatable audit trail, in which the development of themes can be witnessed (Ward et al., 2013). The utility of computer programs such as NVivo9 assist in the organisation of large volumes of data which further increases the accessibility of the audit trail (Ward et al., 2013). Moreover, the availability of all original interview transcripts, the indexing of the transcripts, together with the fieldnotes can increase rigour and transparency (Ryan-Nicholls and Will, 2009).

Rigour may be enhanced by comparing the findings of more than one researcher (Barbour, 1998; Ward et al., 2013). This may include comparing interpretations of sections of data or the development of themes (Ryan-Nicholls and Will, 2009). However, involving multiple researchers, or researchers from different backgrounds may result in difficulties reaching an agreement on themes (Ryan-Nicholls and Will, 2009; Ward et al., 2013). Furthermore, multiple coding of a full dataset has consequences in terms of increased burden and cost (Barbour, 2001). In the present study the findings were discussed with an independent researcher with an expertise in qualitative research.

7.1.2.6.4 Neutrality (recognition of bias)

In terms of bias, the epistemological stance of qualitative interviews involves close interactions between researchers and participants. Indeed, researchers may even be considered as subjects in the research (Sandelowski, 1986). In order to increase rigour, qualitative data analysis involves reflexivity, whereby researchers acknowledge their influence on the study, including their impact on data collection and interpretation, by acknowledging their personal background and beliefs (Murphy et al., 1998a; Ward et al., 2013). However, framework analysis is considered to be a more transparent and rigorous method of qualitative data analysis (Ward et al., 2013). Additionally, clear audit trails may assist the transparency of qualitative research (Murphy et al., 1998a). In further recognition of bias, qualitative research requires an awareness of fair dealing. This involves drawing findings that represent a mixture of views (Murphy et al., 1998a; Mays and Pope, 2000).

7.1.2.7 Ethical issues

7.1.2.7.1 Recruitment and consent

Written consent was obtained before participation in the acceptability study, separate from the signed consent form for the psychometric study. Patients were advised that participation would not affect any current or future physiotherapy treatment. The patient administration system was checked for deceased patients before recruitment. Patients who were unable to read and write in English were excluded from the study since it was beyond the scope of the study to translate the interviews into different languages.

7.1.2.7.2 Participant well-being

The acceptability study did not involve any form of intervention and the telephone interviews were not considered to be related to a distressing topic. However, the discussion may have been emotive for some participants, and therefore participants were advised that the interview recording (or the interview itself) may be stopped at any time.

7.1.2.7.3 Anonymity

In order to maintain patient confidentiality and anonymity, patients were given unique codes for the psychometric study. The same codes were maintained for the acceptability study. Patients' codes and personal data were kept securely on a password protected Microsoft Excel worksheet. The worksheet was stored on two encrypted USB pen-drives

and the signed paper copies of the transcripts and consent forms were kept in a locked filing cabinet in The Pennine Acute Hospitals NHS Trust. The data from the transcripts were entered into NVivo9 on which participants were identified only by their unique code in order to maintain anonymity of their responses.

7.1.2.7.4 Ethical approval

Ethical approval was granted in November 2012 by the NRES Committee North West-Cheshire (REC Ref No. 12/NW/0832) *(see Appendix 21)*. Approval from The Pennine Acute Hospitals NHS Trust was received in February 2013. In addition, the study was lodged with the University of Manchester.

7.1.3 Methods

7.1.3.1 Pilot telephone interview

The pilot telephone interview trialled the interview questions and the recording equipment, together with gauging the duration of the interview. The pilot interview lasted approximately 20 minutes. After observation of the transcription it was considered that with the exception of further probing questions and specific questions regarding the themes of pacing, that the basic interview structure was suitable. The pilot interview was therefore included in the full data analysis, similar to the qualitative study undertaken by Johnson et al. (2009).

7.1.3.2 Participant recruitment

Retrospective and current patients were recruited in a reverse chronological order, that is, patients who returned their questionnaire booklets in the psychometric study most recently were invited first with the aim of recruiting patients who may best remember completing the APQ. Recruitment commenced in March 2013, and recruited those who completed the psychometric study no earlier than March 2012.

Patients were invited to participate over the telephone. Patients were advised about the nature of the interview, that the interview would be recorded and transcribed verbatim, and that the interview would last 20-40 minutes. Those patients who consented to receive further information were sent a participant information sheet, a consent form, an interview appointment form and a pre-paid envelope *(see Appendix 22)*. In addition,

patients were sent blank versions of the APQ, and CPCI and PARQ pacing subscales. The purpose of sending the blank scales was to facilitate discussions about the scales.

Patients were asked to return the signed consent form within approximately three weeks. Patients were also asked to complete the interview appointment form to indicate the day and time that was suitable for them to undertake the interview. Patients were asked to ensure that they had access to a phone (preferably a landline) located in a quiet place so that they would not be interrupted for the duration of the interview. Telephone reminders were made to those patients who agreed to receive further information about the study but did not return the consent form within three weeks. No further contact was attempted after this reminder call if patients did not return the consent form.

7.1.3.3 Data collection

Verbal consent was recorded on the digital recorder before the interviews commenced *(see Appendix 23, Interview outline)*. Fieldnotes were made during the interview and the interview recordings were transcribed. Participants were sent a copy of the transcription to read, make comments and sign. The transcripts, including any amendments were uploaded into NVivo9 for analysis.

7.1.3.4 Data analysis

Demographic statistics were collected in the psychometric study, to include: age, gender, condition and duration of symptoms. Stage 1 of framework analysis, familiarisation, commenced in the undertaking and transcription of all of the interviews by the researcher, together with the documentation of fieldnotes *(see Appendix 24, Fieldnote exemplar)*. This facilitated the researcher's knowledge of the data, which in itself helped the recognition of data saturation, when it was decided to cease further recruitment.

Stage 2, identifying a thematic framework, involved the development of themes and subthemes that emerged from the data. NVivo9 recorded the date that each new theme emerged which increased the transparency of the audit trail. Stage 3, indexing, involved reading each transcript individually and indexing each item that pertained to a theme. If a new theme emerged, all transcripts were re-read with the aim of indexing all relevant items to increase rigour through a constant comparative approach. Frequently, passages of text contained more than one theme and were indexed by all applicable themes.

Stage 4, sorting or charting the data, involved viewing all of the data that had been reorganised into themes to develop summaries. During this stage the themes were refined, where smaller subthemes were amalgamated into larger themes. The reorganisation and development of summaries of the original 46 themes facilitated Stage 5, the interpretation of the data, and projection of relationships between themes. Rigour was increased by referencing emerging concepts and relationships with the original data (Ward et al., 2013). Furthermore, the concepts that arose were compared with the findings of Stages I and II of the study. For the findings of the qualitative study and the process of developing themes through framework analysis, the researcher was advised by an expert in qualitative data analysis. However, due to the volume of qualitative data, it was not feasible for a second researcher to thoroughly analyse the data.

Chapter 7. Stage III: Exploring the Acceptability of the Activity Pacing Questionnaire (APQ)

7.2 Findings

7.2.1 Introduction

Sixteen patients participated in the semi-structured telephone interviews. This section begins by describing the demographics of the participants. The findings from the framework analysis of the qualitative data are reported, to include themes such as the facets of pacing, and the ease of completion of the activity pacing questionnaire (APQ) and the pacing subscales of the Chronic Pain Coping Inventory (CPCI) and the Pain and Activity Relations Questionnaire (PARQ). Links between the themes are discussed, together with potential behavioural typologies that emerged. In addition, there is a section on reflexivity regarding the influence of the researcher on the findings.

7.2.2 Participants

Of the 15 retrospective patients who were called and invited to participate in the interviews, all 15 consented to receive the postal study information pack. Seven patients returned the signed consent form. One patient withdrew their consent when called to undertake the interview due to other commitments. Reminder calls led to one other patient consenting to participate. Therefore, seven retrospective patients consented.

Of the 30 current patients who were invited to participate, seven returned their consent forms. Four patients declined receiving the study information pack and one patient declined participating due to ill health after receiving the study pack. Telephone reminder calls led to two other patients consenting to participate. In total, nine current patients consented to participate.

Combining retrospective and current patients, a total of 16 patients were involved in the telephone interviews out of 41 study packs sent (recruitment rate=39%). The interviews were undertaken between March 2013 and May 2013. The interviews were transcribed immediately after each interview and a sense of saturation was achieved by the 16th interview. Therefore, no further patients were invited to participate.

Of the 16 participants, four (25%) were male and 12 (75%) were female, with an age range of 24-73 years (mean=50.1 years, median=53.5 years). Participants reported low

back pain (n=12), chronic widespread pain (n=4), fibromyalgia (n=2), chronic fatigue syndrome, CFS (n=3) and myalgic encephalomyelitis, ME (n=1). Of note, participants could report more than one condition. As their main condition, participants reported low back pain (n=8), chronic widespread pain (n=4), fibromyalgia (n=2), CFS (n=1) and ME (n=1). The duration of conditions ranged from 0.3-40 years (mean=11.0 years, median=8.5 years).

7.2.3 Themes of the qualitative interviews

The themes from the interviews were generated both deductively and inductively during framework analysis. The progression of the development of themes is shown in Appendix 25. A total of 46 small themes were indexed on NVivo9. These 46 themes initially included some general themes that were pertinent to reflexivity. The themes specific to the concept of pacing were reorganised, leading to a framework of five main themes with a number of subthemes and subdivisions. The main five themes include: themes of pacing, the pacing scales, co-morbidities, coping strategies, and typologies of activity behaviour *(see Appendix 25, Progression of the themes, and Table 7.2.1 Final framework of themes).*

Table 7.2.1 Final framework of themes

Theme	Subtheme	Division of subtheme	Subdivision
1. Pacing themes	Activity limitation	Essential activities	
	Activity planning		
	Activity progression	Deterioration	
	Activity consistency		
	Activity acceptance		
	Other pacing themes		
2. Pacing scales	APQ: ease of completion	Instructions	Types of activities
			Seven day recall
		Scale	Number of intervals
			Word descriptors
		Questions	Relevance
			Number
		Format	
		Stability of the APQ	
	CPCI: ease of completion	Instructions	Seven day recall
		Scale	
		Questions	Relevance
			Speed of activities
			Number
	PARQ: ease of completion	Scale	
		Questions	Relevance
			Number
	Comparing the three scales	Mental fatigue	
3. Co-morbidities	Other illnesses/age	External factor: weather	
	Effect of pain when completing the questionnaire		
	Emotions		
4. Coping strategies	Effects of pacing	Pacing knowledge	
	Other coping strategies	Support from others	Flare up management
5. Activity behaviour typologies	Quota-contingent		
	Symptom-contingent	Pain focused	
	Task avoidance	Avoidance	
	Task persistence	Persistence	
	Task fluctuation (boom-bust)	Boom-bust	
	Task modification (activity pacing)		

7.2.3.1 Pacing themes

The semi-structured telephone interviews began with an open-ended question asking participants to describe their understanding of the term 'activity pacing'. Together with this, probing questions were asked relating to the five themes that arose from exploratory factor analysis in the psychometric study.

7.2.3.1.1 Activity limitation: *"I can't do too much, that's the problem" (RB198)*

When asked their understanding of 'activity pacing' one participant (PG017) broke this term down into two definitions for 'activity' and 'pacing':

> *"In terms of activities, I looked at that as being things like jobs around the house, walking to work, those kinds of things. In terms of pacing, just how much I did them, how often I did them and how long I did them for." (PG017)*

Similarly, PB139 answered:

> *"Activity pacing, I suppose it's pacing yourself to do an activity, how well you do it, how quickly, how you manage it. To manage it within your capabilities." (PB139)*

There was a sense of concepts that inferred being aware of how much activity was undertaken and limiting activities as part of pacing. Indeed, one participant answered this question by stating that they understood 'pacing' to mean their 'limits'. Some participants' responses were in keeping with the APQ factor Activity limitation, such as breaking down tasks, setting boundaries and spreading activities. For example,

> *"I'd break it up into manageable chunks. On a personal level that's usually about 20 minutes-half an hour, then have a rest for about the same period." (PC100)*

> *"The way I understand it is managing your day to day activities, spreading them evenly if you possibly can to reduce some of your symptoms." (RN318)*

The references above also include the use of pacing in terms of symptom management. Similarly to the theme of Activity limitation, participants mentioned strategies such as implementing rest breaks. For some participants using rests was a natural strategy, for others, this was implemented after receiving treatment:

> *"I was terrible before I came to physio. I very literally ran myself into the ground on a good day and collapsed on a heap on the bad days, and just fought my way through it. I'm not very good at resting. I'm still not very good at resting but I've got a lot better. I'm definitely more aware of the benefits of it. It's not necessarily sitting idle, it is just taking a break away from something I'm doing; reading, or just having a conversation with somebody." (RN318)*

Changing position was mentioned as a strategy for activities involving prolonged positions such as driving, or cognitive tasks:

> *"With working, I'm doing a long-distance study. I'll have to take breaks then. Sitting down in certain positions can be quite painful for a prolonged period of time. I try not to push it. I'll always get up and do something else." (PW048)*

Together with physical and positional activities, social activities were bound by limitations:

> *"…a girls' night out or something like that I tend not to go to them. Unless they are going somewhere local, and they're going to go early, and then I'll go for a few hours and then I'll come back. That's the only way I'll go to anything social." (PN240)*

Similarly to the comment above by PN240, activities were not only limited, but avoided:

> "..*if my symptoms were particularly bad I'd probably avoid a certain activity on that specific day." (RN318)*

The author suggests that there may be links between limiting activities and planning activities, for example,

> *"…to make things more logical and organised so I'm not tripping over myself going backwards so I can get things done quickly. If I have to go round several different places or do several different things, I sort of do it slowly..Just work out which way with least effort I can do it to be honest." (PC100)*

Including the reference above, three other participants made comments about limiting the speed at which activities were undertaken.

With reference to specific questions that loaded onto the theme of Activity limitation, APQ18: *"I was creative and found new ways of doing things"* received comments that it was both applicable for one participant (PN240), and inapplicable for another

participant (PB133). PB133 continued to report that APQ15 (which loaded onto Activity limitation) was irrelevant for them:

> *"…like question 15 'I divided each day up into periods of activity and rest' and you can't do that with ME because you never know…It's not that you're tired in your head, or sleepy it's just that your muscles are so exhausted." (PB133)*

Similarly PB133 reported that they found APQ16 irrelevant, and appropriately demonstrated this as 0='never did this' in the Stage II questionnaire booklet.

The majority of participants who interpreted pacing as limiting their activities reported this to a greater extent on days with increased symptoms. However, many participants were aware of their limits most days:

> *"…even on a good day my body will tell me to have a rest." (PN240)*

This awareness of limitations was described as something that had been learnt through the experience of symptoms, together with the attendance of healthcare services. The implementation of limiting activities appeared to relate to the concept of accepting current capabilities:

> *"Something like if I knew I had to clean the windows, I would attempt to do all the windows, whereas now I just do one room, and that's it. So, breaking down the actual task. I mean, there is no race to get them done really. But, this has been hard for me to accept as I say, because I'm a bit of a perfectionist and I always had to get things done when I thought I had to get them done, but it isn't necessary because I physically can't do it any more." (PF011)*

Two participants described implementing a quota-contingent approach to activities, for example,

> *"How much physical time I spend..doing each of those activities." (RB195)*

However, for some participants, there may not be a specific quota of activity, rather, a sense of their own feelings and symptoms:

> *"…see how it goes. I've got a bit of a built in clock at the moment. I usually know when I'm ready." (PC100)*

Several participants acknowledged that limiting activities was a useful strategy to prevent exacerbating symptoms, but unfortunately this was not always feasible, either socially or in the work environment:

> *"…I belong to a choir and usually when we have a concert we have to stand up, which triggers my back off. Sometimes, there isn't the opportunity to sit down for the length of time that I need to make it recover…" (RB043)*

> *"If it's something out of my hands like work, it would be difficult for me to stop the activity even if I was in pain." (PW048)*

The influence of others was raised by participants to include both people encouraging increased activity, but also those advising a limitation of activity:

> *"My friend said that I ought to do everything and if your back hurts, it hurts, but I don't know if that's something I subscribe to really. I don't want it to hurt." (RB043)*

> *"They changed my programme a couple of weeks ago, and I tell you what, I suffered with back ache and I had to go back to my physiotherapy…Even the physio said, just stick to what you know. If you change it, I find you have to come back to me, he said, so just stick to what you know you can do." (RB198)*

From participants' responses, Activity limitation appeared to be an important theme of pacing. Activity limitation appeared to relate to other themes such as Activity planning, Activity acceptance, avoidance, the speed of activities, undertaking essential activities, the influence of others, quota-contingency/symptom-contingency, and knowledge of pacing strategies.

7.2.3.1.2 Activity planning: "*to make things more logical and organised" (PC100)*

As participants described their understanding of pacing, concepts of assessing activities and their own capabilities were mentioned. This is in keeping with APQ37: *"I assessed my activity levels"* which loaded onto Activity planning during factor analysis. Participants also referred to setting goals, a concept which was found to load onto the theme of Activity planning:

> *"…in terms of how much cleaning I would do around the house, I would set myself a more realistic achievement without being in pain. Because, sometimes if I did a lot then I would feel my back would hurt afterwards. Whereas, if I thought if I break this up into chunks, I know it won't hurt." (PG017)*

Of relevance to the above comment by PG017, there is mention of breaking down activities into manageable pieces alongside planning activities. This was a similar outcome following factor analysis in which questions involving breaking down activities loaded onto either Activity limitation or Activity planning.

The types of activities that were frequently planned included physical activities, with reports of housework, shopping, swimming and running. The following reference (PW048) refers to using rest breaks, a facet found to be associated with Activity limitation. Again, there appears to be a relationship between limiting and planning activities:

> *"...if I'm doing an activity in the day, like some sort of exercise routine, I make sure maybe that the next day I won't do anything to give me time to recover." (PW048)*

Furthermore, the identification of planning different activities was stated:

> *"It's probably the more strenuous activities, the things that have an impact on your symptoms. It's trying to get a balance between…the more stressful activities, the more demanding activities, and having some time to enjoy the activities that you want to do." (RN318)*

The above comment by RN318 is similar to the concept of APQ29: *"I switched between activities that use a high amount of energy and activities that use a low amount of energy"* which loaded onto the theme of Activity planning during factor analysis.

This participant (RN318) proceeded to state that although the activities were not specifically timed, suitable adjacent activities would be planned:

> *"Yes, I suppose, it's not like I'd set literally an hour. I'd fit it in alongside other activities. If it was a strenuous activity, I'd fit it alongside less strenuous activities. I'd plan my day in that way rather than a specific set time." (RN318)*

For some participants, planning was used in their approach to activities, to include planning the practicalities of a task such as the duration of the activity, the route to a destination (to include rest points), the priority and order of activities. For others, planning was not always a strategy that was utilised. With specific reference to APQ31, the following comment was made:

"…'I planned in advance how long I would spend on each activity' [APQ31]. I can't plan that, I just have to do it as it comes to me." (RB188)

Similarly to Activity limitation, there were barriers to Activity planning, such as fulfilling caring roles, duties at work, and the condition itself. For example,

"Sometimes it doesn't always go to plan because of work or whatever. I do have a little routine of when I'm exercising or when I'm doing jobs. But obviously maybe it will get thrown out because I'm working or something." (PW048)

"I could think about planning, but because I have ME, it doesn't matter how much I plan, I never know how I'm going to feel or what my abilities are going to be on that particular day." (PB133)

The author suggests that Activity planning may be associated with the themes: Activity limitation, undertaking quota-contingent/symptom-contingent activities and the types of activity.

7.2.3.1.3 Activity progression: *"I was building my activity up" (PG017)*

As participants described their understanding of pacing, most descriptions involved Activity limitation and Activity planning. However, some references were made towards Activity progression:

"It's just pacing yourself, pacing your activities, just doing a little bit more often." (PC100)

However, there were barriers to Activity progression, for example, a decline in the condition or the presence of co-morbidities:

"To be honest with you, I find that I can't do as much as I used to do. It's not only this I have but I've got other problems as well. It's not just the fibromyalgia." (PC082)

"A few years ago I could do that but now I can't. It seems to have gone a little bit worse so I'm not able to do that any more." (PB133)

Of note, PB133 was 61 years old. There appeared to be a link between increasing age (and worsening symptoms) with reduced Activity progression. The following participant (RB108) reported that they previously related pacing to the concept of gradually doing more, but not at present:

"Yes, but I'm 74 now, so I know I can't do what I used to do." (RB108)

Similarly, participant RB188 reported that overall their activities had "slowed down" due to both the condition and increasing age. Of note, this participant was 68 years old. Conversely, some participants found that pacing did involve a gradual increase in activity. Interestingly, the following patients included a 24 year old (PW048), a 35 year old (RN318), and a 25 year old (PG017) who all attended a rehabilitation group involving graded exercise:

> *"Ever since the physio I've been doing I've been able to push myself more and not feel any negative effects." (PW048)*

> *"Yes, I tend to be able to increase my activities as a result of it, not over-do it, but I'd hope to achieve more in a day. It's spreading it over days, so in a week you achieve more because you have more good days." (RN318)*

> *"…I think it was actually one of the physiotherapists who suggested to maybe just do a little bit each day…I do little chunks at a time, and then build up when I felt I could do a bit more, or spread it out a bit more rather than do it all in one go." (PG017)*

Participant PG017 continued to discuss progressing activities in terms of exercises:

> *"And then when I got back to the gym and into exercise again, I didn't do the full work out that I was used to doing, I built up to it by starting off doing something not as intense and built up back to what I was doing before I had pain." (PG017)*

The concept of finding a baseline of activity, that is, building up activities over time from an amount that can be tolerated emerged from the above comments by PG017. The author suggests that Activity limitation, Activity planning and Activity consistency may be used to establish a baseline of activity before commencing Activity progression.

Activity progression was also mentioned in the context of building up activities following a flare up of symptoms:

> *"…I feel in a way that it has been wasted time. I've not been able to do whatever it is, no matter how small or how big. But, I try to catch up…it's very easy to go mad when you've had a bad day and you've not been able to do anything. It's very tempting to rush and do everything, but I've trained myself…to realise that there is no rush." (PF011)*

Alternatively, Activity progression may be used as a means of managing symptoms:

> *"I tend to go with my symptoms nowadays. When I start feeling pain I know I need to up my exercise regime." (RB195)*

Prioritisation of activities was a strategy that was reported to be a facet of pacing, in keeping with the theme of an APQ item that loaded onto Activity progression:

> *"I've got a to-do list. The important stuff is at the top and the not so important stuff is at the bottom." (PC100)*

To summarise, the theme of Activity progression appeared to be related to age and co-morbidities, managing a flare up and Activity limitation, Activity planning and Activity consistency.

7.2.3.1.4 Activity consistency: *"just do a little bit each day" (PG017)*

As participants described their understanding of the term 'pacing', themes emerged that alluded to being consistent with activities:

> *"It means little but often, instead of trying to do everything at once and making yourself worse." (PC082)*

> *"Basically, I don't try to do too much at once and try to spread it out and suit your body as opposed to a ratio that doesn't suit your body by doing too much or too little." (RB195)*

The above concepts appear to have links with Activity limitation and Activity planning, and possibly allude towards Activity acceptance. Participants recognised that being consistent would involve trying to reduce a fluctuating (boom-bust) pattern of activity.

> *"I think I'm quite consistent. The main thing for me was the impact on going to the gym because I did stop doing that for a while. But that was just until I got the pain under control. It wasn't because I'd kind of had a boom then it was a bust. I was building my activity up so that I could get back to doing that regularly." (PG017)*

This participant's (PG017) comment makes reference to using the concept of Activity consistency, with a view to Activity progression. The aim of achieving more consistent activities and reducing 'bad' days was often something that had been implemented following physiotherapy:

> *"Yes, I never used to be like that but since I've had physio, I'm more aware of that. I used to run around like mad on a good day doing everything that I possibly could, but then I'd have more bad days as a result of the good days, so the balance wasn't there. So, now I do make use of the good days but I don't over-do it and I try to stop before I've run myself into the ground." (RN318)*

In order to reduce a 'boom-bust' pattern of activity, participants identified that they needed to try to continue activity on a 'bad' day, but also not 'over-do' things on a 'good' day:

> *"Pacing is to either build yourself up or decrease what you're doing I suppose. Trying to do what you can." (RB188)*

Some participants felt that they had to continue with activities on 'bad' days such as essential tasks of self-care or work. However, there was also modification of activities on 'bad' days to cope with increased symptoms:

> *"Yes, even if my symptoms are bad I still try to do things. I never really lie down and I find that sitting down doesn't really help because you feel your symptoms more. So I do try to stay active, but I'm more conscious of what I'm doing those days." (RN318)*

Although this principle was identified in theory, many patients struggled to maintain a consistent level of activity and reported a reduction in activities on bad days, and experienced an exacerbation of symptoms if they had over-done activities on a previous day. There appeared to be a link between 'bad' days and task avoidance:

> *"On those bad days I just can't do anything. It doesn't matter what I've got to do, it just won't get done. It will have to get done at another time. It's just a life of postponing!" (PC100)*

Alternatively, some participants described activity behaviour akin to task persistence:

> *"Really, for me, I just get on with what I'm doing…You've got to try and push yourself to do it. I'll have a rest when I'm finished doing it sort of thing, whether I've pushed myself or not…"*
> *"…But for me, I just do what I can do, and keep doing it until I actually couldn't do it any more." (PB139)*

The same participant described that a task persistent approach would similarly apply to bad days. In this way, the author postulates that some level of consistency may be achieved:

> *"Yes, I just get on with it, to be quite honest. I'd definitely do the easier things that I could do, but for me I'd try to do the harder things as well. You've got to get on with it, you can't make an invalid of yourself." (PB139)*

Participants highlighted specific APQ items that relate to Activity consistency, such as the confusion of the double negatives in APQ20 and APQ34 regarding 'under-doing'

and ‘over-doing’ activities respectively. Of note both APQ20 and APQ34 were deemed redundant following factor analysis of the APQ. In contrast, APQ38 generated the following positive comment about its applicability:

> *“..question 38 ‘I did a similar amount of activity on ‘good’ and ‘bad’ days’, which I have to make myself do. Sometimes I couldn’t, but six out of seven days I have to make myself do, just to keep mobile.” (RB188)*

The concept of having a consistent approach to activities was acknowledged by participants. However, some barriers to maintaining consistency were mentioned to include work, the condition itself or other illnesses. For example,

> *“My good and bad days..yes are obviously very different. Last week, I had what you call a flare up when I just couldn’t cope with anything at all, so everything had to go by the board and I just had to accept that mentally.” (PF011)*

There appeared to be reported associations between Activity consistency and other themes of Activity limitation, Activity planning, Activity progression, Activity acceptance, co-morbidities, activity behaviours to include boom-bust patterns, task persistence and avoidance, together with prioritising and having knowledge of pacing.

7.2.3.1.5 Activity acceptance*: “there’s always tomorrow” (PF011)*

The APQ questions that loaded onto the theme of Activity acceptance during factor analysis included changing activity targets if they are unrealistic and reducing self-induced pressure to complete tasks. These themes emerged in the qualitative interviews as participants described a change in mindset and approach to activities:

> *“..for somebody like me who is constantly in pain and for whom there isn’t a miracle cure, to actually cope with my life from day to day, I have to mentally make sure that I don’t try to achieve everything in one day and that I have to put into place coping strategies. This I didn’t know about until I actually had some help through the hospital.” (PF011)*

The comment above by PF011 appears to overlap with themes of Activity limitation, Activity planning and Activity consistency. Together with this comment, several other participants described the concept of acceptance and readjusting their activities following the attendance of physiotherapy. However, some difficulties in accepting this change were highlighted in terms of self-imposed expectations:

> *"I live in a two bedroom flat. I should be able to clean the whole thing in a day. I don't, I have to pace it for a week. There are certain things I have to do each day, it's quite annoying really, but there you go." (PN240)*

The APQ theme of Activity acceptance also contains an item regarding being able to say 'no' to activities. Following probing interview questions, most participants agreed that saying 'no' was relevant, and sometimes essential to prevent the consequences of further pain. Saying 'no' was reported to be applicable to both themselves and to others. Furthermore, saying 'no' was a means of reducing negative consequences of symptoms together with negative emotions:

> *"It is 'no' to myself actually yes, but quite often 'no' to other people. You kind of learn what brings your symptoms on, what aggravates them, and some days you've just got to accept that you can't do certain things, you're not up to it. I think if you agreed to them, there's a kind of resentment that builds and that triggers my symptoms as well when I'm feeling like that." (RN318)*

More commonly participants felt able to say 'no' in social contexts to family members and friends. However, being assertive in the work place was not always feasible due to the nature of the employment, together with feelings of guilt on taking breaks. Alternatively, some participants did not consider being assertive to be a facet of pacing.

In relation to concepts of acceptance and assertion, the role of other peoples' acceptance and support arose:

> *"I occasionally have to say 'no' to other people as well, but I am fortunate in having a very patient and understanding husband and the family who have lived with me...I don't think I ever worry about saying no I can't do a thing because they are very supportive. My friends also understand as well if I can't go out, I can't go out and that's it." (PF011)*

However, overly-supportive family members were highlighted in terms of frustration if participants were being advised to rest rather than be active:

> *"...my daughters will say 'sit down..and have a rest' and I get dead annoyed....I feel like I've got to do it....I'm telling them to leave me alone, so I have to be a bit assertive there." (PN240)*

Interestingly, as participants described saying 'no' to activities, it appeared there might be a trend towards the avoidance of activities. Indeed, when asked about being able to say 'no', one participant gave the following answer in terms of avoidance:

"I tried to avoid not doing things because I know it's important to keep active as part of my treatment." (PG017)

It was highlighted that on occasions, saying no was made as an active decision, whereas other times the condition dictated this decision:

"Sometimes it is a conscious decision. If I've got a few things on that week and know I just can't take on any more. Sometimes, it's a case that I've been looking forward to it all week, but by the time it comes round I just haven't got the energy to do it." (PC100)

Therefore, from participants' responses, the theme of Activity acceptance appeared to be related to Activity limitation, Activity planning and Activity consistency, together with other themes of co-morbidities, avoidance and using support from others. Participants reported a change in habits and acceptance of limitations that had arisen with greater knowledge and understanding of the condition following treatment but also experience. Activity acceptance also appeared to be related to emotions, such as resentment, frustration and guilt. Interestingly, the APQ item referring to guilt (APQ27: *"I did not feel guilty when I stopped an activity"*) was omitted following factor analysis.

7.2.3.1.6 Other pacing themes

Participants were invited to add any further comments with regards to pacing, especially in terms of anything that had been missed from the APQ. One participant mentioned the use of making lists and focusing on a singular task rather than multi-tasking. Interestingly, both of these concepts did not reach consensus on Delphi Round 3: APQ Question 4: *"I focused on doing one activity at a time"* (44% votes) and APQ Question 75: *"I made myself a list of jobs that I needed to do"* (62%).

7.2.3.1.7 Summary

Both deductive and inductive methods developed the themes of pacing from the qualitative interviews. The five factors of the APQ: Activity limitation, Activity planning, Activity progression, Activity consistency and Activity acceptance appeared to be in keeping with participants' understanding of pacing. Few further concepts of pacing were suggested that have not been included in the APQ. Therefore, the content of the APQ appears to be generally acceptable. The second theme from the interviews discussed the pacing scales: the APQ and the pacing subscales of the CPCI and PARQ.

7.2.3.2 Pacing scales

7.2.3.2.1 Activity pacing questionnaire (APQ)

The acceptability of the APQ was discussed with reference to the ease of completion, including the instructions, the scale, the questions and the format.

7.2.3.2.1.1 APQ instructions

In relation to the instructions that are given at the beginning of the APQ, participants found the instructions self-explanatory. The instructions included examples of the types of activities to which the questionnaire referred:

> *"…I think that's very good, 'the term 'activity' refers to any type of activity, for example, walking, working, socialising', because I think some people would think of activities like running and jumping about…I think that's fine. I don't think that you could simplify the first bit in any way." (PB133)*

During the interviews, participants did indeed report applying pacing strategies to the above examples of activities. However, not all of the activities given as examples were relevant to each individual according to which activities they perceived to be limited:

> *"…I didn't use some of those examples. I homed in on the more physical aspects, like walking and daily household tasks were the things I thought about the most. It's not socialising or reading. I didn't really take those into account when answering the questions." (PG017)*

The APQ instructs patients to answer in terms of their activities over the past seven days. The seven day recall period received mixed opinions. For the majority of participants (n=10, 63%), seven days was an appropriate amount of time on which to reflect, for example,

> *"I think seven days is a good amount really. Whenever I set out my working patterns or exercise or socialising, it's generally over a week, because then it includes working as well." (PW048)*

> *"For me personally yes, because I don't have good periods for any longer than about 2 or 3 days, or bad periods for any longer than that. So within a week, I personally will have a flare up and then things ease again. It never lasts more than seven days, so I think seven days is a good time. I think it's very difficult to think back a whole fortnight, because if you're constantly in pain, you do forget what the previous week was. But if it had said the last couple of days, I don't think that would give a fair indication of what has been going on…" (PF011)*

Three participants (19%) found a seven day period too long to recollect their activities. Of note, two of these three participants reported problems with mental fatigue:

> *"I think that it is too long. Because sometimes it takes me all my time to think about what I have done the day before. Perhaps two or three days, but I think seven is quite a long time." (PB133)*

Conversely, three other participants (19%) required a longer recall period to engage in different types of activity, or to experience symptoms:

> *"I suppose it would depend. Sometimes I can go seven days and not have any problems. So, on that I don't know really, whether it might be better for 10 days or 14 days or something?" (RB043)*

7.2.3.2.1.2 APQ scale

The APQ ease of completion was discussed with reference to the scoring system of the APQ (0-4 Likert scale). Most participants (n=13) found the 5-point Likert scale easy to use, and the number of options to be appropriate:

> *"It's a good scale that. You can't go up to 10 because that's pushing it a bit too much. The way it is set out is good." (RB188)*

> *"It seems fine. It's quite consistent and it's got a middle ground and two either side…I think five is good. Three is too few." (PW048)*

Three participants suggested fewer options (for example, a 3-point scale). Interestingly, no participants suggested more than five intervals on the Likert scale. However, one participant suggested having a 'not applicable' option.

The scale was discussed in terms of the word descriptors that appear over the numbers ('never did this', 'rarely did this', 'occasionally did this', 'frequently did this' and 'always did this'). Most participants could determine the difference between the levels and found the word descriptors suitable. There were no problems associated with the word anchors at either end of the scale: 0='never did this' and 4='always did this'. However, two participants highlighted some confusion differentiating between the middle three word descriptors:

> *I mean 'frequently' and 'occasionally'? Similar words aren't they?....I think I'd get rid of 'occasionally', no 'frequently'…I'd keep 'never', 'rarely', 'occasionally' and 'always'." (PB139)*

However, another participant (PF011) reported more difficulties separating 'rarely' and 'occasionally', and suggested a 3-point scale:

> *"Well me personally, it would be easier, if it was 'never', 'sometimes' and 'always'. But, that's just making it simple for me personally." (PF011)*

A second participant reported a preference to the term 'sometimes':

> *"I don't know, maybe 'sometimes did this' would have been nice. 'Sometimes' to me could be sometimes during the week you have an attempt at it. 'Occasionally' means a couple of times a year for me. I don't know." (PN240)*

Therefore, there appeared to be some disparity between participants' interpretation and preference of the word descriptors used in the APQ Likert scale.

7.2.3.2.1.3 APQ questions

Most APQ questions appeared to be relevant and understandable for participants. However, some specific questions were highlighted as not being relevant to an individual. For example,

> *"I made sure I had a flare up plan", number 17. A flare up plan could be different. A flare up could be that I can't get out of bed at all, so what do I do then?...So, it's very difficult to try and say that you had a flare up plan. It could work for one day and then the next day it could be totally different." (PB133)*

Question 17 received other comments querying the meaning of a 'flare up plan'. Of note, these comments support the removal of APQ17 from the APQ following factor analysis. The use of terminology such as 'flare up plan' may be more relevant and better understood by those who had attended physiotherapy. Indeed, one participant commented that attending physiotherapy facilitated their understanding of the APQ. A similar issue arose regarding the term 'activity goals' which appears in APQ28:

> *"Well, I suppose, when I went to physio…perhaps we might try to, thinking back, we might try for 1 minute, and then perhaps try to increase it to 2 minutes. So then, that would be setting an activity goal wouldn't it?" (PB133)*

Of note, APQ28 was retained following factor analysis due to satisfactory factor loading, item total correlations and mean score. Conversely, APQ32 received one comment:

"'I use an activity diary to monitor…' [APQ32] well I don't do that any how." (RB198)

Interestingly, APQ32 was removed from the questionnaire in the psychometric study due to having a noticeable low mean score, indicating low utility of this strategy.

APQ20: *"I did not under-do activities on a 'bad' day"* received comments in the qualitative interviews to report confusion regarding the appearance of a double negative in the question:

"Yes, I think if I remember that one, because it almost seems like a double negative. So I wasn't sure which way round to answer it, so that's probably why I left it because I didn't want to answer it strongly and it be the wrong way round and wrongly interpreted." (PG017)

This reiterates some of the written comments made in the questionnaire booklet of the psychometric study. Additionally, APQ20 attracted the following comment, but in terms of feelings of guilt:

"20: 'I did not under-do activities on a bad day'. Now, I think that's a strange one to put in actually…Because if you have a bad day, that's implying that you should, even though you don't feel that you can do it, that you should do it. But, that would make things worse. So I think that's not a good one, 20. And sometimes it makes you feel a little bit guilty as well." (PB133)

In relation to APQ26: *"I used support from others to help me with my activities if required"*, participants discussed both physical and mental support that they received from family or work colleagues, together with help they received from health professionals. One participant made a specific comment regarding APQ26:

"I think you've covered everything, because you've even involved a question about 'do you get support from others' which obviously applies to me. Obviously there will be some people who don't get support." (PF011)

The above participant (PF011) acknowledged that this question may not be relevant to everyone. Indeed, APQ26 was removed in the psychometric study due to low correlations and low contributions to factors during factor analysis. It may be, as highlighted by PF011 that this question is less widely applicable.

Furthermore, some questions may not be relevant for an individual at a certain point in time, or may be limited due to other reasons such as other illnesses:

"Well number 1: 'I gradually increased my activities', well no, I rarely do this. That's obviously with a couple of other health problems as well..." (PN309)

Participants reported some repetition of questions:

"I think it is statements 5 and 13, 'I took a short rest from an activity so that I could complete the activity later' and then 13, 'I broke tasks up into periods of activity and rest'. They seem to be asking the same thing…I think it was on statement 25 and 28 the difference between 'I set activity goals that were meaningful to me' and 'I set activity goals that were realistic for me'. I found that a difficult one…" (PF011)

Following factor analysis both APQ5 and APQ13 were maintained due to satisfactory item total correlations and inter-item correlations. However, it was deemed (in agreement with PF011) that APQ25 was redundant in the psychometric study. Participants reported that on occasions, the appearance of repetitive questions caused difficulties in trying to remember how they previously answered:

"…at times I was thinking I think I've had this question before, what did I put last time, but maybe it's a different question and I'll think about it in it's own right". (PG017)

There were suggestions that the length of the APQ made it more difficult to complete:

"I don't know if it could be more condensed so there are not as many questions. I don't know if it can be or not, or if there needs to be all of the questions." (PB139)

"It's a very long questionnaire. For me it's exhausting filling in the whole thing. If I could just do sort of 5 questions and then leave it and then do another 5." (PB133)

7.2.3.2.1.4 APQ format

Related to the length of the APQ, one participant (PC100) suggested improvements to the format to increase the ease of completion of the APQ:

"Not necessarily the amount but it's the way it's set out…I think, like I say with my condition, it is a little bit daunting. If it was just in chunks of say five or six and then just a little gap. So you could just say to yourself 'I'll do those questions now, then have a cup of tea'. Just psychologically, it would make it less daunting." (PC100)

A further comment was made regarding the format of the APQ suggesting space to write any additional comments.

7.2.3.2.1.5 APQ stability

Interestingly, one participant made a comment that might suggest some stability of the APQ across the period of time between being sent the study pack and the date of the interview (two months, including a reminder telephone call):

> *"They [the questions] were all OK. I looked at it this morning. I thought I'll have a look through, and I marked them when I first got it, and then I thought this morning I'll have a look through and have a think about it and see if I've got to change any of my answers. But, no, just a couple had moved over but otherwise it's alright." (RB188)*

7.2.3.2.2 CPCI pacing subscale

7.2.3.2.2.1 Instructions

Similarly to the APQ, some participants reported difficulties answering the CPCI pacing subscale in terms of the seven-day recall period, in both remembering the week and also having good and bad weeks:

> *"It's like you can only answer for that week when I did it. The following week could be totally different… you could have had a good week that week, or a bad week." (PN240)*

7.2.3.2.2.2 Scale format

Five participants reported that the CPCI pacing subscale was more difficult to complete than the APQ due to answering the CPCI items according to the number of days (0-7) they had undertaken the activity, for example,

> *"…I found this one slightly more difficult because I didn't consciously think about any of those things…so it was hard to count how many times I'd done it…" (PG017)*

One participant suggested that the CPCI pacing subscale would be easier if it was re-worded to yield 'yes'/'no' answers. Conversely, four participants had a preference towards providing an answer in terms of '0-7 days', for example,

> *"Yes, I think that [CPCI pacing subscale] was OK. I think that was better for me actually. I think this is where I could actually break it down into good and bad days. I think it gave a better idea of how many good and bad days I was having." (RN318)*

However, in the psychometric study questionnaire booklet, several participants answered the CPCI pacing subscale in terms of words, for example, 'sometimes' rather

than a number of days. One participant who wrote the answer "none, I just keep going" (in the psychometric study) reported in the acceptability study that they did not find the CPCI pacing subscale questions applicable to their activities. Alternatively, one participant wished to give a longer, more detailed answer than a number of days.

7.2.3.2.2.3 CPCI pacing subscale questions

Comments were made regarding the repetition of the questions contained within the CPCI pacing subscale. In particular, the use of the term 'slow and steady' (which is used in three of the six questions) was raised:

> *"I thought, well, 2, 4, and 5 are all very closely linked aren't they: 'I focused on going slow and steady', then 'I went slow and steady' and 'I paced my activities by going slow and steady'. I couldn't see why there had to be three as they're so similar."(PF011)*

The strategy of going "slow and steady" divided participants whereby some participants found this less applicable:

> *"I don't know so much of the 'slow', but the 'steady' is probably right. I don't think you necessarily have to go slow, but yes probably the steady-gradually rather than just pushing or going too slow. It's just finding that happy medium." (RN318)*

However, sometimes slowing activities down may be helpful:

> *"Yes it would make it easier. Like I was saying with work, because you're going a hundred miles an hour in long shifts, you can definitely feel it more. Whereas if you slow it down…(I've only just realised this recently with the physio), if you slow it down you can find yourself maybe not in as much pain, but you're not pushing yourself as much." (PW048)*

Difficulties were highlighted regarding questions of the CPCI pacing subscale that referred to distracting from, or reducing pain. In particular, it was reported that pain was constant and therefore strategies to avoid pain were not possible:

> *"Number 4 on Pacing Scale 1 [CPCI pacing subscale] 'I went slow and steady to help distract myself from the pain' you can't do that. If your pain is there, it's there and you couldn't go slow and steady for it." (PB133)*

With regards to the length of the CPCI pacing subscale, some participants found this scale less daunting than the APQ due to its brevity. One participant commented that more questions may be beneficial and a further participant made the following comment:

"I think this is easier, the pacing scale is easier, but perhaps not as detailed. For me this is easier than the previous scale [the APQ]…But, it would be better for me because there are only 6 instead of all of those other ones." (PB133)

7.2.3.2.3 PARQ pacing subscale

7.2.3.2.3.1 Scale format

On discussing the ease of completion of the PARQ pacing subscale, several participants preferred the Likert scale format where a number could be circled in comparison to the CPCI pacing subscale. However, in contrast to the Likert scale utilised in the APQ, the PARQ Likert scale has word descriptors only over the numbers 0='never' and 5='always'. The missing word descriptors caused difficulty for some participants:

"Maybe over two and three it could be a problem. I'm not sure how you would get from 'never' to 'always' on that scale. So I guess you would need one is 'not never', four would be 'not always', but what would two and three be?" (PW048)

"The scale was OK, but you could also have the first scale [the APQ scale]: the 'never did this', or 'always did this' as well on it." (RN318)

Questions were relevant but a smaller scale would be preferable:

"Yes…'splitting tasks into parts', 'did you do the tasks more slowly', 'did you pace yourself to get things done'. Yes, I think it did. I think it's easier with the scale. I mean whether you actually need 1-5 or 0-3…Yes, 0-3 might be better. That gives you 'yes', 'sometimes', 'no'." (PB139)

In contrast, one participant stated:

"Yes, or you could do from 0-10 if that would be more helpful for yourselves. But there's nothing wrong with the 0-5." (PN309)

The PARQ scale has six options, therefore there is no middle option as included in the APQ. The PARQ pacing subscale generated the following comment:

"I think it's probably easier to rate it in certain respects because you're given a scale. But there's no middle ground, so I guess if it was 5-point rather than six it might have been a bit easier." (PW048)

7.2.3.2.3.2 PARQ pacing subscale questions

Several participants reported that they found the PARQ pacing subscale questions relevant them. Some PARQ questions were more relevant than others:

" 'I use repeated rest breaks'…but having said that, you could do that and it might not make any difference at all. Pacing does sometimes work and sometimes doesn't…'I pace myself so I don't over do it'. Yes I suppose I do that…" (PF011)

Two participants highlighted that question 6 of the PARQ pacing subscale was less relevant to them, for example,

"Like the bottom one, 'I paced myself to get things done'. Well, sometimes it's something that can't be paced and you've just got to do it." (PC082)

Whereas, for one participant, question 6 was relevant:

"…it is what you do. That shed, would have taken me 2 hours, but I spent all day on it because I took my time and I sat down, had a brew in between and had a look at what I needed to do…That's what you do-you stop, have a little break for half an hour and go back to it. You do pace yourself…yes, you 'pace yourself to get things done'…" (RB119)

Questions 5 of the PARQ pacing subscale: *"I do tasks more slowly so that I can get them done with less pain"* received the following comment:

"I put three for that because that was the middle of the road because I found that a bit hard to answer because I do take tasks more slowly because I can't help that. That's the way I've gone now, but it doesn't control the pain less, because it's just made me that way-it's made me slower." (PN240)

In terms of the speed of activities, this could not always be determined by participants, for example, in the work situation:

"My job doesn't really allow me pre-pace my activities, I work in quite a fast environment. Some days it's very very hectic and other days it's quite quiet. I try and manage that as best I can." (RB195)

Three of the six questions in the PARQ pacing subscale refer to pain. Some participants did not feel able to control their pain. Furthermore for others the use of the term 'pain' did not incorporate other symptoms such as mental fatigue, concentration and mood, whereas the suggestion of the term 'symptoms' may have been more applicable:

"Yes probably, because it's not always pain." (RN318)

"Yes, it's all that, and I find that I can't be mithered as well. I think 'do you know what, I can't be bothered'." (PC082)

Some participants found the PARQ pacing subscale less daunting to approach due to containing only six questions.

7.2.3.2.4 Comparing the three pacing scales

When asked to compare the three pacing scales, several participants reported a preference towards using the Likert scale (as in the APQ and PARQ) in comparison to providing a number of days (0-7) as per the CPCI pacing subscale:

> *"Probably the one where you're given numbers to circle rather than the ones that you have to think of an answer." (RB043)*

> *"I think you just said the key word yourself-the easiest. If you don't have to think and it's a quick tick. It's a bit like when you get asked a question-and if it's multiple choice, then you definitely have a go at it as opposed to if it's an open question." (RB195)*

Several participants found the 6-point Likert scale of the PARQ less easy to use than the 5-point Likert scale of the APQ due to the absence of word descriptors:

> *"Yes I think the 'never did this' and 'rarely did this' options are actually easier to answer, because they are quite literal, rather than the numbers, trying to decide what 'one' on the scale would be." (RN318)*

> *"I think it [PARQ pacing subscale] is more difficult to answer actually, with there being nothing at the top of the columns. I found that the new activity pacing scale was much easier in many ways." (PF011)*

Indeed two participants reported that they carried over the word descriptors from the APQ to answer the PARQ pacing subscale.

The preference towards the APQ was discussed in light of the problems of the length (38 questions in comparison to 6 questions in the CPCI and PARQ pacing subscales), some repetitive questions and questions containing double negatives:

> *"I think the first one was good but I suppose some of the questions were very similar…Pacing scale 2 as I remember that one was good again, because you have the 5 or 6 options and I felt the questions were more relevant to me so I found that one quite easy as well." (PG017)*

> *"The first one is probably I guess the easiest in terms of the scale, the 5-point scale. Some of the questions they seem like double negatives, but the scale seems a lot easier." (PW048)*

In contrast a couple of participants preferred the CPCI scale, and one participant voiced a preference towards answering in words rather than numbers.

Some participants commented that the PARQ may be easier to complete because it was not asked in reference to a seven day period. Of note, one of these participants reported that she struggled to recall one week due to mental fatigue. One participant stated a preference towards the APQ but with a shorter recall period:

> *"Yes, I think probably the first scale with the actual titles with the options, but like I say over a smaller amount of days perhaps." (RN318)*

The problem of pain focused questions (as per the CPCI and PARQ pacing subscales) was highlighted. Some comments referred to the presence of other symptoms, such as mental fatigue rather than pain alone. Other comments reported that pain was a constant feature. Therefore, questions in the CPCI and PARQ pacing subscales that inferred pacing as a means of reducing pain, or stopping an activity before the pain were not applicable.

One participant had a preference towards the PARQ pacing subscale:

> *"I think it seems to me, just looking back and forth, to be a bit more positive. You're not just going slower and giving yourself occasional breaks, because that doesn't make any difference. But to stop the activity before the pain becomes too great, that would be more like what I would do…I just think the wording is more applicable." (PB133)*

7.2.3.2.5 Summary

Participants discussed differing opinions of the strengths and weaknesses of the three pacing scales. The qualitative analysis of these findings has thus far included mostly deductive methods since specific questions were asked regarding the acceptability of the pacing scales, for example, regarding the ease of completion. The analysis moves forward to report the findings that emerged in the analysis inductively. The remaining three themes have been labelled: Co-morbidities, Coping strategies and Activity behaviour typologies.

7.2.3.3 Co-morbidities

The impact of co-morbidities on pacing behaviours emerged during the interviews. This added another dimension to the acceptability of the pacing scales, since co-morbidities appeared to influence the relevance of the pacing themes and scale items according to which pacing strategies were deemed possible to implement.

7.2.3.3.1 Other conditions and age

During the interviews, participants discussed other conditions or the effect of age on pacing. As mentioned previously, age was reported to be a barrier to Activity progression. Conversely, one participant stated:

> *"I think now I've got older that I'm pacing things out a lot more." (RB108)*

Of note, participant RB108 described pacing according to the themes of Activity limitation, Activity planning, Activity consistency and Activity acceptance but did not feel able to progress their activities due to their age (74 years) and current co-morbidities. Participants reported both short-term illnesses (for example, viruses), together with long-term conditions (for example, respiratory problems, gastric problems and other musculoskeletal problems) as barriers to pacing activities, or indeed engaging in activities.

An external factor such as the weather was further mentioned as a limit to pacing:

> *"It depends on the weather really and arthritis. If it's a bit damp I have to go a bit slower and things like that. But, if it's a nice warm day I can usually keep the pace up that I'm used to." (RB188)*

7.2.3.3.2 Effect of symptoms when completing the questionnaire

The effect of symptoms on the day of completing the questionnaire booklet may have also impacted on rating the ease of completion. Furthermore, the effect of symptoms (including mental fatigue) may also affect memory recall:

> *"… but I suppose it depends on the week itself. I must admit some weeks I would struggle to remember seven days and would need less. But, on a good week I probably would have a rough idea over the seven days." (RN318)*

7.2.3.3.3 Emotions

Together with physical conditions, participants mentioned the impact of emotions on their approach to pacing or general activity. In particular, depression was highlighted as a challenge to initiating activity. One participant (RB119) recognised the relationship between mood and symptoms:

> *"I think sometimes people do have it in their heads, when you're feeling low and fed up and you've got a lot of problems, you're at your worse, you feel so bad and your back is so bad, but it's not your back, it's just you. You feel down so everything is going to hurt isn't it?...But when you are at your lowest people will say their pain is really bad. But I know it's not, because everything is going to annoy you on a bad day." (RB119)*

Other emotions that were reported as drivers or consequences of activity included positive moods, guilt, annoyance and resentment.

7.2.3.4 Coping strategies

7.2.3.4.1 Pacing strategies

Since there are mixed opinions regarding the benefits of activity pacing, participants were asked their opinion of pacing:

> *"Pacing is helping me more because if I didn't do it I wouldn't get so much done." (RB108)*

> *"Like I say if you don't spread it, if you don't pace, I found that I used to run myself into the ground on good days but I had far less good days." (RN318)*

RN318 continues:

> *"I have been an awful lot better since the physio. I still have the symptoms, and they have probably progressed rather than getting better, but I'm a lot better at managing them. It's made a huge difference to me…It's kind of opened my eyes a lot more to the quality of life and what's important and what's not." (RN318)*

When asked whether having a consistent routine had led to improvements in the condition, one participant answered:

> *"No, only in my mind, not in pain or anything. My condition, I think it is deteriorating slowly with the arthritis." (RB188)*

In terms of which coping strategies have led to improvements in the condition, the following answers were given:

"I guess pacing is a big part of it because I need to know...if my back is hurting I need to know that I need to do something like stretch it out a bit, but I also know that I can't do too much in case I aggravate it more." (PW048)

"The physical side to be honest. I didn't really know that certain stretches and certain exercises enable me to have a pain free day. And I do now. I don't know whether you'd call that pacing or whether you'd just call that common sense. That's what worked for me." (RB195)

However, within the interviews, there was a participant who did not utilise pacing as a coping strategy. A further participant reported that pacing may not be effective due to the extent of the condition:

"…because of my condition it doesn't matter sometimes how much I think about pacing, it doesn't work. Sometimes pacing doesn't work at all because the ME is so bad. The ME dictates really what I do, and not the pacing." (PB133)

Of note, there were no reports that activity pacing had led to participants' perception of worsening management of the condition.

7.2.3.4.2 Other coping strategies

Other coping strategies that were discussed included the implementation of exercises/stretches, alternating positions, posture awareness, attendance of the physiotherapy rehabilitation programmes, together with socialising and using the support from others. Other strategies included being mindful of mood and emotions, acceptance of 'bad' days and positive thinking, together with distraction.

With particular reference to managing a flare up of symptoms, coping strategies that were implemented included rests and lying down, avoidance of activity, taking painkillers, seeking physiotherapy, and learning from the flare up.

7.2.3.5 Activity behaviour typologies

Interestingly, as participants were interviewed it appeared that there were different approaches to activity. Activity behaviour typologies emerged during the analysis of the qualitative data, to include quota- and symptom-contingent behaviours. Furthermore, participants showed patterns of Task avoidance, Task persistence, Task fluctuation (boom-bust) and Task modification (activity pacing).

7.2.3.5.1 Quota-contingent and symptom-contingent activities

Quota-contingent activities

Several participants described quota-contingent activities, for example, activities driven by a time or distance:

> *"Basically activity pacing, my philosophy on that is it's where you assess what I can do and what I can't do…How long it would take me basically to get from my front door to the bottom of the street, that type of thing." (PN309)*

> *"I do it for an amount of time, and try to ride the pain." (RB188)*

Participants who tended to undertake activities with a quota-contingent approach generally gave examples of physical activities.

Interestingly, one participant reported she did not usually time activities unless she was experiencing increased symptoms:

> *"Usually, if I'm honest, I probably tend to keep going until my symptoms tell me to stop. But, if I know in advance that my symptoms have been bad recently I do set myself a time limit to try to avoid making them worse." (RN318)*

Symptom-contingent activities

Other participants followed a symptom-contingent approach, whereby their activities were generally led by their symptoms:

> *"Your body will tell you, or my body tells me when I've had enough. That's about it really. Your own body will tell you. I don't get up in the morning and say 'right I'll do this, this and this'. I just get up and see how I feel and if I can do it, I do it and if I can't, I don't." (RB119)*

> *"No, I just wait, my body tells me when I'm ready to move again. I certainly don't go by the clock, no. I'm much more free with my timings these days." (PF011)*

Of relevance to symptom-contingency, one participant made the following comment:

> *"Yes, you're always in pain. If you focused totally on your pain all the time you'd never do anything." (PN240)*

7.2.3.5.2 Task avoidance, Task persistence, Task fluctuation and Task modification

Participants' activity behaviours were grouped into four typologies: Task avoidance, Task persistence, Task fluctuation (boom-bust), and Task modification (activity pacing). However, although these four typologies were discrete (Ritchie et al., 2003b), participants sometimes described behaviours that overlapped with other typologies. Furthermore, there appeared to be an overlap between quota- and symptom-contingency and the four behaviour typologies.

Task avoidance

Within the theme of Activity limitation, a trend towards avoidance behaviour emerged:

> *"Certain things at work I can't do. I can't lift up heavy stuff, like a heavy tub, so one of the girls will do it for me. I have to be a bit careful." (RB198)*

> *"…sometimes I want to do things and I know that I'm not going to be able to do things, so I don't do them." (PB133)*

A trend may be evident between those who avoid tasks and those who have a symptom-contingent approach to activities:

> *"I tend to go off how I actually feel. If I feel I am capable of doing something I will do it. If I'm not capable, I won't. I won't do something because someone has said I have to do it, because I know how I feel and how it would affect me." (PB133)*

Sometimes the limits or adaptation of activities were advised by others, to include health professionals, gym instructors and family.

Task persistence

Two participants described a pattern of activity of Task persistence to complete a task, despite symptoms:

> *"I just think I've got to get on with it and that's it. I'll just do it whether or not...if it hurts, well I will stop eventually, but I'll carry on until I've finished the task that I'm doing." (PB139)*

> *"No, I usually start doing it until I start feeling really bad." (PC082)*

Frequently, a flare up of symptoms was reported following excessive Task persistence. This may relate to the boom-bust pattern of activities.

Task fluctuation (boom-bust)

Several participants described activity behaviours in keeping with the boom-bust pattern of activity whereby activity levels markedly increased on a 'good' day leading to overexertion, the consequence of which was an exacerbation of symptoms on the following 'bad' day:

> *"Recently, I've done some decorating and I just wanted to get it done, and then I paid for it three or four days after…It's a complete all or nothing." (PC100)*

> *"If you get up and you feel a lot better than you normally do, you push yourself and then you suffer for it." (PN240)*

For participant PN240 the avoidance pattern emerged in reference to a 'bad' day:

> *"Well, there's certain things that you have to do, but other than what you really have to do, I wouldn't do anything." (PN240)*

Sometimes, participants reported being aware of the consequences, but continued this pattern of activity due to making up for lost time on a 'good' day, or alternatively enjoying the sense of achievement on the 'good' day:

> *"If I have a good day where I feel good in the morning…I wanted to tackle tidying out the shed in the garden and I did it, and it was great and I felt good after it, and I was tired, but for two days after I could do nothing, it just floored me. So things like that, I know my capabilities. I know if I do it, I'll be off for two days but I'll do it." (RB119)*

Although the above participant (RB119) appeared to fit the boom-bust pattern, they also described some avoidance of activities:

> *"I hardly ever sit down, but then I don't like sitting down…At work, I'm on my feet for three hours and it's constant, moving around trolleys, emptying bins, lifting. I work in a kitchen, so it's lifting tins of pasta up and things that I put it in the trolley and get someone else to help put it in. Because, if I don't, I go to put it in and I just drop it because I start shaking with my back and then I just go, so I don't even try it now." (RB119)*

Task modification (activity pacing)

Seven participants described undertaking generally more consistent patterns of activity (within the scope of work and other events) by implementing modified tasks by activity pacing to reduce a foreseen boom-bust pattern:

"Then I went on the self-care programme and pacing was also mentioned again. It's not something I've done all my life, but now that I know about it, yes, I put it into place on good days and on bad days. Obviously on a bad day, my pacing is: 'you're not going to do much today, so sit down' and you have to think about all elements, you have to think about, well prioritise really. And think, if I do such and such a thing, I'm going to be worse off than I am at the moment so don't be silly." (PF011)

Within the above statement from PF011 there are elements of symptom awareness, and possibly avoidance. Symptom awareness was further reported in the following comment by RB195 when asked which activities would require to be paced:

"All my life to be honest now I've completed the course. I know what works for me and what doesn't work for me and everything I do, I pace my life around trying to protect my back and trying to exercise where possible." (RB195)

RB195 continued:

"I now have that level of education, physical education that I know what works and what doesn't work for my body. Whether that's an hour or whether that's a week, it doesn't make any difference, I know that certain things I do will be doing harm to my body and certain things I do will be doing good for my body." (RB195)

Similarly, PG017 who tended towards Task modification, reported symptom awareness:

"At the time I suppose it was how much pain I was in with my back. So if it was particularly painful then I might do a bit less, but if I felt OK I might do a bit more." (PG017)

Throughout the interview with RN318, a general trend towards Task modification and consistency was reported. However, elements of Task persistence, together with boom-bust behaviours were also disclosed:

"I was really poorly Wednesday-Thursday, and Friday I should have rested and I knew that I should have rested. But, I pushed myself in the afternoon to decorate my vestibule…and I was exhausted. I sat down, and then I thought 'no I've just got to carry on and get it done' and I totally messed it up…I kicked myself because I knew that I shouldn't have done it because I didn't feel up to it, and I pressured myself, nobody else pressured me." (RN318)

It may be the case that having a consistent level of activity is easier to implement if the symptoms are less severe:

> *"My pain wasn't as such that I couldn't do anything so I'd always go into work, and do things around the house like cooking. I wouldn't do anything particularly really heavy or go to the gym and do exercises if it was really bad." (PG017)*

The following participant (RB043) generally reported pacing their activities:

> *"Yes, to some extent yes. I don't do anything that's going to put me over the edge as it were." (RB043)*

However, participant RB043 may have a natural fluctuation in activity that involved a tendency to do more on 'good' days:

> *"Probably, I would pace on a bad day. On a good day, I tend to do more things than I probably would do normally." (RB043)*

Furthermore, Task modification appeared to precede Activity progression in finding a baseline.

It is noteworthy that six out of the seven participants who were identified as Task modifiers attended a rehabilitation group. The rehabilitation groups involve education about coping strategies such as pacing, graded activity and goal setting.

Among the typologies, there were relationships between Task fluctuation, and Task avoidance and Task persistence at the two ends of the fluctuation pattern. However, even participants who were categorised as Task modifiers reported occasions of Task persistence, Task avoidance and Task fluctuation.

There appeared to be inter-relationships between not only the pacing themes, but also between the behaviour typologies and the subthemes (for example, co-morbidities). The proposed relationships are shown in Appendix 26, Table 7.4 Relationships between pacing themes, subthemes and behaviour typologies.

7.2.4 Reflexivity

7.2.4.1 Interactions between the researcher and participants

The researcher was a female physiotherapist aged in her thirties. Although the telephone interviews introduced distance between the researcher and participants, judgements would have been made according to accent and phrasing of questions with regards to the researcher's social class and education. The difference in status between the interviewer and the interviewee may have affected participants' responses. On this matter, one participant gave the following response:

> *"I don't know really. You're the expert aren't you really?" (RB198)*

Similarly some participants may have wanted to give socially desirable answers or answers that were agreeable to the researcher. For example, one participant commented that the pacing scales may be improved with more space for additional comments, to provide more information for the benefit of the researcher/clinician. To balance this, one participant did not aim to give 'correct' answers and instead made the following comment about the questionnaire booklet:

> *"No, I filled it in OK. I filled it in truthfully, but maybe that wasn't very good for you." (PB139)*

Indeed, across the sample, participants gave a variety of answers, including both those who reported implementing pacing strategies, and those who did not.

7.2.4.2 Participants' research experience

All participants consented to the interviews being recorded, and there were no requests to stop recording. With regards to the experience of participating in the research, a few participants queried whether the questionnaire length or repetition in items was designed as a "trick" to catch them out. A further comment was made stating that the research process was challenging in light of their condition:

> *"…when you put all that information in front of people, some people aren't bothered, but because of my condition and the fact that I know that I'm not taking things in as I used to do, or could do or should do, it's a bit daunting. You try and do it and you think 'have I answered that or haven't I' and it gets a bit frustrating." (PC100)*

In contrast, participants found the research process interesting and useful to both discuss their opinions and as a prompt to resume some coping strategies that had perhaps waned since attending physiotherapy:

> *"It's nice to talk, to tell somebody about it. I talk to wife…but you can't talk to her like you can talk to somebody who's doing the job. You can't talk to your GP the same as like I can talk over the phone to you…because you can explain how you feel and they listen…There's not a time scale where you've only got five minutes and you're in and out." (RB188)*

7.2.5 Summary

Sixteen participants from the psychometric study were involved in telephone interviews to explore the acceptability of the APQ in comparison to the existing pacing subscales of the CPCI and PARQ, and to discuss the themes of pacing. Participants described pacing as a multifaceted construct, which echoed the findings of Stage I, the Delphi study and Stage II, the psychometric study.

The APQ demonstrated acceptability among the interviewees in terms of comprehensive instructions and the 5-point Likert scale. The seven day recall period was acceptable for the majority of participants. However, other participants suggested both shorter (2-4 days) and longer (10-14 days) recall periods. The problems most commonly reported regarding the APQ included the number of questions, the apparent repetition of questions and some confusing questions. It is noteworthy that participants discussed the full APQ containing all 38 items, as opposed to the 30-item APQ that resulted from factor analysis in the psychometric study.

In addition, other themes emerged during the interviews to include the effect of co-morbidities on pacing and the use of coping strategies. Participants described both symptom- and quota-contingent activities. Furthermore, four distinct activity behaviour typologies emerged: Task avoidance, Task persistence, Task fluctuation and Task modification which will be discussed further in Section 7.3, Stage III Discussion.

Chapter 7. Stage III: Exploring the Acceptability of the Activity Pacing Questionnaire (APQ)

7.3 Discussion

7.3.1 Introduction

This section discusses the sample involved in the acceptability study, together with the five themes that emerged during framework analysis of the qualitative data: the themes of pacing, the pacing scales, co-morbidities, coping strategies and activity behaviour typologies. Issues surrounding rigour and reflexivity are reported. In addition, the strengths and limitations of this stage of the study are discussed.

7.3.2 Participants

It was intended that the sample involved in the qualitative interviews would be reflective of the participants involved in Stage II, the psychometric study. However, due to the nature of non-random sampling, it was not intended that the qualitative study would be statistically representative of the full sample involved in the psychometric study, or indeed the population of patients with chronic conditions (Curtis et al., 2000; Pope et al., 2000). The acceptability sample contained more females than males, in a similar ratio to the psychometric study. The mean age of participants was similar, but a little higher than the psychometric study. The sample involved in the interviews predominantly reported low back pain, but all conditions reported in the psychometric study were represented in the acceptability study. The sample involved in the interviews appeared to reflect those involved in the psychometric study.

The sample size of the acceptability study (n=16) was smaller than initially planned (n=20-30). However, the 16 interviews generated a vast amount of qualitative data to be analysed. Indeed, it has been suggested that sample sizes between 10-50 participants are acceptable for qualitative studies (Ayres, 2007). Furthermore, towards the latter interviews it appeared that no new concepts were emerging, and the author considered that data saturation had been reached. The author made this decision through the continuous immersion in the data, since the author undertook all of the interviews and transcriptions.

7.3.3 Framework themes

7.3.3.1 Themes of pacing

In order to explore the acceptability of the APQ, the content of the APQ items was discussed with reference to the concept of pacing. Open-ended questions were used to explore participants' understanding of the term 'activity pacing', and more specific probing questions discussed the five themes of pacing that emerged through factor analysis of the APQ: Activity limitation, Activity planning, Activity progression, Activity consistency and Activity acceptance. Therefore, the themes of pacing were analysed using framework analysis through predominantly deductive methods. In concordance with the APQ, participants described pacing in terms of breaking down tasks, accepting activity levels, prioritising, switching activities and other strategies included in the APQ.

Participants were invited to report the facets of pacing contained within the APQ that did not coincide with their own interpretation of pacing. This varied across the sample, and it was deemed that all facets of the APQ were still valid and applicable to most, but not all participants. Furthermore, the applicability of themes appeared to vary according to changes in the condition, age or other co-morbidities.

Interestingly, little additional information was added to the description of pacing that had not previously arisen from Stage I, the Delphi technique, where recruitment of patients had been low. The author considers that the questions of the APQ may contain a comprehensive description of the different themes of pacing.

7.3.3.1.1 Activity limitation

The theme of Activity limitation arose in the interviews as a key component of activity pacing. Many participants recognised that in order to manage their condition, they needed to break down tasks and implement strategies such as changing activities and using rest breaks. Such strategies coincide with descriptions of pacing in the literature (Birkholtz et al., 2004a; Nielson et al., 2012). The limitations that were applied were described as both quota- and symptom-contingent. However, Activity limitation was not always feasible, for example, in the working environment. Activity limitation appeared to be affected by the influence of others. For example, some participants limited their activities following the guidance of either family or health professionals.

A possible relationship appeared between the reports of Activity limitation and Activity planning. Indeed, an overlap was seen between the two similar strategies in terms of breaking down tasks and undertaking timed activities. In addition, Activity limitation and Activity acceptance appeared to inter-relate. Participants who described accepting their condition, further reported accepting their capabilities, or their limits. The strategy of Activity limitation also appeared to be linked with avoidance. Similarly, a significant association was found between Activity limitation and avoidance in Stage II, the psychometric study. Furthermore, previous associations have been found between increased pacing (measured using existing pacing subscales) and increased avoidance (McCracken and Samuel, 2007; Kindermans et al., 2011).

During the interviews, Activity limitation appeared to be related to co-morbidities and the management of an exacerbation of symptoms. This reiterates the findings of Stage II, the psychometric study, where associations between Activity limitation and increased pain were found. This may link with previous findings of increased pacing (defined as going slower and breaking down tasks) as the day progresses when increased symptoms of pain and fatigue are reported (Murphy et al., 2008).

7.3.3.1.2 Activity planning

During the interviews, participants described planning their activities and gave examples of switching between different activities, setting goals and assessing activities. This coincides with descriptions of pacing in the literature (Strong, 2002b; Birkholtz et al., 2004b; Nijs et al., 2008), together with the APQ items that loaded onto the theme of Activity planning. Activity planning items additionally refer to setting time limits for activities. Many participants reported that although they did not routinely implement time limits, this might be considered during an exacerbation of symptoms. As participants discussed planning activities, they tended to focus on planning more strenuous activities. Therefore this strategy may not be relevant to all activities. Indeed, some barriers to planning were reported such as work demands, or the condition itself. Of note, participants can answer irrelevant APQ items as ‘0=never did this’ to reflect personally redundant strategies.

7.3.3.1.3 Activity progression

The theme of Activity progression appeared to divide participants' opinions more than the other four APQ pacing themes. This replicated the division of pacing descriptions observed in the literature between those that include activity progression (Strong, 2002b), and those that do not (Nielson et al., 2001), together with diverse descriptions of pacing as adaptive pacing therapy/envelope theory and rehabilitative pacing *(see Literature review, Section 2.3.4)*. During the interviews, Activity progression was reported to be relevant for some participants, but impossible for others, for example, due to worsening heath status.

Unexpectedly, Activity progression was significantly associated with increased pain in the psychometric study. This finding of the psychometric study was not wholly replicated during the interviews. However, during the interviews some participants described Activity progression following an exacerbation of symptoms as part of their recovery. This may in part explain the association between increased pain (that is, during a flare up) and increased Activity progression in the psychometric study.

Participants who found Activity progression to be relevant tended to be younger or those who attended a rehabilitation group. Of note, Activity progression was not statistically associated with age in the psychometric study. The author suggests that although Activity progression may not be useful for all participants at a given time, it is beneficial as an assessment of current activity and change in activity over time.

7.3.3.1.4 Activity consistency

The majority of participants recognised the theme of Activity consistency in trying to reduce an exacerbation of symptoms by not over-doing activities. Similarly, participants reported trying to maintain a level of activity, albeit modified on 'bad' days. Indeed, pacing is considered to involve reducing the overactivity-underactivity cycle (Birkholtz et al., 2004a). Participants who reported a positive experience of a rehabilitation group appeared to implement this strategy more conscientiously. Interestingly, Activity consistency was significantly associated with increased function and lower anxiety, depression and avoidance in the psychometric study. Therefore, Activity consistency may be a beneficial concept to instruct to patients.

Other participants reported a fluctuating pattern of high levels of activity on 'good' days and low levels of activity on 'bad' days. This pattern of activity appeared to suit some participants who did not intend to implement the restrictions of Activity consistency. Therefore, personal choice and lifestyle impacted on this theme (Strong, 2002b).

7.3.3.1.5 Activity acceptance

Activity acceptance appeared to be related to Activity limitation, Activity planning and Activity consistency, together with using support from others, knowledge of the condition and emotions. Activity acceptance appeared to be the most emotive theme of pacing. Hence, the discussion of Activity acceptance led to participants' reporting emotions of guilt, frustration and annoyance. The author suggests that Activity acceptance may involve a change in thought processes whilst adapting activities.

Interestingly, significant associations were found in the psychometric study between increased Activity acceptance and increased pain and avoidance, and decreased physical function. The qualitative findings appear to repeat these relationships where some patients reported avoidance or reduction of activity alongside acceptance. This finding is in contrast to a previous study in which patients with high levels of acceptance reported lower disability and greater activity levels than those with low levels of acceptance (Vowles et al., 2008). However, Vowles et al. (2008) measured acceptance using the Chronic Pain Acceptance Questionnaire which assesses the acceptance of pain. In contrast, the APQ factor Activity acceptance refers to the acceptance of activities. Furthermore, it is noted that whilst the study by Vowles et al. (2008) found statistical relationships among 592-635 patients with chronic pain, only 16 patients were involved in the qualitative interviews, which limits the comparison of the findings.

7.3.3.2 Pacing scales

7.3.3.2.1 Activity pacing questionnaire

In terms of the ease of completion of the pacing scales, the most frequently occurring comments regarding the APQ involved the large number of questions and appearance of repetitive questions. It was intended that during the ongoing development of the APQ there would be a reduction in items with the aim of lessening the burden of the questionnaire. This did indeed occur in the psychometric study. However, participants involved in the interviews were sent a reminder of the full 38-item APQ to replicate the

version that they previously completed. Importantly, the questions that were most frequently highlighted in the interviews as being confusing or repetitive were often those that had been removed following factor analysis. Interestingly, two participants independently suggested changing the format to have blocks of five questions to enhance the ease of completion. The author considers this to be a positive improvement to the APQ format which will be implemented.

Most participants found the APQ instructions comprehensible, and many participants found the examples of activities to which the scale related to be useful. Participants with low back pain or widespread pain with no fatigue considered activities less in terms of mental or social activities. Participants who reported fibromyalgia or widespread pain with fatigue, or chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME) were more likely to report effects on their cognitive activities. Hence, the APQ instructions will remain to prompt patients to consider different types of activities.

The seven day recall period of the APQ divided participants between those who thought it was an appropriate length of time (n=10), those who preferred a shorter recall (n=3) and those who preferred a longer duration (n=3). The reasons for requiring a shorter recall period (for example, 2-4 days) included problems remembering what had happened over a week. This appeared most problematic for participants who suffered with mental fatigue. In contrast, other participants required a longer recall period (for example, 10-14 days) since they may not experience symptoms in a week. However, most participants found the seven day recall period appropriate. This seven day period included both work and leisure activities, and allowed for 'good' and 'bad' days. It is intended that the APQ is applicable for a heterogeneous group of patients with both chronic pain and chronic fatigue. Since there is no recall period that suits all participants, a seven day recall may be the most suitable, similar to other recognised scales (for example, the Hospital Anxiety and Depression Scale). Furthermore, it is envisaged that the APQ will be used at different time points, perhaps when patients experience 'good' and 'bad' weeks. Therefore, APQ scores will be more reflective of changes in habits across longer timeframes.

The majority of participants (n=13) felt that the APQ 5-point Likert scale gave the optimum number of intervals. Indeed, the 5-point scale is the most frequently

implemented Likert scale (Oppenheim, 2000). Three participants reported a preference towards a shorter scale, and a suggestion of a 3-point scale was made. Interestingly both 5-point and 3-point scales provide middle options. The advantage of this is that individuals can choose a 'neutral' middle option where there is no strong preference (Streiner and Norman, 1995). No comments were made to suggest more than five intervals. On reviewing how participants had completed the APQ in the psychometric questionnaire booklet, it was seen that all five intervals on the Likert scale were used. Generally, participants' comments in the interviews matched their responses on the scale in the psychometric study. For example, when participants commented that an item was less relevant to them, they indicated this as a low score on the APQ.

The majority of participants felt that the word descriptors over the five intervals were appropriate with the exception of two participants who struggled to differentiate between 'rarely' and 'occasionally', and 'occasionally' and 'frequently'. Word descriptors may not always convey the same meaning to all individuals. Moreover, the interpretation of word descriptors may vary according to the context (Streiner and Norman, 1995). However, despite this variation between individuals, the author considers that the APQ was used consistently for each individual as their interpretation of the word descriptors within the context of pacing is envisaged to remain quite constant. This may be observed with the acceptable test-retest reliability of the APQ demonstrated in the psychometric study.

Since most participants were happy with the APQ instructions, the number of intervals on the Likert scale, together with the word descriptors, the author believes that the APQ has a good level of acceptability.

7.3.3.2.2 Chronic Pain Coping Inventory pacing subscale

The majority of participants found the Chronic Pain Coping Inventory (CPCI) rating scale more difficult to complete than the APQ. The CPCI pacing subscale requires an answer as a number of days (0-7 days). Participants' responses in the interviews complemented the findings of the psychometric study, in which the CPCI pacing subscale yielded the most missing answers of the three pacing scales and patients frequently gave 'word' rather than numerical answers. This perhaps alludes to lower acceptability of the CPCI rating scale.

Similarly to the APQ, the CPCI pacing subscale encountered problems regarding the seven day recall. An advantage of the CPCI pacing subscale appeared to be the shorter, less daunting length, as it contains only six items. However, participants highlighted the repetition of the phrase 'slow and steady' in three of the six CPCI pacing subscale items. For some participants, the concept of going 'slow and steady' was not relevant. The lower relevance of slowing down as a facet of pacing is in agreement with the findings of the national pacing survey among 49 occupational therapists (Birkholtz et al., 2004b). Specifically, participants in the present study reported that items referring to going 'slow and steady' to distract from pain were impossible due to constant pain. In this way, the pain focused items appeared less acceptable for some participants.

7.3.3.2.3 Pain and Activity Relations Questionnaire pacing subscale

There was a general opinion that the 6-point Likert scale of the Pain and Activity Relations Questionnaire (PARQ) was less acceptable than the APQ 5-point Likert scale. This was due to the length, the absence of a middle option and the missing word descriptors over the Likert scale.

There were mixed opinions regarding the relevance of the items of the PARQ pacing subscale. The relevance of the items was reduced for some participants due to the pain focus. Participants commented that either they could not control their pain, or it was not pain alone that affected their activities, rather a combination of different symptoms.

7.3.3.2.4 Comparisons between the pacing scales

Generally, the APQ appeared to be well understood and acceptable for the majority of participants. The APQ was reported to have clear instructions and an easier scale than the CPCI and PARQ pacing subscales. However, the brevity of the CPCI and PARQ pacing subscales was favoured. The main disadvantages of the initial version of the APQ included the number of questions, repetitive questions and confusing questions. Notably, the specific questions that were highlighted in the interviews as being repetitive or confusing were frequently those that were removed in the psychometric study. Therefore, the number of questions in the APQ has already been reduced.

Interestingly, some participants highlighted difficulties of the questions referring to pain in the CPCI and PARQ pacing subscales. As the questions for the APQ were developed,

such difficulties were foreseen among a heterogeneous group of chronic conditions. As such, the APQ items were written specifically using the term ‘symptoms’ and not ‘pain’. Furthermore, the pain-contingent nature of some of the CPCI and PARQ pacing subscale questions caused difficulties since pain was not always controllable. Conversely, the APQ items do not relate to pain- or indeed symptom-contingent activities, rather, quota-contingency is applied.

7.3.3.3 Co-morbidities

The theme of co-morbidities emerged during the analysis of the qualitative data. There appeared to be a link between co-morbidities and increasing age with decreasing levels of activities. In addition, emotions such as depression were reported to lead to difficulties initiating activities. It is widely recognised that symptoms of chronic conditions include emotional effects due to the consequence of living with long-term symptoms and reduced ability to undertake activities (Clauw and Crofford, 2003; Aggarwal et al., 2006; Schur et al., 2007).

Participants raised an issue regarding the effect of their symptoms or memory on how they answered the pacing scales. There is likely to be some natural variation in how patients answer any questionnaire at different time points. Since the APQ demonstrated acceptable test-retest stability in the psychometric study, it is hoped that natural variation will be negligible, while important differences in pacing will be detected.

7.3.3.4 Coping strategies

Not all participants involved in the interviews reported that they attempted to pace their activities. Of those who did try to pace, the majority felt that pacing held benefits in terms of better management of their condition. This is in agreement with previous findings that patients report pacing to be helpful, often in the absence of empirical data (NICE, 2007). However, some participants felt that pacing, or other coping strategies, were not always effective due to the extent of their symptoms.

Pacing was not the only coping strategy that was implemented by participants, especially during an exacerbation of symptoms. Other strategies included using medication, social support and exercise. These are strategies that are advised in both the literature and in the rehabilitation setting (NICE, 2007; NICE, 2009).

7.3.3.5 Behaviour typologies

As the qualitative data analysis progressed, behaviour typologies emerged inductively. Participants described engaging in activity according to quota- or symptom-contingent strategies. Some participants had a definite preference to either quota- or symptom-contingency. However, other participants undertook their activities by either contingency according to the task itself, or their symptoms.

Four typologies of activity behaviours emerged: Task avoidance, Task persistence, Task fluctuation (boom-bust) and Task modification (activity pacing). It is noteworthy that four similar behaviours were recognised in cluster analysis of the PARQ, that is, 'avoiders', 'doers', 'extreme cyclers' and 'medium cyclers' (McCracken and Samuel, 2007). 'Avoiders' demonstrated low levels of activity and high levels of avoidance and pacing (McCracken and Samuel, 2007). This may share some similarities with the typology of Task avoidance in the present study. 'Doers' had high levels of activity and low levels of pacing, akin to the present typology of Task persistence. 'Extreme cyclers' had high levels of activity, together with high levels of avoidance and pacing. This typology is most similar to Task fluctuation (boom-bust), with the exception of the high levels of pacing. 'Medium cyclers' had high levels of activity, together with a moderate utility of pacing and avoidance, which may share some similarities with the typology of Task modification.

The differences between the typologies that emerged from the present study and that undertaken by McCracken and Samuel (2007) are thought to lie in the different content of the APQ and the PARQ pacing subscale. The author considers that the PARQ pacing subscale reflects the concept of reducing activities rather than the multifaceted nature pacing suggested in the APQ. This may explain in part why 'extreme cyclers' implemented high levels of pacing when measured using the PARQ, as pacing (described as reducing activities in the PARQ pacing subscale) was implemented after a 'boom' of activity. In contrast, participants with Task fluctuation behaviours in the present study did not frequently implement activity pacing, which sustained the pattern of overactivity-underactivity. Furthermore, the 'medium cyclers' implemented pacing moderately (McCracken and Samuel, 2007). In comparison, the task modifiers in the present study were those who consciously implemented pacing to reduce the extremes of either over-activity or under-activity.

7.3.4 Rigour

7.3.4.1 Truth value (representativeness)

In terms of validating the findings of the interviews, participants were asked to read and sign their own transcripts and invited to make amendments. Few amendments were made to the transcripts, including typing errors, misheard words, and a participant clarified one of her responses. Participants were not asked to validate the interpretation of all of the data since participant validation may lead to difficulties with regards to reaching a consensus on all personal interpretations of the data (Barbour, 2001).

The analysis of the qualitative data involved an iterative process to ensure that all data had been indexed. As such, as a new theme arose, all previously analysed transcripts were re-read to check for the presence of this theme. Therefore, every attempt was made to fully index all themes in every interview. All indexed data were included in the development of themes to respect all participants' opinions equally and to facilitate the presence of 'multiple realities', in keeping with the ontological stance of qualitative research (Popay et al., 1998).

To further increase the 'truth value', the findings of the interviews were compared to the findings of the psychometric study. Indeed, the findings of the interviews appeared to concur with the results of the psychometric study. This was seen in terms of the content of the description of pacing, together with the trends between the themes of pacing and the symptoms of chronic conditions. Moreover, the descriptions of pacing and the behaviour typologies corresponded with the findings in previous literature.

7.3.4.2 Applicability

The sample size was smaller than initially envisaged for the acceptability study. Although the interview sample were not intended to be statistically representative of those involved in the psychometric study, they were purposefully recruited to reflect the different ages, conditions and stages of treatment of those involved in Stage II. On examination of the sample demographics, it appeared that this was achieved. Furthermore, recruitment ceased when the author considered that data saturation had been reached. The decision that saturation had been achieved was made through the iterative approach to data analysis, and the immersion of the researcher in the data

(Tuckett, 2004). Indeed, the author undertook all of the interviews and transcriptions, and was therefore immersed in the data throughout the study. However, in terms of bias, it might be suggested that the conclusion of data saturation was heavily influenced by the author's opinion. Furthermore, it may be queried whether saturation is ever truly achieved in qualitative research, since data are generated from individuals' opinions based on time-specific experiences (Wray et al., 2007).

With regards to deviant or negative cases, no participants gave anomalous answers, or fell outside the four behaviour typologies. It was the aim of the study that all participants would be represented fairly in the analysis of the qualitative data. Therefore, participants' language was maintained, and both positive and negative comments regarding activity pacing and the pacing scales were included. Hence, the findings may be generalisable to patients with chronic conditions who have different activity behaviours and who implement different coping strategies. However, in keeping with other qualitative research methods, the findings are not intended to be as widely generalisable as quantitative research (Sandelowski, 1986).

The generalisability of the sample is limited by the exclusion of non-English speaking patients. The method of sampling did not recruit from the 'hard-to-reach' population which may introduce bias (Boynton et al., 2004). Moreover, there is a possibility that participants who consented to the interviews were those of higher education, were more vocal, or had positive experiences of physiotherapy (Sandelowski, 1986; Johnson et al., 2009). However, some of the interviews were noticeably more challenging to undertake than others. A couple of participants had difficulties in answering the questions due to misunderstanding, or losing focus on the questions. Furthermore, one participant reported a negative experience of physiotherapy and denied implementing many of the strategies included in the APQ. It is therefore considered that a range of different participants with varying intellects and physiotherapy experiences were recruited.

7.3.4.3 Consistency

The repeatability of the study was increased by implementing NVivo9 to manage the data. NVivo9 logged the dates of the generation of new themes so that a clear audit trail of emerging themes could be followed. Furthermore, the original transcripts, together with the indexed data were recorded and auditable on NVivo9. The fieldnotes enhanced

the audit trail as any issues or ideas that arose were documented concurrently with the interviews. Moreover, the replication of the study was increased by using the systematic method of framework analysis. Framework analysis is thought to increase the transparency and retrieval of data (Ward et al., 2013).

In order to further increase the consistency of a qualitative study, the analysis or section of the analysis may be repeated by a second researcher (Pope et al., 2000). This process has been advocated to confirm the indexing and framework matrix (Ward et al., 2013). A second researcher may be of marked benefit in cases of increased risk of bias (Pope et al., 2000). Conversely, problems of incorporating more than one researcher can arise due to differing opinions and interpretations, owing to the nature of qualitative research (Pope et al., 2000). For the purpose of the present study, the author was responsible for data analysis due to her immersion in the data from the beginning of data collection. It was not feasible for a second researcher to become equally immersed in the vast amount of qualitative data that were collected within the time limitations of the study. However, the study methods were guided by an expert in this field.

7.3.4.4 Neutrality (recognition of bias)

It has been suggested that purposeful samples reduce sampling bias since it is the aim of a purposeful sample to include a variety of opinions (Ayres, 2007). However, due to the epistemological approach of qualitative research, bias may have arisen from the interaction between the researcher and participants. The influence of the researcher and the relationship between the researcher and participants is discussed in Section 7.3.5.

7.3.5 Reflexivity

7.3.5.1 Interviewer-interviewee relationship

Reflexivity has been defined as the "sensitivity to the ways in which the researcher's presence in the research setting has contributed to the data collected and their own *a priori* assumptions have shaped the data analysis" (Murphy et al., 1998a, p188). Therefore, reflexivity involves a self-conscious evaluation of the influence of the researcher on the research to include the researcher's age, gender and background (Murphy et al., 1998a; Mays and Pope, 2000).

Participants were informed that the interviewer was a physiotherapist and researcher. Therefore, there was an inherent difference in power status (Kuper et al., 2008). This difference in status was raised by a couple of participants who believed the interviewer was the expert. In contrast, other participants recognised that their opinions were the subject of interest and gave confident and decisive answers. Indeed, the interviewees were advised that they were considered to be the experts due to their unique experiences (Popay et al., 1998). Furthermore, the gender and ethnicity of researchers may impact on interviewees' responses, in terms of both their answers and participation (Streiner and Norman, 1995). However, the advantage of telephone interviews is that bias does not arise from personal appearances (Streiner and Norman, 1995).

Just as participants may have made judgements about the researcher, so may the researcher have had pre-conceived ideas about the interviewees. The researcher was aware of the demographics of participants, to include their condition, age, ethnicity and working status. This was required to facilitate appropriate questioning during the telephone interviews, for example, understanding the possible symptoms of participants' conditions. Of note, during data analysis, the transcripts were identified only by participants' anonymous codes. However, as behavioural trends emerged, the demographic data were observed to interpret possible patterns between participants of different ages, or attendance of rehabilitation groups.

The researcher has instructed the rehabilitation groups in the physiotherapy departments from which participants were recruited, and one participant had attended a group under the researcher's instruction. This participant's experience of the rehabilitation group and previous rapport with the researcher may have influenced the answers that were given, or indeed their participation. It is queried whether some participants may have repeated the instructions that they received in the rehabilitation groups in answer to the interview questions (Larun and Malterud, 2011). Moreover, participants' answers may have been biased by social desirability whereby participants give answers that they deem to be 'correct' (Streiner and Norman, 1995).

Most participants reported positive experiences of physiotherapy, while two patients reported more negative experiences. Therefore, it is hoped that participants felt they could answer the questions honestly. Participants remained in their own homes during

the interviews. This may have promoted answers that were more reflective of everyday life than had the interviews occurred under clinical conditions. This may increase the external validity of the findings (Sandelowski, 1986).

The researcher's own experience in teaching pacing and her own pre-conceived ideas about pacing will have influenced her question style. Indeed, interviewers' question phrasing may unintentionally allude to their preferred answer (Streiner and Norman, 1995). Furthermore, the questions in the present study were driven by the themes of pacing that resulted from the psychometric study. However, the role of the researcher as a physiotherapist with a specialism in this field may be seen to be advantageous for a thorough exploration into the topic. Moreover, the researcher followed a script for each participant and all interviews were recorded which increases transparency.

7.3.5.2 Author's development

Before commencing the acceptability study the author attended training on both undertaking and analysing qualitative interviews, and on the NVivo9 program. From commencing the first pilot interview through to the last interview, the author's interview skills were developing. As the author gained confidence, further clarification of answers was sought from participants.

Through the simultaneous processes of conducting and transcribing interviews, the author was able to reflect on the interviews and implement improvements to the subsequent interviews. For example, the author became aware that some questions that were intended to be open-ended may have become leading questions, and was thereafter mindful of the phrasing of questions. However, this was not always possible as certain issues were discussed, for example, comparing the rating scales of the different pacing scales, or the content of the scales. In highlighting these topics, the author alerted participants to issues that may not have previously been noticed. This holds the advantage of increasing the detail and richness of the discussion, but may have also influenced the answers that were received. The author tried to avoid disclosing that the APQ had been developed by the present research team to reduce this potential bias on participants' answers. However, at times this was unavoidable.

7.3.6 Strengths and limitations of the study

The semi-structured telephone interviews were an apposite method of exploring the acceptability of the APQ. The semi-structured nature of the interviews facilitated discussions into the ease of completion of the APQ in comparison to two existing pacing subscales. Together with this, the content of the APQ was discussed, with reference to the five themes of pacing that were identified in the psychometric study. This facilitated the deductive development of themes from the interviews. Furthermore, the semi-structured interviews provided a script for the researcher to follow to increase consistency across the interviews. However, the interviews also incorporated open-ended questions and individualised probing questions. This flexibility in the interviews facilitated the emergence of other themes inductively. Therefore, the interviews were advantageous not only to explore the acceptability of the APQ, but to also add evidence to the concept of pacing, and support the findings of Stages I and II of the study regarding the different themes of pacing. In addition, the interviews generated further information regarding activity pacing, such as the effect of co-morbidities on the implementation of pacing strategies.

The purposive sample appeared to reflect the heterogeneous sample that was involved in Stage II, the psychometric study. The author believes that a variety of opinions were attained which provided a less biased opinion. Added to this, the acceptability interviews increased service-user involvement in the development of the APQ. It was an aim of this stage to gather patients' opinions of pacing, together with the ease of completion of the APQ. This follows the lower recruitment of patients into the expert panel in Stage I, the Delphi technique. The author believes that a more relevant and acceptable pacing scale has been developed as a consequence.

It is considered that framework analysis was a suitable method of qualitative analysis. Framework analysis is appropriate for the analysis of semi-structured interviews that include questions based on pre-planned themes of specific enquiry, together with allowing for new themes to emerge inductively. Framework analysis is apt for studies where themes can be explored and does not focus purely on developing new themes as other qualitative methods, for example, the constant comparison approach in grounded theory (Ward et al., 2013). Moreover, framework analysis was an accessible process of data analysis for a novice researcher, since it provided a clear five-step process.

Unique to this stage of the study, the qualitative methods enabled the emergence of activity behaviour typologies. Although this was not a specific aim of the study, it became apparent in the interviews that pacing was being described differently by participants with diverse approaches to activities. Of note, the four typologies of activity behaviour that emerged are similar to the typologies of avoidance, persistence, boom-bust and pacing that have been described in previous literature (McCracken and Samuel, 2007; Andrews et al., 2012).

There were some difficulties associated with undertaking the telephone interviews. Occasionally, participants were interrupted during the interviews which may not have occurred had the interviews been face-to-face. In addition, the telephone interviews compromised the non-verbal data that may have been presented and the rapport with participants. However, the author suggests that the telephone interviews encouraged clarity of verbal explanation where no physical gesture could compensate, thus improving the quality of the interview transcripts. Conducting the interviews at home may have encouraged recruitment into the study due to less inconvenience and cost for participants. There were some practical problems, for example, participants struggling to hear questions or the phone-line crackling. Furthermore, there were some problems navigating participants through the questionnaire booklet to ensure they were looking at the scale under discussion.

On occasions, participants reported difficulties remembering which questions/scales they found confusing when they completed the pacing scales in the psychometric study. This was due to memory recall and the duration of time between completing the questionnaire booklet and undertaking the interviews. The length of time taken to analyse all of the interview data was longer than envisaged. However, lengthier time requirements may be expected for qualitative research (Ward et al., 2013).

7.3.7 Summary

In summary, the interviews facilitated the exploration of the acceptability of the APQ by discussing the scale with participants who had completed the psychometric study. The interviews generated discussions into both the ease of completion of the scale, together with descriptions of activity pacing. The purpose of inviting participants to discuss their opinions was to increase the involvement of patients in the development of the scale with the aim of increasing the clinical utility of the APQ.

The findings of the acceptability study uncovered few concepts of pacing that had not been included in the APQ items. This adds evidence to suggest that the APQ contains a comprehensive description of pacing. Overall, the APQ was reported to be acceptable to participants, with the exception of the number of items. Indeed, it was the shorter length of the existing pacing subscales of the PARQ and CPCI that received favourable comments, as opposed to their content or rating scales.

Four activity behaviour typologies emerged from the analysis of participants' responses: Task avoidance, Task persistence, Task fluctuation (boom-bust) and Task modification (activity pacing). These typologies agreed with previous literature which enhanced the validity of the study.

Chapter 8. Discussion

8.1 Introduction

The aim of the study was to develop an activity pacing questionnaire (APQ) for chronic pain and/or fatigue. This was achieved through the implementation of a three stage mixed methods study. Stage I involved a Delphi technique to develop the APQ items, Stage II assessed the psychometric properties of the APQ using statistical methods, and Stage III explored the acceptability of the APQ, together with the concept of activity pacing via telephone interviews with patients. Chapters 5-7 reported the three stages to include the methods, the findings and detailed discussions (including strengths and limitations of each stage). The purpose of this chapter is to reflect on the conceptual framework that was projected in Chapter 3 and to review the mixed methods approach that was employed in the study. The findings of Chapters 5-7 will be summarised, synthesised and compared to existing literature. The overall strengths and limitations of the study will be summarised, together with a review of the author's development throughout the PhD. Following this, the areas for future study and clinical implications will be proposed. This chapter will close with the conclusion.

8.2 Reflections on the conceptual framework

8.2.1 Themes of pacing

In Chapter 3, Conceptual framework, it was proposed that pacing may be a multifaceted construct *(see Chapter 3, Figure 3.1 Different models of the themes of activity pacing).* This proposition was contrary to existing literature that described pacing as unidimensional (Kindermans et al., 2011), or being defined by divergent strategies of either adaptive pacing therapy (White et al., 2007; Nielson et al., 2012), or rehabilitative pacing (involving graded activity) (Sharpe, 2002; Birkholtz et al., 2004b; Nijs et al., 2006). However, this proposal was in keeping with the suggestion that pacing is more complex than some existing descriptions (Birkholtz et al., 2004b). Stage II, the psychometric study, identified five themes of pacing: Activity limitation, Activity planning, Activity progression, Activity consistency and Activity acceptance. These themes have been applied to the model *(see Figure 8.1 APQ pacing themes).*

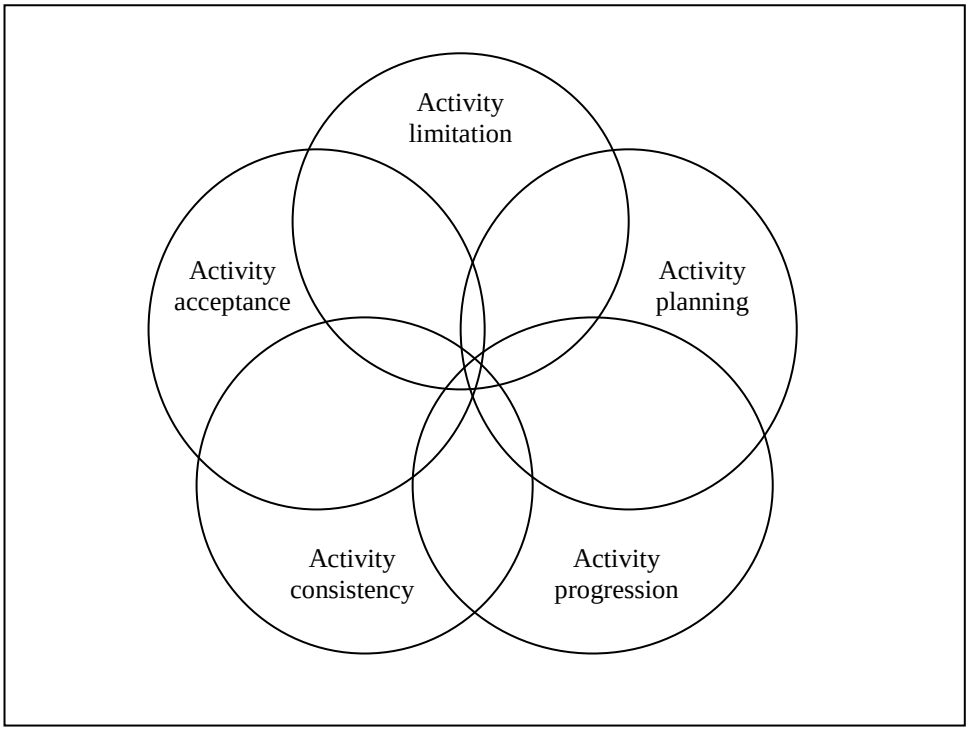

Figure 8.1 APQ pacing themes

The author believes that the five themes of pacing may overlap, and that more than one theme may be implemented simultaneously. The five themes showed significant associations with each other in the psychometric study (all $p<0.001$). This model was further supported in the Stage III telephone interviews, during which participants reported implementing the five themes of pacing to varying extents according to their symptoms and the activity. Moreover, the APQ pacing themes appeared to be utilised both simultaneously and sequentially. For example, some participants reported utilising themes of Activity limitation, Activity planning, together with Activity acceptance and Activity consistency to restore a baseline of achievable activity following an exacerbation of symptoms. As able, some participants then described the theme of Activity progression to gradually increase their activities following the stabilisation of the condition. However, the themes of pacing may not necessarily occur in this order. Indeed, some participants reported both themes of Activity limitation (reducing over-exertion) and Activity progression (reducing under-exertion) to establish Activity consistency. Due to the correlative nature of the findings from the psychometric study (as opposed to causative), together with the small sample involved in the qualitative interviews, the possible relationships and sequential order of the pacing themes may be speculative at this stage. Furthermore, the pacing themes that are relevant to each

individual appear to be related to other factors such as co-morbidities, age and behaviour typology. The model of the themes of pacing therefore requires further investigation.

8.2.2 Health behaviour models

8.2.2.1 The health belief model

The conceptual framework of the study was discussed with reference to established health behaviour models. The health belief model (HBM) proposes different determinants of the implementation of health behaviour changes (Janz and Becker, 1984; Rosenstock et al., 1988). Although the aim of the study was not to specifically assess the HBM of activity pacing, this study identified factors that are associated with pacing and that can be viewed within an HBM framework *(see Figure 8.2 The health belief model of activity pacing).*

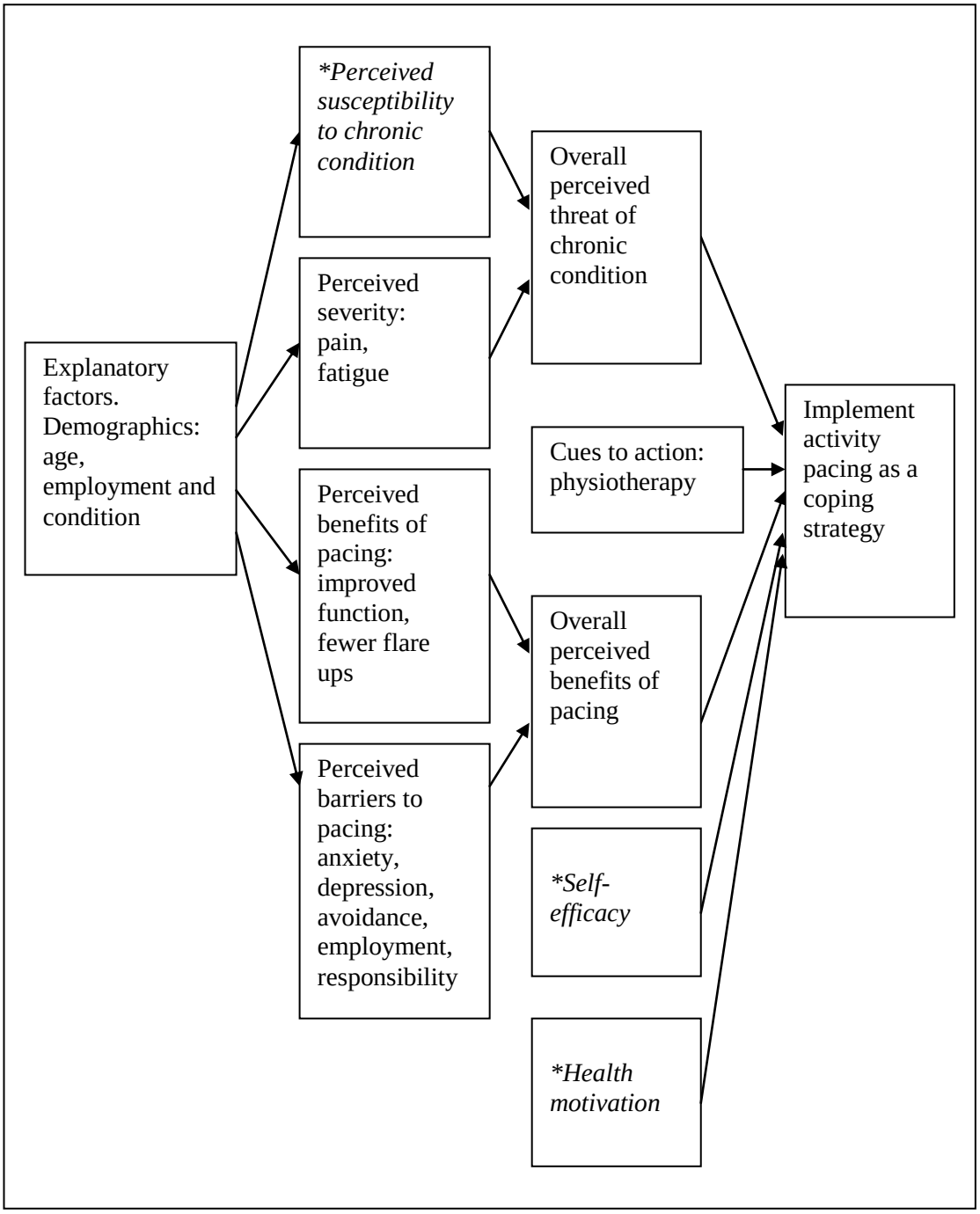

Figure 8.2 The health belief model of activity pacing (adapted model from Parahoo (1997) p110, and Ogden (2007), p24

**The boxes in italics represent factors that were not investigated.*

As proposed in Chapter 3, some demographic factors were associated with activity pacing in Stage II, the psychometric study. Specifically, age, employment status and condition were all significantly associated with pacing.

‘Perceived susceptibility’ (that is, the belief of the likelihood of the condition) was not assessed. In the psychometric study, the factors that were associated with pacing that may be categorised as ‘perceived severity’ include pain and fatigue. ‘Perceived benefits’ may include physical and mental function, which were significantly associated with the APQ themes of pacing in Stage II of the study. During Stage III, the acceptability interviews, the benefits of pacing reported by patients included increased activity levels with fewer exacerbations of symptoms. ‘Perceived barriers’ may include anxiety, depression and avoidance, which were significantly associated with pacing in the psychometric study. Barriers that emerged from the acceptability interviews included employment responsibilities and other family roles and responsibilities.

‘Cues to action’ were not formally assessed in the psychometric study. However, symptoms may act as a ‘cue to action’. The attendance of physiotherapy may also trigger the utility of pacing, since differences were found in pacing between patients who had received pacing instructions and those who had not. This notion was further substantiated in the acceptability interviews. Further investigation could utilise the APQ to assess changes in pacing that occur pre- to post-treatment. Self-efficacy and health motivation were not measured during this study.

In previous studies, ‘perceived barriers’ have been the strongest predictor of the HBM (Janz and Becker, 1984; Glanz et al., 2002). However, in the psychometric study, the factor that had the strongest associations with pacing was pain. The author proposes that pain may be classified under ‘perceived severity’ (as in Figure 8.2), but also as a potential barrier to pacing.

8.2.2.2 The theory of planned behaviour

The theory of planned behaviour (TPB) was additionally proposed as a health behaviour model that may be relevant to pacing. Following Stages II and III of the study, the factors that appeared to be associated with pacing have been added to the TPB *(see Figure 8.3 The theory of planned behaviour model of activity pacing).*

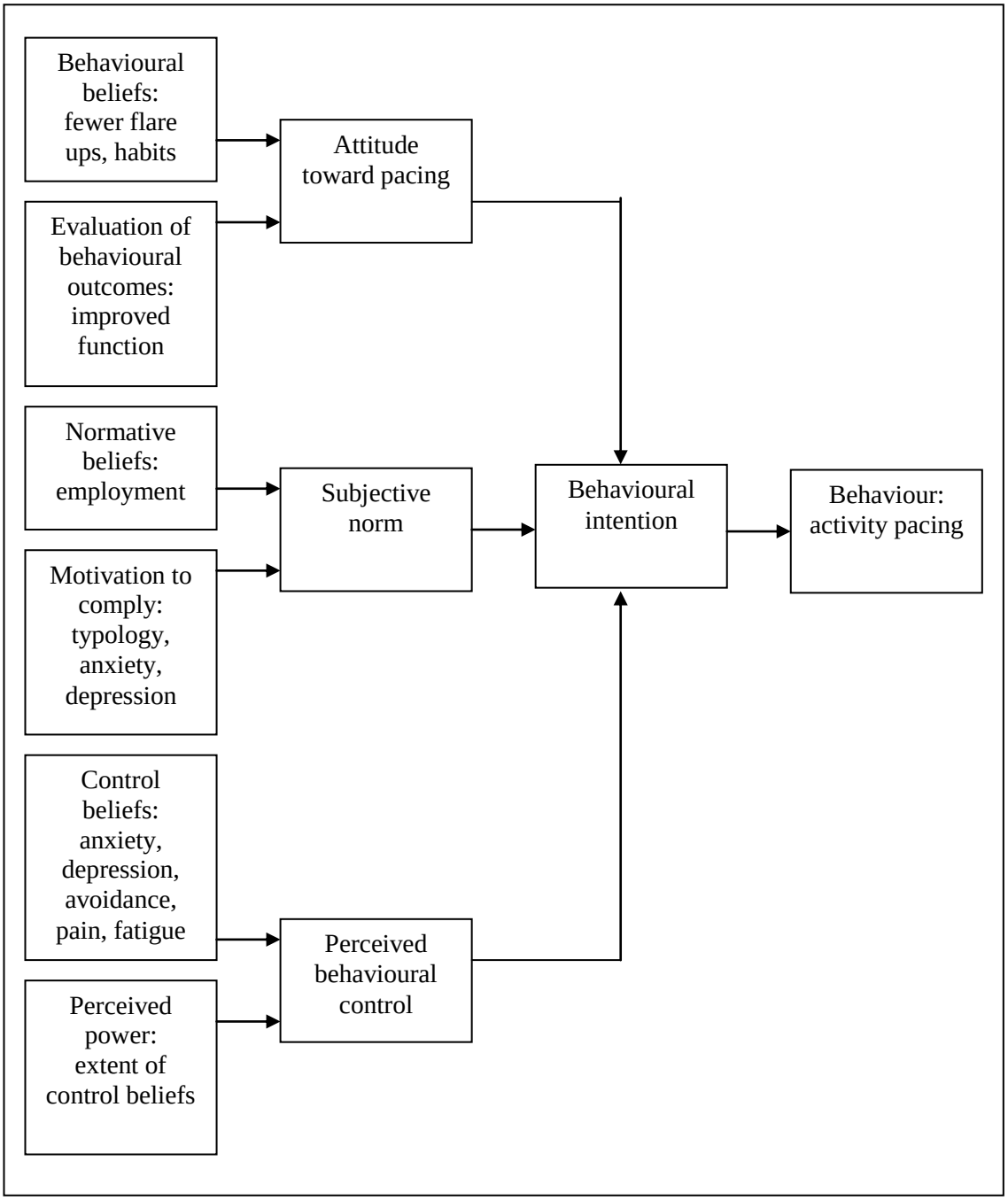

Figure 8.3 The theory of planned behaviour model of activity pacing (adapted from Montaño and Kasprzyk, 2002, p68)

'Attitude toward pacing' in the TPB model refers to the opinion of pacing. This is determined by 'behavioural beliefs' together with 'evaluation of behavioural outcomes'. 'Behavioural beliefs' includes the belief that pacing relates to specific outcomes or attributes. Outcomes, such as improved activity levels and symptoms, and attributes of behavioural habits were reported by patients during the acceptability interviews. 'Evaluation of behavioural outcomes' includes the perceived value of utilising pacing.

This may be reflected as the measure of mental and physical function in the psychometric study, together with patients' reported opinions towards pacing in the acceptability interviews.

'Subjective norm' (the perception of social approval) is driven by 'normative beliefs' and 'motivation to comply'. 'Normative beliefs' may include factors that were highlighted in the acceptability interviews, such as employers' expectations of patients. For example, pacing through using rest breaks may not be feasible at work. In terms of 'motivation to comply', patients who identified fluctuating (boom-bust) behaviours during the interviews did not necessarily express a desire to change this pattern.

'Perceived behavioural control' refers to the ease or difficulty of implementing pacing. This is led by 'control beliefs', including the likelihood of an obstacle or a catalyst. Obstacles such as employment demands or other responsibilities emerged in the acceptability interviews. Obstacles that were assessed in the psychometric study include anxiety, depression and avoidance. Catalysts to implementing pacing may include symptoms of pain and fatigue. However, as reported in the acceptability interview, pain and fatigue may form obstacles to implementing some themes of pacing, for example, Activity progression. 'Perceived power' refers to the extent of the obstacles.

Therefore, both the HBM and TPB have relevance to the study. However, it is of note that in the HBM and TPB models of pacing, the relationships between pacing and the associated factors are correlative and not causal. Furthermore, for simplicity, pacing has been illustrated as a single concept. However, each of the five themes of pacing requires a slightly adjusted model according to the significant associations that were found.

8.2.3 Behaviour typologies

8.2.3.1 Task avoidance, persistence, fluctuation and modification

Following Stage III, the acceptability interviews, four typologies of activity behaviour emerged: Task avoidance, Task persistence, Task fluctuation (boom-bust) and Task modification (pacing). These typologies are similar to behaviours that have been found in previous literature. Specifically, during the development of the Pain and Activity Relations Questionnaire (PARQ), four activity behaviour typologies were identified: 'avoiders', 'medium cyclers', 'doers' and 'extreme cyclers' (McCracken and Samuel,

2007). Following this, Kindermans et al. (2011) identified six activity patterns: 'pain avoidance', 'activity avoidance', 'task-contingent persistence', 'excessive persistence', 'pain-contingent persistence' and 'pacing'. Furthermore, Cane et al. (2013) developed the Patterns of Activity Measure-Pain (POAM-P) containing items that described three activity patterns: 'avoidance', 'overdoing' and 'pacing'.

The four typologies that emerged during the acceptability interviews appear to be most similar to those of Kindermans et al. (2011) and Cane et al. (2013), since pacing is considered to be a different behaviour from task persistence and avoidance. Conversely, McCracken and Samuel (2007) did not find that pacing was a separate behaviour, rather, that pacing was most frequently implemented by 'avoiders' and 'extreme cyclers'. Of note, the six activity patterns found by Kindermans et al. (2011) were identified using factor analysis of four different scales of task persistence, avoidance and pacing (the POAM-P, the PARQ, Behavioural Responses to Illness Questionnaire and the Chronic Pain Coping Inventory, CPCI). In contrast, McCracken and Samuel (2007) identified four activity behaviours using cluster analysis of PARQ data. The three activity patterns of the POAM-P were pre-selected for the scale and not identified following analysis. The four behaviour typologies that were found in the APQ study emerged from qualitative interviews. Therefore, different methods were employed to explore activity behaviours among patients with chronic conditions. Further exploration into different behaviour typologies is warranted. The APQ can potentially assist such future study as it appears to provide a comprehensive measure of pacing.

Task persistence has previously been found to be negatively associated with pacing (Kindermans et al., 2011). Furthermore, task persistence has been found to be a separate construct from pacing (Nielson and Jensen, 2004). Indeed, the CPCI pacing subscale was purposefully written to be different from the CPCI task persistence subscale (Nielson et al., 2001). Although the four behaviour typologies that emerged from the acceptability interviews concur that Task persistence and Task modification are different, the author suggests that there may be some overlap between the two behaviours. Indeed, the APQ pacing themes of Activity consistency and Activity progression may involve some continuation/persistence of activity. The author suggests that items of the CPCI task persistence subscale, such as, *"Kept doing what I was doing"* may be similar to the APQ theme of Activity consistency.

Task persistence has been found to be associated with reduced pain, disability and depression, and better physical and psychological function (Ersek et al., 2006; Karsdorp and Vlaeyen, 2009; Andrews et al., 2012). In Stage II, the psychometric study, Activity consistency was significantly associated with reduced anxiety, depression, fatigue and avoidance, and improved mental and physical function, similar to the above findings. An unexpected association was found between Activity progression and increased pain. This is akin to previous associations between 'increasing activity levels' of the Coping Strategies Questionnaire and increased pain, whereby pain may be provoked by higher activity levels (Andrews et al., 2012).

The author suggests that there may be an overlap between avoidance behaviour and the APQ themes of Activity limitation, Activity planning and Activity acceptance. This overlap was first highlighted in Stage I of the study. Some members of the expert panel queried the use of rest breaks and breaking down activities as alluding to avoidance. Such items loaded on to the themes of Activity limitation and Activity planning in Stage II, the psychometric study. The author proposes that APQ22: *"I was able to say 'no' if I was unable to do an activity"* of the theme Activity acceptance, may also overlap with avoidance. Activity limitation, Activity planning and Activity acceptance showed associations with increased pain, anxiety, depression, avoidance, and reduced function. This is similar to previous associations that have been found between avoidance and increased pain, anxiety, depression and disability, together with reduced function (Silver et al., 2002; Nijs et al., 2004; Turk et al., 2004; Karsdorp and Vlaeyen, 2009; Andrews et al., 2012).

Task modification (activity pacing) emerged from the interviews as a different behaviour from Task avoidance, Task persistence and Task fluctuation. Indeed, the varying APQ themes of pacing may challenge different behaviours. Therefore, in keeping with the literature, pacing has emerged in the study as a behaviour and a management strategy *(see Chapter 2, Literature review, Section 2.3)*. It is recommended that "over-active" patients implement pacing strategies of breaking down tasks and reducing activity levels, whereas "under-active" patients implement pacing strategies of gradually increasing activities (Nielson et al., 2012). Following this, the author proposes that patients with avoidance behaviours implement APQ themes of Activity consistency and Activity progression. Conversely, patients with Task persistence tendencies

implement Activity limitation, Activity planning, Activity consistency and Activity acceptance. Patients with fluctuating patterns of activity may benefit from all five APQ pacing themes on varying occasions, with particular emphasis on Activity consistency. Indeed, one aim of activity pacing is considered to improve fluctuations in activity that occur in the overactivity-underactivity cycle (Birkholtz et al., 2004a; Gill and Brown, 2009). Figure 8.4 below shows the possible relationship between the behaviour typologies, and projects the overlap between Task modification with both Task avoidance and Task persistence, together with the opposition of Task fluctuation.

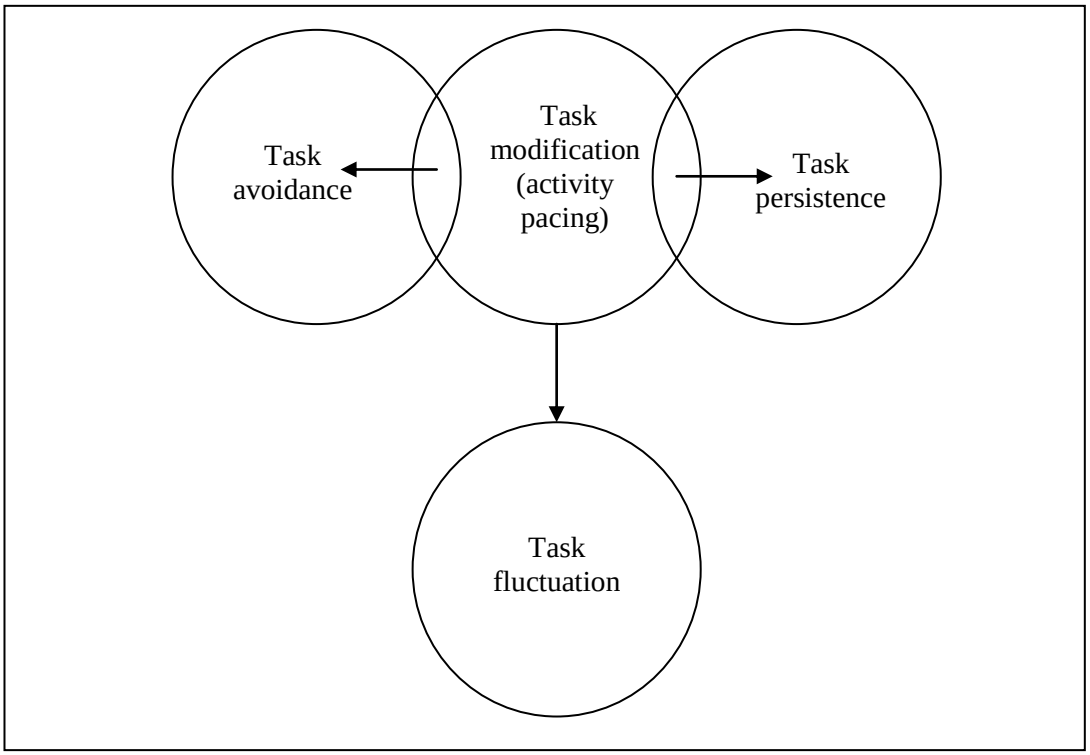

Figure 8.4 Relationships between activity typologies

8.2.3.2 Symptom- and quota-contingency

During the acceptability interviews, activity behaviours emerged as being symptom- and quota-contingent. The concepts of symptom- and quota-contingency in terms of pacing were introduced in Chapter 2, Literature review, Section 2.3.4.1. In Stage I, the Delphi technique, the concept of symptom-contingency was less well favoured in comparison to quota-contingency. Indeed, only 3 of 17 items (18%) that referred to symptoms reached consensus of inclusion. These three items referred to changing activities, gradually increasing activities and accepting limitations as opposed to avoiding or stopping activities as per symptom-contingency. As a result of the Delphi technique, 4 of the 12 items (33%) that referred to quota-contingency were voted to be

included in the APQ. Therefore, the items of the APQ had a tendency towards the recommendation of quota-contingent pacing principles, as opposed to symptom-contingent principles. This is in keeping with pacing principles originally proposed by Fordyce in 1976 (Birkholtz et al., 2004a; Nielson et al., 2012).

There are recommendations towards quota-contingency rather than symptom-contingency to challenge activity withdrawal and deconditioning due to the expectation of worsening symptoms (Birkholtz et al., 2004a; Gill and Brown, 2009; Nielson et al., 2012). Moreover, the advantages of quota-contingency include regaining control over activity, preventing the underactivity-overactivity cycle (and its consequential psychosocial effects), being able to gradually increase activities and facilitating the measurement of such improvements (Birkholtz et al., 2004a; Birkholtz et al., 2004b).

8.3 Reflections on the mixed methods

The author believes that implementing the three stage mixed methods led to the development of a multifaceted and clinically relevant scale, together with demonstrating the initial reliability, validity and acceptability of the APQ. The benefit of the three stages include that the findings of each stage could be compared against the previous stage(s). Although a method of triangulation (that is, undertaking concurrent data collection and corroboration) was not implemented, the three stages facilitated the re-iteration of several findings. Similar themes arose across all three stages of the study, which additionally concurred with existing literature, such as the differences/overlap between pacing, avoidance and increasing activities *(see Chapter 2, Literature review, Section 2.3)*. Furthermore, the broad themes of pacing that were suggested in Stage I, the Delphi technique, were extracted and assessed using factor analysis in Stage II. The themes and any omissions were discussed during Stage III. Therefore, the utility of mixed methods included validating and explaining the findings (Doyle et al., 2009).

The mixed method approach had an exploratory sequential design, also termed the instrument development design (Creswell et al., 2004). Therefore, this method was ideal to develop a new pacing scale. Stage I of the study required a constructivist approach to develop the items of the APQ from qualitative data. The author believes that the content validity of the APQ was increased by collecting qualitative data from an expert panel in the Delphi technique. However, implementing qualitative methods may have increased

the potential for bias due to more flexible methods of data collection and analysis (Johnson and Onwuegbuzie, 2004; Doyle et al., 2009). Indeed, the researcher influenced both the phrasing of the initial open-ended question of Round 1 of the Delphi technique, together with the analysis of the qualitative data in the development of the potential APQ items. The Delphi technique itself involved mixed methods, since consensus was determined according to statistical summaries of the panel's voting patterns on Rounds 2 and 3 on the qualitative data that were generated in Round 1. The author proposes that some of the limitations associated with qualitative methods were addressed through the subsequent quantitative methods of Stage II.

Stage II was beneficial in attempting to reduce bias by utilising a large sample (n=311), and by implementing robust methods of data collection and analysis. This postpositivist approach increased the generalisability of the findings, and reduced the researcher's influence compared with the previous qualitative methods (Johnson and Onwuegbuzie, 2004; Doyle et al., 2009; Creswell and Plano Clark, 2011). Stage II assessed the psychometric properties of the APQ which would not have been feasible using qualitative methods. However, purely quantitative studies also have limitations. Since quantitative methods are driven by researcher's own hypotheses and incorporate minimal external input, such studies may lack relevance to the individual due to increased generalisability to the population (Creswell and Plano Clark, 2011). The author suggests that implementing an initial qualitative stage of the study challenged the above limitation of quantitative methods. Indeed, the item pool assessed in Stage II of the study was generated from the qualitative methods that were implemented in Stage I, and not the opinions of the researcher (as observed in existing pacing subscales).

The study incorporated an additional stage to the traditional exploratory sequential design. Stage III of the study explored the acceptability of the APQ as a clinically useful scale. The acceptability interviews involved patients which was advantageous to address the low recruitment rate of patients into the Delphi technique. This allowed the findings of both Stages I and II of the study to be discussed and verified by a sample of patients, while exploring their unique opinions (Johnson and Onwuegbuzie, 2004). The problem associated with quantitative studies (as in Stage II) in lacking detail specific to individuals was addressed using qualitative interviews, thus increasing service user involvement and real life reflections on the newly developed scale (Kutner et al., 1999).

However, there is an ongoing debate whether quantitative and qualitative methods should be combined in mixed methods due to the different ontological, epistemological, axiological, methodological and rhetoric approaches (Barbour, 1998; Doyle et al., 2009; Creswell and Plano Clark, 2011) *(see Chapter 4, Research methodology, Section 4.2.5)*. Contrary to this, it is argued that qualitative and quantitative methods share some commonalities. Both methods seek to answer a specific research question, to explain findings and implement strategies as appropriate to reduce bias (Johnson and Onwuegbuzie, 2004). However, the researcher requires skills in both quantitative and qualitative research, which may be time consuming and possibly expensive (Johnson and Onwuegbuzie, 2004). To ensure adequate capabilities in both methods, the author sought training and guidance from an experienced team.

The author believes that the mixed methods were justified to fulfil the aims of the study to develop the APQ. Indeed, developing an instrument may be considered rationale itself for selecting a mixed methods approach, in order to generate and then assess items (Doyle et al., 2009). Moreover, mixed methods are appropriate to answer complex research questions (Doyle et al., 2009; Creswell and Plano Clark, 2011). The author considers activity pacing to be a complex construct since there is currently no consensus regarding a comprehensive definition, a widely used pacing scale, or the effects of pacing. Mixed methods facilitated the utility of both inductive and deductive methods to answer the research question. Therefore, mixed methods have the potential to increase the insight into the study through the collection of data from different perspectives (Creswell and Plano Clark, 2011). Indeed, the author believes that mixed methods encouraged the presentation of diverse opinions of pacing and different behaviour typologies, necessary to explore the multifaceted nature of pacing.

The three stage mixed methods enabled a larger sample of both clinicians and patients to be involved in the development of the APQ in comparison to existing pacing subscales. Of note, two different samples were involved in the study. Forty-two participants completed all three rounds of Delphi. However, 17 additional participants (6 patients, 11 clinicians) completed Round 1 of Delphi, and their contribution to the initial item pool for the APQ was included in Rounds 2 and 3 of Delphi. The 311 patients who completed Stage II of the study were separate to the expert panel of the Delphi technique. Sixteen patients involved in Stage II undertook the acceptability

interviews of Stage III. In total, 370 participants contributed to the development of the APQ, including patients, physiotherapists, occupational therapists, nurses, one clinical psychologist and one rheumatology consultant. Implementing mixed methods therefore increased the generalisability of the findings (Johnson and Onwuegbuzie, 2004).

8.4 Summary of the findings

8.4.1 Stage I: the Delphi technique

As a result of the three-round Delphi technique, 37 questions were voted to be included in the APQ by attaining ≥ 70% votes of inclusion from the expert panel. This number increased to 38 following the division of one item into two separate items. On face value, the APQ appeared to demonstrate content validity, that is, the APQ scale items reflected a comprehensive description of the underpinning theory of pacing (Oppenheim, 2000). Indeed, the APQ appears to contain facets of pacing that are in keeping with existing literature. Such facets include breaking down activities, gradually increasing levels of activities and setting time limits for activities (Birkholtz et al., 2004a; Birkholtz et al., 2004b; Nielson et al., 2012). In comparison to existing pacing subscales, the APQ contains more facets of pacing, and novel items that refer to prioritising activities, assessing activity levels, accepting activity levels, reducing feelings of guilt, having a flare-up plan, using an activity diary, being creative, being assertive and setting goals.

The expert panel queried whether ‘rest breaks’ were pre-planned or consequential, perhaps in the absence of pacing. Panellists further queried some items that appeared to allude to avoidance and not pacing. Interestingly, most of these items did not reach consensus of inclusion. Those items that were voted to be included referred to breaking down tasks, switching activities, using pre-planned rests and gradually increasing activities that have been previously avoided, as opposed to complete avoidance of activity. Items that referred to energy conservation, in keeping with adaptive pacing/the envelope theory were voted to be excluded from the APQ. Some panellists questioned whether ‘pacing up’ or gradually increasing activities was a separate construct from pacing. However, two items were voted to be included in the APQ regarding gradually increasing activities. From the APQ items that reached consensus it appeared that panellists followed a rehabilitative approach more than an adaptive approach to pacing.

A small number of panellists queried whether the same pacing scale was appropriate for patients with either chronic pain or fatigue, or both. It has been suggested that strategies that benefit patients with fatigue may differ from those that benefit patients with pain (Nielson et al., 2012). Conversely, the author proposes that since many patients present with symptoms of both pain and fatigue, and co-existing conditions of chronic pain and fatigue, a pacing scale that is relevant to a heterogeneous group of conditions is warranted. This notion is in keeping with recommendations for holistic treatments to manage diverse symptoms associated with chronic conditions (Aggarwal et al., 2006).

8.4.2 Stage II: The psychometric study

Stage II, the psychometric study, explored the construct validity of the APQ in identifying the internal structure of the APQ (including the themes of pacing), together with associations between the themes of pacing and other validated measures. Factor analysis confirmed the existence of different themes of pacing that emerged during Stage I, and also suggested in Chapter 2, Literature review, Section 2.3. Specifically, five themes of pacing emerged: Activity limitation, Activity planning, Activity progression, Activity consistency and Activity acceptance. Stage II found that all five themes of pacing demonstrated good internal consistency with high values of Cronbach's alpha (α=0.724-0.933). The internal consistency for the APQ appears to be more acceptable than the CPCI pacing subscale (α=0.93) and the PARQ pacing subscale (α=0.91), which may be indicative of item repetition in small scales (both n=6) (DeVellis, 1991; Pett et al., 2003).

The APQ was refined through the removal of eight redundant items: APQ17: *"I made sure I had a flare up plan",* APQ20: *"I did not under-do activities on a 'bad' day",* APQ34: *"I did not over-do activities on a 'good day'",* APQ32: *"I used an activity diary to monitor my activity pattern",* APQ2: *"I was aware of the effect that different types of activities had on me",* APQ26: *"I used support from others to help me with my activities",* APQ27: *"I did not feel guilty when I stopped an activity"* and APQ25: *"I set activity goals that were meaningful to me"*. Of note, APQ28: *"I set activity goals that were realistic for me"* was retained.

Therefore, not all of the novel concepts of pacing that were voted to be included in the APQ following the Delphi technique were retained following factor analysis. However,

despite the removal of some items, the APQ contains more themes than existing pacing subscales. Following the comments made in the Delphi technique regarding 'pacing up', it is of interest that the two items referring to gradually increasing activities loaded together during factor analysis to form APQ factor 3, Activity progression. Previously, gradually increasing activities has been considered to be a facet of pacing (Birkholtz et al., 2004a; Gill and Brown, 2009), a second phase of pacing following stabilisation (Nijs et al., 2006), or indeed an outcome of pacing (Nielson et al., 2001).

Interestingly, the item that achieved the highest percentage of votes among the expert panel in the Delphi technique on Round 3, APQ34: *"I did not over-do activities on a 'good' day"*, was removed from the APQ in Stage II due to multiple missing answers. Similarly, APQ20: *"I did not under-do activities on a 'bad' day"* was removed. Both items, received comments in the questionnaire booklet regarding the confusion of the apparent double negative in the questions. Hence, patients involved in the psychometric study expressed dissimilar opinions to the clinician-dominant expert panel involved in the Delphi. Therefore, the multi-stage study identified clinically important concepts of pacing (such as not over-doing or under-doing activity), while highlighting the importance of the acceptability of such items. However, the concept of avoiding over- and under-exertion has been maintained within the theme of Activity consistency.

All five themes of the APQ correlated with the two existing pacing subscales of the CPCI and PARQ. Although, the author considers the APQ to be different to the existing pacing subscales, the significant correlations may add evidence of concurrent validity of the APQ. Of note, the strongest correlation between the existing pacing subscales and the APQ was with Activity limitation. This may be due to the items contained within this theme (such as breaking down tasks and using rest breaks) which are similar to the existing pacing subscales. Conversely, lower correlations were found between the existing pacing subscales and Activity progression and Activity consistency. These themes contain items such as gradually increasing activities and undertaking activities on 'bad' days, which are less similar to the existing pacing subscales.

Stage II, the psychometric study, demonstrated interesting associations between the APQ themes and symptoms of chronic conditions. Activity limitation was significantly associated with increased current and usual pain, anxiety, depression, avoidance and

worse physical function. Activity planning was similarly associated with increased current pain, avoidance and worse physical function. Activity progression was significantly associated with increased current and usual pain. Activity acceptance was significantly associated with increased current and usual pain, avoidance and worse physical function. Of note, Activity consistency showed significant associations with symptoms in the opposite direction to the other four APQ themes. Activity consistency was significantly associated with lower mental and physical fatigue, lower anxiety and depression, lower avoidance and higher physical and mental function. Interestingly, Activity consistency was the only APQ theme significantly associated with measures of fatigue or mental function. Therefore, while Activity limitation, Activity planning, Activity progression and Activity acceptance were associated with worse symptoms, Activity consistency was associated with improved symptoms. If such findings are replicated in causative studies, there may be important clinical implications. Specifically, clinicians may be advised to instruct pacing strategies that promote Activity consistency in preference to other pacing strategies.

The existing literature regarding the associations between pacing and symptoms has found similar conflicting results, that is better symptoms (Nielson et al., 2001; Nielson and Jensen, 2004; Andrews et al., 2012; Cane et al., 2013), together with worse symptoms (Van Lankveld et al., 1994; McCracken and Samuel, 2007; Karsdorp and Vlaeyen, 2009; Andrews et al., 2012). However, previous findings have implemented existing pacing subscales that the author considers to be unidimensional. Indeed, the pacing subscales of the CPCI, PARQ and POAM-P have found pacing to be unidimensional using exploratory factor analysis (Kindermans et al., 2011). Conversely, the findings of the APQ study suggest that different themes of pacing (within the same scale and the same sample) are associated with improved and worsened symptoms.

Of note, Activity limitation, Activity planning and Activity acceptance are most similar to existing pacing subscales, where items allude to some reduction in activity, similar to adaptive pacing therapy. In comparison, Activity consistency appears to be more reflective of rehabilitative pacing techniques. It is interesting that rehabilitative, rather than adaptive pacing appears to coincide with better symptoms. However, the author considers that Activity progression is also reflective of rehabilitative pacing, yet there were unexpected associations between Activity progression and increased pain. The

explanation for this is unclear. The author suggests that progressing activities may lead to short-term increases in pain as a natural consequence of increased exertion. Future longitudinal study could explore this association.

Furthermore, the five factors of the APQ demonstrated fair-good to excellent stability over a test-retest period of 29.6 days (intraclass correlations range, ICC: 0.50-0.79, $p<0.001$). The APQ demonstrated adequate stability using robust methods of intraclass correlations together with the Bland and Altman method. Interestingly, the APQ demonstrated generally higher test-retest reliability than the pacing subscales of the CPCI (ICC range: 0.27 to 0.48, $p<0.05$) and PARQ (ICC range: 0.38 to 0.68, $p<0.001$).

In terms of the acceptability of the three pacing scales, the psychometric study found that the PARQ pacing subscale had the highest ease of completion on a 0-4 rating scale (mean=2.41), followed by the APQ (mean=2.23), with the CPCI pacing subscale being the least easy to complete (mean=2.01). There were fewest missing answers per item on the APQ compared to the PARQ pacing subscale, with the CPCI having many more missing answers. Therefore, the APQ and the PARQ pacing subscale appear easier to complete than the CPCI pacing subscale. From the comments in Stage II, the ease of completion of the APQ may have been compromised by the large number of items and the readability of some of the questions (as mentioned above). In addition, several patients commented that the seven day recall period of the APQ was not long enough to measure the variances in their condition which occurred over longer periods of time. However, to increase the representativeness of the seven day period, repeated measures would be taken at different time points (Oppenheim, 2000).

The CPCI pacing subscale may be the least easy to complete due to problems of the seven day rating scale. Instead of providing numerical answers (0-7 days), patients gave word answers, hence the high number of missing answers. Several patients noted the repetition in the CPCI items (that is, ‘slow and steady’) that the author highlighted in Chapter 2, Literature review, Section 2.3.5.2. Furthermore, several patients reported that the concept of going slower may not be relevant. One issue pertinent to both the CPCI and PARQ pacing subscales was that the pain-focused items were not always appropriate. Instead, some patients reported not experiencing pain, or that fatigue was their main problem.

8.4.3 Stage III: The acceptability study

The advantages of implementing Stage III included further exploration into the acceptability of the APQ, while simultaneously addressing the low recruitment rate of patients into Stage I of the study. The semi-structured interviews facilitated the discussion of patients' opinions regarding what pacing involves, thereby replicating the open-ended question of Round 1 of the Delphi technique. Probing questions were utilised to explore patients' opinions of the five themes of pacing that had emerged following factor analysis in Stage II. Of note, the interviews involved discussions of the 38-item APQ (before the removal of redundant questions).

During the interviews, patients suggested pacing strategies that were in keeping with APQ factor 1, Activity limitation (for example, breaking down tasks, using rest breaks and spreading activities). Participants mentioned other pacing strategies involving scheduling activities and setting goals, which loaded onto APQ factor 2, Activity planning in Stage II. Similarly to Stage II, there appeared to be an overlap in concepts between Activity limitation and Activity planning. The theme of Activity progression divided participants, whereby some participants referred to gradually increasing their activities, while others were unable to progress their activities. This concurs with the mixed opinions regarding gradually increasing activities in Stage I of the study, together with existing literature regarding pacing. The unexpected association between Activity progression and increased pain that was found in Stage II may be explained in part by comments in Stage III. Some patients explained that a gradual increase in activities occurred after a flare up of symptoms. Several participants recognised Activity consistency as a facet of pacing. Participants agreed with the concept of reducing over- and under-exertion. Participants verified the presence of the APQ theme of Activity acceptance, and discussed concepts such as accepting their own abilities, together with being assertive with others. Similarly to Stage II, participants in Stage III described relationships between Activity acceptance and Activity limitation.

The interviews highlighted that the relevance of the APQ items varied between participants. The relevance of each item appeared to be dependent on the individual, the condition/stage of the condition, together with other factors such as co-morbidities and external factors such as work or other people. The APQ scale allows for patients to mark '0=never did this' for items that are not applicable to an individual. Therefore, no

items were removed following the interviews. The removal of items at this stage would have reflected only a small number of opinions, and would therefore represent less generalisable decisions.

The acceptability interviews were beneficial to confirm the removal of some APQ items during Stage II. Several participants reiterated the confusion regarding the appearance of double negatives in items APQ20 and APQ34. Furthermore, APQ17, APQ26 and APQ32 regarding the use of a flare up plan, an activity diary and support from others respectively, received comments that these strategies were not applicable. In addition, one participant highlighted the similarity between APQ25 and APQ28. These items had been split into two following the Delphi technique. This repetition had been acknowledged in the psychometric study, leading to removal of APQ25.

Of the novel ideas that the APQ contains in comparison to the existing pacing subscales, no items were deemed inappropriate following the acceptability interviews. No new concepts were suggested as missing from the scale specifically. Therefore, despite the low recruitment of patients into the expert panel of the Delphi study, it appears on face value that the APQ contains a comprehensive description of pacing. However, the concept of finding a baseline emerged indirectly from an interview. One patient described pacing in terms of finding a baseline of activity and then gradually increasing activities. This may indicate different stages of pacing, or that different themes of pacing are relevant at different times. For example, Activity limitation and Activity planning may precede Activity progression. Although it was put forward in Round 1 of the Delphi study, the concept of finding a baseline was omitted from the 94 items that were submitted for consensus on Rounds 2 and 3 of Delphi. This removal was justified by the already extensive list of items, the infrequent occurrence of this concept in the qualitative data of Round 1, and the quandary whether this term would be widely understood. However, ‘finding a baseline’ has previously been described as a facet of pacing (Birkholtz et al., 2004a; Birkholtz et al., 2004b; White et al., 2007; Nijs et al., 2008; Nielson et al., 2012). The importance and wide understanding of this concept remains unknown.

The interviews reiterated some of the findings of Stage II regarding the acceptability of the APQ, and the CPCI and PARQ pacing subscales. Most participants who were

interviewed found the APQ to be acceptable in terms of the 5-point Likert scale and the detailed instructions. The majority of participants (n=10) found the seven day recall period of the APQ to be acceptable, although three participants suggested a shorter recall period. Conversely, three participants suggested longer recall period, similarly to some comments made in Stage II. In the absence of an ideal recall period, seven days has been maintained. Generally, participants preferred the rating scale of the APQ over that of the CPCI and the PARQ pacing subscales. Furthermore, the items of the CPCI and PARQ pacing subscales that refer to pain were less acceptable to patients with coexisting symptoms, or symptoms of pain that could not be altered despite pacing. However, the brevity of the CPCI and PARQ pacing subscales was favoured, although recognised as being less detailed. Of note, eight items of the APQ have already been removed. Following two comments made in the interviews, the format of the APQ will be modified to present questions in blocks of five to improve the ease of completion.

Participants reiterated the repetition of the term 'slow and steady' in the CPCI pacing subscale. The speed of the activity was relevant to some participants but not for others. The conflict of relevance of the speed of activity is in keeping with the current literature. Of note, during the Delphi technique, items referring to the speed of activities did not reach consensus. Consensus was driven by a panel dominated by clinicians, to whom activity speed may be perceived as being less important than for some patients.

Unique to this stage of the study, were the emerging behaviour typologies. Patients described their activity behaviours that could be categorised as: Task avoidance, Task persistence, Task fluctuation and Task modification (activity pacing). Specific activities were also undertaken via symptom- and quota-contingency. There appeared to be relationships between Activity limitation and the behaviour typology of Task avoidance. This further coincided with a symptom-contingent approach to activities. Task persistence and Task fluctuation may be related since Task persistence was reported to trigger a flare up of symptoms for some participants, therefore leading to a reduction in activities. This concurs with existing literature that describes over-activity being followed by under-activity, or enforced rest (Birkholtz et al., 2004a). Conversely, Task modification appeared to be related to Activity consistency and patients reported better management of symptoms when applying principles of maintaining a consistent level of activity. This reiterates the associations found in Stage II, whereby Activity consistency

correlated with reduced fatigue, anxiety, depression, avoidance and increased function. Of note, during the interviews, Task modification was described with reference to having an awareness of symptoms. This may prove to be a different concept to symptom-contingency. The author suggests that symptom awareness may facilitate improved decision-making regarding an individual's modified approach to activity in order to achieve consistency. In comparison, symptom-contingency may precede avoidance behaviours and Activity limitation.

Therefore, in addition to exploring the acceptability of the APQ, the telephone interviews also explored the themes of pacing, and identified behaviour typologies. The qualitative data generated from the interviews added evidence to the findings of Stages I and II of the study, facilitated explanations for some associations, and highlighted important factors that can impact on pacing, such as behaviour typologies.

8.4.4 Comparisons with existing pacing subscales

The APQ is a comprehensive, stand-alone questionnaire that contains 30 items which appears to reflect the multifaceted nature of pacing. This contrasts existing pacing scales which form only subscales of other measures, contain between 6-10 items, and appear to reflect limited facets of pacing. The existing pacing subscales of the CORS, CPCI, PARQ and POAM-P contain items referring to using rest breaks, breaking down activities, going 'slow and steady' and varying activities (Van Lankveld et al., 1994; Nielson et al., 2001; McCracken and Samuel, 2007; Cane et al., 2013). As discussed in Chapter 2, Literature review, Section 2.3, such concepts are in keeping with adaptive pacing therapy/the envelope theory. The above scales may allude to a general decrease in activities, or even avoidance.

The APQ themes of Activity limitation and Activity planning appear to be most similar to existing pacing subscales insomuch as containing items referring to breaking down tasks, switching activities and using rest breaks. However, no items of the APQ refer to the speed or avoidance of activities. In comparison to existing subscales, the APQ contains themes of Activity progression and Activity consistency, which appear to coincide with rehabilitative pacing as opposed to adaptive pacing. Indeed, it is suggested that pacing may not be a beneficial strategy if it is not used to encourage activity progression (Andrews et al., 2012).

The APQ contains items that are novel in comparison to existing pacing subscales such as gradually increasing activities, prioritising activities, planning activities, setting goals, assessing activity levels, having consistent levels of activities and accepting activity levels. These facets have previously been suggested as components of pacing (Friedberg and Jason, 2001; Sharpe, 2002; Birkholtz et al., 2004a; Birkholtz et al., 2004b; Nijs et al., 2008; Gill and Brown, 2009; Nielson et al., 2012). The APQ contains a concept of being assertive (*APQ22: "I was able to say 'no' if I was unable to do an activity"*). This may be akin to the concept of negotiating, which has previously been cited as a component of pacing (Birkholtz et al., 2004a). Additionally, the APQ contains an item regarding being creative *(APQ18: "I was creative and found new ways of doing tasks").* Pacing has been described by similar concepts of problem-solving and developing new techniques (Strong, 2002b; Gill and Brown, 2009).

The APQ does not have the pain-contingent focus that is observed in the CPCI and PARQ pacing subscales. Pain-contingency underpins energy conservation/adaptive pacing therapy (Nielson et al., 2012). In contrast, only three of the 30 APQ items refer to symptoms, and as stated previously, these items do not infer symptom-contingency. Instead, the APQ contains quota-contingent items which is in keeping with literature advising quota-contingency as opposed to symptom-contingency (Birkholtz et al., 2004a; Gill and Brown, 2009). Interestingly, quota-contingency is considered to be a facet of operant pacing, or rehabilitative pacing (Nielson et al., 2012). Of note, the term 'symptoms' and not 'pain' was specifically used in the APQ to increase the relevance of the scale across different chronic conditions.

Unlike the pacing subscales of the CPCI, PARQ and the POAM-P, the APQ does not contain any items that refer to the speed of the activity, or going at a 'steady pace'. This is in keeping with the suggestion that pacing does not necessarily equate to slowing down (Birkholtz et al., 2004b). Indeed, individuals with fear-avoidant behaviours may benefit from speeding up (Birkholtz et al., 2004b).

The increased content of the APQ may be due to the methods of development involving a heterogeneous sample with a wide range of opinions. This contrasts the narrow field of opinions involved in the development of the existing pacing subscales. The author suggests that the content of the APQ may also reflect evolving attitudes towards the

management of chronic conditions. With increasing awareness of the fear-avoidance model, clinicians are implementing more rehabilitative treatments, such as cognitive behavioural therapy and graded exercise therapy, of which pacing is considered a component (Wallman et al., 2004; Beissner et al., 2009; McBeth et al., 2011).

In addition, the APQ was developed to address other limitations of existing pacing subscales, such as limited instructions (for example, not specifying a recall period, or the activities to which the items referred), less acceptable rating scales, and being developed for specific chronic conditions. In comparison to the CPCI and PARQ pacing subscales, the APQ demonstrates better test-retest reliability, internal consistency, face validity and acceptability.

8.4.5 Findings requiring further investigation

The mixed method approach enabled the confirmation of the multi-faceted nature of pacing, together with the iteration and verification of findings, and the justification of the removal of APQ items. However, mixed methods may highlight anomalous results (Creswell et al., 2004). Although the author has not identified any anomalous findings, the mixed methods highlighted areas for further research. For example, Stage III showed that the speed of activities may be important to patients, but less important to the clinician-dominant expert panel of Stage I. Similarly, clinicians may promote quota-contingency (as seen in Stage I), in opposition to patients' symptom-contingent behaviours (as reported in Stage III). Furthermore, the inclusion of the concept of gradually increasing activities as a facet of pacing both agrees and disagrees with varying opinions of clinicians and patients in Stages I and III, together with existing literature. Moreover, there were unexpected associations between Activity progression and increased pain in Stage II. Participants were asked to complete the APQ by reflecting on their activities over the past seven days. Therefore, the physiological effects of an increase in activities may still be experienced within the week, hence the reports of increased pain. Further study will confirm whether Activity progression is a facet, or indeed a phase of pacing. Furthermore, there may be an omission from the APQ in the concept of 'finding a baseline'.

8.4.6 Novel findings

There is a paucity of research evidence regarding activity pacing to provide a clear description. Although this study did not aim to define pacing, a comprehensive pacing scale has been developed which contains more themes of pacing than existing pacing subscales. The APQ may assist the development of a multifaceted definition of pacing, following future study to confirm the themes of pacing. This is the first stand-alone pacing scale known to have been developed. Additionally, the APQ was developed from the opinions of both patients and clinicians. This study contributes to a conceptual model of activity pacing, to include preliminary associations between different themes of pacing, psychometric measures, and activity behaviours of Task avoidance, Task persistence, Task fluctuation and Task modification.

Important relationships have been shown between Activity consistency and improved symptoms. This challenges recent findings of the large scale randomised controlled PACE trial in which pacing was found to be ineffective (White et al., 2011). The author proposes that pacing has the potential to be a beneficial strategy if it is described and measured in terms of Activity consistency as opposed to adaptive pacing therapy.

8.5 Strengths and limitations of the study

The literature review identified a gap in the knowledge regarding the understanding of pacing and the absence of a widely used pacing scale to clarify the current conflicting effects of pacing on the symptoms of chronic conditions. The mixed methods research design that was implemented was ideal to develop the APQ, and to start to disentangle some of the confusion regarding activity pacing. The three stage mixed methods approach is considered to be a strength of the study since each stage of the study built upon the previous stage and acted to substantiate previous findings. The three stages facilitated the development and initial validation of the APQ. Moreover, an advantage of implementing mixed methods includes readdressing the limitations that are associated with using only quantitative or qualitative methods (Creswell et al., 2004; Johnson and Onwuegbuzie, 2004; Doyle et al., 2009). Indeed, mixed methods may be considered to be superlative to ‘mono-methods’ (Johnson and Onwuegbuzie, 2004).

Since the development of the APQ involved the synthesis of clinicians’ and patients’ opinions of pacing, it is expected that the APQ contains questions that are clinically

relevant and understandable. It is intended that the APQ is used across a heterogeneous group of patients with chronic conditions and by a variety of healthcare professionals. In terms of feasibility, the APQ is inexpensive, easy-to-use, and may be administered by post or in healthcare settings.

Although a heterogeneous sample was involved, the sample of each stage of the study may have limited generalisability. As stated previously, the expert panel involved in the Delphi technique involved fewer patients than envisaged (n=13 envisaged, n=4 completed). Due to the disproportionate dropout rates during the three rounds of Delphi, this stage may be affected by attrition bias (Juni et al., 2001). If this stage were to be repeated, a greater proportion of patients would be invited to participate in the light of the lower recruitment rates. Despite the small number of patients, this is the first study to which the author is aware that has involved both patients and clinicians in the development of an activity pacing questionnaire.

The generalisability of the sample involved in Stage II, the psychometric study, may be limited due to differences between the responders and non-responders. Those taking part were more likely to be female, older, report a longer duration of their condition, and have attended a rehabilitation group and completed their treatment. Furthermore, the test-retest arm of Stage II involved only current patients for practical purposes of recruitment. It was expected that current patients may have higher response rates due to increased relevance of the study. Indeed, higher recruitment rates were observed among current patients (19.7% and 30.5%, individual and group treatment respectively) in comparison to retrospective patients (12.6% before reminders). However, the study recruited to target which permitted reliable factor analysis and test-retest analysis on the sample of respondents.

The sample size of the acceptability interviews (n=16) was smaller than envisaged (n=20-30), which may limit the transferability of the findings. However, the author believed that data saturation had been reached. Moreover, it was not intended that the qualitative sample was statistically representative of the population. Instead, the interview sample was purposive, and deemed appropriate to represent the range of patients with chronic conditions who were involved in Stage II.

The method of recruitment was selected specifically according to the design of each stage of the study, whilst attempting to minimise bias. As such, purposive sampling was selected for the qualitative methods of Stages I and III, and consecutive sampling for Stage II. Throughout the whole study, the sample was limited to those individuals with a good understanding of the English language, and the sample did not access participants who may be considered 'hard-to-reach', such as those who do not attend health services. This may reduce the external validity of the findings, that is, the generalisability to other populations (Juni et al., 2001). However, it was beyond the scope of the study to translate the development stages of the APQ into different languages. Furthermore, the aim of the study was to develop the APQ for clinical use for those who do attend the health services.

Each stage of the study lasted longer than envisaged. This was due to a larger panel in Stage I than envisaged (n=42 completed, versus n=33 envisaged), leading to increased data analysis. The lower response rates in Stage II resulted in wider recruitment from two sites, and consequently more administrative work. Furthermore, the qualitative data of Stage III required more time to transcribe and analyse than predicted. The impact of this may have been some loss of participant motivation or interest in the study. With this in mind, future study may involve sending more study packs simultaneously across different sites. In addition, it is foreseen that with increased research experience, the processes of data collection, entry and analysis will become more efficient. However, the use of reminder questionnaires and telephone calls was beneficial to increase the recruitment rates in an attempt to reduce non-response bias (Edwards et al., 2002).

As discussed in Chapters 5-7, bias may have arisen during each stage of the study. One source of bias is the influence of the researcher on the design of the study, the collection of data and data analysis. However, methods were implemented to reduce bias and increase transparency of the study. Strategies included 'quasi-anonymity' of participants, clear audit trails, and the encouragement of participant comments to highlight queries or omissions at each stage of the study. The quantitative data were cross-checked for accuracy, and the iterative analysis of qualitative data improved repeatability and checking for anomalies. However, as is usual, the data from questionnaires or interviews were subjective. No objective measures were employed in the study which may be a potential limitation.

Finally, it cannot be assumed that the APQ is a 'perfect' representation of pacing. A different expert panel in Stage I may have generated a different item pool, and therefore different themes of pacing may have emerged in Stage II. Indeed, a different research team may have analysed the data differently from each stage of the study and removed different items according to varying criteria. It may be that the concept of activity pacing itself may continue to evolve over time with increasing knowledge regarding the management of chronic conditions. However, the APQ appears to have face validity in terms of reflecting both existing literature and opinions of clinicians and patients. Moreover, in the absence of a gold standard measure of pacing, the author proposes that the APQ is currently the most comprehensive and acceptable activity pacing scale.

8.6 Personal development

As a researcher, the mixed method study has increased my knowledge of different research designs, specifically: consensus, questionnaire and interview methods. Skills have been extended in statistical data analysis and framework analysis, involving SPSS and NVivo programs respectively. I have become efficient in data management, in the administration of >1,000 study packs and utilising coding systems. Skills have been developed in applying for ethical approval and ensuring research governance. I have presented posters at relevant conferences and published an article to report Stage I, the Delphi technique (Antcliff et al., 2013). Preparing manuscripts, applications for funding; and planning, writing and revising the PhD thesis have developed my writing and dissemination skills. I have gained confidence in critically appraising literature, and I have reviewed two articles for peer-reviewed journals.

As a clinician, I have gained transferable skills of increased communication, questioning, and networking. I have developed skills in presenting and explaining theoretical concepts, and applying evidence-based practice. I feel that I have an increased understanding of patients' responses to physiotherapy according to different activity behaviours through undertaking this research study. Personally, I have increased organisational and problem-solving skills, self-motivation and determination, together with improved confidence and reflective skills.

8.7 Future study

The APQ has demonstrated initial reliability and validity. However, since validity and reliability are estimations of the inference of the scores, not the scale per se, validity and reliability need to be confirmed in other circumstances (Cook and Beckman, 2006). Indeed, validation is considered to be an ongoing assessment (Cook and Beckman, 2006). Therefore, the APQ requires further validation using a different sample. Future study could involve patients with other chronic conditions, for example, osteoarthritis and rheumatoid arthritis to whom pacing strategies are recommended. Such study would allow comparisons of pacing habits between different conditions. In addition, if the APQ proves to be a useful measure, it may be validated in other languages to increase its clinical utility.

The APQ currently contains 30 items but it is envisaged that future study will lead to the redundancy of further questions. This may be especially apparent in the largest factor, Activity limitation, in which some items may be repetitive. A reduction in the number of items could ease the completion of the APQ, since this was the most commonly reported problem associated with the scale. Future study may confirm the five factor solution of the APQ, together with the factor loadings of the APQ items. Furthermore, the conceptual relationship between the five themes of pacing in terms of overlap/order of implementation requires further investigation. This may clarify whether Activity progression is a component or a phase of pacing. Moreover, future study could explore the debate between symptom- and quota-contingency. Further study may identify that the APQ has omitted facets that are important to pacing, such as the speed of activities, or 'finding a baseline'.

At present, there is a paucity of literature regarding the effects of pacing on patients' symptoms, and studies have employed predominantly correlative investigations. Since pacing has previously been measured as an adaptive strategy and found to have associations with avoidance and worse symptoms (Kindermans et al., 2011), the author suggests that future research is required to explore the effects of pacing as a multifaceted construct. The APQ has the potential to assess the effects of specific themes of pacing in future longitudinal studies. The author proposes that improved and worsened symptoms may be seen according to different themes of pacing. This may confirm possible correlations between improved symptoms and Activity consistency,

and clarify the effects of Activity progression. Furthermore, investigating the effects of pacing on patients' symptoms may potentially highlight anomalies in the scale if unusual findings are shown (Cook and Beckman, 2006).

In addition to the symptoms measured in the study, future study would benefit from assessing self-efficacy. Self-efficacy has previously been associated with pacing (Turner et al., 2005), and is a facet of the fear-avoidance model (Asmundson et al., 1997; Woby et al., 2007). Moreover, self-efficacy is considered to be an important determinant in the implementation of an action, as observed in the HBM and the TPB. Future study could expand on the conceptual model of pacing by exploring factors such as different 'cues to action' to develop the HBM, and to explore whether pain and fatigue are catalysts or obstacles to develop the TPB.

In the absence of a gold standard measure of pacing with which to compare the APQ, objective measures of physical activity would benefit future studies. The gold standard measure of physical activity is the doubly labelled water technique (Griffin et al., 2012). This measures energy expenditure via average daily metabolic rate, which is assessed from isotope levels in urine samples (Verbunt et al., 2001). However, the doubly labelled water technique is costly and requires complex analyses (Verbunt et al., 2001). More feasible objective measures of physical activity include accelerometers or pedometers (Griffin et al., 2012). Longitudinal studies may measure the effects of pacing when it is delivered as a lone treatment, since most existing studies have implemented pacing alongside other interventions. Additionally, longitudinal studies could explore the sensitivity to change of the APQ. This would determine the minimally important change in the APQ that demonstrates a change in pacing behaviour.

This study has added evidence to hypotheses that pacing is a complex strategy. This may initiate interesting discussions into the multifaceted nature of pacing, or the possible multi-phase nature of pacing. The APQ may be used as a process measure, if utilised to measure patients' change in pacing habits, or as an outcome measure, in association with changes in patients' symptoms. Once its behaviour and properties are better understood, the APQ could be used as a measure of pacing to assess the efficacy of rehabilitation interventions.

8.8 Implications for clinical practice and policy

Holistic treatments are advised to manage overlapping symptoms commonly presented in chronic conditions (Aggarwal et al., 2006). However, within this holism it is imperative to individually tailor treatments. If treatments are tailored according to avoidant, persistent and fluctuating activity behaviours, improved outcomes may be seen (Murphy et al., 2010; van Koulil et al., 2010). Following further refinement and validation, the APQ could potentially be used clinically to identify subgroups of patients with different activity behaviours and to facilitate the implementation of tailored treatments. Furthermore, the APQ could be used to measure patient's pacing behaviours and changes in behaviour that occur with treatment.

This study identified five themes of pacing in the APQ, and a number of items within each theme. At present, there is no consensus of definition of pacing, and pacing is instructed to patients according to varying strategies. With future confirmation of the themes of the APQ, a comprehensive operational definition of pacing could be developed, the facets of which could be instructed in the clinical setting.

It is noteworthy that this study showed that Activity limitation, Activity planning, Activity progression and Activity acceptance were associated with worse symptoms, whereas Activity consistency was associated with improved symptoms. Clinicians should be aware of the potential impact of different pacing themes on the effects on patients' symptoms. If similar results are found in longitudinal studies, it may be that clinicians implement strategies of Activity consistency into rehabilitation programmes. On confirmation of such findings, recommendations can be added to clarify the enigma of pacing that exists in guidelines such as the National Institute for Clinical Excellence guidelines for CFS/ME (NICE, 2007).

8.9 Conclusion

The three stage mixed methods study fulfilled the original aim of the study to develop an activity pacing questionnaire for chronic pain and/or fatigue. The originality of this study includes being the first study of which the author is aware that has developed a pacing scale by synthesising the views of both patients and clinicians. As a result, the 30 items of the APQ appear to contain a more comprehensive description of pacing in comparison to existing pacing subscales. The APQ has shown initial validity, reliability and acceptability among patients with chronic conditions. Future research will confirm the psychometric properties of the APQ, to include the five themes of pacing: Activity limitation, Activity planning, Activity progression, Activity consistency and Activity acceptance. This study has facilitated the development of a conceptual model for pacing, and highlighted trends of activity behaviours to include Task avoidance, Task persistence, Task fluctuation and Task modification (activity pacing).

Future study may implement the APQ to measure how patients with chronic conditions pace their activities and how this ability changes with treatment, as both a measure of patients' progress and treatment efficacy. Following further validation, if the APQ is shown to be a robust measure of pacing, it can be utilised to investigate the effects of pacing on the symptoms of patients with chronic pain and/or fatigue. This would add empirical evidence to what is at present a coping strategy of unknown clinical benefits (Birkholtz et al., 2004a; NICE, 2007; Gill and Brown, 2009).

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APPENDICES

Chapter 5. Stage I: The development of the activity pacing questionnaire (APQ): A Delphi technique

Appendix 1. Letter of ethical approval for the Delphi study

Oldham Local Research Ethics Committee
Room 181
Gateway House
Piccadilly South
Manchester
M60 7LP

Telephone: 0161 237 2336
Facsimile: 0161 237 2383

15 June 2009

Dr Steve Woby
Research & Development Manager
The Pennine Acute Hospitals NHS Trust
North Manchester General Hospital
Trust HQ, 1st Floor, Room 138
Crumpsall, Manchester
M8 5RB

Dear Dr Woby

Study Title:	**The Development of an Activity Pacing Questionnaire for chronic pain and/or fatigue: A Delphi Technique.**
REC reference number:	**09/H1011/49**
Protocol number:	**1**

The Research Ethics Committee reviewed the above application at the meeting held on 11 June 2009. The Committee thanks Miss Antcliff for attending to discuss the study.

Ethical opinion

The Committee asked at which point confidentiality moved to anonymity and Miss Antcliff explained that the responses would be allocated a code and analysis would be only of the coded responses. A separate list will be kept of which codes have not responded to follow up.

Miss Antcliff told the Committee that ethnicity of the health professionals was requested just as it would be for patients – diversity underlies why the carry out research, to get different ideas. She also explained that the questionnaires are sent out in the post prior to the clinic so that potential participants have an opportunity to read the information prior to attending the clinic.

The members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion

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

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

For NHS research sites only, management permission for research ("R&D approval") should be obtained from the relevant care organisation(s) in accordance with NHS research governance arrangements. Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk. Where the only involvement of the NHS organisation is as a Participant Identification Centre, management permission for research is not required but the R&D office should be notified of the study. Guidance should be sought from the R&D office where necessary.

Sponsors are not required to notify the Committee of approvals from host organisations.

It is responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The documents reviewed and approved at the meeting were:

Document	*Version*	*Date*
CV - Deborah Antcliff		21 May 2009
Participant Consent Form: Patient	1	26 May 2009
Participant Consent Form: Clinician	1	26 May 2009
Participant Information Sheet	1	26 May 2009
GP/Consultant Information Sheets	1	26 May 2009
Letter of invitation to participant	1	26 May 2009
Questionnaire: Patient Background Questions and Round1 Delphi	1	26 May 2009
Questionnaire: Clinical Background Questions and Round 1 Delphi	1	26 May 2009
Protocol	1	26 May 2009
Investigator CV		
Sponsor Signature		01 June 2009
Application	2.0	26 May 2009

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

Statement of compliance

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

After ethical review

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

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

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

- Notifying substantial amendments
- Adding new sites and investigators
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

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

09/H1011/49	**Please quote this number on all correspondence**

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

Yours sincerely

Professor Jois Stansfield
Vice-Chair

Email: carol.ebenezer@northwest.nhs.uk

Enclosures: *List of names and professions of members who were present at the meeting and those who submitted written comments*
"After ethical review – guidance for researchers"

Copy to: *Dr Keith Wiener*

Oldham Local Research Ethics Committee

Attendance at Committee meeting on 11 June 2009

Committee Members:

Name	*Profession*	*Present*	*Notes*
Mr John Addison	Manager, Education Centre Libraries	Yes	
Mrs Samantha Byres	Senior Pharmacist	Yes	
Mrs Anne Carpenter	Lay Member	Yes	
Miss Wendy Cook	Oncology Research Nurse	Yes	
Mr Dominic Franklin	Lay Member	Yes	
Dr Peter Stanley Klimiuk	Consultant Rheumatologist	No	
Dr Alan Nye	General Practitioner	No	
Mrs Julie Owen	Clinical Nurse Manager, Rehab/Rheumatology	Yes	
Dr Nandhini Prakash	Consultant Paediatrician	Yes	
Dr Steven Pryjmachuk	Lecturer	Yes	
Professor Jois Stansfield	Professor of Speech Pathology	Yes	
Dr Chithambaran Veerappan	Associate Specialist, Anaesthetics	No	
Mr Mohammed Zubair	PhD Student	Yes	

Also in attendance:

Name	*Position (or reason for attending)*
Mrs Carol Ebenezer	Committee Co-ordinator
Miss Shehnaz Ishaq	Assistant Co-ordinator

Appendix 2. Patient invitation letter, information booklet and Round 1 of Delphi

(The clinician invitation letter and information booklet were very similar to those written for patients, with the exception of a few appropriate alterations.)

Physiotherapy Department A
North Manchester General Hospital
Delaunays Road
Crumpsall
Manchester
M8 5RB

Insert date

Dear

You have been referred to physiotherapy by your doctor for your (*insert condition: back pain/chronic widespread pain/chronic fatigue syndrome/ME)*. The physiotherapy department is currently undertaking a research study to develop a new questionnaire that can be used to assess activity pacing. The attached information is to invite you to participate in this research study. Accompanying this letter you will find an information booklet about the research study, two consent forms, background questions and the first study questionnaire. Please take a moment to read the information booklet before deciding whether to take part in the study or not. There will be a total of three rounds of questionnaires to complete including this one. Each round of questionnaires should take no longer than thirty minutes to answer and the study is expected to last approximately four months. Your personal details and your answers to the questionnaires will remain strictly confidential throughout the study.

If you decide to take part, please complete the hospital copy of the consent form, the background questions and the first study questionnaire. Once complete, please return these documents to the physiotherapy department in the prepaid envelope provided within three weeks. Please sign the personal copy of the consent form and keep this together with the study information booklet for your own records. If you are suitable for the study, the next questionnaire will be sent out to you in approximately three weeks via post or e-mail according to your preference. If the consent form is not received back in three weeks, it will be assumed that you do not wish to participate in the study and no further contact will be made.

You will receive the same physiotherapy treatment whether you decide to participate or not. You need to follow the instructions to contact the physiotherapy department when you receive the letter asking you to make a physiotherapy appointment.

Thank you for taking the time to read this information.

Yours Sincerely

Deborah Antcliff BSc (Hons), MCSP
(Senior Physiotherapist)

MANCHESTER 1824
The University of Manchester

The Pennine Acute Hospitals NHS
NHS Trust

Physiotherapy Department A
North Manchester General Hospital
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PARTICIPANT INFORMATION BOOKLET

TITLE OF THE STUDY: The development of an activity pacing questionnaire for chronic pain and/or fatigue: A Delphi technique.

You are being invited to take part in a research study to develop a questionnaire looking at activity pacing. The questionnaire will be developed using a Delphi technique which is explained below. Before you decide whether to take part, 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. Ask us if there is anything that is not clear, or if you would like more information.

What is the purpose of the study?

Medical conditions that have been present for three months or longer are said to be chronic conditions. Examples include chronic low back pain, chronic widespread pain (sometimes called fibromyalgia) and chronic fatigue syndrome/myalgic encephalomyelitis (ME). Healthcare workers try to help manage these chronic conditions with different techniques, including activity pacing. There are many different opinions about what activity pacing actually involves. For some people, activity pacing involves breaking down tasks into manageable pieces, whereas for others it involves spreading activities out over a period of time. Other people would say that activity pacing does not involve either of these things. It is important that treatments can change the way patients pace their activity. In order to assess whether treatments can change pacing, we need a way of measuring how well a person paces their activity. At the moment there are no widely used measures that can assess how well a person paces. The aim of this study is to develop a questionnaire that can be used to measure activity pacing. The Delphi technique will be used to help us develop the questionnaire.

What is the Delphi Technique?

The Delphi technique is a method of reaching an agreement about a subject where previously there has been limited or inconclusive information. The Delphi technique used in this study will involve sending three ‘rounds’ of questionnaires to an expert panel of patients and clinicians to reach an agreement of what questions should be included in the activity pacing questionnaire.

Why have I been chosen?

Your doctor has referred you for physiotherapy because of your *(insert condition)*. You may therefore be suitable to take part in this study. It is important that you complete the background questions so that we can see if you are suitable for the study.

Do I have to take part?

It is up to you to decide whether or not to take part. You will receive the same physiotherapy treatment whether you participate in the study or not. If no response is made within three weeks, it will be assumed that you do not wish to participate in the study and no further contact will be made. If you do 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. **Whether you decide to take part in the study or not, you need to follow the instructions to contact the physiotherapy department when you receive the letter asking you to make a physiotherapy appointment.**

What will the study involve?

If you agree to participate please complete both consent forms, the background questions and round one of Delphi. Round one requires you to list what you consider to be the ten most important factors involved in activity pacing. Each round of Delphi should take no more than thirty minutes to complete. You can receive rounds two and three by either post or e-mail.

Once we have checked that you meet the inclusion criteria, you will be sent round two approximately three weeks after the deadline for round one. In the unlikely situation that you do not meet the inclusion criteria you will not receive any further rounds of questions. Round two will require you to rate a list of possible questions to be included in the activity pacing questionnaire. You will be asked to return round two within three weeks of receiving the questions. If no reply is made after two weeks you may receive a telephone call reminder and then be given one more week to complete the questionnaire.

If round two is returned, round three will be sent out to you approximately two weeks after the round two deadline. Round three will require you to rate the same questions as round two. However, on round three you will also be shown the group scores for round two, any important comments and your own previous scores. You will be asked to return round three within three weeks, and you may receive a telephone reminder if you have not replied after two weeks. If you complete round three you will be sent a copy of the questions to be included and excluded in the final questionnaire approximately two weeks after round three is returned.

What are the possible disadvantages or risks of taking part?

There are no risks associated with taking part in the study. The only inconvenience associated with participating in the study is the completion of three rounds of Delphi. The first round is enclosed with

this information booklet. Each round should take no longer than thirty minutes to complete and you will have three weeks to return each round. Pre-paid envelopes will be provided for each round if you choose to complete Delphi via post. You can alternatively complete round two and three via e-mail. The whole study is expected to last approximately four months.

What are the possible benefits of taking part?

If you participate in the study your opinions will be used to help to decide what questions should be included in an activity pacing questionnaire for chronic pain and/or fatigue. If this questionnaire is shown to be valid and reliable, it can be used by healthcare professionals to assess how patients pace their activities.

What if new information becomes available?

Sometimes during the course of a research study, new information becomes available about the subject that is being studied. If this happens, we will tell you about it and discuss with you whether you want to continue in the study. If you decide to withdraw it will not affect the physiotherapy treatment you receive. If you decide to continue in the study you will be asked to sign an updated consent form.

On receiving new information, we might consider it to be in your best interests to withdraw you from the study. If this happens, we will explain the reasons and arrange for your care to continue.

What will happen if I do not want to carry on with the study once I have consented?

You are free to withdraw from the study at any stage and without giving an explanation. If you do not respond to any of the three rounds of Delphi within the deadlines provided then we will assume that you do not wish to continue in the study and no further contact will be made. If you stop participating in the study, any data collected in previous rounds of Delphi will be recorded as incomplete data. If you inform us that you wish to withdraw completely from the study we will destroy your data. Only the results from round three will determine the exact content of the final activity pacing questionnaire. Your physiotherapy treatment will not be affected by the completion of the study.

Will my taking part in this study be kept confidential?

If you agree to participate, any information about you will be kept strictly confidential by the research team. Any information about you that leaves the hospital will have your name and address removed so that it does not identify you. On round one of Delphi you will be allocated a study code which will be recorded on the front of all of your questionnaires. This study code will be used throughout any data collection or analysis. You will remain anonymous within the expert panel and you will not be identified by any comments you make during the Delphi rounds or in any publication of the study. Participant codes and responses will not be seen by anyone other than those involved in the research team.

The research team will however need to keep a separate log of your identity, post or e-mail address and telephone number with your individual code in order to complete the Delphi rounds. This is

required so that on round three we can provide you with the answers you gave in round two. Paper copies of the rounds of Delphi will be kept securely by the research team throughout the duration of the study. Once the study is complete, the raw data will be kept securely by University of Manchester for ten years and then it will be destroyed.

What if something goes wrong?

In the unlikely event that you are harmed by taking part in this research study due to negligence, you may have grounds for a legal action. However, you may have to pay for any legal action. If you wish to complain, or have any concerns about the way you have been approached or treated during the course of this study by trust employees and you do not feel able to discuss this with the research team, the normal National Health Service complaints procedures will be available to you.

What will happen to the results of the research study?

The results of the study will be published in a medical journal. If you are interested in obtaining a copy of any publication please feel free to contact us. We would like to assure you that you, as an individual will not be identified in any publication of the study.

Who is organising and funding the research?

The study is organised by The Pennine Acute Hospitals NHS Trust and The University of Manchester, School of Medicine. This study is funded by a Pennine Acute Hospitals Research and Development Grant.

Who has reviewed the study?

This study has been reviewed and granted ethical approval by the Oldham Research Ethics Committee.

Contact for Further Information

For further information about the study, please contact Miss Deborah Antcliff or Dr Steve Woby at North Manchester General Hospital on 0161 720 2423. You can also send your question by e-mail on Deborah.Antcliff@pat.nhs.uk or Steve.Woby@pat.nhs.uk

What do I do now?

If you wish to participate in the study, please complete and return the hospital consent form, the background questions and round one of Delphi in the pre-paid addressed envelope enclosed within three weeks of receiving this letter. Please sign and keep the personal copy of the consent form and the study information for your own records. **Whether you wish to participate in the study or not, please follow the instructions when you receive your letter from the physiotherapy department to make a physiotherapy appointment.**

Thank you for your time in reading this information sheet.

The University of Manchester

The Pennine Acute Hospitals NHS Trust

Physiotherapy Department A
North Manchester General
Hospital
Delaunays Road
Crumpsall
Manchester
M8 5RB

CONSENT FORM

HOSPITAL COPY

Study Code ☐

Title of Project: The development of an activity pacing questionnaire for chronic pain and/or fatigue: A Delphi technique

Name of Researcher: Miss Deborah Antcliff

1. *Please tick*

I confirm that I have read the information booklet dated May 2009. I have understood what the study involves and I have had the opportunity to ask any questions. I am aware that I can contact the research team at any point during the study. ☐

2. *Please tick*

I understand that my participation is voluntary and I am free to withdraw at any time, without giving any reason, and without my medical care or legal rights being affected. ☐

3. *Please tick*

I agree to participate in this questionnaire design study. ☐

4. *Please tick*

I consent to receiving a telephone call reminder if round two or three of Delphi are not returned two weeks after being sent. ☐

Name of participant	Today's date	Signature
Name of person taking consent	Today's date	Signature

The University of Manchester

The Pennine Acute Hospitals NHS Trust

Physiotherapy Department A
North Manchester General
Hospital
Delaunays Road
Crumpsall
Manchester
M8 5RB

CONSENT FORM

PERSONAL COPY

Study Code ☐

Title of Project: The development of an activity pacing questionnaire for chronic pain and/or fatigue: A Delphi technique

Name of Researcher: Miss Deborah Antcliff

1. *Please tick*

I confirm that I have read the information booklet dated May 2009. I have understood what the study involves and I have had the opportunity to ask any questions. I am aware that I can contact the research team at any point during the study. ☐

2. *Please tick*

I understand that my participation is voluntary and I am free to withdraw at any time, without giving any reason, and without my medical care or legal rights being affected. ☐

3. *Please tick*

I agree to participate in this questionnaire design study. ☐

4. *Please tick*

I consent to receiving a telephone call reminder if round two or three of Delphi are not returned two weeks after being sent. ☐

Name of participant	Today's date	Signature
Name of person taking consent	Today's date	Signature

MANCHESTER 1824

The University of Manchester

The Pennine Acute Hospitals NHS Trust

BACKGROUND QUESTIONS

Study code ☐ Today's date _____

Instructions for Completion

1. Where there are a choice of answers, please tick the appropriate box(es)

For example, Are you?

employed	✓
unemployed	
self-employed	
retired	

2. Where there is a box marked with a unit, please enter the appropriate values

For example, 40 Years 10 Months

Please write a number in the box

1. How old are you? ☐ Years ☐ Months

Please tick

2. Are you? ☐ Male ☐ Female

Please tick one box

3. What is your ethnic group?

- ☐ White
- ☐ Mixed
- ☐ Asian or Asian British
- ☐ Black or Black British
- ☐ Chinese
- ☐ Other ethnic group *(please state)* _____

Please tick any box that applies

4. Do you have?

- ☐ Back pain
- ☐ Pains on many different sites
- ☐ Fibromyalgia
- ☐ Chronic fatigue syndrome
- ☐ Myalgic encephalomyelitis
- ☐ Other condition *(please state)* _____

Please write a number in the box

5. How long have you had the above condition?

☐ Years ☐ Months

(If you have ticked more than one condition, please state how long you have had the longest standing condition)

(Please continue on page 3)

Please tick one box

6. Are you?

- ☐ Working full-time
- ☐ Working part-time
- ☐ Not working because of the above condition
- ☐ Not working, but not because of the above condition
- ☐ Unemployed but seeking work
- ☐ Working full time at home
- ☐ Student
- ☐ Retired
- ☐ Semi-retired
- ☐ Other *(please state)*_____

Please tick

7. Are you a member of a support group?

☐ Yes ☐ No

Please state (e.g. ME support group) _____

8. What is your preferred method of receiving round two and three of Delphi?

☐ Post ☐ E-mail

E-mail address_____

9. Do you consent to receiving a telephone reminder if round two or three of Delphi have not been returned two weeks after being sent to you?

☐ Yes ☐ No

Telephone Number _____

Thank you for completing the above questions. Please now complete Delphi round 1

MANCHESTER 1824

The University of Manchester

The Pennine Acute Hospitals NHS Trust

DELPHI: ROUND 1

Study code

Date Round 1 sent: _____

Date Round 1 due back: _____

Only complete this question if you are the named person participating in the study

Healthcare professionals advise patients to manage their symptoms using different coping strategies. One strategy that is frequently recommended is activity pacing. There are different opinions about what activity pacing actually involves. For example, for some, activity pacing involves breaking down tasks into manageable pieces, whereas for others it involves spreading activities out over a period of time. Other people would say that activity pacing does not involve either of these things.

In your opinion what do you think activity pacing involves? There are no right or wrong answers. Please list up to 10 answers. If you cannot list ten answers, give as many as you can. You can make additional comments in the space provided on page 5.

1. _____

2. _____

3. _____

4. _____

5. _____

(Please continue on page 5)

(Continue your answer from page 4 here)

6. _____

7. _____

8. _____

9. _____

10. _____

Additional comments can be written in the box below:

Thank you for taking the time to complete round one of Delphi. We would be grateful if you can now return round one, together with the background questions and the signed hospital copy of the consent form in the pre-paid envelope to North Manchester General Hospital within three weeks. You will then receive round two in about three weeks.

Appendix 3. Delphi Round 2 covering letter and questionnaire

(This was the same for both patients and clinicians)

Physiotherapy Department A
North Manchester General Hospital
Delaunays Road
Crumpsall
Manchester
M8 5RB
Deborah.Antcliff@pat.nhs.uk

Tel No. 0161 720 2423
Fax No. 0161 720 2490

Insert date

Dear

Thank you for your participation in the research study to develop an Activity Pacing Questionnaire for chronic pain and/or fatigue. There has been an excellent response to Round 1 of Delphi, and there have been a large number of answers in response to the initial question. As a consequence of this excellent response, it has taken longer than anticipated to analyse all of the answers that were received in Round 1, which has led to a slight delay in sending out Round 2. Round 2 consists of a list of questions that could possibly be contained in the Activity Pacing Questionnaire. These questions are based on the answers that were received in Round 1. Round 2 of Delphi involves you rating the extent to which you think that each question should be included in the Activity Pacing Questionnaire.

Since there were such a diverse number of responses in Round 1, a large pool of questions has been generated for Round 2. It is usual at this stage of developing a questionnaire for there to be a far greater number of questions than is expected to be included in the final questionnaire. In addition, some of the questions may appear to be quite similar to each other, which once again is quite normal at this stage of questionnaire development.

I would be most grateful if you would take the time to complete Round 2 and return it within approximately 3 weeks. Round 3 will then be sent in approximately 8 weeks to decide which questions reach a consensus of agreement to be included in the final Activity Pacing Questionnaire.

I would like to take this opportunity to thank you for your continuing help in this research study.

Yours Sincerely

Deborah Antcliff BSc (Hons), MCSP
(Senior Physiotherapist)

MANCHESTER 1824

The University of Manchester

The Pennine Acute Hospitals NHS Trust

DELPHI: ROUND 2

Study code

Date Round 2 sent:

Date Round 2 due back:

Thank you for completing Round 1 of Delphi. The information gathered in Round 1 has been used to develop a list of questions that could be included in the Activity Pacing Questionnaire for chronic pain and/or fatigue. The questions in the Activity Pacing Questionnaire are designed to be answered by patients with chronic pain and/or fatigue based on their activity over the previous week. The activity that the questionnaire refers to includes physical, mental, social, emotional, work and self-care activities.

Please read each of the following questions carefully and record the extent to which you think that each question should be included in the Activity Pacing Questionnaire. Remember, you are not rating how much you do the action in the question, you are rating whether the question should be included in the Activity Pacing Questionnaire.

A section has been included at the end of the questionnaire should you wish to make additional comments. Please complete this round and return it within 3 weeks in the pre-paid envelope provided. If you consented to a telephone reminder, you may receive a call if the questionnaire has not been returned after 2 weeks.

Please rate the extent to which you think each question should be included in the Activity Pacing Questionnaire for chronic pain and/or fatigue. Please rate each question on a scale from 0 to 4, where 0 means you completely disagree that the question should be included in the questionnaire, and 4 means you completely agree that the question should be included in the questionnaire.

Please mark your answer with a cross in <u>one</u> box for each question.

	Over the past week…	Completely Disagree **(0)**	Disagree **(1)**	Neither Agree nor Disagree **(2)**	Agree **(3)**	Completely Agree **(4)**
1	I broke down activities into manageable pieces	☐	☐	☐	☐	☐
2	I broke a difficult activity down into parts and then built it up in manageable steps	☐	☐	☐	☐	☐
3	I split activities up and did parts throughout the week	☐	☐	☐	☐	☐
4	I focused on doing one activity at a time	☐	☐	☐	☐	☐
5	I broke tasks up into periods of activity and rest	☐	☐	☐	☐	☐
6	I divided the day up into periods of activity and rest	☐	☐	☐	☐	☐
7	I made sure I had a rest period after being active	☐	☐	☐	☐	☐
8	I took a short rest from activity so that I could complete the activity later	☐	☐	☐	☐	☐

		Completely Disagree **(0)**	Disagree **(1)**	Neither Agree nor Disagree **(2)**	Agree **(3)**	Completely Agree **(4)**
9	I took regular breaks whilst doing an activity	☐	☐	☐	☐	☐
10	I stopped an activity and had a rest before I did too much	☐	☐	☐	☐	☐
11	I had periods of planned rest that did not involve sleeping	☐	☐	☐	☐	☐
12	I had quality rests during the day to help to prevent an increase in my symptoms	☐	☐	☐	☐	☐
13	I used relaxation techniques	☐	☐	☐	☐	☐
14	I tried to relax if I noticed I was feeling tense	☐	☐	☐	☐	☐
15	I changed my position regularly to ease my symptoms	☐	☐	☐	☐	☐
16	I changed my position according to a set time and not according to my symptoms	☐	☐	☐	☐	☐
17	I changed activities before I had an increase in my symptoms	☐	☐	☐	☐	☐
18	I had a balance of choice and demand activities	☐	☐	☐	☐	☐

		Completely Disagree (0)	Disagree (1)	Neither Agree nor Disagree (2)	Agree (3)	Completely Agree (4)
19	I did a variety of different activities	☐	☐	☐	☐	☐
20	I alternated my activities so that I used different muscles	☐	☐	☐	☐	☐
21	I alternated the type of activity that I was doing (for example changing from a physical activity to a cognitive activity)	☐	☐	☐	☐	☐
22	I was aware of the impact that different types of activities had on me (for example physical, mental, work, social and emotional activities)	☐	☐	☐	☐	☐
23	I spread different types of activities across the day	☐	☐	☐	☐	☐
24	I spread my activities out over a set period of time	☐	☐	☐	☐	☐
25	I spread out less important tasks over a longer period of time	☐	☐	☐	☐	☐
26	I spread my activities throughout the day so that I stayed within my daily energy limit	☐	☐	☐	☐	☐
27	I spread out the activities that require a high amount of energy	☐	☐	☐	☐	☐
28	I switched between activities that use a high amount of energy and activities that use a low amount of energy	☐	☐	☐	☐	☐

		Completely Disagree **(0)**	Disagree **(1)**	Neither Agree nor Disagree **(2)**	Agree **(3)**	Completely Agree **(4)**
29	I used smaller amounts of energy in one go so that I could spread my energy out over a longer period of time	☐	☐	☐	☐	☐
30	I reduced my level of activity in order to save some energy for later	☐	☐	☐	☐	☐
31	I stayed within my own limits	☐	☐	☐	☐	☐
32	I changed the way I did activities so that I used less energy	☐	☐	☐	☐	☐
33	I spent less time on some activities so that I could do them every day	☐	☐	☐	☐	☐
34	I spent less time on activities that I find stressful	☐	☐	☐	☐	☐
35	I attempted fewer activities so that I could achieve more on those activities that I did attempt	☐	☐	☐	☐	☐
36	I did my activities without putting pressure on myself to complete them	☐	☐	☐	☐	☐
37	I did my activities at a slower speed	☐	☐	☐	☐	☐
38	I took my time and did not rush	☐	☐	☐	☐	☐

		Completely Disagree **(0)**	Disagree **(1)**	Neither Agree nor Disagree **(2)**	Agree **(3)**	Completely Agree **(4)**
39	I was consistent and steady with my activities	☐	☐	☐	☐	☐
40	I worked at a set speed on each task	☐	☐	☐	☐	☐
41	I did not over-do activities on a ‘good’ day	☐	☐	☐	☐	☐
42	I did not under-do activities on a ‘bad’ day	☐	☐	☐	☐	☐
43	I kept to a consistent level of activity every day	☐	☐	☐	☐	☐
44	I developed a routine so I that I had a balance between being active and inactive	☐	☐	☐	☐	☐
45	I made sure I did some activity every day, even if I had a ‘bad’ day	☐	☐	☐	☐	☐
46	I did a similar amount of activity every day despite my symptoms	☐	☐	☐	☐	☐
47	I did an amount of activity that I could manage without being forced to rest afterwards	☐	☐	☐	☐	☐
48	I did a similar level of activity on ‘good’ and ‘bad’ days	☐	☐	☐	☐	☐

		Completely Disagree **(0)**	Disagree **(1)**	Neither Agree nor Disagree **(2)**	Agree **(3)**	Completely Agree **(4)**
49	I did an amount of activity that I find challenging but realistic	☐	☐	☐	☐	☐
50	I kept to my planned activity target regardless of my symptoms	☐	☐	☐	☐	☐
51	I tried to maintain a level of activity that I had before the onset of my symptoms	☐	☐	☐	☐	☐
52	I pushed myself to finish a task	☐	☐	☐	☐	☐
53	I gradually increased activities that I had previously been avoiding because of my symptoms	☐	☐	☐	☐	☐
54	I gradually increased how long I could spend on my activities	☐	☐	☐	☐	☐
55	I gradually increased my activities despite my symptoms	☐	☐	☐	☐	☐
56	I increased the difficulty of my activities as time went on	☐	☐	☐	☐	☐
57	I did some exercise so that I would increase my fitness	☐	☐	☐	☐	☐
58	I assessed my activity levels	☐	☐	☐	☐	☐

		Completely Disagree **(0)**	Disagree **(1)**	Neither Agree nor Disagree **(2)**	Agree **(3)**	Completely Agree **(4)**
59	I used an activity diary to monitor my activity pattern	☐	☐	☐	☐	☐
60	I timed how long I spent doing different activities	☐	☐	☐	☐	☐
61	I analysed how much energy I would need to do each activity	☐	☐	☐	☐	☐
62	I set activity goals that were meaningful and realistic for me	☐	☐	☐	☐	☐
63	I changed my activity targets if they were unrealistic	☐	☐	☐	☐	☐
64	I changed unhelpful habits into more helpful habits	☐	☐	☐	☐	☐
65	I was creative and found new ways of doing tasks	☐	☐	☐	☐	☐
66	I used a problem solving approach when doing my activities	☐	☐	☐	☐	☐
67	I had a flexible and adaptable approach to my tasks	☐	☐	☐	☐	☐
68	I prioritised my activities for each day	☐	☐	☐	☐	☐

		Completely Disagree (0)	Disagree (1)	Neither Agree nor Disagree (2)	Agree (3)	Completely Agree (4)
69	I put my activities in order of importance and did the most important activity first	☐	☐	☐	☐	☐
70	I planned my activities around important events that were happening	☐	☐	☐	☐	☐
71	I planned in advance how long I would spend on each activity	☐	☐	☐	☐	☐
72	I allowed myself enough time to do a task	☐	☐	☐	☐	☐
73	I did most of my activities at the time of day when I felt most able	☐	☐	☐	☐	☐
74	I followed my own daily plan of activity	☐	☐	☐	☐	☐
75	I made myself a list of jobs that I needed to do	☐	☐	☐	☐	☐
76	I used support from others to help me with my activities if required	☐	☐	☐	☐	☐
77	I was able to share out some tasks if I was unable to do all of them myself	☐	☐	☐	☐	☐
78	I was able to say ‘no’ if I was unable to do an activity	☐	☐	☐	☐	☐

		Completely Disagree (0)	Disagree (1)	Neither Agree nor Disagree (2)	Agree (3)	Completely Agree (4)
79	I organised any help or equipment that I needed to do my activities if required	☐	☐	☐	☐	☐
80	I used energy saving techniques or equipment	☐	☐	☐	☐	☐
81	I reduced my use of aids or adaptive equipment	☐	☐	☐	☐	☐
82	I rewarded myself if I did an activity that I found challenging	☐	☐	☐	☐	☐
83	I accepted that I have some limitations due to my symptoms	☐	☐	☐	☐	☐
84	I did not feel guilty when I stopped an activity	☐	☐	☐	☐	☐
85	I set realistic time limits for specific tasks so that I did not over-do things	☐	☐	☐	☐	☐
86	I worked on a task for a set amount of time/distance and not according to my symptoms	☐	☐	☐	☐	☐
87	I did a set amount of activity regardless of how I felt emotionally	☐	☐	☐	☐	☐
88	I avoided over-doing activities that I thought might cause a flare up of my symptoms	☐	☐	☐	☐	☐

		Completely Disagree **(0)**	Disagree **(1)**	Neither Agree nor Disagree **(2)**	Agree **(3)**	Completely Agree **(4)**
89	I made sure I had a flare up plan	☐	☐	☐	☐	☐
90	My symptoms decided how much activity I did each day	☐	☐	☐	☐	☐
91	I listened to my body and took a break when my symptoms increased	☐	☐	☐	☐	☐
92	I avoided working at levels of discomfort so that I did not increase my symptoms	☐	☐	☐	☐	☐
93	I stopped an activity if it increased my symptoms beyond a level that I can manage	☐	☐	☐	☐	☐
94	I stopped an activity before I became too tired	☐	☐	☐	☐	☐

Please make any comments about specific questions in the table below. If you decide to make any comments please note that these comments may be displayed on Round 3 of Delphi for all participants to see. All comments will remain anonymous and you will not be identified by any comments that you wish to make.

Question Number	Comments

General comments can be made in the box below:

Thank you for completing Round 2 of Delphi. Please now return this round in the pre-paid envelope provided. Please return this round by 8th December 2009. If you consented to receiving a telephone reminder you may receive a call if this round is not returned after 2 weeks.

If you return this round within 3 weeks, you will receive Round 3, approximately 8 weeks after the deadline for Round 2. Round 3 will be the last round of Delphi.

Appendix 4. Delphi Round 3 covering letter

(The questionnaire was the same as Round 2 with participants' answers from Round 2 highlighted by a red text box and the group percentage scores under each point on the Likert scale)

Physiotherapy Department A
North Manchester General Hospital
Delaunays Road
Crumpsall
Manchester
M8 5RB
Deborah.Antcliff@pat.nhs.uk

Tel No. 0161 720 2423
Fax No. 0161 720 2490

Insert date

Dear

Thank you for your ongoing participation in the research study to develop an Activity Pacing Questionnaire for chronic pain and/or fatigue. The results from Round 2 have been used to calculate the extent to which all of the participants think that each question should be included in the final Activity Pacing Questionnaire. This has been calculated as percentage scores. Round 3 contains the same questions as Round 2, together with the percentage scores and your own individual scores from Round 2. In addition, there is a Comments Booklet which highlights suggestions made by other participants about some of the questions. The purpose of Round 3 is to reach a consensus about which questions should be included in the final questionnaire by looking at the group scores and comments from Round 2.

I would be most grateful if you would take the time to complete Round 3 and return it within approximately 3 weeks in the prepaid envelope. Round 3 will be the last round of the Delphi process. If you wish to receive a copy of the final scores for each question please tick the box on page 13 of the Delphi Round 3 booklet, and this will be sent out in approximately 8 weeks.

I would like to take this opportunity to thank you for your continuing help in this research study.

Yours Sincerely

Deborah Antcliff BSc (Hons), MCSP
(Senior Physiotherapist)

Appendix 5. Delphi results tables

Appendix 5, Table 5.1
Questions voted to be included in the APQ (with readability scores)

	Qu No.	% 3 or 4 score on Round 2	% 3 or 4 score on Round 3	Readability score	Question
1	1	93%	93%	30.5	I broke down activities into manageable pieces
2	3	75%	86%	78.2	I split activities up and did parts throughout the week
3	5	69%	73%	61.3	I broke tasks up into periods of activity and rest
4	6	80%	83%	49.5	I divided each day up into periods of activity and rest
5	8	60%	71%	61.8	I took a short rest from an activity so that I could complete the activity later
6	11	77%	85%	80.3	I had periods of planned rest that did not involve sleeping
7	17	60%	71%	42.6	I changed activities before my symptoms worsened
8	19	76%	76%	30.5	I did a variety of different activities
9	21	73%	85%	61.3	I alternated the type of activity that I was doing
10	22	72%	78%	65.7	I was aware of the effect that different types of activities had on me
11	23	90%	93%	56.7	I spread different types of activities across the day
12	27	81%	93%	60.7	I spread out the activities that require a high amount of energy
13	28	79%	86%	42.6	I switched between activities that use high and low amounts of energy
14	33	66%	83%	78.8	I spent less time on some activities so that I could do them every day
15	36	80%	79%	53.6	I did my activities without putting pressure on myself to complete them

	Qu No.	% 3 or 4 score on Round 2	% 3 or 4 score on Round 3	Readability score	Question
16	41	96%	100%	66.1	I did not over-do activities on a ‘good’ day
17	42	80%	83%	66.1	I did not under-do activities on a ‘bad’ day
18	43	73%	71%	44.4	I kept to a consistent level of activity every day
19	44	74%	76%	63.6	I developed a routine so I that I had a balance between being active and inactive
20	45	98%	98%	74.2	I made sure I did some activity every day, even if I had a ‘bad’ day
21	48	69%	81%	67.7	I did a similar amount of activity on ‘good’ and ‘bad’ days
22	53	86%	90%	43.9	I gradually increased activities that I had been avoiding because of my symptoms
23	54	93%	90%	64.9	I gradually increased how long I could spend on my activities
24	58	66%	74%	32.5	I assessed my activity levels
25	59	79%	79%	19.0	I used an activity diary to monitor my activity pattern
26	62	93%	93%	66.1	I set activity goals that were meaningful to me
27	62	93%	93%	66.1	I set activity goals that were realistic for me
28	63	92%	95%	47.3	I changed my activity targets if they were unrealistic
29	65	71%	73%	100.0	I was creative and found new ways of doing tasks
30	68	91%	95%	42.6	I prioritised my activities for each day
31	70	78%	83%	57.2	I planned my activities around events that were important to me
32	71	73%	81%	81.8	I planned in advance how long I would spend on each activity

	Qu No.	% 3 or 4 score on Round 2	% 3 or 4 score on Round 3	Readability score	Question
33	76	70%	74%	69.9	I used support from others to help me with my activities if required
34	78	78%	74%	71.1	I was able to say ‘no’ if I was unable to do an activity
35	83	79%	83%	64.9	I accepted that I have some limitations due to my symptoms
36	84	71%	76%	78.2	I did not feel guilty when I stopped an activity
37	85	89%	88%	67.5	I set realistic time limits for specific tasks so that I did not over-do things
38	89	64%	73%	92.9	I made sure I had a flare-up plan

NB The readability scores are measured using the Flesch Reading Ease score. The scores shown are those following amendments to improve readability.

Appendix 5, Table 5.2
Round 3 votes for all 94 potential questions of the APQ

	Over the past week…	Completely Disagree (0)	Disagree (1)	Neither Agree nor Disagree (2)	Agree (3)	Completely Agree (4)
1	I broke down activities into manageable pieces	0%	0%	7%	29%	63%
2	I broke a difficult activity down into parts and then built it up in manageable steps	5%	14%	12%	24%	45%
3	I split activities up and did parts throughout the week	0%	2%	12%	57%	29%
4	I focused on doing one activity at a time	5%	27%	24%	24%	20%
5	I broke tasks up into periods of activity and rest	0%	12%	15%	29%	44%
6	I divided the day up into periods of activity and rest	0%	7%	10%	39%	44%
7	I made sure I had a rest period after being active	5%	34%	24%	29%	7%
8	I took a short rest from activity so that I could complete the activity later	2%	7%	19%	64%	7%
9	I took regular breaks whilst doing an activity	0%	12%	22%	39%	27%
10	I stopped an activity and had a rest before I did too much	5%	10%	17%	55%	14%
11	I had periods of planned rest that did not involve sleeping	0%	5%	10%	43%	43%
12	I had quality rests during the day to help to prevent an increase in my symptoms	2%	22%	41%	22%	12%
13	I used relaxation techniques	12%	10%	17%	29%	32%

		Completely Disagree (0)	Disagree (1)	Neither Agree nor Disagree (2)	Agree (3)	Completely Agree (4)
14	I tried to relax if I noticed I was feeling tense	8%	21%	18%	33%	21%
15	I changed my position regularly to ease my symptoms	8%	15%	23%	45%	10%
16	I changed my position according to a set time and not according to my symptoms	10%	18%	30%	33%	10%
17	I changed activities before I had an increase in my symptoms	7%	2%	20%	56%	15%
18	I had a balance of choice and demand activities	7%	15%	32%	37%	10%
19	I did a variety of different activities	2%	17%	5%	66%	10%
20	I alternated my activities so that I used different muscles	2%	10%	39%	32%	17%
21	I alternated the type of activity that I was doing (for example changing from a physical activity to a cognitive activity)	2%	0%	12%	51%	34%
22	I was aware of the impact that different types of activities had on me (for example physical, mental, work, social and emotional activities)	2%	10%	10%	39%	39%
23	I spread different types of activities across the day	0%	3%	5%	65%	28%
24	I spread my activities out over a set period of time	0%	13%	23%	58%	8%
25	I spread out less important tasks over a longer period of time	7%	12%	50%	17%	14%
26	I spread my activities throughout the day so that I stayed within my daily energy limit	10%	10%	23%	40%	18%
27	I spread out the activities that require a high amount of energy	7%	0%	0%	73%	20%

		Completely Disagree (0)	Disagree (1)	Neither Agree nor Disagree (2)	Agree (3)	Completely Agree (4)
28	I switched between activities that use a high amount of energy and activities that use a low amount of energy	7%	2%	5%	71%	14%
29	I used smaller amounts of energy in one go so that I could spread my energy out over a longer period of time	5%	20%	27%	41%	7%
30	I reduced my level of activity in order to save some energy for later	10%	33%	19%	36%	2%
31	I stayed within my own limits	7%	19%	24%	43%	7%
32	I changed the way I did activities so that I used less energy	10%	14%	26%	43%	7%
33	I spent less time on some activities so that I could do them every day	2%	5%	10%	69%	14%
34	I spent less time on activities that I find stressful	14%	29%	31%	19%	7%
35	I attempted fewer activities so that I could achieve more on those activities that I did attempt	10%	27%	24%	39%	0%
36	I did my activities without putting pressure on myself to complete them	0%	14%	7%	69%	10%
37	I did my activities at a slower speed	10%	21%	48%	17%	5%
38	I took my time and did not rush	0%	10%	64%	12%	14%
39	I was consistent and steady with my activities	0%	10%	24%	52%	14%
40	I worked at a set speed on each task	5%	36%	55%	5%	0%
41	I did not over-do activities on a ‘good’ day	0%	0%	0%	33%	67%
42	I did not under-do activities on a ‘bad’ day	5%	7%	5%	33%	50%

		Completely Disagree (0)	Disagree (1)	Neither Agree nor Disagree (2)	Agree (3)	Completely Agree (4)
43	I kept to a consistent level of activity every day	0%	12%	17%	43%	29%
44	I developed a routine so I that I had a balance between being active and inactive	0%	10%	15%	39%	37%
45	I made sure I did some activity every day, even if I had a ‘bad’ day	0%	3%	0%	35%	63%
46	I did a similar amount of activity every day despite my symptoms	5%	10%	19%	43%	24%
47	I did an amount of activity that I could manage without being forced to rest afterwards	5%	10%	20%	34%	32%
48	I did a similar level of activity on ‘good’ and ‘bad’ days	7%	7%	5%	55%	26%
49	I did an amount of activity that I find challenging but realistic	2%	17%	24%	43%	14%
50	I kept to my planned activity target regardless of my symptoms	10%	21%	24%	33%	12%
51	I tried to maintain a level of activity that I had before the onset of my symptoms	29%	43%	17%	5%	7%
52	I pushed myself to finish a task	43%	7%	29%	10%	12%
53	I gradually increased activities that I had previously been avoiding because of my symptoms	0%	2%	7%	57%	33%
54	I gradually increased how long I could spend on my activities	0%	2%	7%	62%	29%
55	I gradually increased my activities despite my symptoms	3%	23%	33%	40%	3%
56	I increased the difficulty of my activities as time went on	2%	12%	21%	55%	10%

		Completely Disagree (0)	Disagree (1)	Neither Agree nor Disagree (2)	Agree (3)	Completely Agree (4)
57	I did some exercise so that I would increase my fitness	10%	10%	23%	45%	13%
58	I assessed my activity levels	2%	5%	19%	43%	31%
59	I used an activity diary to monitor my activity pattern	2%	5%	14%	52%	26%
60	I timed how long I spent doing different activities	2%	5%	36%	48%	10%
61	I analysed how much energy I would need to do each activity	10%	12%	32%	37%	10%
62	I set activity goals that were meaningful and realistic for me	3%	0%	5%	18%	75%
63	I changed my activity targets if they were unrealistic	5%	0%	0%	29%	67%
64	I changed unhelpful habits into more helpful habits	12%	2%	26%	19%	40%
65	I was creative and found new ways of doing tasks	5%	13%	10%	48%	25%
66	I used a problem solving approach when doing my activities	5%	14%	19%	38%	24%
67	I had a flexible and adaptable approach to my tasks	2%	7%	24%	41%	24%
68	I prioritised my activities for each day	2%	2%	0%	38%	57%
69	I put my activities in order of importance and did the most important activity first	10%	17%	29%	37%	7%
70	I planned my activities around important events that were happening	2%	2%	12%	60%	24%
71	I planned in advance how long I would spend on each activity	2%	5%	12%	62%	19%

		Completely Disagree (0)	Disagree (1)	Neither Agree nor Disagree (2)	Agree (3)	Completely Agree (4)
72	I allowed myself enough time to do a task	2%	7%	43%	38%	10%
73	I did most of my activities at the time of day when I felt most able	10%	24%	29%	33%	5%
74	I followed my own daily plan of activity	2%	7%	26%	52%	12%
75	I made myself a list of jobs that I needed to do	5%	12%	21%	55%	7%
76	I used support from others to help me with my activities if required	7%	5%	14%	60%	14%
77	I was able to share out some tasks if I was unable to do all of them myself	7%	12%	15%	54%	12%
78	I was able to say ‘no’ if I was unable to do an activity	5%	5%	17%	26%	48%
79	I organised any help or equipment that I needed to do my activities if required	5%	7%	19%	62%	7%
80	I used energy saving techniques or equipment	10%	10%	48%	30%	3%
81	I reduced my use of aids or adaptive equipment	7%	19%	48%	24%	2%
82	I rewarded myself if I did an activity that I found challenging	10%	19%	29%	40%	2%
83	I accepted that I have some limitations due to my symptoms	2%	2%	12%	71%	12%
84	I did not feel guilty when I stopped an activity	10%	7%	7%	62%	14%
85	I set realistic time limits for specific tasks so that I did not over-do things	2%	2%	7%	52%	36%
86	I worked on a task for a set amount of time/distance and not according to my symptoms	10%	12%	14%	29%	36%

		Completely Disagree (0)	Disagree (1)	Neither Agree nor Disagree (2)	Agree (3)	Completely Agree (4)
87	I did a set amount of activity regardless of how I felt emotionally	7%	10%	31%	38%	14%
88	I avoided over-doing activities that I thought might cause a flare up of my symptoms	12%	17%	19%	43%	10%
89	I made sure I had a flare up plan	13%	13%	3%	28%	45%
90	My symptoms decided how much activity I did each day	38%	14%	12%	26%	10%
91	I listened to my body and took a break when my symptoms increased	14%	26%	17%	33%	10%
92	I avoided working at levels of discomfort so that I did not increase my symptoms	14%	17%	52%	12%	5%
93	I stopped an activity if it increased my symptoms beyond a level that I can manage	2%	14%	24%	52%	7%
94	I stopped an activity before I became too tired	7%	10%	24%	52%	7%

Chapter 6. Assessing the psychometric properties of the activity pacing questionnaire (APQ)

Appendix 6. Patient invitation letter, information sheet and questionnaire booklet

(The information sheet for current patients is shown. Retrospective patients received very similar information with the exception of the invitation to the test-retest study)

The University of Manchester

The Pennine Acute Hospitals NHS Trust

Physiotherapy Department A
North Manchester General Hospital
Delaunays Road
Crumpsall
Manchester
M8 5RB

Title of the study: Assessing the New Activity Pacing Questionnaire (APQ)

Insert date

Dear

I am writing to invite you to take part in a study that is being undertaken in the physiotherapy department in partnership with the University of Manchester. You have been referred to physiotherapy to help to manage your condition. One way in which physiotherapists advise patients to manage their condition is by pacing their activities. At present, we do not have a way of measuring this. The purpose of this research is to develop a new questionnaire that can be used to measure pacing. If you choose to participate you will be helping us to develop an activity pacing questionnaire which we hope will be used in future clinical practice.

The attached information sheet describes fully why we are carrying out this research and what it will involve if you decide to participate. Please take a moment to read the information sheet before deciding whether to take part in the study or not. If you decide to take part, you will be asked to complete one or two booklets of questionnaires. Each questionnaire should take no longer than 20 minutes to complete. You are asked to return the completed questionnaire booklet and signed consent form to the physiotherapy department in the prepaid envelope provided within three weeks.

You will receive the same physiotherapy treatment whether you decide to participate or not. You need to follow the instructions to contact the physiotherapy department if you receive a letter asking you to make a physiotherapy appointment.

Thank you for taking the time to read this information. Your help in this research study is greatly appreciated.

Yours sincerely

Deborah Antcliff BSc (Hons), MCSP
(Senior Physiotherapist)

The University of Manchester

The Pennine Acute Hospitals NHS Trust

Physiotherapy Department A
North Manchester General Hospital
Delaunays Road
Crumpsall
Manchester
M8 5RB

Participant Information Sheet

Title of the study: Assessing the New Activity Pacing Questionnaire (APQ)

I am inviting you to take part in a research study to develop a new questionnaire to measure activity pacing. The first stage of the development of the activity pacing questionnaire has been undertaken in a previous study. The next stage is to further develop and test whether the questionnaire measures what it is supposed to, and if it produces consistent results. Before you decide whether to take part, it is important for you to understand why the research is being done and what it will involve. Please take the time to read the following information carefully. Please contact the lead researcher, Miss Deborah Antcliff (Senior Physiotherapist) if you would like more information.

What is the purpose of the study?

Healthcare workers such as physiotherapists try to help manage medical conditions by using different techniques. One such technique is by advising patients to pace their activities. At the moment healthcare workers do not have a way of measuring if patients are pacing their activities. It is important for healthcare workers to be able to measure how patients are pacing their activities to see if patients are progressing with treatment and to help to plan treatment programmes. We have recently completed stage one of the research to develop an activity pacing questionnaire. The aim of the current study is to further develop the questionnaire so that it can be used in clinical practice.

Why have I been invited?

Your doctor has referred you for physiotherapy because of your condition. You may therefore be suitable to take part in this study. It is important that you complete the background questions contained within the questionnaire booklet so that we can check that you are suitable for the study.

Do I have to take part?

It is up to you to decide whether or not to take part. If we do not receive your questionnaire booklet back within three weeks, we will send you a reminder letter and questionnaire booklet. If we do not hear from you three weeks after the reminder booklet is sent, we will assume that you do not wish to participate and no further contact will be made in the post. On arrival into the physiotherapy department, you may be asked if you wish to participate in the study if you have not already done so. If you do 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 now or in the future.**

What will the study involve?

The study involves your completion of one or possibly two booklets of questionnaires. If you agree to participate please complete the consent form, and the questionnaire booklet, including the background questions about yourself. The questionnaire booklet should take no more than 20 minutes to complete. We ask that you return the consent form and the questionnaire booklet within three weeks of receiving this study pack. If we do not receive this back within three weeks, we will send you a reminder letter and questionnaire booklet. If no contact is made three weeks after the reminder is sent, we will assume that you do not wish to participate and no further contact will be made in the post. You may be asked on arrival into the physiotherapy department if you wish to participate in the study if you have not already done so. If you consent to participating in the study when you are asked in the physiotherapy department, you will be asked to complete the questionnaire booklet within three weeks and you can choose to do this in the physiotherapy department or at home.

If you return the consent form and questionnaire booklet, you may be sent a second smaller questionnaire booklet 1-2 weeks later. You will be asked to return the second booklet within three weeks of receiving the questions. If no reply is made after three weeks you will be sent a reminder letter and booklet of questionnaires. If no contact is made after the reminder second booklet of questionnaires is sent, it will be assumed that you do not wish to continue to participate in the study and no further contact will be made. We hope that a total of 300 patients will participate in this study to help us to develop a new activity pacing questionnaire.

What are the possible disadvantages or risks of taking part?

There are no risks associated with taking part in the study and there will be no change to your treatment. We will only be asking you to complete either one or two booklets of questionnaires.

The first booklet of questionnaires is enclosed with this information sheet. The first questionnaire booklet should take no longer than 20 minutes to complete and you will be asked to return it within three weeks. If you receive the second smaller booklet, it should take only 15 minutes to complete and you will be asked to return it within three weeks. Pre-paid envelopes will be provided to return the questionnaires in the post. The maximum time you could be involved in the study is 14 weeks.

What are the possible benefits of taking part?

We cannot promise that the study will help you directly, but the information we get from this study will help us to improve the treatment we provide for patients.

What will happen if I do not want to carry on with the study once I have consented?

You are free to withdraw from the study at any stage and without giving an explanation. If you do not respond to any of the questionnaire booklets within the deadlines, we will assume that you do not wish to continue in the study and no further contact will be made in the post. If you inform us that you wish to withdraw completely from the study we will ask you if we can use any of your existing data, or whether you wish for all of your data to be destroyed. We would like to stress that your physiotherapy treatment will not be affected by your decision.

Will my taking part in this study be kept confidential?

Yes. If you agree to participate, any information about you will be kept strictly confidential by the research team. The lead researcher in this study is a physiotherapist working in the department and is experienced in maintaining patient confidentiality. Your questionnaire booklets will have your name and address removed so that they do not identify you. You have been allocated a unique study code which will be recorded on the front of your questionnaires. This study code will be used throughout all data collection or analysis. You will remain anonymous during data collection and data analysis and you will not be identified in any publication that follows from the study. The questionnaires will only be assessed by the research team. In rare situations, the results of the study may be audited by the University of Manchester, the NHS or a regulatory authority to monitor the study.

Paper copies of the questionnaires will be kept securely by the research team throughout the duration of the study, and your personal information will be encrypted for electronic storage. Once the study is complete, the questionnaires will be kept securely by University of Manchester for ten years and then they will be destroyed.

What if something goes wrong?

In the unlikely event that you feel you have been harmed by taking part in this research study due to negligence, you may have grounds for a legal action. However, you may have to pay for any legal action. If you wish to complain, or have any concerns about the way you have been approached or treated during the course of this study by trust employees and you do not feel able to discuss this with the research team, the normal National Health Service complaints procedures will be available to you.

What will happen to the results of the research study?

The results of the study will be published in a PhD thesis and a medical journal. If you wish to obtain a copy of the results or any publication please feel free to contact us. We would like to assure you again that no individual will be identified in any publication of the study.

Who is organising and funding the research?

The study is organised by The Pennine Acute Hospitals NHS Trust and The University of Manchester, School of Nursing, Midwifery and Social Work. This study is funded by a Pennine Acute Hospitals NHS Trust Research and Development Grant.

Who has reviewed the study?

This study has been reviewed and granted ethical approval by the North West – Greater Manchester North Research Ethics Committee.

Contact for Further Information

For further information about the study, please contact Deborah Antcliff, Senior Physiotherapist, North Manchester General Hospital on 0161 720 2423. You can also send your questions by e-mail to Deborah.Antcliff@pat.nhs.uk

What do I do now?

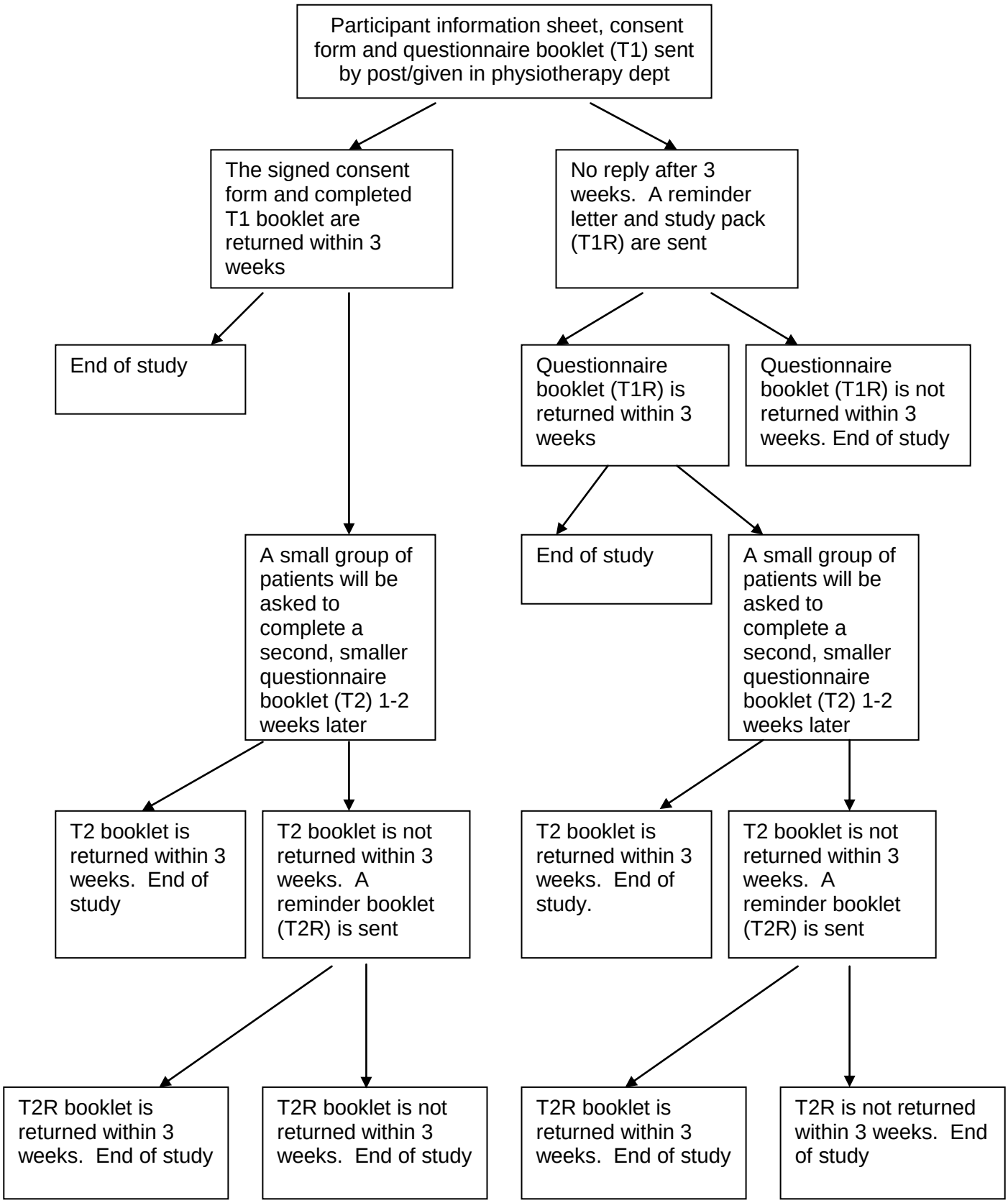
If you wish to participate in the study, please complete and return the consent form, and the questionnaire booklet in the pre-paid addressed envelope enclosed within three weeks of receiving this letter. Please keep the study information sheet for your own records.

Whether you wish to participate in the study or not, please follow the instructions if you receive a letter from the physiotherapy department to make a physiotherapy appointment.

The flow chart overleaf summarises what will happen if you choose to participate in the study.

Thank you for your time in reading this information sheet.

Flow chart of the study



The University of Manchester

The Pennine Acute Hospitals NHS Trust

Physiotherapy Department A
North Manchester General Hospital
Delaunays Road
Crumpsall
Manchester
M8 5RB

Consent Form

Please sign and return to the hospital with the questionnaire booklet

Study Code ☐

Title of the study: Assessing the New Activity Pacing Questionnaire (APQ)

Name of the researcher: Miss Deborah Antcliff

Please initial box

1. I confirm that I have read the information sheet dated June 2011. I understand what the study involves and have had the opportunity to ask any questions and have had these answered satisfactorily. I am aware that I can contact Miss Deborah Antcliff at any point during the study. ☐

2. I understand that my participation is voluntary and I am free to withdraw at any time, without giving any reason, and without my medical care or legal rights being affected. ☐

3. I understand that sections of my medical notes relevant to my taking part in research may be looked at by authorised individuals from the Pennine Acute Hospitals NHS Trust where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records. ☐

4. I agree to participate in this questionnaire design study. ☐

Name of Patient	Date	Signature
Name of Person taking consent (if different from researcher)	Date	Signature
Researcher	Date	Signature

When completed: 1 for patient; 1 for researcher site file; 1 (original) to be kept in medical notes

MANCHESTER 1824

The University of Manchester

The Pennine Acute Hospitals NHS Trust

Questionnaire Booklet

Study code [ ]

Date sent _____

Today's date_____

Instructions for Completion

1. When there is a choice of answers, please tick the box that applies. For some questions more than one box may apply

For example, do you suffer with any of the following:

[ ]	Back pain
[✓]	Pains on many different sites
[ ]	Fibromyalgia
[ ]	Chronic fatigue syndrome
[ ]	Myalgic encephalomyelitis
[ ]	Other condition *(please state)* _____

2. Where there is a box marked with a unit, please enter the appropriate values. For example,

What is your age? [**40**] Years

3. Where there is a choice of numbers to circle, please circle one. For example,

Please circle the number that best describes your pain 0 1 (2) 3 4 5

We would first like to ask you 5 questions about yourself. This helps us to understand a bit about your background

1. How old are you? ☐ Years

2. Are you ☐ Male ☐ Female

3. Are you
   - ☐ Married/Living as married
   - ☐ Single
   - ☐ Separated
   - ☐ Divorced
   - ☐ Widowed

4. What is your ethnic group?
   - ☐ White
   - ☐ Mixed
   - ☐ Asian or Asian British
   - ☐ Black or Black British
   - ☐ Chinese
   - ☐ Any other ethnic group (Please write in) _____

5. Are you
   - ☐ Working full-time
   - ☐ Working part-time
   - ☐ Working full-time in the home
   - ☐ Not working due to the condition with which you have been referred to physiotherapy
   - ☐ Not working because of other health problems or disability
   - ☐ Unemployed but seeking work
   - ☐ Student
   - ☐ Semi-retired
   - ☐ Retired

Thank you for completing questions 1 to 5. We would now like to ask you 6 questions about your condition on the next page.

6. Have you been referred to physiotherapy mainly for the management of any of the following conditions? *(Please tick all that apply)*

☐	Back pain
☐	Pains on many different sites
☐	Fibromyalgia
☐	Chronic fatigue syndrome
☐	Myalgic encephalomyelitis
☐	Other condition *(please state)* _____

7. If you have ticked more than one condition, which condition affects your daily activities the most?

_____

8. How long have you had your condition? *(If you have ticked more than one condition, please give the length of time for which you have had the condition that you answered in question 7.)*

☐ Years ☐ Months

9. Do you suffer with pain because of your condition? ☐ Yes ☐ No

If you ticked 'Yes' to Question 9, please proceed to Questions 10 and 11

10. Please **circle** the **number** that best describes your current pain

No pain	0	1	2	3	4	5	6	7	8	9	10	Worst Possible pain

11. Please **circle** the **number** that best describes your usual pain

No pain	0	1	2	3	4	5	6	7	8	9	10	Worst Possible pain

Thank you for completing the above background questions. Please can you now complete the new Activity Pacing Questionnaire on the next page. This questionnaire contains 38 questions and some of the questions may seem repetitive. There are no trick questions or right or wrong answers. Your completion of this questionnaire will help us to find out which questions are not needed in the questionnaire. Please try to give an answer for all of the questions.

The New Activity Pacing Questionnaire

Please read each of the statements below and circle a number from 0 to 4 that best describes your activity over the past 7 days (0 means that you never did this, and 4 means you always did this). The term 'activity' refers to any type of activity, for example, walking, working, socialising, reading or daily household tasks.

	Over the past 7 days…..	Never did this	Rarely did this	Occasionally did this	Frequently did this	Always did this
1	I gradually increased activities that I had been avoiding because of my symptoms	0	1	2	3	4
2	I was aware of the effect that different types of activities had on me	0	1	2	3	4
3	I prioritised my activities for each day	0	1	2	3	4
4	I gradually increased how long I could spend on my activities	0	1	2	3	4
5	I took a short rest from an activity so that I could complete the activity later	0	1	2	3	4
6	I had periods of planned rest that did not involve sleeping	0	1	2	3	4
7	I changed activities before I had an increase in my symptoms	0	1	2	3	4
8	I alternated the type of activity that I was doing	0	1	2	3	4
9	I split activities up and did parts throughout the week	0	1	2	3	4
10	I planned my activities around events that were important to me	0	1	2	3	4
11	I accepted that I have some limitations due to my symptoms	0	1	2	3	4
12	I spent less time on some activities so that I could do them every day	0	1	2	3	4
13	I broke tasks up into periods of activity and rest	0	1	2	3	4

Please continue overleaf

The new Activity Pacing Questionnaire continued

	Over the past 7 days…..	Never did this	Rarely did this	Occasionally did this	Frequently did this	Always did this
14	I kept to a consistent level of activity every day	0	1	2	3	4
15	I divided each day up into periods of activity and rest	0	1	2	3	4
16	I spread out the activities that require a high amount of energy	0	1	2	3	4
17	I made sure I had a flare up plan	0	1	2	3	4
18	I was creative and found new ways of doing tasks	0	1	2	3	4
19	I spread different types of activities across the day	0	1	2	3	4
20	I did not under-do activities on a ‘bad’ day	0	1	2	3	4
21	I did a variety of different activities	0	1	2	3	4
22	I was able to say ‘no’ if I was unable to do an activity	0	1	2	3	4
23	I changed my activity targets if they were unrealistic	0	1	2	3	4
24	I did my activities without putting pressure on myself to complete them	0	1	2	3	4
25	I set activity goals that were meaningful to me	0	1	2	3	4
26	I used support from others to help me with my activities if required	0	1	2	3	4
27	I did not feel guilty when I stopped an activity	0	1	2	3	4
28	I set activity goals that were realistic for me	0	1	2	3	4
29	I switched between activities that use a high amount of energy and activities that use a low amount of energy	0	1	2	3	4
30	I made sure I did some activity every day, even if I had a ‘bad’ day	0	1	2	3	4

Please complete the last eight questions overleaf

The new Activity Pacing Questionnaire continued

	Over the past 7 days…..	Never did this	Rarely did this	Occasionally did this	Frequently did this	Always did this
31	I planned in advance how long I would spend on each activity	0	1	2	3	4
32	I used an activity diary to monitor my activity pattern	0	1	2	3	4
33	I broke down activities into manageable pieces	0	1	2	3	4
34	I did not over-do activities on a 'good' day	0	1	2	3	4
35	I set realistic time limits for specific tasks so that I did not over-do things	0	1	2	3	4
36	I developed a routine so that I had a balance between being active and inactive	0	1	2	3	4
37	I assessed my activity levels	0	1	2	3	4
38	I did a similar amount of activity on 'good' and 'bad' days	0	1	2	3	4

We would like to ask you how you found the new Activity Pacing Questionnaire to complete. *Please tick one box:*

Very difficult to complete ☐ Difficult to complete ☐ Neither difficult or easy to complete ☐ Easy to complete ☐ Very easy to complete ☐

Please write any comments you have about the new Activity Pacing Questionnaire here. For example, were there enough instructions to understand the questionnaire? Did you have difficulty with any specific questions? Was there anything that made this questionnaire easy to complete?

To compare the new Activity Pacing Questionnaire with two other pacing scales, please can you complete the two following shorter pacing scales. Some of the questions may be similar to questions that you have just answered. We apologise for this repetition, but this is an important process to help us to assess the new Activity Pacing Questionnaire.

Pacing Scale 1.

Please answer how many days in the past week you have done the following things:

		How many days in the last week have you done this?
1	I was able to do more by just going a little slower and giving myself occasional breaks	
2	I focussed on going 'slow and steady' instead of on my pain	
3	I broke up tasks into manageable pieces so I could still get a lot done despite my pain	
4	I went 'slow and steady' to help distract myself from my pain	
5	I paced my activities by going 'slow but steady'	
6	By going at a reasonable pace (not too fast or slow) pain had less effect on what I was doing	

We would like to ask you how you found Pacing Scale 1 to complete. *Please tick one box:*

Very difficult to complete ☐ Difficult to complete ☐ Neither difficult or easy to complete ☐ Easy to complete ☐ Very easy to complete ☐

Please write any comments you have about Pacing Scale 1 here. For example, were there enough instructions to understand the scale? Did you have difficulty with any specific questions? Was there anything that made this scale easy to complete?

Pacing Scale 2.

Please indicate how frequently each of the following statements is true for you. For each item circle a rating from 0 (never) to 5 (always).

		Never					Always
1	I stop activities before the pain becomes too great and I return to them later	0	1	2	3	4	5
2	I use repeated rest breaks to help me complete activities	0	1	2	3	4	5
3	I pace myself so I don't overdo it during activities that tend to cause pain	0	1	2	3	4	5
4	I split tasks into parts and do them one step at a time	0	1	2	3	4	5
5	I do tasks more slowly so that I can get them done with less pain	0	1	2	3	4	5
6	I pace myself to get things done	0	1	2	3	4	5

We would like to ask you how you found Pacing Scale 2 to complete. *Please tick one box:*

Very difficult to complete ☐ Difficult to complete ☐ Neither difficult or easy to complete ☐ Easy to complete ☐ Very easy to complete ☐

Please write any comments you have about Pacing Scale 2 here. For example, were there enough instructions to understand the scale? Did you have difficulty with any specific questions? Was there anything that made this scale easy to complete?

Thank you for completing the three pacing scales. Now we would like to ask you how your condition affects how tired or lacking in energy you feel (your level of fatigue). Please complete the following fatigue scale by circling the number that best describes your level of fatigue over the past month.

		Much worse than usual	Worse than usual	No more than usual	Better than usual
1	Do you have problems with tiredness?	1	2	3	4
2	Do you need to rest more?	1	2	3	4
3	Do you feel sleepy or drowsy?	1	2	3	4
4	Do you have a problem with starting things?	1	2	3	4
5	Are you lacking in energy?	1	2	3	4
6	Do you have less strength in your muscles?	1	2	3	4
7	Do you feel weak?	1	2	3	4
8	Do you have difficulty concentrating?	1	2	3	4
9	Do you have problems thinking clearly?	1	2	3	4
10	Do you make slips of the tongue when speaking?	1	2	3	4
11	How is your memory?	1	2	3	4

Thank you for completing the fatigue scale. This next questionnaire is designed to help us know how you feel. Please read each item and tick the box opposite of the reply which comes closest to how you have been feeling in the past week.
Please don't take too long over your replies; your immediate reaction to each item will probably be more accurate than a long thought-out response. (Please tick only one box in each section)

I feel tense or 'wound up':
- Most of the time ☐
- A lot of the time ☐
- Time to time, Occasionally ☐
- Not at all ☐

I feel cheerful:
- Not at all ☐
- Not often ☐
- Sometimes ☐
- Most of the time ☐

I feel restless as if I have to be on the move:
- Very much indeed ☐
- Quite a lot ☐
- Not very much ☐
- Not at all ☐

I still enjoy the things I used to enjoy:
- Definitely as much ☐
- Not quite so much ☐
- Only a little ☐
- Hardly at all ☐

I can sit at ease and feel relaxed:
- Definitely ☐
- Usually ☐
- Not often ☐
- Not at all ☐

I look forward with enjoyment to things:
- As much as I ever did ☐
- Rather less than I used to ☐
- Definitely less than I used to ☐
- Hardly at all ☐

I get a sort of frightened feeling as if something awful is about to happen:
- Very definitely and quite badly ☐
- Yes, but not too badly ☐
- A little, but it doesn't worry me ☐
- Not at all ☐

I feel as if I am slowed down:
- Nearly all of the time ☐
- Very often ☐
- Sometimes ☐
- Not at all ☐

I get sudden feelings of panic:
- Very often indeed ☐
- Quite often ☐
- Not very often ☐
- Not at all ☐

I can laugh and see the funny side of things:
- As much as I always could ☐
- Not quite so much now ☐
- Definitely not so much now ☐
- Not at all ☐

I get a sort of frightened feeling like 'butterflies' in the stomach:
- Not at all ☐
- Occasionally ☐
- Quite often ☐
- Very often ☐

I can enjoy a good book or radio or TV programme:
- Often ☐
- Sometimes ☐
- Not often ☐
- Very seldom ☐

Worrying thoughts go through my mind:
- A great deal of the time ☐
- A lot of the time ☐
- From time to time but not too often ☐
- Only occasionally ☐

I have lost interest in my appearance:
- Definitely ☐
- I don't take so much care as I should ☐
- I may not take quite as much care ☐
- I take just as much care as ever ☐

Thank you for completing the questionnaire on page 10. There are now just 2 questionnaires left.
Please circle the number to indicate how much you agree with each statement below.

		Never					Always
1	I can't think straight when in pain	0	1	2	3	4	5
2	During painful episodes it is difficult for me to think of anything besides the pain	0	1	2	3	4	5
3	When I hurt I think about pain constantly	0	1	2	3	4	5
4	I find it hard to concentrate when I hurt	0	1	2	3	4	5
5	I worry when I am in pain	0	1	2	3	4	5
6	I go immediately to bed when I feel severe pain	0	1	2	3	4	5
7	I will stop any activity as soon as I sense pain coming on	0	1	2	3	4	5
8	As soon as pain comes on I take medication to reduce it	0	1	2	3	4	5
9	I avoid important activities when I hurt	0	1	2	3	4	5
10	I try to avoid activities that cause pain	0	1	2	3	4	5
11	I think that if my pain gets too severe, it will never decrease	0	1	2	3	4	5
12	When I feel pain I am afraid that something terrible will happen	0	1	2	3	4	5
13	When I feel pain I think that I might be seriously ill	0	1	2	3	4	5
14	Pain sensations are terrifying	0	1	2	3	4	5
15	When pain comes on strong I think that I might become paralysed or more disabled	0	1	2	3	4	5
16	I begin trembling when engaged in an activity that increases pain	0	1	2	3	4	5
17	Pain seems to cause my heart to pound or race	0	1	2	3	4	5
18	When I sense pain I feel dizzy or faint	0	1	2	3	4	5
19	Pain makes me nauseous	0	1	2	3	4	5
20	I find it difficult to calm my body down after periods of pain	0	1	2	3	4	5

Thank you for completing this questionnaire. Please turn to the next page to complete the final questionnaire.

Your Health and Well-Being

This survey asks for your views about your health. This information will help keep track of how you feel and how well you are able to do your usual activities.
Thank you for completing this survey!

For each of the following questions, please tick the one box that best describes your answer.

1. In general, would you say your health is:

Excellent	Very good	Good	Fair	Poor
☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

2. The following questions are about activities you might do during a typical day. Does <u>your health now limit you</u> in these activities? If so, how much?

		Yes, limited a lot	Yes, limited a little	No, not limited at all
a	<u>Moderate activities</u>, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	☐ 1	☐ 2	☐ 3
b	Climbing <u>several</u> flights of stairs	☐ 1	☐ 2	☐ 3

(IQOLA SF-12v2 Acute, English (United Kingdom) 8/02)

3. During the past week, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of your physical health?

	All of the time	Most of the time	Some of the time	A little of the time	None of the time
a Accomplished less than you would like	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
b Were limited in the kind of work or other activities	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

4. During the past week, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

	All of the time	Most of the time	Some of the time	A little of the time	None of the time
a Accomplished less than you would like	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
b Did work or other activities less carefully than usual	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

5. During the past week, how much did pain interfere with your normal work (including both work outside the home and housework)?

Not at all	A little bit	Moderately	Quite a bit	Extremely
☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

6. These questions are about how you feel and how things have been with you during the past week. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past week…

	All of the time	Most of the time	Some of the time	A little of the time	None of the time
a Have you felt calm and peaceful?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
b Did you have a lot of energy?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
c Have you felt downhearted and low?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

7. During the past week, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)?

All of the time	Most of the time	Some of the time	A little of the time	None of the time
☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

Thank you for completing these questions!

Please turn to the next page to find out what you need to do next. There is also space on the following page if you wish to make any general comments.

Thank you for completing this booklet of questionnaires. Your time and effort are greatly appreciated. Please can you now return this questionnaire booklet, together with the signed hospital copy of the consent form in the prepaid envelope provided (or to the physiotherapy staff if you have completed this questionnaire booklet in the physiotherapy department).

If you consent to receiving a telephone call to discuss any of your comments or any missing answers please tick here: ☐

If you consent to receiving a telephone call please may we have your number?

Telephone Number: _____

With sincere thanks again

Please use the space below if you would like to make any general comments.

Appendix 7. Correspondence regarding ethical approval for the psychometric study

National Research Ethics Service
NRES Committee North West - Greater Manchester North
3rd Floor, Barlow House
4 Minshull Street
Manchester
M1 3DZ
Tel: 0161 625 7817
Email: cynthia.carter@northwest.nhs.uk

Miss Deborah Antcliff
Senior Physiotherapist
North Manchester General Hospital
Physiotherapy 'A'
Delaunays Road
M8 5RB

20 June 2011

Dear Miss Antcliff

Study title:	**Determining the Psychometric Properties of an Activity Pacing Questionnaire for Chronic Pain and/or Fatigue**
REC reference:	**11/NW/0295**
Protocol number:	**N/A**

Thank you for your letter of 15 June 2011, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

Confirmation of ethical opinion

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

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion

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

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

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

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

Document	*Version*	*Date*
Covering Letter		26 April 2011
Covering Letter		15 June 2011
Investigator CV	Antcliff	26 April 2011
Investigator CV	Keeley	14 March 2011
Letter of invitation to participant	3 - Current patient	15 June 2011
Letter of invitation to participant	3 - Retrospective patient	15 June 2011
Other: Test-retest covering letter	1	26 April 2011
Other: Test-retest reminder covering letter	1	26 April 2011
Other: Current patient reminder letter	3	15 June 2011
Other: Retrospective patient reminder letter	3	15 June 2011
Participant Consent Form	3	15 June 2011
Participant Information Sheet: Current patient	3	15 June 2011
Participant Information Sheet: Retrospective patient	3	15 June 2011
Protocol	1	26 April 2011
Questionnaire: Current patient Booklet 1	1	26 April 2011
Questionnaire: Current patient group Booklet 1	1	26 April 2011
Questionnaire: Retrospective patient Booklet 1	1	26 April 2011
Questionnaire: Booklet 2	1	26 April 2011
REC application	3.1	20 April 2011
Response to Request for Further Information	1	15 June 2011

Statement of compliance

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

After ethical review

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

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

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

Notifying substantial amendments
Adding new sites and investigators
Progress and safety reports
Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

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

11/NW/0295	**Please quote this number on all correspondence**

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

Yours sincerely

C. Carter

Dr Peter Klimiuk
Chair

Enclosures: "After ethical review – guidance for researchers" SL-AR2

Copy to: Miss Katie Doyle, R&D office for Pennine Acute NHS Hospitals Foundation Trust

Penn Acute

NHS

National Research Ethics Service

NRES Committee North West - Greater Manchester North
3rd Floor, Barlow House
4 Minshull Street
Manchester
M1 3DZ
Tel: 0161 625 7817
Email: cynthia.carter@northwest.nhs.uk

Miss Deborah Antcliff
Senior Physiotherapist
North Manchester General Hospital
Physiotherapy 'A'
Delaunays Road
M8 5RB

12 July 2011

Dear Miss Antcliff

Study title:	**Determining the Psychometric Properties of an Activity Pacing Questionnaire for Chronic Pain and/or Fatigue**
REC reference:	**11/NW/0295**
Protocol number:	**N/A**
Amendment number:	**1**
Amendment date:	**29 June 2011**

The above amendment was reviewed by the Sub-Committee in correspondence.

Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Protocol	2	27 June 2011
Notice of Substantial Amendment (non-CTIMPs)	1	29 June 2011

Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

R&D approval

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

Statement of compliance

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

11/NW/0295:	**Please quote this number on all correspondence**

Yours sincerely

pp **Dr Peter Klimiuk**
Chair

Enclosures: List of names and professions of members who took part in the review

Copy to: Miss Katie Doyle, R&D office for Pennine Acute NHS Hospitals Foundation Trust

NRES Committee North West - Greater Manchester North

Attendance at Sub-Committee of the REC meeting on 12 July 2011

Name	*Profession*	*Capacity*
Mr Ken Cook	Acute Care Manager - Later Life	Expert
Dr Peter Klimiuk	Consultant Rheumatologist	Expert

Appendix 7, Email confirmation to use anonymous data from the non-responders

FW: Aggregate Anonymised Data: Caldicott Approval

Bradley Sally (RW6) PAHNT [Sally.Bradley@pat.nhs.uk]

Sent: 11 May 2012 15:24

To: Woby Steve (RW6) PAHNT [Steve.Woby@pat.nhs.uk]

Cc: Noon Trish (RW6) PAHNT [Trish.Noon@pat.nhs.uk]

Attachments: 11PHYSIO01 REC Approval le~1.pdf (859 KB) ; 11PHYSIO01 Amendment 1 29.~1.pdf (303 KB) ; 11PHYSIO01 PAT Sponsorship~1.pdf (2 MB) ; 11PHYSIO01 PROTOCOL.PDF (6 MB) ; 11PHYSIO01 R&D Approval le~1.pdf (678 KB)

Steve, approved as below, thanks Sally

Dr Sally Bradley

Medical Director
Pennine Acute Hospitals

From: Noon Trish (RW6) PAHNT
Sent: 11 May 2012 12:38
To: Bradley Sally (RW6) PAHNT
Subject: FW: Aggregate Anonymised Data: Caldicott Approval

Dear Sally

Having reviewed the above documentation, there are no outstanding Information Governance issues that would prevent the request to use anonymised data (as outlined below) from being approved.

Regards

Trish

Trish Noon LLM

Job title - Information Governance Manager
IM&T Services

Telephone 0161 604 5760 **4 5760 (internal)**
Mobile
Service Desk 0161 604 5678
Email trish.noon@pat.nhs.uk

Room F 17 IM&T Services
North Manchester General Hospital
Delaunay's Road
Crumpsall
Manchester
M8 5RB

From: Noon Trish (RW6) PAHNT
Sent: 11 May 2012 09:43
To: Bradley Sally (RW6) PAHNT
Subject: RE: Aggregate Anonymised Data: Caldicott Approval

Dear Sally

I have spoken to Steve Woby and he is going to send me the project registration and Ethics approval documentation.
As only anonymised data will be used they don't need to sign a non-disclosure agreement.

I will forward the documentation once I have reviewed it.

Regards

Trish

Trish Noon LLM

Job title - Information Governance Manager
IM&T Services

Telephone 0161 604 5760 **4 5760 (internal)**
Mobile
Service Desk 0161 604 5678
Email trish.noon@pat.nhs.uk

Room F 17 IM&T Services
North Manchester General Hospital
Delaunay's Road
Crumpsall
Manchester
M8 5RB

From: Bradley Sally (RW6) PAHNT
Sent: 11 May 2012 08:19
To: Noon Trish (RW6) PAHNT
Subject: FW: Aggregate Anonymised Data: Caldicott Approval

Do we not need to see the research protocol? Do I need to get them to sign something? Thanks Sally

Dr Sally Bradley

Medical Director
Pennine Acute Hospitals

From: Woby Steve (RW6) PAHNT
Sent: 10 May 2012 21:03
To: Bradley Sally (RW6) PAHNT
Cc: Noon Trish (RW6) PAHNT
Subject: Aggregate Anonymised Data: Caldicott Approval

Dear Sally,
Deborah Antcliff is a senior physiotherapist based at NMGH who is undertaking her PhD at the University of Manchester (I am one of her supervisors). As part of this study we would like to use anonymised data (age & sex) to determine whether responders (those who consented) to our study differed from non-responders (those who didn't respond to our study invite). As Caldicott Guardian, are you happy to authorise the use of this anonymised data? No identifiable data will be used.
Thanks

Best Wishes
Steve

Dr. Steve Woby B.Sc (Hons), Ph.D
Head of Research & Development
The Pennine Acute Hospitals NHS Trust

Trust Headquarters, 1st Floor (Room 138), North Manchester General Hospital, Delaunays Road, Crumpsall, Manchester, M8 5RB
T: +44 (0)161 720 2229 **| M:** 0779 145 8483 **| E:** steve.woby@pat.nhs.uk **| F:** 0161 720 4717
R&D intranet page: http://nww.pat.nhs.uk/PortalVBVS/Default.aspx?tabindex=2&tabid=291

Appendix 8. Test-retest invitation letter and questionnaire booklet

The University of Manchester

The Pennine Acute Hospitals NHS Trust

Physiotherapy Department A
North Manchester General Hospital
Delaunays Road
Crumpsall
Manchester
M8 5RB

Title of the study: Assessing the New Activity Pacing Questionnaire (APQ)

Insert date

Dear

Thank you for completing the first booklet of questionnaires in the study. Your time and effort are greatly appreciated. I would like to invite you to complete a second, shorter questionnaire booklet. This booklet contains only five questionnaires and should take no longer than 15 minutes to complete. The five questionnaires are the same as five of the questionnaires that you previously completed in the first booklet. The importance of asking you to complete these questionnaires a second time is to test whether they provide us with consistent results when they are completed a few weeks later.

Please complete this second, shorter booklet of questionnaires and return it to us in the prepaid envelope provided, or to the physiotherapy department within three weeks. If we do not receive this questionnaire booklet back within three weeks, you will receive a reminder letter and questionnaire booklet. If you do not return the reminder booklet within three weeks, we will assume that you do not wish to participate and no further contact will be made.

May we remind you again that your personal details and your answers to the questionnaires will remain strictly confidential throughout the study.

You will receive the same physiotherapy treatment whether you wish to continue to participate or not. You need to follow the instructions to contact the physiotherapy department if you receive a letter asking you to make a physiotherapy appointment.

Thank you again for your participation. Your help in this research study is greatly appreciated.

Yours sincerely

Deborah Antcliff BSc (Hons), MCSP
(Senior Physiotherapist)

MANCHESTER 1824

The University of Manchester

The Pennine Acute Hospitals NHS Trust

Questionnaire Booklet 2

Study code

Date sent _____

Today's date_____

Thank you for completing the first booklet of questionnaires. Please can you now complete this second, shorter booklet of questionnaires. It contains some of the same questionnaires that you completed in the first booklet. Please do not worry if you cannot remember the answers that you gave in the first questionnaire booklet. This is not a test of your memory. Some of the questions may seem to be repetitive but there are no trick questions. Remember there are no right or wrong answers.

Instructions for Completion

4. Where there is a choice of numbers to circle, please circle one. For example,

   Please circle the number that best describes your pain 0 1 (2) 3 4 5

5. Where there is a box marked with a unit, please enter the appropriate values. For example,

   How many days in the last week have you paced your activities?

   5 Days

We would firstly like to ask you if you have noticed any changes in your condition since you completed the first booklet of questionnaires. For example, do you feel your symptoms have improved or have they worsened? However, you may not have noticed any changes in your condition. If your condition has noticeably changed since completing the first questionnaire booklet, please try to describe these changes in the space below.

Now we would like to ask you two questions about your pain:

1. Please **circle** the **number** that best describes your current pain

No pain	0	1	2	3	4	5	6	7	8	9	10	Worst Possible pain

2. Please **circle** the **number** that best describes your usual pain

No pain	0	1	2	3	4	5	6	7	8	9	10	Worst Possible pain

Thank you for completing the above questions. Please can you now complete the new Activity Pacing Questionnaire. This is the same questionnaire that you completed in the first booklet of questionnaires. We apologise for this repetition, but this helps us to assess the questionnaire.

The New Activity Pacing Questionnaire

Please read each of the statements below and circle a number from 0 to 4 that best describes your activity over the past 7 days (0 means that you never did this, and 4 means you always did this). The term 'activity' refers to any type of activity, for example, walking, working, socialising, reading or daily household tasks.

	Over the past 7 days…..	Never did this	Rarely did this	Occasionally did this	Frequently did this	Always did this
1	I gradually increased activities that I had been avoiding because of my symptoms	0	1	2	3	4
2	I was aware of the effect that different types of activities had on me	0	1	2	3	4
3	I prioritised my activities for each day	0	1	2	3	4
4	I gradually increased how long I could spend on my activities	0	1	2	3	4
5	I took a short rest from an activity so that I could complete the activity later	0	1	2	3	4
6	I had periods of planned rest that did not involve sleeping	0	1	2	3	4
7	I changed activities before I had an increase in my symptoms	0	1	2	3	4
8	I alternated the type of activity that I was doing	0	1	2	3	4
9	I split activities up and did parts throughout the week	0	1	2	3	4
10	I planned my activities around events that were important to me	0	1	2	3	4
11	I accepted that I have some limitations due to my symptoms	0	1	2	3	4
12	I spent less time on some activities so that I could do them every day	0	1	2	3	4
13	I broke tasks up into periods of activity and rest	0	1	2	3	4

Please continue overleaf

	Over the past 7 days…..	Never did this	Rarely did this	Occasionally did this	Frequently did this	Always did this
14	I kept to a consistent level of activity every day	0	1	2	3	4
15	I divided each day up into periods of activity and rest	0	1	2	3	4
16	I spread out the activities that require a high amount of energy	0	1	2	3	4
17	I made sure I had a flare up plan	0	1	2	3	4
18	I was creative and found new ways of doing tasks	0	1	2	3	4
19	I spread different types of activities across the day	0	1	2	3	4
20	I did not under-do activities on a ‘bad’ day	0	1	2	3	4
21	I did a variety of different activities	0	1	2	3	4
22	I was able to say ‘no’ if I was unable to do an activity	0	1	2	3	4
23	I changed my activity targets if they were unrealistic	0	1	2	3	4
24	I did my activities without putting pressure on myself to complete them	0	1	2	3	4
25	I set activity goals that were meaningful to me	0	1	2	3	4
26	I used support from others to help me with my activities if required	0	1	2	3	4
27	I did not feel guilty when I stopped an activity	0	1	2	3	4
28	I set activity goals that were realistic for me	0	1	2	3	4
29	I switched between activities that use a high amount of energy and activities that use a low amount of energy	0	1	2	3	4
30	I made sure I did some activity every day, even if I had a ‘bad’ day	0	1	2	3	4

Please complete the last eight questions overleaf

The new Activity Pacing Questionnaire continued

	Over the past 7 days…..	Never did this	Rarely did this	Occasionally did this	Frequently did this	Always did this
31	I planned in advance how long I would spend on each activity	0	1	2	3	4
32	I used an activity diary to monitor my activity pattern	0	1	2	3	4
33	I broke down activities into manageable pieces	0	1	2	3	4
34	I did not over-do activities on a 'good' day	0	1	2	3	4
35	I set realistic time limits for specific tasks so that I did not over-do things	0	1	2	3	4
36	I developed a routine so that I had a balance between being active and inactive	0	1	2	3	4
37	I assessed my activity levels	0	1	2	3	4
38	I did a similar amount of activity on 'good' and 'bad' days	0	1	2	3	4

To compare the new Activity Pacing Questionnaire with two other pacing scales, please can you complete the following shorter pacing scales. Some of the questions may be similar to questions that you have just answered. We apologise for this repetition, but this is an important process to help us to assess the new Activity Pacing Questionnaire.

Pacing Scale 1.

Please answer how many days in the past week you have done the following things:

		How many days in the last week have you done this?
1	I was able to do more by just going a little slower and giving myself occasional breaks	
2	I focussed on going ‘slow and steady’ instead of on my pain	
3	I broke up tasks into manageable pieces so I could still get a lot done despite my pain	
4	I went ‘slow and steady’ to help distract myself from my pain	
5	I paced my activities by going ‘slow but steady’	
6	By going at a reasonable pace (not too fast or slow) pain had less effect on what I was doing	

Pacing Scale 2.

Please indicate how frequently each of the following statements is true for you. For each item circle a rating from 0 (never) to 5 (always).

		Never					Always
1	I stop activities before the pain becomes too great and I return to them later	0	1	2	3	4	5
2	I use repeated rest breaks to help me complete activities	0	1	2	3	4	5
3	I pace myself so I don’t overdo it during activities that tend to cause pain	0	1	2	3	4	5
4	I split tasks into parts and do them one step at a time	0	1	2	3	4	5
5	I do tasks more slowly so that I can get them done with less pain	0	1	2	3	4	5
6	I pace myself to get things done	0	1	2	3	4	5

Thank you for completing the three pacing scales. Now we would like to ask you how your condition affects how tired or lacking in energy you feel (your level of fatigue). Please complete the following fatigue scale by circling the number that best describes your level of fatigue over the past month. This is the last questionnaire in the booklet.

		Much worse than usual	Worse than usual	No more than usual	Better than usual
1	Do you have problems with tiredness?	1	2	3	4
2	Do you need to rest more?	1	2	3	4
3	Do you feel sleepy or drowsy?	1	2	3	4
4	Do you have a problem with starting things?	1	2	3	4
5	Are you lacking in energy?	1	2	3	4
6	Do you have less strength in your muscles?	1	2	3	4
7	Do you feel weak?	1	2	3	4
8	Do you have difficulty concentrating?	1	2	3	4
9	Do you have problems thinking clearly?	1	2	3	4
10	Do you make slips of the tongue when speaking?	1	2	3	4
11	How is your memory?	1	2	3	4

Thank you for completing the final questionnaire. Please turn to the next page to find out what you need to do next. There is also space on the following page if you wish to make any general comments.

Thank you for completing this booklet of questionnaires. Your time and effort are greatly appreciated. Please can you now return this questionnaire booklet in the prepaid envelope provided (or to the physiotherapy staff if you have completed this questionnaire booklet in the physiotherapy department).

If you consent to receiving a telephone call to discuss any of your comments or any missing answers please tick here ☐

If you consent to receiving a telephone call please may we have your number _____

With sincere thanks again

Please use the space below if you would like to make any general comments.

Appendix 9. Psychometric results:
Participants' demographics and symptoms

Appendix 9, Table 6.1 Demographic characteristics: all retrospective patients versus all current patients

Characteristic	Details	Retrospective (n=147)	Current (n=164)	Total (n=311)	Statistical analysis results
Gender	Male Female	43 (29.3%) 104 (70.7%)	56 (34.1%) 108 (65.9%)	99 (31.8%) 212 (68.2%)	Chi-square=0.86, df=1, p=0.355
Age (in years)	Mean (SD) Median (min-max)	48.1 (13.7) 48.0 (19-91.0)	43.7 (14.6) 45.0 (18-76.0)	45.8 (14.3) 46.0 (18-91.0)	Levene's F=1.96, df=1,309, p=0.162 Student's t=2.73, df=309, p=0.007
Marital status	Married/living as married Single Separated Divorced Widowed	83 (57.6%) 37 (25.7%) 5 (3.5%) 15 (10.4%) 4 (2.8%)	77 (47.2%) 59 (36.2%) 3 (1.8%) 22 (13.5%) 2 (1.2%)	160 (52.1%) 96 (31.3%) 8 (2.6%) 37 (12.1%) 6 (2.0%)	Fisher's Exact Test p=0.153
Ethnicity	White Mixed Asian/Asian British Black/Black British Chinese Other	137 (93.8%) 3 (2.1%) 1 (0.7%) 2 (1.4%) 2 (1.4%) 1 (0.7%)	134 (82.2%) 3 (1.8%) 13 (8.0%) 6 (3.7%) 1 (0.6%) 6 (3.7%)	271 (87.7%) 6 (1.9%) 14 (4.5%) 8 (2.6%) 3 (1.0%) 7 (2.3%)	Fisher's Exact Test p=0.003
Employment	Working full-time Working part-time Working full-time in the home Not working due to present condition Not working due to other condition Unemployed but seeking work Student Semi-retired Retired	64 (45.4%) 19 (13.5%) 2 (1.4%) 14 (9.9%) 16 (11.3%) 5 (3.5%) 2 (1.4%) 1 (0.7%) 18 (12.8)	51 (35.2%) 21 (14.5%) 5 (3.4%) 17 (11.7%) 17 (11.7%) 13 (9.0%) 5 (3.4%) 3 (2.1%) 13 (9.0%)	115 (40.2%) 40 (14.0%) 7 (2.4%) 31 (10.8%) 33 (11.5%) 18 (6.3%) 7 (2.4%) 4 (1.4%) 31 (10.8%)	Fisher's Exact Test p=0.295

Appendix 9, Table 6.2 Clinical characteristics: all retrospective patients versus all current patients

Characteristic	Details	Retrospective (n=147)	Current (n=164)	Total (n=311)	Statistical analysis results
Condition[†]	Back pain	102 (69.4%)	126 (77.3%)	228 (73.2%)	Chi-square=2.49, df=1, p=0.115
	Chronic widespread pain	44 (29.9%)	68 (41.7%)	112 (36.1%)	Chi-square=4.65, df=1, p=0.031
	Fibromyalgia	27 (18.4%)	17 (10.4%)	44 (14.2%)	Chi-square=4.00, df=1, p=0.046
	CFS	24 (16.3%)	19 (11.7%)	43 (13.9%)	Chi-square=1.41, df=1, p=0.253
	ME	12 (8.2%)	4 (2.5%)	16 (5.2%)	Chi-square=5.15, df=1, p=0.023
	Other condition	20 (13.6%)	17 (10.4%)	37 (11.9%)	Chi-square=0.74, df=1, p=0.389
Main condition	Back pain	80 (63.0%)	93 (66.9%)	173 (65.0%)	Fisher's Exact Test p=0.439
	Chronic widespread pain	14 (11.0%)	22 (15.8%)	36 (13.5%)	
	Fibromyalgia	11 (8.7%)	10 (7.2%)	21 (7.9%)	
	CFS	13 (10.2%)	10 (7.2%)	23 (8.6%)	
	ME	4 (3.1%)	1 (0.7%)	5 (1.9%)	
	Other	5 (3.9%)	3 (2.2%)	8 (3.0%)	
Duration of condition (years)	Mean (SD)	7.26 (8.08)	6.82 (8.94)	7.04 (8.51)	Mann Whitney U=7418.00, Z=-2.25, p=0.024
	Median (min-max)	4.50 (0.50-50)	3.00 (0.25-48)	4.00 (0.25-50)	
		(n=127)*	(n=139)*	Total n=266*	

[†] Participants could have more than one condition but only one main condition.

*Duration of condition was calculated from the available valid data.

Appendix 9, Table 6.3 Patients' symptoms: all retrospective patients versus all current patients (part 1)

Symptom	Details	Retrospective	Current	Total	Statistical analysis results
Pain present?	Yes	135 (92.5%)	158 (96.9%)	n=293 (94.8%)	Chi-square=3.13, df=1, p=0.077
Current pain[a]	Mean (SD) Median (min-max)	4.72 (2.85) 5.00 (0-9.00)	6.30 (2.58) 7.00 (0-10.00)	5.55 (2.82) 6.00 (0-10.00)	Levene's F=5.71, df=1,297, p=0.018 Student's t=5.01, df=284.3, p<0.001
Usual pain[a]	Mean (SD) Median (min-max)	4.90 (2.66) 5.00 (0-10.00)	6.28 (2.42) 7.00 (0-10.00)	5.64 (2.63) 6.00 (0-10.00)	Levene's F=2.24, df=1,300, p=0.136 Student's t=-4.71, df=300, p<0.001
Physical Fatigue[b]	Mean (SD) Median (min-max)	10.80 (4.84) 10.00 (0-21.00)	12.20 (4.85) 12.00 (0-21.00)	11.54 (4.89) 11.00 (0-21.00)	Levene's F=0.001, df=1,301, p=0.978 Student's t=-2.52, df=301, p=0.012
Mental fatigue[b]	Mean (SD) Median (min-max)	5.73 (2.68) 5.00 (0-12.00)	6.01 (2.90) 5.00 (0-12.00)	5.88 (2.80) 5.00 (0-12.00)	Levene's F=1.72, df=1,302, p=0.190 Student's t=-0.89, df=302, p=0.374
Anxiety[c]	Mean (SD) Median (min-max)	8.39 (4.86) 8.00 (0-21.00)	10.06 (4.82) 10.00 (0-20.00)	9.26 (4.90) 9.00 (0-21.00)	Levene's F=0.13, df=1,291, p=0.909 Student's t=-2.94, df=291, p=0.004
Depression[c]	Mean (SD) Median (min-max)	6.35 (4.70) 5.00 (0-21.00)	8.64 (4.65) 9.00 (0-21.00)	7.57 (4.80) 8.00 (0-21.00)	Mann-Whitney U=7695.50, Z=-4.46, p<0.001

[a] Current and usual pain were measured using two Numerical Rating Scales (0-10); [b] Physical and mental fatigue were measured using the Chalder Fatigue Questionnaire; [c] Anxiety and depression were measured using the Hospital Anxiety and Depression Scale.

Appendix 9, Table 6.3 Patients' symptoms: all retrospective patients versus all current patients (part 2)

Symptom	Details	Retrospective	Current	Total	Statistical analysis results
Cognitive anxiety[d]	Mean (SD) Median (min-max)	14.06 (6.07) 14.50 (0-25.00)	17.21 (6.04) 18.00 (0-25.00)	15.71 (6.25) 16.00 (0-25.00)	Levene's F=0.02, df=1,297, p=0.904 Student's t=-4.49, df=297, p<0.001
Escape and avoidance[d]	Mean (SD) Median (min-max)	12.07 (6.05) 11.00 (0-25.00)	14.80 (6.85) 16.00 (0-25.00)	13.5 (6.61) 14.00 (0-25.00)	Levene's F=3.74, df=1,284, p=0.054 Student's t=-3.56, df=284, p<0.001
Fearful thoughts[d]	Mean (SD) Median (min-max)	8.04 (6.98) 6.00 (0-25.00)	11.85 (7.85) 12.00 (0-25.00)	10.07 (7.68) 9.00 (0-25.00)	Mann Whitney U=7614.00, Z=-4.18, p<0.001
Physiological Anxiety[d]	Mean (SD) Median (min-max)	7.47 (7.06) 6.00 (0-25.00)	10.42 (7.79) 10.50 (0-25.00)	9.02 (7.58) 8.00 (0-25.00)	Mann-Whitney U=8586.50, Z=-3.27, p=0.001
Physical function[e]	Mean (SD) Median (min-max)	39.55 (11.27) 40.50 (11-64.00)	37.01 (9.86) 37.00 (13-61.00)	38.23 (10.62) 38.00 (11-64.00)	Levene's F=2.82, df=1,298, p=0.094 Student's t=2.08, df=298, p=0.039
Mental function[e]	Mean (SD) Median (min-max)	45.63 (11.67) 46.00 (12-64.00)	39.18 (12.98) 39.50 (10-67.00)	42.27 (12.76) 42.00 (10-67.00)	Levene's F=0.66, df=1,298, p=0.42 Student's t=4.51, df=298, p<0.001

[d] Cognitive anxiety, escape and avoidance, fearful thoughts and physiological anxiety were measured using the Pain Anxiety Symptoms Scale;
[e] Physical and mental function were measured using the Short Form-12.

Appendix 9, Table 6.4 Retrospective patients' demographic characteristics: individual treatment versus rehabilitation group

Characteristic	Details	Individual treatment (n=89)	Group treatment (n=58)	All retrospective patients (n=147)	Statistical analysis results
Gender	Male	28 (31.5%)	15 (25.9%)	43 (29.3%)	Chi-square=0.53, df=1, p=0.466
	Female	61 (68.5%)	43 (74.1%)	104 (70.7%)	
Age (in years)	Mean (SD)	50.1 (14.5)	45.1 (11.8)	48.1 (13.7)	Levene's F=1.41, df=1,145, p=0.238
	Median (min-max)	50.0 (19-91.0)	45.5 (20-69.0)	48.0 (19-91.0)	Student's t=2.21, df=145, p=0.029
Marital status	Married/living as married	52 (60.5%)	31 (53.4%)	83 (57.6%)	Fisher's Exact Test p=0.740
	Single	20 (23.3%)	17 (29.3%)	37 (25.7%)	
	Separated	2 (2.3%)	3 (5.2%)	5 (3.5%)	
	Divorced	9 (10.5%)	6 (10.3%)	15 (10.4%)	
	Widowed	3 (3.5%)	1 (1.7%)	4 (2.8%)	
Ethnicity	White	83 (94.3%)	54 (93.1%)	137 (93.8%)	Fisher's Exact Test p=0.549
	Mixed	1 (1.1%)	2 (3.4%)	3 (2.1%)	
	Asian/Asian British	0 (0.0%)	1 (1.7%)	1 (0.7%)	
	Black/Black British	2 (2.3%)	0 (0.0%)	2 (1.4%)	
	Chinese	1 (1.1%)	1 (1.7%)	2 (1.4%)	
	Other	1 (1.1%)	0 (0.0%)	1 (0.7%)	
Employment	Working full-time	40 (47.1%)	24 (42.9%)	64 (45.4%)	Fisher's Exact Test p=0.342
	Working part-time	13 (15.3%)	6 (10.7%)	19 (13.5%)	
	Working full-time in the home	0 (0.0%)	2 (3.6%)	2 (1.4%)	
	Not working due to present condition	1 (1.2%)	13 (2.3%)	14 (9.9%)	
	Not working due to other condition	11 (12.9%)	5 (8.9%)	16 (11.3%)	
	Unemployed but seeking work	3 (3.5%)	2 (3.6%)	5 (3.5%)	
	Student	2 (2.4%)	0 (0%)	2 (1.4%)	
	Semi-retired	0 (0%)	1 (1.8%)	1 (0.7%)	
	Retired	15 (17.6%)	3 (5.4%)	18 (12.8%)	

Appendix 9, Table 6.5 Current patients' demographic characteristics: individual treatment versus rehabilitation group

Characteristic	Details	Individual treatment (n=134)	Group treatment (n=30)	All current patients (n=164)	Statistical analysis results
Gender	Male	46 (34.3%)	10 (33.3%)	56 (34.1%)	Chi-square=0.01, df=1, p=0.917
	Female	88 (65.7%)	20 (66.7%)	108 (65.9%)	
Age (in years)	Mean (SD)	42.3 (14.3)	50.0 (14.4)	43.7 (14.6)	Levene's F=0.14, df=1,162, p=0.713
	Median (min-max)	43.0 (18-76.0)	50.0 (24-75.0)	45.0 (18-76.0)	Student's t=-2.64, df=162, p=0.009
Marital status	Married/living as married	61 (45.9%)	16 (53.3%)	77 (47.2%)	Fisher's Exact Test p=0.247
	Single	52 (39.1%)	7 (23.3%)	59 (36.2%)	
	Separated	3 (2.3%)	0 (0.0%)	3 (1.8%)	
	Divorced	15 (11.3%)	7 (23.3%)	22 (13.5%)	
	Widowed	2 (1.5%)	0 (0.0%)	2 (1.2%)	
Ethnicity	White	109 (82.0%)	25 (83.3%)	134 (82.2%)	Fisher's Exact Test p=0.594
	Mixed	2 (1.5%)	1 (3.3%)	3 (1.8%)	
	Asian/Asian British	12 (9.0%)	1 (3.3%)	13 (8.0%)	
	Black/Black British	4 (3.0%)	2 (6.7%)	6 (3.7%)	
	Chinese	1 (0.8%)	0 (0.0%)	1 (0.6%)	
	Other	5 (3.8%)	1 (3.3%)	6 (3.7%)	
Employment	Working full-time	40 (34.8%)	11 (36.7%)	51 (35.2%)	Fishers Exact Test p=0.969
	Working part-time	16 (13.9%)	5 (16.7%)	21 (14.5%)	
	Working full-time in the home	4 (3.5%)	1 (3.3%)	5 (3.4%)	
	Not working due to present condition	14 (12.2%)	3 (10.0%)	17 (11.7%)	
	Not working due to other condition	13 (11.3%)	4 (13.3%)	17 (11.7)	
	Unemployed but seeking work	12 (10.4%)	1 (3.3%)	13 (9.0%)	
	Student	4 (3.5%)	1 (3.3%)	5 (3.4%)	
	Semi-retired	2 (1.7%)	1 (3.3%)	3 (2.1%)	
	Retired	10 (8.7%)	3 (10.0%)	13 (9.0%)	

Appendix 9, Table 6.6 Retrospective patients' clinical characteristics: individual treatment versus rehabilitation group

Characteristic	Details	Individual treatment (n=89)	Group treatment (n=58)	All retrospective patients (n=147)	Statistical analysis results
Condition[†]	Back pain Chronic widespread pain Fibromyalgia CFS ME Other condition	69 (77.5%) 24 (27.0%) 8 (9.0%) 4 (4.5%) 4 (4.5%) 12 (13.5%)	33 (56.9%) 20 (34.5%) 19 (32.8%) 20 (34.5%) 8 (13.8%) 8 (13.8%)	102 (69.4%) 44 (29.9%) 27 (18.4%) 24 (16.3%) 12 (8.2%) 20 (13.6%)	Chi-square=7.04, df=1, p=0.008 Chi-square=0.95, df=1, p=0.331 Chi-square=13.23, df=1, p<0.001 Chi-square=23.12, df=1, p<0.001 Fisher's Exact Test p=0.063 Chi-square=0.003, df=1, p=0.957
Main condition	Back pain Chronic widespread pain Fibromyalgia CFS ME Other	56 (69.1%) 11 (13.6%) 5 (6.2%) 3 (3.7%) 3 (3.7%) 3 (3.7%)	24 (52.2%) 3 (6.5%) 6 (13.0%) 10 (21.7%) 1 (2.2%) 2 (4.3%)	80 (63.0%) 14 (11.0%) 11 (8.7%) 13 (10.2%) 4 (3.1%) 5 (3.9%)	Fisher's Exact Test p=0.014
Duration of condition (years)	Mean (SD) Median (min-max)	7.42 (8.50) 5.00 (0.50-50.00)	7.04 (7.54) 4.00 (0.50-40.00)	7.26 (8.08) 4.50 (0.50-50) (n=127)*	Mann Whitney U=1931.50, Z=-0.15, p=0.885

[†] Participants could have more than one condition but only one main condition

*Duration of condition was calculated based from the available valid data.

Appendix 9, Table 6.7 Current patients' clinical characteristics: individual treatment versus rehabilitation group

Characteristic	Details	Individual treatment (n=89)	Group treatment (n=58)	All current patients (n=147)	Statistical analysis results
Condition[†]	Back pain	101 (75.9%)	25 (83.3%)	126 (77.3%)	Chi-square=0.76, df=1, p=0.383
	Chronic widespread pain	55 (41.4%)	13 (43.3%)	68 (41.7%)	Chi-square=0.04, df=1, p=0.843
	Fibromyalgia	15 (11.3%)	2 (6.7%)	17 (10.4%)	Fisher's Exact Test p=0.741
	CFS	16 (12.0%)	3 (10.0%)	19 (11.7%)	Fisher's Exact Test p>0.999
	ME	4 (3.0%)	0 (0.0%)	4 (2.5%)	Fisher's Exact Test p>0.999
	Other condition	12 (9.0%)	5 (16.7%)	17 (10.4%)	Fisher's Exact Test p=0.317
Main condition	Back pain	77 (70.0%)	16 (55.2%)	93 (66.9%)	Fisher's Exact Test p=0.373
	Chronic widespread pain	14 (12.7%)	8 (27.6%)	22 (15.8%)	
	Fibromyalgia	8 (7.3%)	2 (6.9%)	10 (7.2%)	
	CFS	8 (7.3%)	2 (6.9%)	10 (7.2%)	
	ME	1 (0.9%)	0 (0.0%)	1 (0.7%)	
	Other	2 (1.8%)	1 (3.4%)	3 (2.2%)	
Duration of condition (years)	Mean (SD)	6.50 (8.46)	7.81 (11.03)	6.82 (8.94)	Mann Whitney U=1418.50, Z=-0.04, p=0.972
	Median (min-max)	3.00 (0.25-48.00)	4.50 (0.42-40.00)	3.00 (0.25-48) (n=139)*	

[†] Participants could have more than one condition but only one main condition

*Duration of condition was calculated based from the available valid data.

Appendix 9, Table 6.8 Retrospective patients' symptoms: individual treatment versus rehabilitation group (part 1)

Symptom	Details	Individual treatment	Group treatment	All retrospective patients	Statistical analysis results
Pain present?	Yes	79 (89.8%)	56 (96.6%)	135 (92.5%)	Fisher's Exact Test p=0.201
Current pain[a]	Mean (SD) Median (min-max)	4.57 (2.82) 5.00 (0-9.00)	4.93 (2.91) 6.00 (0-9.00)	4.72 (2.85) 5.00 (0-9.00)	Levene's F=0.18, df=1, 139, p=0.669 Student's t=-0.73, df=139, p=0.466
Usual pain[a]	Mean (SD) Median (min-max)	4.78 (2.91) 5.00 (0-10.00)	5.09 (2.25) 5.00 (0-9.00)	4.90 (2.66) 5.00 (0-10.00)	Levene's F=7.05, df=1, 139, p=0.009 Student's t=-0.72, df=135.3, p=0.474
Physical fatigue[b]	Mean (SD) Median (min-max)	10.73 (4.81) 10.00 (0-21.00)	10.89 (4.91) 10.00 (3-21.00)	10.80 (4.84) 10.00 (0-21.00)	Levene's F=0.06, df=1,140, p=0.804 Student's t=-0.20, df=140, p=0.844
Mental fatigue[b]	Mean (SD) Median (min-max)	5.48 (2.49) 4.00 (0-12.00)	6.11 (2.92) 5.00 (0-12.00)	5.73 (2.68) 5.00 (0-12.00)	Levene's F=3.14, df=1,140, p=0.079 Student's t=-1.370, df=140, p=0.173
Anxiety[c]	Mean (SD) Median (min-max)	8.14 (4.77) 8.00 (0-20.00)	8.77 (5.00) 9.00 (1.00-21.00)	8.39 (4.86) 8.00 (0-21.00)	Levene's F=0.16, df=1,138, p=0.689 Student's t=-0.76, df=138, p=0.458
Depression[c]	Mean (SD) Median (min-max)	5.91 (4.34) 5.00 (0-19.00)	6.98 (5.15) 6.00 (0-21.00)	6.35 (4.70) 5.00 (0-21.00)	Mann Whitney U=2070.00, Z=-1.15, p=0.251

[a] Current and usual pain were measured using two Numerical Rating Scales (0-10); [b] Physical and mental fatigue were measured using the Chalder Fatigue Questionnaire; [c] Anxiety and depression were measured using the Hospital Anxiety and Depression Scale.

Appendix 9, Table 6.8 Retrospective patients' symptoms: individual treatment versus rehabilitation group (part 2)

Symptom	Details	Individual treatment	Group treatment	All retrospective patients	Statistical analysis results
Cognitive anxiety[d]	Mean (SD) Median (min-max)	13.63 (6.48) 14.00 (0-25.00)	14.73 (5.38) 16.00 (0-25.00)	14.06 (6.07) 14.50 (0-25.00)	Levene's F=2.34, df=1,140, p=0.128 Student's t=-1.06, df=140, p=0.291
Escape and avoidance[d]	Mean (SD) Median (min-max)	11.98 (6.54) 11.50 (0-25.00)	12.20 (5.27) 11.00 (2-25.00)	12.07 (6.05) 11.00 (0-25.00)	Mann Whitney U=2176.00, Z=-0.17, p=0.866
Fearful thoughts[d]	Mean (SD) Median (min-max)	8.42 (7.07) 8.00 (0-25.00)	7.46 (6.87) 6.00 (0-25.00)	8.04 (6.98) 6.00 (0-25.00)	Mann Whitney U=2066.50, Z=-0.771, p=0.441
Physiological Anxiety[d]	Mean (SD) Median (min-max)	7.19 (6.81) 4.00 (0-25.00)	7.89 (7.45) 6.00 (0-25.00)	7.47 (7.06) 6.00 (0-25.00)	Mann Whitney U=2260.50, Z=-0.51, p=0.613
Physical function[e]	Mean (SD) Median (min-max)	40.16 (10.95) 40.50 (11-60.00)	38.64 (11.77) 40.00 (17-64.00)	39.55 (11.27) 40.50 (11-64.00)	Levene's F=0.46, df=1,142, p=0.500 Student's t=0.80, df=142, p=0.428
Mental function[e]	Mean (SD) Median (min-max)	45.74 (12.03) 44.50 (12-64.00)	45.45 (11.21) 48.50 (12-63.00)	45.63 (11.67) 46.00 (12-64.00)	Levene's F=0.301, df=1,142, p=0.584 Student's t=0.15, df=142, p=0.882

[d] Cognitive anxiety, escape and avoidance, fearful thoughts and physiological anxiety were measured using the Pain Anxiety Symptoms Scale;
[e] Physical and mental function were measured using the Short Form-12.

Appendix 9, Table 6.9 Current patients' symptoms: individual treatment versus rehabilitation group (part 1)

Symptom	Details	Individual treatment	Group treatment	All current patients	Statistical analysis results
Pain present?	Yes	128 (96.2%)	30 (100.0%)	158 (96.9%)	Fisher's Exact Test p=0.585
Current pain [a]	Mean (SD) Median (min-max)	6.50 (2.57) 7.00 (0-10.00)	5.36 (2.48) 5.50 (1.00-9.00)	6.30 (2.58) 7.00 (0-10.00)	Levene's F=0.13, df=1,156, p=0.721 Student's t=2.15, df=156, p=0.033
Usual pain [a]	Mean (SD) Median (min-max)	6.28 (2.51) 7.00 (0-10.00)	6.27 (2.02) 6.00 (2.00-10.00)	6.28 (2.42) 7.00 (0-10.00)	Levene's F=1.86, df=1,159, p=0.174 Student's t=0.03, df=159, p=0.974
Physical fatigue [b]	Mean (SD) Median (min-max)	12.59 (4.72) 12.00 (0-21.00)	10.50 (5.11) 9.00 (3.00-20.00)	12.20 (4.85) 12.00 (0-21.00)	Levene's F=0.91, df=1,159, p=0.341 Student's t=2.16, df=159, p=0.033
Mental fatigue [b]	Mean (SD) Median (min-max)	6.17 (2.89) 6.00 (0-12.00)	5.33 (2.89) 4.00 (0-11.00)	6.01 (2.90) 5.00 (0-12.00)	Levene's F=0.53, df=1,160, p=0.153 Student's t=1.45, df=160, p=0.153
Anxiety [c]	Mean (SD) Median (min-max)	10.36 (4.81) 10.00 (0-20.00)	8.83 (4.78) 8.00 (0-20.00)	10.06 (4.82) 10.00 (0-20.00)	Levene's F=0.10, df=1,151, p=0.755 Student's t=1.56, df=151, p=0.121
Depression [c]	Mean (SD) Median (min-max)	8.91 (4.75) 9.00 (0-21.00)	7.47 (4.02) 8.00 (1.00-15.00)	8.64 (4.65) 9.00 (0-21.00)	Levene's F=0.75, df=1,156, p=0.387 Student's t=1.54, df=156, p=0.125

[a] Current and usual pain were measured using two Numerical Rating Scales (0-10); [b] Physical and mental fatigue were measured using the Chalder Fatigue Questionnaire; [c] Anxiety and depression were measured using the Hospital Anxiety and Depression Scale.

Appendix 9, Table 6.9 Current patients' symptoms: individual treatment versus rehabilitation group (part 2)

Symptom	Details	Individual treatment	Group treatment	All current patients	Statistical analysis results
Cognitive anxiety [d]	Mean (SD) Median (min-max)	17.62 (6.10) 19.00 (0-25.00)	15.41 (5.51) 15.00 (5-25.00)	17.21 (6.04) 18.00 (0-25.00)	Mann Whitney U=1386.00, Z=-2.13, p=0.033
Escape and avoidance [d]	Mean (SD) Median (min-max)	15.23 (6.96) 17.00 (0-25.00)	12.85 (6.10) 14.00 (0-25.00)	14.80 (6.85) 16.00 (0-25.00)	Mann Whitney U=1277.50, Z=-1.88, p=0.061
Fearful thoughts [d]	Mean (SD) Median (min-max)	12.35 (7.96) 13.00 (0-25.00)	9.77 (7.12) 8.00 (0-25.00)	11.85 (7.85) 12.00 (0-25.00)	Mann Whitney U=1526.50, Z=-1.58, p=0.114
Physiological Anxiety [d]	Mean (SD) Median (min-max)	11.02 (7.86) 11.00 (0-25.00)	7.90 (7.07) 5.50 (0-23.00)	10.42 (7.79) 10.50 (0-25.00)	Mann Whitney U=1465.50, Z=-1.913, p=0.056
Physical function [e]	Mean (SD) Median (min-max)	36.57 (9.63) 36.00 (13-61.00)	38.93 (10.76) 39 (18-56.00)	37.01 (9.86) 37.00 (13-61.00)	Levene's F=0.46, df=1,154, p=0.498 Student's t=-1.16, df=154, p=0.247
Mental function [e]	Mean (SD) Median (min-max)	38.39 (13.09) 38.00 (10-67.00)	42.62 (12.11) 45.00 (21-62.00)	39.18 (12.98) 39.50 (10-67.00)	Levene's F=0.00, df=1,154, p=0.993 Student's t=-1.591, df=154, p=0.114

[d] Cognitive anxiety, escape and avoidance, fearful thoughts and physiological anxiety were measured using the Pain Anxiety Symptoms Scale;
[e] Physical and mental function were measured using the Short Form-12.

Appendix 9, Table 6.10 Demographic and clinical characteristics: total responders versus total non-responders

Characteristic	Details	Non-responders (n=1295)	Responders (n=329)†	Total (n=1624)	Statistical analysis results
Gender	Male Female Total	472 (40.1%) 704 (59.9%) (n=1176)	104 (31.6%) 225 (68.4%) (n=329)	576 (38.3%) 929 (61.7%) (n=1505)	Chi-square=7.91, df=1, p=0.005
Age (in years)	Mean (SD) Median (min-max) Total	42.4 (13.8) 42.0 (18-100) (n=1221)	45.9 (14.3) 46 (18-90) (n=328)	43.2 (14.0) 42.0 (18-100) (n=1549)	Levene's F=1.44, df=1,1547, p=0.230 Student's t=-4.00, df=1547, p<0.001
Condition*	Back pain Chronic widespread pain Fibromyalgia CFS ME	1123 (91.9%) 50 (4.1%) 77 (6.3%) 43 (3.5%) 16 (1.3%)	244 (74.2%) 128 (38.9%) 46 (14.0%) 49 (14.9%) 21 (6.4%)	1367 (88.1%) 178 (11.5%) 123 (7.9%) 92 (5.9%) 37 (2.4%)	Chi-square=77.97, df=1, p<0.001 Chi-square=309.24, df=1, p<0.001 Chi square=20.94, df=1, p<0.001 Chi square=60.11, df=1, p<0.001 Chi-square=28.65, df=1, p<0.001
Duration of condition (years)	Mean (SD) Median (min-max)	3.56 (5.72) 1.17 (0.25-40) (n=778)	6.93 (8.30) 4.00 (0.17-50)** (n=290)	4.48 (6.69) 2.00 (0.17-50) (n=1068)	Mann Whitney U=68454.50, Z=-9.92, p<0.001

†=Total number of responders including the 18 patients who did not meet the inclusion criteria for the study
*=There were 1551 valid cases for the variable 'condition'
**=The patient who had her symptoms for 0.17 years, that is 2 months was excluded from the study as she did not meet the inclusion criteria.

Appendix 9, Table 6.11 Retrospective patients' treatment type and treatment completion: non-responders versus responders

Characteristic	Details	Non-responders (n=647)	Responders (n=155)	Total (n=802)	Statistical analysis results
Treatment type	Individual Group	520 (80.4%) 127 (19.6%)	95 (61.3%) 60 (38.7%)	615 (76.7%) 187 (23.3%)	Chi-square=25.46, df=1, p<0.001
Treatment completion	No Yes	324 (50.7%) 315 (49.3%)	55 (35.7%) 99 (64.3%)	379 (47.8%) 414 (52.2%)	Chi-square=11.18, df=1, p=0.001

Appendix 10. Exploratory factor analysis of the APQ

Appendix 10, Table 6.12 Mean scores, standard deviation, median, range and number of missing answers for each of the 38 APQ questions

	Mean (SD)	Median (range)	Number of missing answers
APQ1	1.75 (1.31)	2.00 (0-4)	10
APQ2	2.88 (1.15)	3.00 (0-4)	11
APQ3	2.14 (1.36)	2.00 (0-4)	13
APQ4	1.76 (1.26)	2.00 (0-4)	8
APQ5	2.10 (1.40)	2.00 (0-4)	12
APQ6	1.73 (1.40)	2.00 (0-4)	12
APQ7	1.72 (1.30)	2.00 (0-4)	13
APQ8	1.87 (1.29)	2.00 (0-4)	14
APQ9	2.02 (1.39)	2.00 (0-4)	10
APQ10	2.30 (1.41)	3.00 (0-4)	11
APQ11	2.80 (1.22)	3.00 (0-4)	6
APQ12	1.74 (1.31)	2.00 (0-4)	11
APQ13	1.92 (1.39)	2.00 (0-4)	10
APQ14	2.10 (1.32)	2.00 (0-4)	8
APQ15	1.75 (1.36)	2.00 (0-4)	6
APQ16	2.04 (1.47)	2.00 (0-4)	10
APQ17	1.34 (1.42)	1.00 (0-4)	19
APQ18	1.66 (1.32)	2.00 (0-4)	12
APQ19	1.87 (1.31)	2.00 (0-4)	10
APQ20	1.80 (1.37)	2.00 (0-4)	17
APQ21	2.14 (1.22)	2.00 (0-4)	11
APQ22	2.53 (1.35)	3.00 (0-4)	8
APQ23	2.28 (1.35)	2.00 (0-4)	8
APQ24	2.25 (1.32)	2.00 (0-4)	9
APQ25	2.15 (1.42)	2.00 (0-4)	14
APQ26	1.93 (1.46)	2.00 (0-4)	8
APQ27	2.00 (1.44)	2.00 (0-4)	7
APQ28	2.23 (1.36)	2.00 (0-4)	10
APQ29	1.90 (1.34)	2.00 (0-4)	10
APQ30	2.46 (1.32)	3.00 (0-4)	7
APQ31	1.33 (1.31)	1.00 (0-4)	12
APQ32	0.47 (0.94)	0.00 (0-4)	15
APQ33	1.57 (1.30)	2.00 (0-4)	16
APQ34	1.85 (1.29)	2.00 (0-4)	17
APQ35	1.67 (1.34)	2.00 (0-4)	15
APQ36	1.86 (1.34)	2.00 (0-4)	14
APQ37	1.56 (1.32)	2.00 (0-4)	17
APQ38	1.96 (1.38)	2.00 (0-4)	12

Appendix 10, Table 6.13 Eight component solution for the 38-item APQ using Principal Component Analysis

APQ item	Component							
	1	2	3	4	5	6	7	8
APQ1	.592		-.509					
APQ2	.455			.483			.347	
APQ3	.668							
APQ4	.641		-.466					
APQ5	.661	-.436						
APQ6	.664							
APQ7	.644							
APQ8	.703						-.324	
APQ9	.701	-.345						
APQ10	.728							
APQ11	.555			.381	.344			
APQ12	.717							
APQ13	.762	-.362						
APQ14	.386	.591						
APQ15	.744							-.328
APQ16	.745							
APQ17	.662					.449		
APQ18	.663					.477		
APQ19	.758							
APQ20	.509							.457
APQ21	.473	.496						
APQ22	.425		.501					.348
APQ23	.604		.371					
APQ24	.567		.340					
APQ25	.701							
APQ26	.519							
APQ27	.345		.374			.375	.365	
APQ28	.716							
APQ29	.741							
APQ30	.439	.621						
APQ31	.643			-.386				
APQ32	.363			-.522				
APQ33	.730							
APQ34	.581							
APQ35	.768							
APQ36	.711							
APQ37	.620							
APQ38		.549			.407			
Variance explained (%)	38.9	6.6	4.6	4.4	3.3	2.8	2.8	2.7
Cumulative variance (%)	38.9	45.5	50.1	54.5	57.8	60.6	63.4	66.1

Appendix 11. Reliability of the APQ:
Inter-item correlations, item total correlations and Cronbach's alpha

Appendix 11, Table 6.14 APQ factor 1: corrected item total correlations, Cronbach's alpha if item deleted, mean and standard deviation. Of note, Cronbach's alpha for APQ factor 1 with all items included=0.932

APQ item	Corrected item total correlation	Cronbach's alpha if item deleted	Mean (SD)	Number
5	0.73	0.925	2.11 (1.40)	274
6	0.66	0.928	1.72 (1.40)	274
7	0.61	0.930	1.72 (1.29)	274
8	0.72	0.926	1.88 (1.26)	274
9	0.73	0.925	2.01 (1.38)	274
10	0.67	0.928	2.03 (1.40)	274
11	0.55	0.932	2.82 (1.22)	274
12	0.75	0.925	1.74 (1.30)	274
13	0.82	0.922	1.92 (1.40)	274
15	0.75	0.925	1.73 (1.35)	274
16	0.72	0.926	2.05 (1.45)	274
19	0.73	0.926	1.87 (1.29)	274

Appendix 11, Table 6.15 APQ factor 1: inter-item correlations

	APQ5	APQ6	APQ7	APQ8	APQ9	APQ10	APQ11	APQ12	APQ13	APQ15	APQ16	APQ19
APQ5	1.000	.531	.462	.533	.573	.493	.559	.628	.682	.564	.551	.495
APQ6	.531	1.000	.422	.477	.455	.507	.384	.482	.628	.605	.479	.520
APQ7	.462	.422	1.000	.635	.467	.495	.374	.514	.488	.392	.451	.463
APQ8	.533	.477	.635	1.000	.583	.513	.347	.595	.576	.551	.559	.614
APQ9	.573	.455	.467	.583	1.000	.529	.405	.626	.666	.597	.618	.583
APQ10	.493	.507	.495	.513	.529	1.000	.443	.588	.551	.484	.482	.574
APQ11	.559	.384	.374	.347	.405	.443	1.000	.467	.524	.394	.396	.367
APQ12	.628	.482	.514	.595	.626	.588	.467	1.000	.677	.558	.548	.575
APQ13	.682	.628	.488	.576	.666	.551	.524	.677	1.000	.710	.639	.576
APQ15	.564	.605	.392	.551	.597	.484	.394	.558	.710	1.000	.665	.670
APQ16	.551	.479	.451	.559	.618	.482	.396	.548	.639	.665	1.000	.627
APQ19	.495	.520	.463	.614	.583	.574	.367	.575	.576	.670	.627	1.000

Appendix 11, Table 6.16 APQ factor 2: corrected item total correlations, Cronbach's alpha if item deleted, mean and standard deviation. Of note, Cronbach's alpha for factor 2 with all items included=0.911

APQ item	Corrected item total correlation	Cronbach's alpha if item deleted	Mean (SD)	Number
18	0.59	0.908	1.59 (1.31)	277
25	0.70	0.900	2.12 (1.42)	277
28	0.74	0.898	2.20 (1.39)	277
29	0.69	0.901	1.84 (1.33)	277
31	0.67	0.902	1.27 (1.28)	277
33	0.73	0.899	1.54 (1.28)	277
35	0.77	0.896	1.60 (1.32)	277
36	0.71	0.900	1.79 (1.33)	277
37	0.64	0.905	1.50 (1.30)	277

Appendix 11, Table 6.17 APQ factor 2: inter-item correlations

	APQ18	APQ25	APQ28	APQ29	APQ31	APQ33	APQ35	APQ36	APQ37
APQ18	1.000	.477	.484	.514	.399	.458	.481	.444	.393
APQ25	.477	1.000	.681	.513	.498	.541	.572	.527	.505
APQ28	.484	.681	1.000	.661	.505	.589	.544	.537	.493
APQ29	.514	.513	.661	1.000	.508	.610	.571	.489	.391
APQ31	.399	.498	.505	.508	1.000	.536	.671	.518	.523
APQ33	.458	.541	.589	.610	.536	1.000	.595	.599	.507
APQ35	.481	.572	.544	.571	.671	.595	1.000	.668	.570
APQ36	.444	.527	.537	.489	.518	.599	.668	1.000	.584
APQ37	.393	.505	.493	.391	.523	.507	.570	.584	1.000

Appendix 11, Table 6.18 APQ factor 3: corrected item total correlations, Cronbach's alpha if item deleted, mean and standard deviation. Of note, Cronbach's alpha for factor 3 with all items included=0.828

APQ item	Corrected item total correlation	Cronbach's alpha if item deleted	Mean (SD)	Number
1	0.70	0.751	1.73 (1.31)	293
3	0.61	0.836	2.14 (1.37)	293
4	0.75	0.698	1.75 (1.26)	293

Appendix 11, Table 6.19 APQ factor 3: inter-item correlations

	APQ1	APQ3	APQ4
APQ1	1.000	.536	.719
APQ3	.536	1.000	.604
APQ4	.719	.604	1.000

Appendix 11, Table 6.20 APQ factor 4: corrected item total correlations, Cronbach's alpha if item deleted, mean and standard deviation. Of note, Cronbach's alpha for factor 4 with all items included=0.774

APQ item	Corrected item total correlation	Cronbach's alpha if item deleted	Mean (SD)	Number
14	0.57	0.723	2.12 (1.32)	292
21	0.54	0.737	2.14 (1.22)	292
30	0.68	0.661	2.46 (1.34)	292
38	0.52	0.750	1.95 (1.38)	292

Appendix 11, Table 6.21 APQ factor 4: inter-item correlations

	APQ14	APQ21	APQ30	APQ38
APQ14	1.000	.480	.487	.407
APQ21	.480	1.000	.537	.303
APQ30	.487	.537	1.000	.556
APQ38	.407	.303	.556	1.000

Appendix 11, Table 6.22 APQ factor 5: corrected item total correlations, Cronbach's alpha if item deleted, mean and standard deviation. Of note, Cronbach's alpha for factor 5 with all items included=0.724

APQ item	Corrected item total correlation	Cronbach's alpha if item deleted	Mean (SD)	Number
22	0.53	0.655	2.55 (1.34)	299
23	0.60	0.567	2.29 (1.35)	299
24	0.51	0.680	2.24 (1.32)	299

Appendix 11, Table 6.23 APQ factor 5: inter-item correlations

	APQ22	APQ23	APQ24
APQ22	1.000	.516	.396
APQ23	.516	1.000	.487
APQ24	.396	.487	1.000

Appendix 11, Table 6.24 Summary of the items removed from the APQ

Number of items removed	APQ item removed	Reason for removal
1	APQ17: *"I made sure I had a flare up plan"*	High number of missing answers (n=19), alluding to possible misunderstanding (in particular the term 'flare-up plan', which a participant specifically stated they did not understand) or a less frequently used item. (This contributed to the lower number of complete cases that could be analysed.)
2	APQ20: *"I did not under-do activities on a 'bad' day"*	High number of missing answers (n=17), alluding to possible misunderstanding (in particular the inference of the double negative) or a less frequently used item. (This contributed to the lower number of complete cases that could be analysed.)
3	APQ34: *"I did not over-do activities on a 'good' day"*	High number of missing answers (n=17), alluding to possible misunderstanding (in particular the inference of the phrase: "I did not" on the 0-4 Likert scale) or a less frequently used item. (This contributed to the lower number of complete cases that could be analysed.)
4	APQ32: *"I used an activity diary to monitor my activity pattern"*	Very low mean score (mean=0.47), alluding to an infrequently used action, and an item that may not have been sensitive to the full range of answers (0-4).
5	APQ2: *"I was aware of the effect that different types of activities had on me"*	Following the removal of APQ32, APQ2 was the only item that loaded predominantly onto component 4 (see Appendix 10, Table 6.13). Additionally, one participant commented that APQ2 did not make sense.
6	APQ26: *"I used support from others to help me with my activities"*	Low correlations with other items. Lowest loading on component 1 following the removal of APQ20. Item may be potentially inappropriate for patients with no support.
7	APQ27: *"I did not feel guilty when I stopped an activity"*	Low correlations with other items and small contributions to multiple (4) components. Lone item loading predominantly on component 6. Negative comments from participants suggested possible confusion on the inference of the phrase "I did not" on the 0-4 Likert scale.
8	APQ25: *"I set activity goals that were meaningful to me"*	APQ25 appeared repetitive of APQ28 and was removed in favour of removing APQ28 due to having a lower mean, lower item-total correlations and a lower factor loading. Removing APQ25 reduced Cronbach's alpha from 0.911 to a more acceptable 0.900 (suggestive of less repetition).

Appendix 12. Principal axis factor analysis of the 30-item APQ and correlations between the APQ factors

Appendix 12, Table 6.25 APQ 30 items: mean and standard deviation

	Mean	Std. Deviation	Analysis N
APQ1	1.69	1.30	245
APQ3	2.10	1.37	245
APQ4	1.70	1.25	245
APQ5	2.02	1.41	245
APQ6	1.67	1.41	245
APQ7	1.68	1.29	245
APQ8	1.81	1.26	245
APQ9	1.95	1.39	245
APQ10	2.27	1.42	245
APQ11	2.76	1.25	245
APQ12	1.65	1.28	245
APQ13	1.84	1.39	245
APQ14	2.09	1.31	245
APQ15	1.66	1.34	245
APQ16	2.01	1.46	245
APQ18	1.62	1.32	245
APQ19	1.83	1.29	245
APQ21	2.18	1.19	245
APQ22	2.56	1.36	245
APQ23	2.27	1.31	245
APQ24	2.23	1.31	245
APQ28	2.23	1.39	245
APQ29	1.85	1.35	245
APQ30	2.43	1.33	245
APQ31	1.29	1.26	245
APQ33	1.51	1.26	245
APQ35	1.60	1.33	245
APQ36	1.79	1.32	245
APQ37	1.49	1.31	245
APQ38	1.94	1.37	245

Appendix 12, Table 6.26 Five factor solution for the 30-item APQ Principal Axis Factoring with Varimax rotation

APQ item	Factor				
	1	2	3	4	5
1			.713		
3	.401		.507		
4	.326		.696		
5	.754				
6	.609				
7	.502		.363		
8	.570		.343		
9	.665				
10	.547				.351
11	.580				
12	.700				
13	.816	.341			
14				.545	
15	.659	.408			
16	.625	.405			
18	.349	.334	.336		
19	.580	.325			
21				.534	
22					.618
23	.337				.606
24				.330	.381
28		.497			.474
29	.384	.470	.362		
30				.819	
31		.626			
33	.437	.581			
35	.409	.661			
36		.589		.367	
37		.577			
38				.587	
Variance explained (%)	21.2%	12.0%	8.4%	7.8%	6.5%
Cumulative Variance (%)	21.2%	33.2%	41.5%	49.3%	55.9%

Appendix 12, Figures 6.1 to 6.5 Histograms showing the distribution of scores for the five APQ factors (allowing one missing answer per subscale)

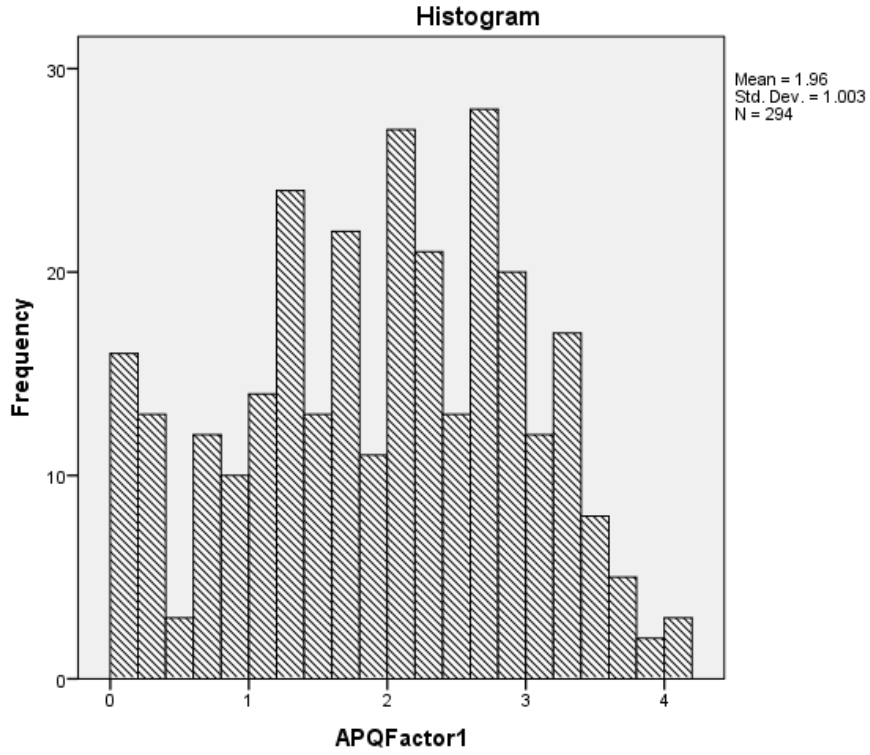


Figure 6.1 Distribution of scoring for APQ factor 1: Activity limitation

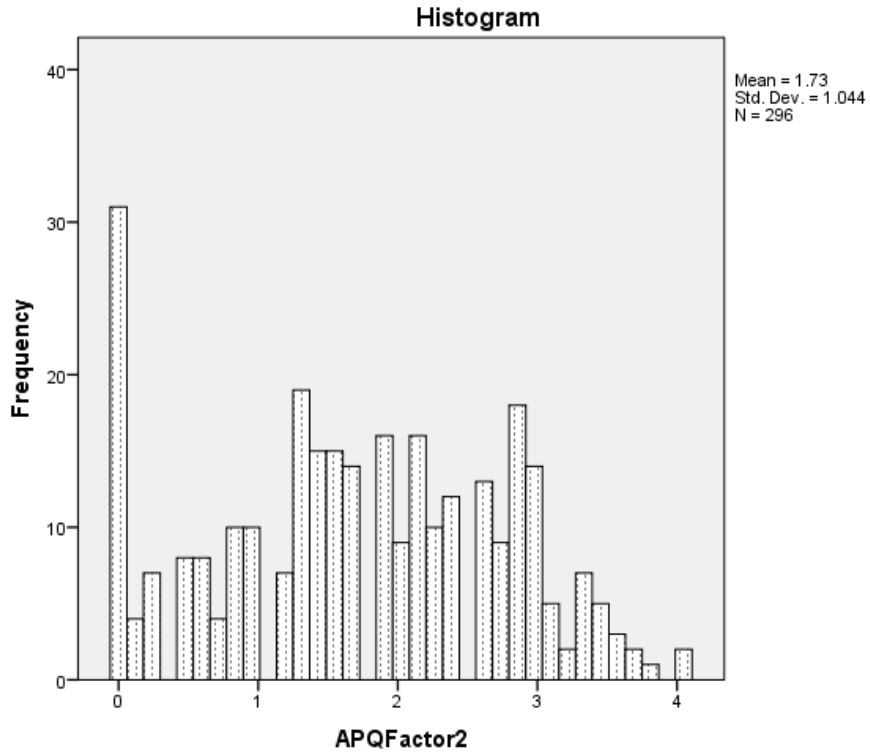


Figure 6.2 Distribution of scoring for APQ factor 2: Activity planning

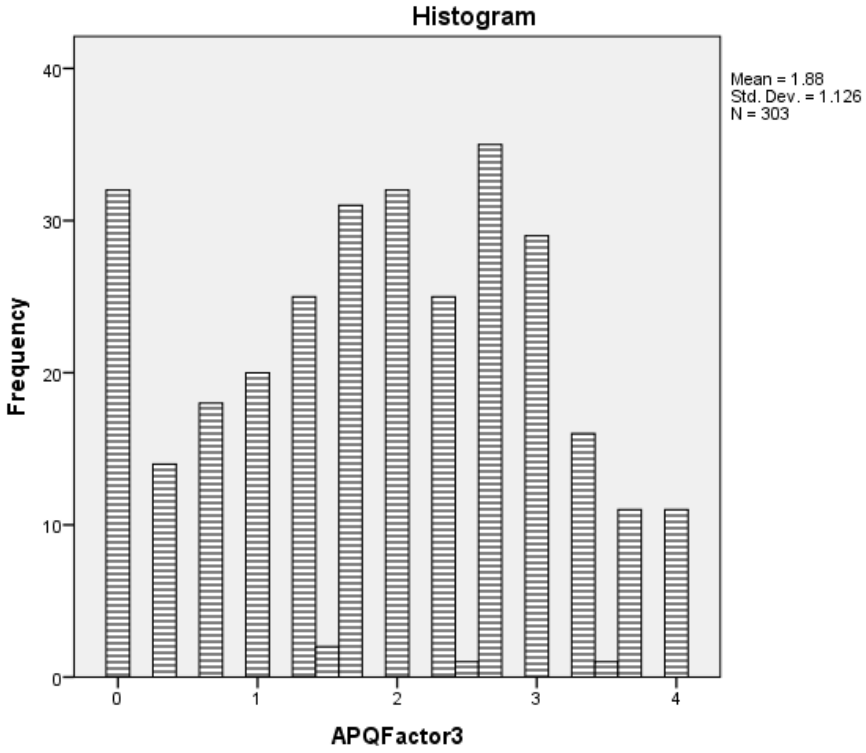


Figure 6.3 Distribution of scoring for APQ factor 3: Activity progression

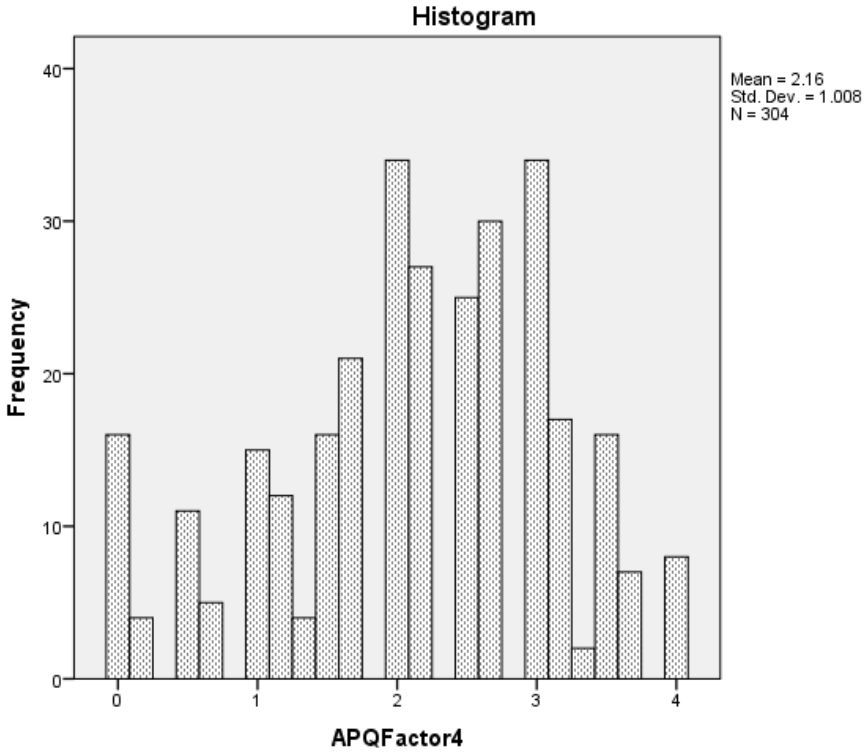


Figure 6.4 Distribution of scoring for APQ factor 4: Activity consistency

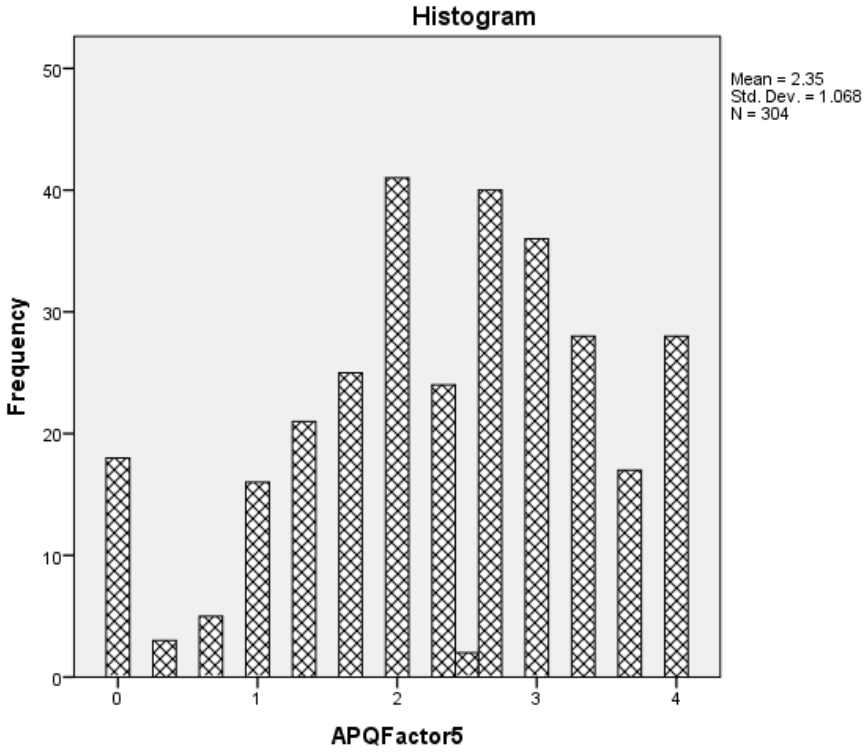


Figure 6.5 Distribution of scoring for APQ factor 5: Activity acceptance

Appendix 12, Table 6.27 Pearson's correlations between the APQ five factors for complete data (upper triangle) and allowing one missing value (lower triangle)

		APQ Factor 1 Activity limitation	APQ Factor 2 Activity planning	APQ Factor 3 Activity progression	APQ Factor 4 Activity consistency	APQ Factor 5 Activity acceptance
APQ Factor 1	Correlation	1.00	0.745**	0.623**	0.322**	0.568**
	P-value		<0.001	<0.001	<0.001	<0.001
	N	294 \ 271	254	264	263	268
APQ Factor 2	Correlation	0.761**	1.00	0.608**	0.474**	0.565**
	P-value	<0.001		<0.001	<0.001	<0.001
	N	288	296 \ 282	274	278	278
APQ Factor 3	Correlation	0.635**	0.625**	1.00	0.429**	0.384**
	P-value	<0.001	<0.001		<0.001	<0.001
	N	293	295	303 \ 293	282	288
APQ Factor 4	Correlation	0.360**	0.493**	0.427**	1.00	0.363**
	P-value	<0.001	<0.001	<0.001		<0.001
	N	294	296	301	304 \ 292	288
APQ Factor 5	Correlation	0.588**	0.577**	0.393**	0.354**	1.00
	P-value	<0.001	<0.001	<0.001	<0.001	
	N	294	296	301	304	304 \ 299
** Correlation is significant at the 0.01 level (2-tailed)						

Appendix 13. Validity of the APQ: correlations between the APQ factors and existing pacing subscales

Appendix 13, Table 6.28 Correlations between the APQ five factors and the Chronic Pain Coping Inventory (CPCI) pacing subscale items

		APQ Factor 1 Activity limitation	APQ Factor 2 Activity planning	APQ Factor 3 Activity progression	APQ Factor 4 Activity consistency	APQ Factor 5 Activity acceptance
CPCIPS1 (days)	Pearson Correlation	.501**	.394**	.379**	.206**	.314**
	Sig. (2-tailed)	.000	.000	.000	.001	.000
	N	251	257	259	258	258
CPCIPS2 (days)	Pearson Correlation	.484**	.422**	.389**	.255**	.351**
	Sig. (2-tailed)	.000	.000	.000	.000	.000
	N	253	258	258	259	259
CPCIPS3 (days)	Pearson Correlation	.575**	.501**	.450**	.313**	.345**
	Sig. (2-tailed)	.000	.000	.000	.000	.000
	N	249	254	256	254	254
CPCIPS4 (days)	Pearson Correlation	.449**	.427**	.341**	.233**	.291**
	Sig. (2-tailed)	.000	.000	.000	.000	.000
	N	249	254	254	255	255
CPCIPS5 (days)	Pearson Correlation	.500**	.466**	.390**	.275**	.381**
	Sig. (2-tailed)	.000	.000	.000	.000	.000
	N	251	255	256	256	256
CPCIPS6 (days)	Pearson Correlation	.381**	.381**	.394**	.312**	.218**
	Sig. (2-tailed)	.000	.000	.000	.000	.001
	N	234	239	239	240	240
** Correlation is significant at the 0.01 level (2-tailed)						

Appendix 13, Table 6.29 Correlations between the APQ five factors and the Pain and Activity Relations Questionnaire (PARQ) pacing subscale items

		APQ Factor 1 Activity limitation	APQ Factor 2 Activity planning	APQ Factor 3 Activity progression	APQ Factor 4 Activity consistency	APQ Factor 5 Activity acceptance
PARQPS1	Pearson Correlation	.412**	.369**	.185**	.181**	.415**
	Sig. (2-tailed)	.000	.000	.001	.002	.000
	N	287	289	295	297	297
PARQPS2	Pearson Correlation	.686**	.581**	.404**	.177**	.503**
	Sig. (2-tailed)	.000	.000	.000	.002	.000
	N	283	285	291	293	293
PARQPS3	Pearson Correlation	.557**	.486**	.330**	.310**	.461**
	Sig. (2-tailed)	.000	.000	.000	.000	.000
	N	287	288	294	295	295
PARQPS4	Pearson Correlation	.657**	.611**	.409**	.301**	.471**
	Sig. (2-tailed)	.000	.000	.000	.000	.000
	N	282	284	291	292	292
PARQPS5	Pearson Correlation	.559**	.476**	.380**	.179**	.416**
	Sig. (2-tailed)	.000	.000	.000	.002	.000
	N	285	287	293	295	295
PARQPS6	Pearson Correlation	.634**	.559**	.445**	.267**	.486**
	Sig. (2-tailed)	.000	.000	.000	.000	.000
	N	285	286	292	294	294
** Correlation is significant at the 0.01 level (2-tailed)						

Appendix 13, Table 6.30 Mean score and standard deviation of the items in the CPCI pacing subscale

CPCI pacing subscale item	Mean in days (SD)	Median (range)	Number of missing answers
1	2.96 (3.06)	2.50 (0-7)	49
2	3.06 (2.82)	3.00 (0-7)	50
3	2.87 (2.71)	2.00 (0-7)	54
4	3.04 (2.80)	3.00 (0-7)	55
5	3.26 (2.83)	3.00 (0-7)	53
6	2.98 (2.87)	2.00 (0-7)	68

Appendix 13, Table 6.31 Mean score and standard deviation of the items in the PARQ pacing subscale

PARQ pacing subscale item	Mean (SD)	Median (range)	Number of missing answers
1	2.83 (1.70)	3.00 (0-5)	11
2	2.58 (1.73)	3.00 (0-5)	16
3	2.94 (1.68)	3.00 (0-5)	14
4	2.54 (1.72)	3.00 (0-5)	17
5	2.67 (1.76)	3.00 (0-5)	13
6	3.02 (1.69)	3.00 (0-5)	15

Appendix 14. Validity of the APQ: correlations between APQ factors and validated measures

Appendix 14, Table 6.32 Pearson's correlations between APQ factors and validated measures

		APQ Factor 1 Activity limitation	APQ Factor 2 Activity planning	APQ Factor 3 Activity progression	APQ Factor 4 Activity consistency	APQ Factor 5 Activity acceptance
Current Pain (0-10) [a]	r (p-value)	0.200 (0.001)	0.118 (0.046)	0.136 (0.020)	-0.075 (0.199)	0.162 (0.006)
	N	284	287	292	292	292
Usual Pain (0-10) [a]	r (p-value)	0.174 (0.003)	0.104 (0.077)	0.169 (0.004)	-0.046 (0.435)	0.125 (0.031)
	N	287	289	295	295	295
Physical Fatigue [b]	r (p-value)	0.051 (0.386)	-0.110 (0.062)	-0.065 (0.266)	-0.295 (<0.001)	0.027 (0.641)
	N	289	290	297	298	298
Mental Fatigue [b]	r (p-value)	0.028 (0.630)	-0.092 (0.116)	-0.023 (0.686)	-0.219 (<0.001)	0.033 (0.570)
	N	290	291	298	299	299
Anxiety [c]	r (p-value)	0.119 (0.045)	0.021 (0.725)	0.036 (0.546)	-0.154 (0.009)	0.040 (0.498)
	N	283	283	289	289	289
Depression [c]	r (p-value)	0.133 (0.025)	-0.026 (0.667)	-0.008 (0.892)	-0.286 (<0.001)	0.027 (0.645)
	N	284	284	290	292	292
Cognitive anxiety [d]	r (p-value)	0.135 (0.023)	0.009 (0.878)	0.062 (0.289)	-0.195 (0.001)	0.121 (0.038)
	N	284	286	292	294	294
Escape and avoidance [d]	r (p-value)	0.245 (<0.001)	0.146 (0.015)	0.086 (0.149)	-0.152 (0.011)	0.194 (0.001)
	N	276	275	281	282	282
Fearful thoughts [d]	r (p-value)	0.205 (0.001)	0.070 (0.241)	0.084 (0.153)	-0.180 (0.002)	0.105 (0.076)
	N	279	281	287	287	287
Physiological anxiety [d]	r (p-value)	0.186 (0.002)	0.103 (0.083)	0.077 (0.193)	-0.250 (<0.001)	0.093 (0.113)
	N	283	285	291	293	293
Physical Function [e]	r (p-value)	-0.340 (<0.001)	-0.124 (0.035)	-0.111 (0.056)	0.174 (0.003)	-0.144 (0.013)
	N	289	290	296	297	297
Mental Function [e]	r (p-value)	-0.064 (0.281)	0.034 (0.568)	0.025 (0.663)	0.279 (<0.001)	-0.009 (0.877)
	N	289	290	296	297	297

[a] Current and usual pain were measured using two Numerical Rating Scales (0-10); [b] Physical and mental fatigue were measured using the Chalder Fatigue Questionnaire; [c] Anxiety and depression were measured using the Hospital Anxiety and Depression Scale; [d] Cognitive anxiety, escape and avoidance, fearful thoughts and physiological anxiety were measured using the Pain Anxiety Symptoms Scale; [e] Physical and mental function were measured using the Short Form-12.

Appendix 15. Associations between the APQ and participants' demographics

Appendix 15, Table 6.33 Associations between the APQ factors and participants' demographics

		APQ Factor 1 Activity limitation	APQ Factor 2 Activity planning	APQ Factor 3 Activity progression	APQ Factor 4 Activity consistency	APQ Factor 5 Activity acceptance
Duration (years)	Pearson Correlation	r=0.029	r=-0.040	r=-0.036	r=-0.009	r=0.059
	p-value	p=0.647	p=0.520	p=0.568	p=0.883	p=0.340
	N	253	255	261	261	261
Age (years)	Pearson Correlation	r=0.135	r=0.097	r=0.032	r=0.067	r=0.157
	p-value	p=0.021	p=0.096	p=0.582	p=0.247	p=0.006
	N	294	296	303	304	304
Gender	Male					
	Mean (SD)	1.97 (1.02)	1.70 (1.08)	1.84 (1.17)	2.11 (1.03)	2.34 (1.11)
	N	94	96	99	98	98
	Female					
	Mean (SD)	1.96 (1.00)	1.74 (1.03)	1.90 (1.10)	2.19 (1.00)	2.36 (1.05)
	N	200	200	204	206	206
	Levene's test	F=0.11, df=1,292, p=0.744	F=0.85, df=1,294, p=0.358	F=0.63, df=1,301, p=0.428	F=0.21, df=1,302, p=0.646	F=1.62, df=1,302, p=0.204
	t-test	t=0.05, df=292, p=0.962	t=-0.35, df=294, p=0.724	t=-0.44, df=301, p=0.659	t=-0.62, df=302, p=0.536	t=-0.20, df=302, p=0.839

Appendix 15, Table 6.34 Comparisons of APQ factor scores between retrospective and current patients

APQ Factor	Descriptive statistics	Retrospective patients	Current patients	Total	Statistical analysis results
Factor 1 Activity limitation	Mean (SD) Median (min-max) (n=140)	1.97 (1.00) 2.12 (0-4.00)	1.95 (1.01) 1.96 (0-4.00) (n=154)	1.96 (1.00) 2.04 (0-4.00) (n=294)	Levene's F=0.01, df=1,292, p=0.913 Student's t=0.15, df=292, p=0.885
Factor 2 Activity planning	Mean (SD) Median (min-max) (n=138)	1.75 (0.97) 1.86 (0-3.71)	1.70 (1.11) 1.71 (0-4.00) (n=158)	1.73 (1.04) 1.71 (0-4.00) (n=296)	Levene's F=5.11, df=1,294, p=0.025 Student's t=0.41, df=294.0, p=0.683
Factor 3 Activity progression	Mean (SD) Median (min-max) (n=143)	1.97 (1.11) 2.00 (0-4.00)	1.80 (1.14) 1.83 (0-4.00) (n=160)	1.88 (1.13) 2.00 (0-4.00) (n=303)	Levene's F=0.31, df=1,301, p=0.581 Student's t=1.32, df=301, p=0.189
Factor 4 Activity consistency	Mean (SD) Median (min-max) (n=144)	2.22 (0.97) 2.25 (0-4.00)	2.12 (1.04) 2.25 (0-4.00) (n=160)	2.16 (1.01) 2.25 (0-4.00) (n=304)	Levene's F=1.56, df=1,302, p=0.213 Student's t=0.85, df=302, p=0.397
Factor 5 Activity acceptance	Mean (SD) Median (min-max) (n=144)	2.31 (1.04) 2.33 (0-4.00)	2.39 (1.10) 2.67 (0-4.00) (n=160)	2.35 (1.07) 2.33 (0-4.00) (n=304)	Levene's F=1.04, df=1,302, p=0.308 Student's t=-0.68, df=302, p=0.496

Appendix 15, Table 6.35 Comparisons of APQ factor scores between current patients pre-treatment and current patients attending a rehabilitation group

APQ Factor	Descriptive statistics	Current patients treated individually	Current patients treated in a group	Total current patients	Statistical analysis results
Factor 1 Activity limitation	Mean (SD) Median (min-max)	1.92 (1.06) 1.92 (0-4.00) (n=124)	2.08 (0.78) 2.00 (0.75-3.46) (n=30)	1.95 (1.01) 1.96 (0-4.00) (n=154)	Levene's F=5.15, df=1,152, p=0.025 Student's t=-0.94, df=57.9, p=0.351
Factor 2 Activity planning	Mean (SD) Median (min-max)	1.61 (1.17) 1.46 (0-4.00) (n=128)	2.10 (0.67) 2.14 (0.86-3.29) (n=30)	1.70 (1.11) 1.71 (0-4.00) (n=158)	Levene's F=15.90, df=1,156, p<0.001 Student's t=-3.01, df=75.6, p=0.004
Factor 3 Activity progression	Mean (SD) Median (min-max)	1.70 (1.18) 1.67 (0-4.00) (n=130)	2.24 (0.83) 2.33 (0.33-4.00) (n=30)	1.80 (1.14) 1.83 (0-4.00) (n=160)	Levene's F=7.71, df=1,158, p=0.006 Student's t=-2.91, df=58.9, p=0.005
Factor 4 Activity consistency	Mean (SD) Median (min-max)	2.04 (1.07) 2.00 (0-4.00) (n=130)	2.44 (0.84) 2.50 (0.25-3.75) (n=30)	2.12 (1.04) 2.25 (0-4.00) (n=160)	Levene's F=2.80, df=1,158, p=0.096 Student's t=-1.91, df=158, p=0.059
Factor 5 Activity acceptance	Mean (SD) Median (min-max)	2.38 (1.15) 2.67 (0-4.00) (n=130)	2.43 (0.84) 2.33 (1-4.00) (n=30)	2.39 (1.10) 2.67 (0-4.00) (n=160)	Levene's F=3.88, df=1,158, p=0.051 Student's t=-0.23, df=158, p=0.823

Appendix 15, Table 6.36 Frequency of the different ethnic groups

Ethnicity	Frequency (%)
White	224(88.5%)
Mixed	4(1.6%)
Asian/Asian British	9(3.6%)
Black/Black British	6(2.4%)
Chinese	3(1.2%)
Other	6(2.4%)
Total	252

Appendix 15, Table 6.37 Comparisons of APQ factor scores across marital status

APQ Factor	Marital status	Number	Mean (SD)	Statistical analysis results
Factor 1 Activity limitation	Married Single Divorced	154 92 33 (n=279)	1.95 (1.02) 1.87 (0.96) 1.97 (1.05)	Levene's F=0.34, df=2,276, p=0.710 ANOVA: F=0.21, df=2,276, p=0.808
Factor 2 Activity planning	Married Single Divorced	153 94 33 (n=280)	1.77 (1.11) 1.60 (0.91) 1.65 (1.54)	Levene's F=2.66, df=2,277, p=0.072 ANOVA F=0.77, df=2,277, p=0.466
Factor 3 Activity progression	Married Single Divorced	159 94 34 (n=287)	1.90 (1.16) 1.76 (1.12) 1.93 (1.07)	Levene's F=0.84, df=2,284, p=0.434 Welch's test: F=0.55, df=2,284, p=0.579
Factor 4 Activity consistency	Married Single Divorced	157 95 35 (n=287)	2.26 (1.00) 1.98 (1.01) 2.13 (1.11)	Levene's F=0.60, df=2,284, p=0.548 ANOVA: F=2.23, df=2,284, p=0.110
Factor 5 Activity acceptance	Married Single Divorced	157 95 35 (n=287)	2.38 (1.11) 2.28 (0.97) 2.23 (1.20)	Levene's F=2.34, df=2,284, p=0.095 ANOVA: F=0.44, df=2,284, p=0.642

NB 'Separated' and 'widowed' were excluded from this analysis due to small numbers of patients with this marital status. Excluding patients who were separated and widowed did not affect the statistical significance of the results.

Appendix 15, Table 6.38 Frequency of categories of employment status

Employment status	Frequency(%)
Full-time	104(41.1%)
Part-time	32(12.6%)
Full-time at home	5(2.0%)
Not working due to condition	23(9.1%)
Not working-other reason	29(11.5%)
Unemployed	13(5.1%)
Student	6(2.4%)
Semi-retired	3(1.2%)
Retired	24(9.5%)
Total	239(94.5%)

Appendix 15, Table 6.39 Comparisons of APQ factor scores across employment status

APQ Factor	Employment details	Number	Mean (SD)	Statistical analysis results
Factor 1 Activity limitation (n=256)	Full-time	111	1.78 (0.99)	Levene's F=1.26, df=5,250, p=0.281
	Part-time	39	1.89 (1.05)	ANOVA: F=4.08, df=5,250, p<0.001
	Not working due to condition	29	2.66 (0.81)	
	Not working (other reason)	30	2.03 (1.05)	
	Unemployed (seeking work)	18	1.75 (0.78)	
	Retired	29	2.12 (1.01)	
Factor 2 Activity planning (n=255)	Full-time	110	1.62 (1.04)	Levene's F=1.84, df=5,249, p=0.106
	Part-time	39	1.76 (1.07)	ANOVA: F=1.70, df=5,249, p=0.135
	Not working due to condition	31	2.12 (0.78)	
	Not working (other reason)	28	1.92 (1.17)	
	Unemployed (seeking work)	18	1.40 (1.06)	
	Retired	29	1.83 (1.15)	
Factor 3 Activity progression (n=262)	Full-time	115	1.86 (1.17)	Levene's F=2.44, df=5,256, p=0.035
	Part-time	40	2.14 (1.22)	Welch's test: F=4.42, df=5,75.94, p<0.001
	Not working due to condition	31	2.41 (0.72)	
	Not working (other reason)	30	1.96 (1.07)	
	Unemployed (seeking work)	17	1.43 (1.11)	
	Retired	29	1.48 (1.12)	
Factor 4 Activity consistency (n=261)	Full-time	114	2.27 (0.99)	Levene's F=0.38, df=5,255, p=0.862
	Part-time	39	2.34 (1.09)	ANOVA: F=1.00, df=5,255, p=0.417
	Not working due to condition	31	2.03 (1.00)	
	Not working (other reason)	30	1.93 (1.06)	
	Unemployed (seeking work)	18	2.20 (0.78)	
	Retired	29	2.32 (0.88)	
Factor 5 Activity acceptance (n=261)	Full-time	114	2.18 (1.11)	Levene's F=0.50, df=5,255, p=0.776
	Part-time	39	2.43 (0.99)	ANOVA: F=1.42, df=5,255, p=0.219
	Not working due to condition	31	2.65 (0.97)	
	Not working (other reason)	30	2.37 (1.13)	
	Unemployed (seeking work)	18	2.24 (1.10)	
	Retired	29	2.59 (1.06)	

NB 'Working full time in the home', 'student' and 'semi-retired' were excluded from this analysis due to small numbers of patients in these groups. Excluding these groups did not affect the statistical significance of the results.

Appendix 15, Table 6.40 Comparisons of APQ factor scores between all patients with and without back pain

APQ Factor	Descriptive statistics	Patients without back pain	Patients with back pain	Total	Statistical analysis results
Factor 1 Activity limitation	Mean (SD) Median (min-max) (n=78)	2.20 (0.98) 2.35 (0-4.00) (n=78)	1.88 (1.00) 1.92 (0-4.00) (n=216)	1.96 (1.00) 2.04 (0-4.00) (n=294)	Levene's F=0.43, df=1,292, p=0.513 Student's t=2.47, df=292, p=0.014
Factor 2 Activity planning	Mean (SD) Median (min-max) (n=79)	1.89 (0.94) 2.00 (0-3.50) (n=79)	1.68 (1.08) 1.57 (0-4.00) (n=216)	1.73 (1.04) 1.71 (0-4.00) (n=296)†	Levene's F=3.14, df=1,293, p=0.077 Student's t=1.54, df=293, p=0.126
Factor 3 Activity progression	Mean (SD) Median (min-max) (n=81)	2.09 (1.11) 2.33 (0-4.00) (n=81)	1.81 (1.13) 1.67 (0-4.00) (n=221)	1.88 (1.13) 2.00 (0-4.00) (n=303)†	Levene's F=0.14, df=1,300, p=0.713 Student's t=1.96, df=300, p=0.051
Factor 4 Activity consistency	Mean (SD) Median (min-max) (n=80)	2.16 (1.00) 2.25 (0-4.00) (n=80)	2.17 (1.02) 2.25 (0-4.00) (n=223)	2.16 (1.01) 2.25 (0-4.00) (n=304)†	Levene's F=0.26, df=1,301, p=0.608 Student's t=-0.11, df=301, p=0.917
Factor 5 Activity acceptance	Mean (SD) Median (min-max) (n=80)	2.34 (0.97) 2.33 (0-4.00) (n=80)	2.36 (1.10) 2.50 (0-4.00) (n=223)	2.35 (1.07) 2.33 (0-4.00) (n=304)†	Levene's F=2.24, df=1,301, p=0.136 Student's t=-0.12, df=301, p=0.904

†=The total number of patients is greater than the sum of patients with and without back pain due to one patient omitting details regarding their condition. Of note, this difference does not affect the sum of the largest factor, that is, APQ factor 1.

Appendix 15, Table 6.41 Comparisons of APQ factor scores between all patients with and without chronic widespread pain

APQ Factor	Descriptive statistics	Patients without chronic widespread pain	Patients with chronic widespread pain	Total	Statistical analysis results
Factor 1 Activity limitation	Mean (SD) Median (min-max) (n=188)	1.83 (0.95) 1.92 (0-4.00) (n=188)	2.20 (1.06) 2.42 (0-4.00) (n=106)	1.96 (1.00) 2.04 (0-4.00) (n=294)	Levene's F=3.14, df=1,292, p=0.078 Student's t=-3.03, df=292, p=0.003
Factor 2 Activity planning	Mean (SD) Median (min-max) (n=189)	1.62 (1.01) 1.57 (0-4.00) (n=189)	1.93 (1.08) 2.14 (0-4.00) (n=106)	1.73 (1.04) 1.71 (0-4.00) (n=296)†	Levene's F=1.44, df=1,293, p=0.232 Student's t=-2.52, df=293, p=0.012
Factor 3 Activity progression	Mean (SD) Median (min-max) (n=193)	1.76 (1.12) 1.67 (0-4.00) (n=193)	2.10 (1.11) 2.00 (0-4.00) (n=109)	1.88 (1.13) 2.00 (0-4.00) (n=303)†	Levene's F=0.12, df=1,300, p=0.731 Student's t=-2.56, df=300, p=0.011
Factor 4 Activity consistency	Mean (SD) Median (min-max) (n=194)	2.17 (0.96) 2.25 (0-4.00) (n=194)	2.15 (1.09) 2.25 (0-4.00) (n=109)	2.16 (1.01) 2.25 (0-4.00) (n=304)†	Levene's F=2.92, df=1,301, p=0.089 Student's t=0.19, df=301, p=0.846
Factor 5 Activity acceptance	Mean (SD) Median (min-max) (n=194)	2.30 (1.03) 2.33 (0-4.00) (n=194)	2.45 (1.13) 2.67 (0-4.00) (n=109)	2.35 (1.07) 2.33 (0-4.00) (n=304)†	Levene's F=2.62, df=1,301, p=0.107 Student's t=-1.13, df=301, p=0.258

†=The total number of patients is greater than the sum of patients with and without chronic widespread pain due to one patient omitting details regarding their condition. Of note, this difference does not affect the sum of the largest factor, that is, APQ factor 1.

Appendix 15, Table 6.42 Comparisons of APQ factor scores between all patients with and without fibromyalgia

APQ Factor	Descriptive statistics	Patients without fibromyalgia	Patients with fibromyalgia	Total	Statistical analysis results
Factor 1 Activity limitation	Mean (SD) Median (min-max) (n=252)	1.92 (0.98) 2.00 (0-4.00) (n=252)	2.24 (1.09) 2.38 (0-4.00) (n=42)	1.96 (1.00) 2.04 (0-4.00) (n=294)	Levene's F=0.10, df=1,292, p=0.757 Student's t=-1.93, df=292, p=0.054
Factor 2 Activity planning	Mean (SD) Median (min-max) (n=252)	1.69 (1.05) 1.71 (0-4.00) (n=252)	1.97 (0.97) 2.00 (0-3.86) (n=43)	1.73 (1.04) 1.71 (0-4.00) (n=296)†	Levene's F=0.95, df=1,293, p=0.331 Student's t=-1.66, df=293, p=0.099
Factor 3 Activity progression	Mean (SD) Median (min-max) (n=258)	1.83 (1.14) 2.00 (0-4.00) (n=258)	2.21 (1.03) 2.50 (0-4.00) (n=44)	1.88 (1.13) 2.00 (0-4.00) (n=303)†	Levene's F=2.08, df=1,300, p=0.151 Student's t=-2.09, df=300, p=0.037
Factor 4 Activity consistency	Mean (SD) Median (min-max) (n=259)	2.16 (1.01) 2.25 (0-4.00) (n=259)	2.21 (1.02) 2.25 (0-4.00) (n=44)	2.16 (1.01) 2.25 (0-4.00) (n=304)†	Levene's F=0.09, df=1,301, p=0.770 Student's t=-0.298, df=301, p=0.766
Factor 5 Activity acceptance	Mean (SD) Median (min-max) (n=259)	2.32 (1.07) 2.32 (0-4.00) (n=259)	2.54 (1.07) 2.67 (0-4.00) (n=44)	2.35 (1.07) 2.33 (0-4.00) (n=304)†	Levene's F=0.06, df=1,301 p=0.806 Student's t=-1.25, df=301, p=0.213

†=The total number of patients is greater than the sum of patients with and without fibromyalgia due to one patient omitting details regarding their condition. Of note, this difference does not affect the sum of the largest factor, that is, APQ factor 1.

Appendix 15, Table 6.43 Comparisons of APQ factor scores between all patients with and without chronic fatigue syndrome (CFS)

APQ Factor	Descriptive statistics	Patients without CFS	Patients with CFS	Total	Statistical analysis results
Factor 1 Activity limitation	Mean (SD) Median (min-max) (n=251)	1.88 (1.00) 1.92 (0-4.00) (n=251)	2.42 (0.90) 2.62 (0-4.00) (n=43)	1.96 (1.00) 2.04 (0-4.00) (n=294)	Levene's F=2.79, df=1,292, p=0.096 Student's t=-3.28, df=292, p=0.001
Factor 2 Activity planning	Mean (SD) Median (min-max) (n=252)	1.68 (1.08) 1.71 (0-4.00) (n=252)	2.02 (0.78) 2.14 (0-3.29) (n=43)	1.73 (1.04) 1.71 (0-4.00) (n=296)†	Levene's F=10.87, df=1,293, p=0.001 Student's t=-2.49, df=72.6, p=0.015
Factor 3 Activity progression	Mean (SD) Median (min-max) (n=259)	1.81 (1.15) 1.67 (0-4.00) (n=259)	2.33 (0.89) 2.33 (0-4.00) (n=43)	1.88 (1.13) 2.00 (0-4.00) (n=303)†	Levene's F=8.96, df=1,300, p=0.003 Student's t=-3.40, df=67.3, p=0.001
Factor 4 Activity consistency	Mean (SD) Median (min-max) (n=260)	2.18 (1.03) 2.25 (0-4.00) (n=260)	2.11 (0.91) 2.25 (0-4.00) (n=43)	2.16 (1.01) 2.25 (0-4.00) (n=304)†	Levene's F=1.63, df=1,301, p=0.202 Student's t=0.39, df=301, p=0.695
Factor 5 Activity acceptance	Mean (SD) Median (min-max) (n=260)	2.32 (1.09) 2.33 (0-4.00) (n=260)	2.51 (0.92) 2.33 (0.33-4.00) (n=43)	2.35 (1.07) 2.33 (0-4.00) (n=304)†	Levene's F=1.55, df=1,301, p=0.214 Student's t=-1.11, df=301, p=0.269

†=The total number of patients is greater than the sum of patients with and without CFS due to one patient omitting details regarding their condition. Of note, this difference does not affect the sum of the largest factor, that is, APQ factor 1.

Appendix 15, Table 6.44 Comparisons of APQ factor scores between all patients with and without myalgic encephalomyelitis (ME)

APQ Factor	Descriptive statistics	Patients without ME	Patients with ME	Total	Statistical analysis results
Factor 1 Activity limitation	Mean (SD) Median (min-max) (n=278)	1.92 (1.00) 2.00 (0-4.00) (n=278)	2.66 (0.77) 2.88 (1.08-4.00) (n=16)	1.96 (1.00) 2.04 (0-4.00) (n=294)	Levene's F=2.82, df=1,292, p=0.094 Student's t=-2.89, df=292, p=0.004
Factor 2 Activity planning	Mean (SD) Median (min-max) (n=279)	1.72 (1.06) 1.71 (0-4.00) (n=279)	1.92 (0.80) 1.93 (0.43-3.17) (n=16)	1.73 (1.04) 1.71 (0-4.00) (n=296)†	Levene's F=3.33, df=1,293, p=0.069 Student's t=-0.74, df=293, p=0.459
Factor 3 Activity progression	Mean (SD) Median (min-max) (n=286)	1.85 (1.12) 2.00 (0-4.00) (n=286)	2.46 (1.09) 2.50 (0.67-4.00) (n=16)	1.88 (1.13) 2.00 (0-4.00) (n=303)†	Levene's F=0.29, df=1,300, p=0.866 Student's t=-2.10, df=300, p=0.036
Factor 4 Activity consistency	Mean (SD) Median (min-max) (n=287)	2.16 (1.02) 2.25 (0-4.00) (n=287)	2.22 (0.84) 2.25 (1-4.00) (n=16)	2.16 (1.01) 2.25 (0-4.00) (n=304)†	Levene's F=1.25, df=1,301, p=0.265 Student's t=-0.21, df=301, p=0.831
Factor 5 Activity acceptance	Mean (SD) Median (min-max) (n=287)	2.33 (1.08) 2.33 (0-4.00) (n=287)	2.71 (0.91) 2.67 (1-4.00) (n=16)	2.35 (1.07) 2.33 (0-4.00) (n=304)†	Levene's F=1.03, df=1,301, p=0.312 Student's t=-1.37, df=301, p=0.171

†=The total number of patients is greater than the sum of patients with and without ME due to one patient omitting details regarding their condition. Of note, this difference does not affect the sum of the largest factor, that is, APQ factor 1.

Appendix 15, Table 6.45 Comparisons of APQ factor scores between all patients with and without another condition

APQ Factor	Descriptive statistics	Patients without another condition	Patients with another condition	Total	Statistical analysis results
Factor 1 Activity limitation	Mean (SD) Median (min-max) (n=260)	1.98 (0.97) 2.08 (0-4.00) (n=260)	1.79 (1.25) 1.96 (0-4.00) (n=34)	1.96 (1.00) 2.04 (0-4.00) (n=294)	Levene's F=7.48, df=1,292, p=0.007 Student's t=0.86, df=38.4, p=0.395
Factor 2 Activity planning	Mean (SD) Median (min-max) (n=261)	1.76 (1.03) 1.71 (0-4.00) (n=261)	1.51 (1.16) 1.46 (0-4.00) (n=34)	1.73 (1.04) 1.71 (0-4.00) (n=296)†	Levene's F=1.32, df=1,293, p=0.252 Student's t=1.31, df=293, p=0.191
Factor 3 Activity progression	Mean (SD) Median (min-max) (n=267)	1.91 (1.11) 2.00 (0-4.00) (n=267)	1.71 (1.29) 1.67 (0-4.00) (n=35)	1.88 (1.13) 2.00 (0-4.00) (n=303)†	Levene's F=2.81, df=1,300, p=0.095 Student's t=0.95, df=300, p=0.341
Factor 4 Activity consistency	Mean (SD) Median (min-max) (n=267)	2.20 (1.00) 2.25 (0-4.00) (n=267)	1.94 (1.05) 2.13 (0-4.00) (n=36)	2.16 (1.01) 2.25 (0-4.00) (n=304)†	Levene's F=0.16, df=1,301, p=0.692 Student's t=1.45, df=301, p=0.147
Factor 5 Activity acceptance	Mean (SD) Median (min-max) (n=267)	2.38 (1.06) 2.33 (0-4.00) (n=267)	2.13 (1.15) 1.15 (0-4.00) (n=36)	2.35 (1.07) 2.33 (0-4.00) (n=304)†	Levene's F=0.60, df=1,301, p=0.441 Student's t=1.33, df=301, p=0.184

†=The total number of patients is greater than the sum of patients with and without another condition due to one patient omitting details regarding their condition. Of note, this difference does not affect the sum of the largest factor, that is, APQ factor 1.

Appendix 15, Table 6.46 Comparisons of APQ factor scores between patients' main conditions

APQ Factor	Details	Number	Mean (SD)	Statistical analysis results
Factor 1 Activity limitation	Back pain Chronic widespread pain Fibromyalgia CFS Total	165 34 19 23 241	1.84 (0.96) 2.22 (1.10) 2.42 (0.79) 2.43 (0.82) 2.00 (0.98)	Levene's F=2.40, df=3,237, p=0.069 ANOVA: F=4.78, df=3,237, p=0.003
Factor 2 Activity planning	Back pain Chronic widespread pain Fibromyalgia CFS Total	163 33 21 23 240	1.68 (1.08) 2.17 (1.00) 2.18 (0.76) 1.93 (0.64) 1.81 (1.03)	Levene's F=4.47, df=3,236, p=0.004 Welch test: F=3.89, df=3,55.2, p=0.014
Factor 3 Activity progression	Back pain Chronic widespread pain Fibromyalgia CFS Total	168 35 21 23 247	1.81 (1.13) 2.04 (1.19) 2.22 (0.90) 2.35 (1.01) 1.93 (1.12)	Levene's F=1.63, df=3,243, p=0.183 ANOVA: F=2.31, df=3,243, p=0.077
Factor 4 Activity consistency	Back pain Chronic widespread pain Fibromyalgia CFS Total	169 34 21 23 247	2.23 (0.98) 2.34 (1.14) 2.23 (0.72) 2.11 (0.96) 2.23 (0.98)	Levene's F=2.09, df=3,243, p=0.103 ANOVA: F=0.26, df=3,243, p=0.856
Factor 5 Activity acceptance	Back pain Chronic widespread pain Fibromyalgia CFS Total	169 34 21 23 247	2.34 (1.08) 2.50 (1.12) 2.76 (0.87) 2.39 (0.84) 2.40 (1.05)	Levene's F=1.18, df=3,243, p=0.320 ANOVA: F=1.11, df=3,243, p=0.345

NB ME and 'other condition' were excluded from this analysis due to small numbers of patients rating those conditions as their main conditions. Excluding ME and 'other condition' did not affect the statistical significance of the results.

Appendix 16. Test-retest reliability of the APQ: participants' demographics

Appendix 16, Table 6.47 Comparison of demographic characteristics between patients involved in the test-retest study with patients not involved in the test-retest study. Of note, the comparison is between current patients only, since no retrospective patients were invited to participate in the test-retest study.

Characteristic	Details	Non test-retest patients (n=95)	Test-retest patients (n=69)	Total (n=164)	Statistical analysis results
Gender	Male Female	37 (38.9%) 58 (61.1%)	19 (27.5%) 50 (72.5%)	56 (34.1%) 108 (65.9%)	Chi-square=2.31, df=1, p=0.128
Age (in years)	Mean (SD) Median (min-max)	40.7 (13.8) 40.0 (18-73.0)	47.9 (14.7) 49.0 (20-76.0)	43.7 (14.6) 45.0 (18-76.0)	Levene's F=0.22, df=1,162, p=0.643 Student's t=-3.18, df=162, p=0.002
Marital status	Married/living as married Single Separated Divorced Widowed	44 (46.8%) 36 (38.3%) 1 (1.1%) 11 (11.7%) 2 (2.1%)	33 (47.8%) 23 (33.3%) 2 (2.9%) 11 (15.9%) 0 (0.0%)	77 (47.2%) 59 (36.2%) 3 (1.8%) 22 (13.5%) 2 (1.2%)	Fisher's Exact Test p=0.645
Ethnicity	White Mixed Asian/Asian British Black/Black British Chinese Other	73 (77.7%) 3 (3.2%) 12 (12.8%) 3 (3.2%) 1 (1.1%) 2 (2.1%)	61 (88.4%) 0 (0.0%) 1 (1.4%) 3 (4.3%) 0 (0.0%) 4 (5.8%)	134 (82.2%) 3 (1.8%) 13 (8.0%) 6 (3.7%) 1 (0.6%) 6 (3.7%)	Fisher's Exact Test p=0.018
Employment	Working full-time Working part-time Working full-time in the home Not working due to present condition Not working due to other condition Unemployed but seeking work Student Semi-retired Retired	28 (33.7%) 11 (13.3%) 4 (4.8%) 11 (13.3%) 10 (12.0%) 10 (12.0%) 3 (3.6%) 0 (0.0%) 6 (7.2%)	23 (37.1) 10 (16.1%) 1 (1.6%) 6 (9.7%) 7 (11.3%) 3 (4.8%) 2 (3.2%) 3 (4.8%) 7 (11.3%)	51 (35.2%) 21 (14.5%) 5 (3.4%) 17 (11.7%) 17 (11.7%) 13 (9.0%) 5 (3.4%) 3 (2.1%) 13 (9.0%)	Fisher's Exact test p=0.436

Appendix 16, Table 6.48 Comparison of the clinical characteristics between patients involved in the test-retest study with patients not involved in the test-retest study. Of note, the comparison is between current patients only, since no retrospective patients were invited to participate in the test-retest arm of the study.

Characteristic	Details	Non test-retest patients (n=95)	Test-retest patients (n=69)	Total (n=164)	Statistical analysis results
Condition	Back pain	76 (80.9%)	50 (72.5%)	126 (77.3%)	Chi-square=1.60, df=1, p=0.207
	Chronic widespread pain	41 (43.6%)	27 (39.1%)	68 (41.7%)	Chi-square=0.33, df=1, p=0.566
	Fibromyalgia	9 (9.6%)	8 (11.6%)	17 (10.4%)	Chi-square=0.17, df=1, p=0.677
	CFS	7 (7.4%)	12 (17.4%)	19 (11.7%)	Chi-square=3.82, df=1, p=0.051
	ME	2 (2.1%)	2 (2.9%)	4 (2.5%)	Fisher's exact p>0.999
Main condition	Back pain	59 (75.6%)	34 (55.7%)	93 (66.9%)	Fisher's Exact Test p=0.009
	Chronic widespread pain	11 (14.1%)	11 (18.0%)	22 (15.8%)	
	Fibromyalgia	3 (3.8%)	7 (11.5%)	10 (7.2%)	
	CFS	2 (2.6%)	8 (13.1%)	10 (7.2%)	
	ME	0 (0%)	1 (1.6%)	1 (0.7%)	
	Other	3 (3.8%)	0 (0%)	3 (2.2%)	
Duration of condition (years)	Mean (SD)	5.77 (8.34)	8.25 (9.51)	6.82 (8.94)	Mann Whitney U=1948.00, Z=-1.91, p=0.057
	Median (min-max)	2.91 (0.25-48.00)	4.75 (0.42-40.00)	3.00 (0.25-48)	

Appendix 16, Table 6.49 Comparison of the symptoms of patients involved in the test-retest study with patients not involved in the test-retest study. Of note, the comparison is between current patients only, since no retrospective patients were invited to participate in the test-retest study.

Characteristic	Details	Non test-retest patients (n=95)	Test-retest patients (n=69)	Total (n=164)	Statistical analysis results
Pain present?	Yes	91 (96.8%)	67 (97.1%)	158 (96.9%)	Fishers Exact Test p>0.999
Current pain [a]	Mean (SD) Median (min-max)	6.40 (2.61) 7.00 (0.00-10.00)	6.16 (2.56) 7.00 (1.00-10.00)	6.30 (2.58) 7.00 (0-10.00)	Mann Whitney U=2904.00, Z=-0.513, p=0.608
Usual pain [a]	Mean (SD) Median (min-max)	6.35 (2.44) 7.00 (0.00-10.00)	6.18 (2.41) 6.00 (0.00-10.00)	6.28 (2.42) 7.00 (0-10.00)	Levene's F=0.44, df=1,159, p=0.834 Student's t=0.46, df=159, p=0.646
Physical fatigue [b]	Mean (SD) Median (min-max)	12.89 (4.56) 13.00 (0-21.00)	11.26 (5.10) 10.50 (0-21.00)	12.20 (4.85) 12.00 (0-21.00)	Levene's F=1.49, df=1,159, p=0.224 Student's t=2.13, df=159, p=0.035
Mental fatigue [b]	Mean (SD) Median (min-max)	6.27 (2.93) 6.00 (0-12.00)	5.66 (2.84) 4.00 (0-12.00)	6.01 (2.90) 5.00 (0-12.00)	Mann Whitney U=2788.00, Z=-1.41, p=0.159

[a] Current and usual pain were measured using two Numerical Rating Scales (0-10); [b] Physical and mental fatigue were measured using the Chalder Fatigue Questionnaire.

Appendix 17. Test-retest reliability of the APQ:
APQ data

Appendix 17, Table 6.50 Mean scores and internal consistency for all APQ factors at the initial (T1) and the second measure (T2). Of note, these scores compare data only from participants involved in the test-retest arm of the study. Furthermore, the corrected APQ mean scores were used, that is, allowing for one missing answer.

	Mean score			Cronbach's α		
	Initial measure (T1)	Second measure (T2)	Change (T1-T2)	Initial measure (T1)	Second measure (T2)	Change (T1-T2)
APQ factor 1	2.06	2.15	-0.09	0.94	0.94	0.00
APQ factor 2	1.83	1.91	-0.08	0.90	0.90	0.00
APQ factor 3	1.78	1.88	-0.10	0.83	0.81	0.02
APQ factor 4	2.21	2.39	-0.18	0.78	0.77	0.01
APQ factor 5	2.53	2.46	0.07	0.64	0.69	-0.05

Appendix 17, Table 6.51 Pearson's correlations for all APQ factors across the test-retest period

		T2 APQ Factor1	T2 APQ Factor2	T2 APQ Factor3	T2 APQ Factor4	T2 APQ Factor5
APQFactor1	Pearson Correlation	.792**	.679**	.477**	.254*	.601**
	Sig. (2-tailed)	.000	.000	.000	.039	.000
	N	64	66	67	66	66
APQFactor2	Pearson Correlation	.637**	.681**	.471**	.432**	.502**
	Sig. (2-tailed)	.000	.000	.000	.000	.000
	N	65	67	68	67	67
APQFactor3	Pearson Correlation	.677**	.682**	.621**	.379**	.411**
	Sig. (2-tailed)	.000	.000	.000	.002	.001
	N	65	67	68	67	67
APQFactor4	Pearson Correlation	.224	.359**	.209	.501**	.148
	Sig. (2-tailed)	.073	.003	.087	.000	.233
	N	65	67	68	67	67
APQFactor5	Pearson Correlation	.411**	.292*	.122	.019	.595**
	Sig. (2-tailed)	.001	.017	.321	.877	.000
	N	65	67	68	67	67
** Correlation is significant at the 0.01 level (2-tailed).						
* Correlation is significant at the 0.05 level (2-tailed).						

Appendix 17, Table 6.52 Intraclass correlations of the APQ factors

APQ factor	Number of data sets eligible for analysis	Intra-class correlation (ICC)
APQ factor 1 Activity limitation	64 of 69 (92.8%)	ICC=0.79, (95% CI 0.68-0.87), p<0.001
APQ factor 2 Activity planning	67 of 69 (97.1%)	ICC=0.68, (95% CI 0.53-0.79), p<0.001
APQ factor 3 Activity progression	68 of 69 (98.6%)	ICC=0.62, (95% CI 0.45-0.75), p<0.001
APQ factor 4 Activity consistency	67 of 69 (97.1%)	ICC=0.50, (95% CI 0.30-0.66), p<0.001
APQ factor 5 Activity acceptance	67 of 69 (97.1%)	ICC=0.59, (95% CI 0.41-0.73), p<0.001

Appendix 17, Table 6.53 Summary data for the Bland and Altman plots

APQ factor	Number	Mean difference (T1-T2)	Standard deviation (SD)	Mean -/+ 2SD range:
APQ factor 1 Activity limitation	64	-0.07	0.63	-1.33 to 1.19
APQ factor 2 Activity planning	67	-0.06	0.82	-1.70 to 1.58
APQ factor 3 Activity progression	68	-0.10	0.93	-1.96 to 1.76
APQ factor 4 Activity consistency	67	-0.18	0.93	-2.04 to 1.64
APQ factor 5 Activity acceptance	67	0.06	0.89	-1.72 to 1.84

Appendix 18. Test-retest reliability of the CPCI and PARQ pacing subscales

Appendix 18, Table 6.54 Mean scores and internal consistency of the CPCI and PARQ pacing subscales at T1 and T2. Of note, the scores include only the data from those patients involved in the test-retest arm of the study.

	Mean score			Cronbach's α		
	Initial measure (T1)	Second measure (T2)	Change (T1-T2)	Initial measure (T1)	Second measure (T2)	Change (T1-T2)
CPCI pacing scale (0-7 days rating scale)	3.23	3.61	-0.38	0.95	0.91	0.04
PARQ pacing scale (0-5 rating scale)	2.74	2.89	-0.15	0.89	0.90	-0.01

Appendix 18, Table 6.55 Pearson's correlations between T1 and T2 for the CPCI pacing subscale

		CPCI pacing subscale 1 (days)	CPCI pacing subscale 2 (days)	CPCI pacing subscale 3 (days)	CPCI pacing subscale 4 (days)	CPCI pacing subscale 5 (days)	CPCI pacing subscale 6 (days)
CPCI pacing subscale 1 (days)	Pearson Correlation	.447**	.419**	.461**	.528**	.407**	.473**
	Sig. (2-tailed)	.000	.001	.000	.000	.001	.000
	N	60	60	59	58	60	58
CPCI pacing subscale 2 (days)	Pearson Correlation	.268*	.266*	.275*	.462**	.276*	.231
	Sig. (2-tailed)	.042	.044	.038	.000	.036	.086
	N	58	58	57	56	58	56
CPCI pacing subscale 3 (days)	Pearson Correlation	.366**	.281*	.304*	.605**	.305*	.405**
	Sig. (2-tailed)	.004	.033	.020	.000	.019	.002
	N	59	58	58	57	59	56
CPCI pacing subscale 4 (days)	Pearson Correlation	.208	.169	.167	.430**	.265*	.124
	Sig. (2-tailed)	.114	.204	.211	.001	.042	.362
	N	59	58	58	57	59	56
CPCI pacing subscale 5 (days)	Pearson Correlation	.235	.182	.225	.405**	.349**	.220
	Sig. (2-tailed)	.074	.171	.089	.002	.007	.102
	N	59	58	58	57	59	56
CPCI pacing subscale 6 (days)	Pearson Correlation	.313*	.283*	.333*	.474**	.302*	.459**
	Sig. (2-tailed)	.019	.034	.013	.000	.024	.000
	N	56	56	55	54	56	54
** Correlation is significant at the 0.01 level (2-tailed).							
* Correlation is significant at the 0.05 level (2-tailed).							

Appendix 18, Table 6.56 Intraclass correlations of the CPCI pacing subscale items

CPCI pacing subscale items	Intra-class correlation (ICC)
Item 1	ICC=0.48, (95% CI 0.22-0.63), p<0.001
Item 2	ICC=0.27, (95% CI 0.01-0.49), p=0.021
Item 3	ICC=0.30, (95% CI 0.05-0.52), p=0.010
Item 4	ICC=0.43, (95% CI 0.19-0.62), p<0.001
Item 5	ICC=0.35, (95% CI 0.10-0.55), p=0.003
Item 6	ICC=0.46, (95% CI 0.22-0.65), p<0.001
CPCI pacing subscale total	ICC=0.47, (95% CI 0.24-0.65), p<0.001

Appendix 18, Table 6.57 Pearson's correlations between T1 and T2 for the PARQ pacing subscale

		PARQ pacing subscale 1	PARQ pacing subscale 2	PARQ pacing subscale 3	PARQ pacing subscale 4	PARQ pacing subscale 5	PARQ pacing subscale 6
PARQ pacing subscale 1	Pearson Correlation	.376**	.312*	.256*	.203	.237	.253*
	Sig. (2-tailed)	.002	.011	.040	.104	.057	.042
	N	63	65	65	65	65	65
PARQ pacing subscale 2	Pearson Correlation	.532**	.477**	.447**	.537**	.388**	.480**
	Sig. (2-tailed)	.000	.000	.000	.000	.002	.000
	N	62	64	64	64	64	64
PARQ pacing subscale 3	Pearson Correlation	.480**	.426**	.492**	.478**	.439**	.392**
	Sig. (2-tailed)	.000	.000	.000	.000	.000	.001
	N	63	65	65	65	65	65
PARQ pacing subscale 4	Pearson Correlation	.375**	.307*	.436**	.565**	.415**	.522**
	Sig. (2-tailed)	.002	.013	.000	.000	.001	.000
	N	63	65	65	65	65	65
PARQ pacing subscale 5	Pearson Correlation	.545**	.483**	.440**	.464**	.560**	.349**
	Sig. (2-tailed)	.000	.000	.000	.000	.000	.004
	N	63	65	65	65	65	65
PARQ pacing subscale 6	Pearson Correlation	.473**	.481**	.428**	.414**	.441**	.604**
	Sig. (2-tailed)	.000	.000	.000	.001	.000	.000
	N	63	65	65	65	65	65
** Correlation is significant at the 0.01 level (2-tailed). * Correlation is significant at the 0.05 level (2-tailed).							

Appendix 18, Table 6.58 Intraclass correlations of the PARQ pacing subscale items

PARQ pacing subscale items	Intra-class correlation (ICC)
Item 1	ICC=0.38, (95% CI 0.14-0.57), p<0.001
Item 2	ICC=0.48, (95% CI 0.26-0.65), p<0.001
Item 3	ICC=0.49, (95% CI 0.28-0.66), p<0.001
Item 4	ICC=0.56, (95% CI 0.37-0.71), p<0.001
Item 5	ICC=0.56, (95% CI 0.37-0.71), p<0.001
Item 6	ICC=0.60, (95% CI 0.42-0.74), p<0.001
PARQ pacing subscale total	ICC=0.68, (95% CI 0.52-0.79), p<0.001

Appendix 19. Correlations between changes in pain and fatigue and pacing scales over the test-retest period

Appendix 19, Table 6.59 Pearson's correlations and intraclass correlations of the pain and fatigue scales over the test-retest period

Validated measure	Pearson's correlation	Intra-class correlation
Current pain numerical rating scale	r=0.68, p<0.001	ICC=0.68, (95% CI 0.52-0.79), p<0.001
Usual pain numerical rating scale	r=0.68, p<0.001	ICC=0.68, (95% CI 0.52-0.79), p<0.001
Chalder fatigue questionnaire-physical fatigue	r=0.38, p=0.002	ICC=0.38, (95% CI 0.15-0.57), p<0.001
Chalder fatigue questionnaire-mental fatigue	r=0.57, p<0.001	ICC=0.57, (95% CI 0.39-0.71), p<0.001

Appendix 19, Table 6.60 Change in pain scores over the test-retest period

Scale	Details	Number	Mean (SD)	Statistical analysis results
Pain NRS	Current pain (T1)	65	6.08 (2.55)	Paired t-test: t=1.37, (95% CI -0.16-0.87), p=0.175
	Current pain (T2)	65	5.72 (2.61)	
Pain NRS	Usual pain (T1)	67	6.19 (2.43)	Paired t-test: t=1.59, (95% CI -0.09-0.81), p=0.117
	Usual pain (T2)	67	5.84 (2.14)	

Appendix 19, Table 6.61 Pearson's correlations between change in pain and change in APQ factors, CPCI pacing subscale and PARQ pacing subscale scores

Pacing scale difference (T1-T2)	Current pain difference (T1-T2)	Usual pain difference (T1-T2)
APQ Factor 1 Activity limitation	r=0.05, p=0.690	r=-0.02, p=0.858
APQ Factor 2 Activity planning	r=0.02, p=0.854	r=0.18, p=0.147
APQ Factor 3 Activity progression	r=-0.11, p=0.408	r=-0.06, p=0.647
APQ Factor 4 Activity consistency	r=-0.21, p=0.105	r=0.05, p=0.677
APQ Factor 5 Activity acceptance	r=0.17, p=0.192	r=0.00, p=0.978
CPCI pacing subscale 1	r=-0.06, p=0.656	r=-0.02, p=0.857
CPCI pacing subscale 2	r=-0.20, p=0.144	r=-0.17, p=0.204
CPCI pacing subscale 3	r=-0.16, p=0.246	r=-0.04, p=0.755
CPCI pacing subscale 4	r=-0.09, p=0.525	r=-0.11, p=0.440
CPCI pacing subscale 5	r=0.00, p=0.994	r=-0.10, p=0.440
CPCI pacing subscale 6	r=-0.23, p=0.108	r=-0.08, p=0.556
PARQ pacing subscale 1	r=-0.03, p=0.838	r=0.06, p=0.623
PARQ pacing subscale 2	r=-0.12, p=0.378	r=-0.20, p=0.113
PARQ pacing subscale 3	r=-0.16, p=0.211	r=-0.23, p=0.069
PARQ pacing subscale 4	r=-0.05, p=0.694	r=-0.22, p=0.083
PARQ pacing subscale 5	r=-0.03, p=0.832	r=-0.14, p=0.261
PARQ pacing subscale 6	r=-0.02, p=0.883	r=-0.12, p=0.343

Appendix 20. Correlations between participants' self-reported change and pacing scales over the test-retest period

Appendix 20, Table 6.62 One-way ANOVA between participants self-reported change in condition and change in pain and fatigue

		Sum of Squares	df	Mean Square	F	Sig.
Current pain difference	Between Groups	72.615	2	36.307	10.539	.000
	Within Groups	196.369	57	3.445		
	Total	268.983	59			
Usual pain difference	Between Groups	6.323	2	3.161	.992	.377
	Within Groups	184.890	58	3.188		
	Total	191.213	60			
Physical fatigue difference	Between Groups	168.410	2	84.205	2.990	.058
	Within Groups	1605.227	57	28.162		
	Total	1773.637	59			
Mental fatigue difference	Between Groups	41.987	2	20.994	3.389	.041
	Within Groups	359.259	58	6.194		
	Total	401.246	60			

Appendix 20, Table 6.63 One-way ANOVA between participants self-reported change in condition and change in APQ factor scores

		Sum of Squares	df	Mean Square	F	Sig.
APQ Factor 1 difference	Between Groups	.343	2	.172	.407	.667
	Within Groups	23.164	55	.421		
	Total	23.507	57			
APQ Factor 2 difference	Between Groups	.188	2	.094	.129	.879
	Within Groups	42.239	58	.728		
	Total	42.428	60			
APQ Factor 3 difference	Between Groups	3.328	2	1.664	1.895	.159
	Within Groups	51.805	59	.878		
	Total	55.133	61			
APQ Factor 4 difference	Between Groups	2.655	2	1.328	1.525	.226
	Within Groups	50.496	58	.871		
	Total	53.151	60			
APQ Factor 5 difference	Between Groups	1.644	2	.822	1.073	.349
	Within Groups	44.440	58	.766		
	Total	46.084	60			

Appendix 20, Table 6.64 One-way ANOVA between participants self-reported change in condition and change in CPCI pacing subscale scores

		Sum of Squares	df	Mean Square	F	Sig.
CPCI pacing subscale 1 difference	Between Groups	27.741	2	13.871	1.757	.183
	Within Groups	402.574	51	7.894		
	Total	430.315	53			
CPCI pacing subscale 2 difference	Between Groups	25.046	2	12.523	1.037	.362
	Within Groups	603.822	50	12.076		
	Total	628.868	52			
CPCI pacing subscale 3 difference	Between Groups	34.250	2	17.125	1.749	.184
	Within Groups	489.636	50	9.793		
	Total	523.887	52			
CPCI pacing subscale 4 difference	Between Groups	50.310	2	25.155	2.805	.070
	Within Groups	439.459	49	8.969		
	Total	489.769	51			
CPCI pacing subscale 5 difference	Between Groups	15.932	2	7.966	.788	.460
	Within Groups	515.327	51	10.104		
	Total	531.259	53			
CPCI pacing subscale 6 difference	Between Groups	55.589	2	27.795	3.345	.044
	Within Groups	382.247	46	8.310		
	Total	437.837	48			

Appendix 20, Table 6.65 One-way ANOVA between participants self-reported change in condition and change in PARQ pacing subscale scores

		Sum of Squares	df	Mean Square	F	Sig.
PARQ pacing subscale 1 difference	Between Groups	1.906	2	.953	.274	.761
	Within Groups	187.568	54	3.473		
	Total	189.474	56			
PARQ pacing subscale 2 difference	Between Groups	3.534	2	1.767	.567	.571
	Within Groups	171.569	55	3.119		
	Total	175.103	57			
PARQ pacing subscale 3 difference	Between Groups	1.897	2	.949	.381	.685
	Within Groups	139.492	56	2.491		
	Total	141.390	58			
PARQ pacing subscale 4 difference	Between Groups	1.855	2	.928	.379	.686
	Within Groups	136.890	56	2.444		
	Total	138.746	58			
PARQ pacing subscale 5 difference	Between Groups	.234	2	.117	.048	.953
	Within Groups	137.325	56	2.452		
	Total	137.559	58			
PARQ pacing subscale 6 difference	Between Groups	5.983	2	2.991	1.640	.203
	Within Groups	102.119	56	1.824		
	Total	108.102	58			

Chapter 7. Exploring the acceptability of the Activity Pacing Questionnaire (APQ)

Appendix 21. Letters of ethical approval for the acceptability study

NHS
Health Research Authority
National Research Ethics Service

NRES Committee North West - Cheshire

HRA NRES Centre North West
Barlow House
3rd Floor
4 Minshull Street
Manchester
M1 3DZ

Tel: 0161 625 7816
Fax: 0161 625 7299

16 November 2012

Miss Deborah Antcliff
Senior Physiotherapist
The Pennine Acute Hospitals NHS Trust
Physiotherapy 'A'
North Manchester General Hospital
Delaunays Road, Manchester
M8 5RB

Dear Miss Antcliff

Study title:	**Exploring the Acceptability of an Activity Pacing Questionnaire for Chronic Pain and/or Fatigue**
IRAS project number:	**115349**
REC reference:	**12/NW/0832**
Protocol number:	**N/A**

The Proportionate Review Sub-committee of the NRES Committee North West - Cheshire reviewed the above application on 14 November 2012.

Ethical opinion

On behalf of the Committee, the sub-committee gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion

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

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

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations.

Other Conditions Specified by the REC:

1. The Committee would like to see the Consent Form revised to:
    i. Include the following sentence: 'I agree to the telephone interview being tape recorded'.

2. The Committee would like to see the Participant Information Sheet revised to:
    i. Under the heading 'Who has reviewed the study' amend this to: 'This study has been reviewed and granted ethical approval by the NRES Committee Northwest - Cheshire Research Ethics Committee.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

You should notify the REC in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. Confirmation should also be provided to host organisations together with relevant documentation.

Approved documents

The documents reviewed and approved were:

Document	*Version*	*Date*
Covering Letter		06 November 2012
Evidence of insurance or indemnity		01 November 2012
Interview Schedules/Topic Guides	Interview outline - 1	10 October 2012
Investigator CV	Miss Deborah Antcliff	05 November 2012
Investigator CV	Professor Philip Keeley	17 October 2012
Letter from Sponsor		01 November 2012
Letter of invitation to participant	1	10 October 2012
Other: Interview appointment form	1	10 October 2012
Protocol	1	02 November 2012
Questionnaire: Questionnaire booklet	1	10 October 2012
REC application	3.4	06 November 2012
Summary/Synopsis	Flow diagram of project - 1	10 October 2012
Summary/Synopsis		

Membership of the Proportionate Review Sub-Committee

The members of the Sub-Committee who took part in the review are listed on the attached sheet.

Statement of compliance

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

After ethical review

Reporting requirements

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

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review

12/NW/0832	Please quote this number on all correspondence

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

Yours sincerely

Mr Jonathan Deans
Chair

Email: nrescommittee.northwest-cheshire@nhs.net

Enclosures: List of names and professions of members who took part in the review

"After ethical review – guidance for researchers"

Copy to: Lynne Macrae
Dr Steve Woby, The Pennine Acute Hospitals NHS Trust

NRES Committee North West - Cheshire

Attendance at PRS Sub-Committee of the REC meeting on 14 November 2012

Committee Members:

Name	*Profession*	*Present*	*Notes*
Mrs Maureen Benbow	Senior Lecturer	Yes	
Dr Nick Bronnert	GP	Yes	
Rev'd Stephen Burmester	Vicar	No	
Mr Jonathan Deans	Consultant ENT Surgeon	No	
Dr Sue Elves	Consultant Clinical Psychologist	No	
Mrs Elizabeth Gordon	Lay Member	Yes	
Mr Ezzat Kozman	Consultant Gynaecologist	No	
Dr Fred Mostafa	Consultant Anaethetist/Intensivist	Yes	
Dr Noel Murphy	Consultant Paediatrician	Yes	
Dr Jane Richardson	University Lecturer in Health Research	No	
Mrs Pam Rushworth	Pharmacist Member	Yes	
Dr Lenny Thornton	Consultant Psychiatrist (Retired)	Yes	
Mr Peter Ward	Lay member	Yes	
Mrs Jean Welch	Lay Member	Yes	
Mrs Ann Williams	Lay Member	Yes	

Also in attendance:

Name	*Position (or reason for attending)*
Miss Diane Catterall	Co-ordinator
Miss Annya Sekula	Senior Coordinator

NHS
Health Research Authority
National Research Ethics Service

NRES Committee North West - Cheshire

HRA NRES Centre North West
Barlow House
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Tel: 0161 625 7816
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22 November 2012

Miss Deborah Antcliff
Senior Physiotherapist
The Pennine Acute Hospitals NHS Trust
Physiotherapy 'A'
North Manchester General Hospital
Delaunays Road
Manchester
M8 5RB

Dear Miss Antcliff

Full title of study: **Exploring the Acceptability of an Activity Pacing Questionnaire for Chronic Pain and/or Fatigue**
IRAS project number: **115349**
REC reference number: **12/NW/0832**

Thank you for your email of 19 November 2012. I can confirm the REC has received the documents listed below as evidence of compliance with the approval conditions detailed in our letter dated 16 November 2012. Please note these documents are for information only and have not been reviewed by the committee.

Documents received

The documents received were as follows:

Document	*Version*	*Date*
Participant Consent Form	2	19 November 2012
Participant Information Sheet	2	19 November 2012

You should ensure that the sponsor has a copy of the final documentation for the study. It is the sponsor's responsibility to ensure that the documentation is made available to R&D offices at all participating sites.

12/NW/0832 **Please quote this number on all correspondence**

Yours sincerely

Miss Diane Catterall
Committee Co-ordinator E-mail: nrescommittee.northwest-cheshire@nhs.net

Copy to: Lynne Macrae,
Dr Steve Woby, The Pennine Acute Hospitals NHS Trust

Appendix 22. Patient invitation letter, information sheet and consent form

The University of Manchester

The Pennine Acute Hospitals NHS Trust

Physiotherapy Department A
North Manchester General Hospital
Delaunays Road
Crumpsall
Manchester
M8 5RB

Title of the study: Exploring the Acceptability of the New Activity Pacing Questionnaire

Insert date

Dear

I am writing following our recent telephone conversation regarding the study that is being undertaken in the physiotherapy departments of the Pennine Acute Hospitals NHS Trust in partnership with the University of Manchester. Thank you for previously completing a questionnaire booklet to help us to assess the new Activity Pacing Questionnaire. I am writing today to invite you to take part in the next stage of the study. The next stage of the study involves asking your opinion of how you found the new Activity Pacing Questionnaire to complete.

The enclosed participant information sheet describes fully why we are carrying out this research and what it will involve if you decide to participate. Please take a moment to read the information sheet before deciding whether or not to take part in the study. If you decide to take part, you will be asked to participate in one telephone interview which will last approximately 20 to 40 minutes at a time convenient for you.

I have enclosed a copy of the new Activity Pacing Questionnaire, together with Pacing Scale 1 and Pacing Scale 2 which you previously completed as part of the questionnaire booklet. You do not need to complete these questionnaires again. I have sent them to you as a reminder of the questionnaires so that we may discuss them during the telephone interview. In addition, I have sent you a consent form to ask if you are willing to participate in the telephone interview. If you feel able to participate in the interview, please sign and date the consent form and return it in the prepaid envelope. Please also complete the interview appointment form stating when is the most suitable time for me to call you to undertake the interview. Please return the consent form and the interview appointment form with three weeks if you are able to participate.

Your participation does not involve you attending the physiotherapy department and you do not need to complete the questionnaire booklet again. Your participation in this interview study will not affect any future physiotherapy treatment that you receive.

Thank you for previously returning the questionnaire booklet, and for taking the time to read this information. Your help in this research study is greatly appreciated.

Yours sincerely

Deborah Antcliff BSc (Hons), MCSP
(Senior Physiotherapist)

The University of Manchester

The Pennine Acute Hospitals NHS Trust

Physiotherapy Department A
North Manchester General Hospital
Delaunays Road
Crumpsall
Manchester
M8 5RB

Participant Information Sheet

Title of the study: Exploring the Acceptability of the New Activity Pacing Questionnaire

You are being invited to take part in a research study to further develop a new questionnaire to measure activity pacing. You previously participated in the study to assess whether the new Activity Pacing Questionnaire measures what it is supposed to, and if it produces consistent results. The next stage of the study is to discuss your opinions of how you found the questionnaire to complete. Before you decide whether to take part, it is important for you to understand why the research is being done and what it will involve. Please take the time to read the following information carefully.

What is the purpose of the study?

Physiotherapists often advise patients to pace their activities to help them to manage the symptoms of their condition. At the moment we do not have a way of measuring if patients are pacing their activities. It is important to measure how patients are pacing their activities to see if patients are progressing with treatment and to improve our treatment programmes. We have developed a new Activity Pacing Questionnaire, which you completed in the previous study. The purpose of this study is to ask your opinions of the new Activity Pacing Questionnaire so that we may develop a questionnaire that patients find acceptable.

Why have I been invited?

We will interview patients who have attended physiotherapy, and who have completed a questionnaire booklet in the previous study. The answers that you gave in the questionnaire booklet show that you are suitable to participate in this next stage of the study.

Do I have to take part?

It is up to you to decide whether or not to take part. If we do not receive your consent form and interview appointment form back within three weeks, we may give you a reminder telephone call. If we do not hear from you three weeks after the reminder call, we will assume that you do not wish to participate and no further contact will be made. If you do 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 now or in the future.

What will the study involve?

The study involves your participation in one telephone interview with Miss Deborah Antcliff (Senior Physiotherapist) which will last between 20 and 40 minutes. If you agree to participate please complete the consent form, and the interview appointment form to state when it is suitable for us to undertake the interview. Please state a day and time for the interview when you have access to a comfortable room that will be free from interruptions for approximately 20 to 40 minutes. If possible, please state your landline number on the interview appointment form to reduce the risk of signal problems or other disturbances.

We ask that you return the consent form and the interview appointment form in the prepaid envelope within three weeks of receiving this study pack. If we do not receive this back within three weeks, we may give you a reminder telephone call. If no contact is made three weeks after the reminder call, we will assume that you do not wish to participate and no further contact will be made.

The telephone interview will consist of questions relating to the new Activity Pacing Questionnaire, and Pacing Scale 1 and Pacing Scale 2. We have sent you a booklet containing these three scales. You do <u>not</u> need to complete these questionnaires again. You have been sent these questionnaires so that we may discuss them in the interview. The interview will consist of questions regarding your opinions about pacing and how easy you found the questionnaires to complete.

The interview will be tape-recorded so that it may be typed up word for word. The purpose of this is to ensure that we do not miss out anything that you say. You will be sent a typed version of the interview and you will be invited to check and sign it, and return it in a prepaid envelope. There will be opportunity for you to make any comments on the typed version. We hope that between 20 and 30 patients will participate in the telephone interviews to discuss their opinions of the new Activity Pacing Questionnaire.

What are the possible disadvantages or risks of taking part?

There are no risks associated with taking part in the study and there will be no change to any future treatment that you receive. Your participation involves the completion of one telephone interview which will last approximately 20 to 40 minutes.

What are the possible benefits of taking part?

We cannot promise that the study will help you directly, but the information we get from this study will help us to improve the treatment we provide for patients.

What will happen if I do not want to carry on with the study once I have consented?

You are free to withdraw from the study at any stage and without giving an explanation. If you do not respond to the reminder telephone call to ask if you consent to participating in the study, we will assume that you do not wish to participate in the interview and no further contact will be made. If you wish to cease the recording of the interview at any time, we can stop the tape recorder and continue the interview without recording. Alternatively, we can stop the interview altogether. If you inform us that you wish to withdraw completely from the study we will ask you if we can use any of your existing data, or whether you wish for all of your data to be destroyed. We would like to stress that your physiotherapy treatment will not be affected by your decision.

Will my taking part in this study be kept confidential?

Yes. If you agree to participate, any information about you will be kept strictly confidential by the research team. The lead researcher in this study is a physiotherapist working in the department and is experienced in maintaining patient confidentiality. You have been allocated a unique study code in the previous study. The same unique study code will be used to identify you in this stage of the study and throughout data analysis. You will not be identified in any publication that follows from the study. The typed interviews will only be analysed by the research team. In rare situations, the results of the study may be audited by the University of Manchester, the NHS or a regulatory authority to monitor the study.

The typed interviews and the tape recordings will be kept securely by the research team throughout the duration of the study, and your personal information will be encrypted for electronic storage. Once the study is complete, the typed interviews and tapes will be kept securely by University of Manchester for fifteen years and then they will be destroyed.

What if there is a problem?

Complaints:

If you have a concern about any aspect of the study, you should ask to speak to the researchers who will do their best to answer your questions. If they are unable to resolve your concern or you wish to make a complaint regarding the study, please contact a

University Research Practice and Governance Co-ordinator on (0161) 2757583 or (0161) 2758093 or by email to research-governance@manchester.ac.uk.

Harm:

In the unlikely event that something goes wrong and you are harmed during the research you may have grounds for a legal action for compensation against the University of Manchester or the Pennine Acute Hospitals NHS Trust but you may have to pay for your legal costs. The normal National Health Service complaints mechanism will still be available to you.

What will happen to the results of the research study?

The results of the study will be published in a PhD thesis and in professional healthcare journals. If you wish to obtain a copy of the results or any publication please feel free to contact us. We would like to assure you again that no individual will be identified in any publication of the study.

Who is organising and funding the research?

The study is organised by The Pennine Acute Hospitals NHS Trust and The School of Nursing, Midwifery and Social Work, University of Manchester. This study is currently funded by a Pennine Acute Hospitals NHS Trust Research and Development Grant.

Who has reviewed the study?

This study has been reviewed and granted ethical approval by the NRES Committee Northwest – Cheshire Research Ethics Committee.

Contact for Further Information

For further information please contact Deborah Antcliff, Senior Physiotherapist in North Manchester General Hospital on 0161 720 2423, or e-mail: Deborah.Antcliff@pat.nhs.uk

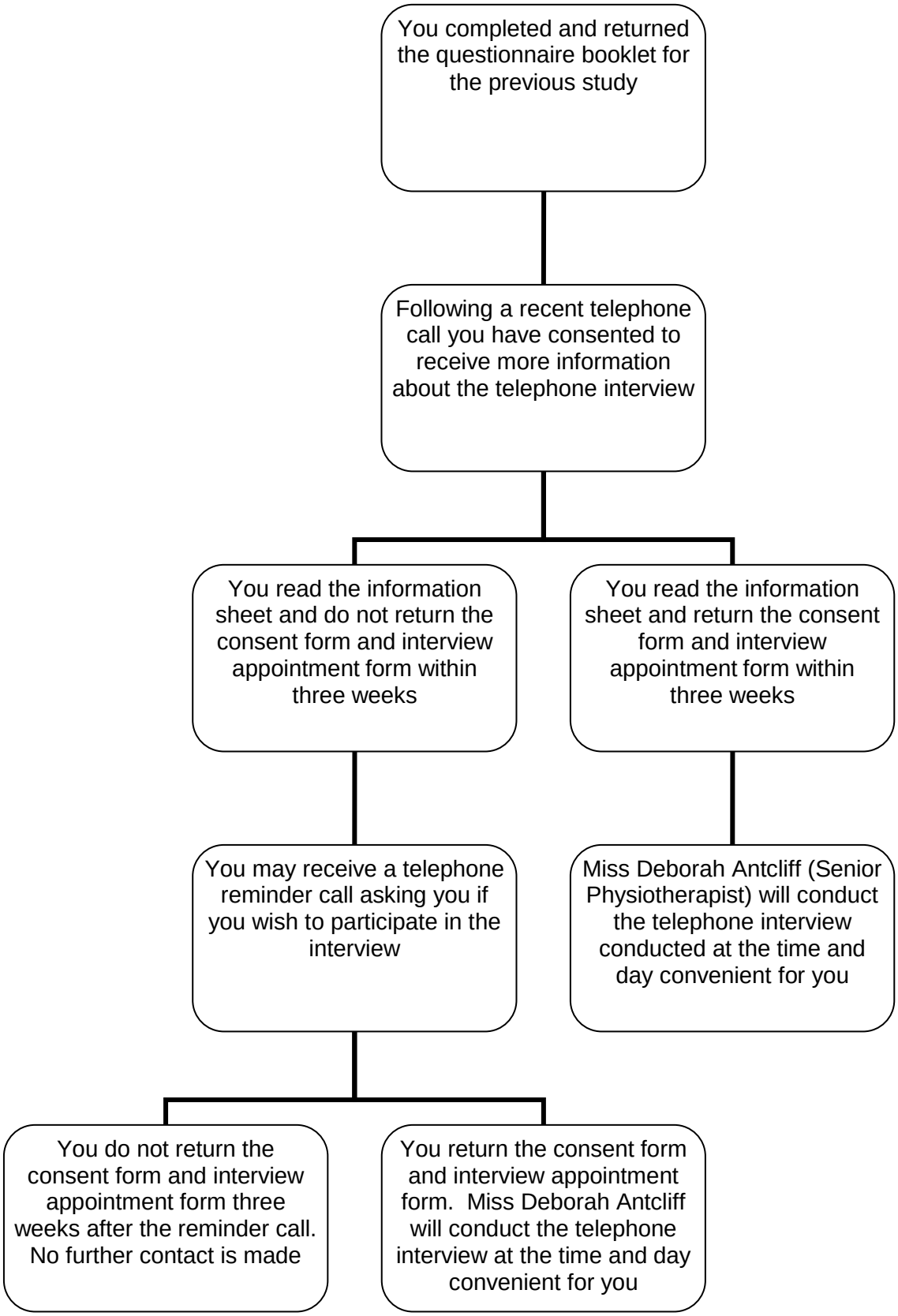
What do I do now?

If you wish to participate in the study, please complete and return the consent form, and the interview appointment form in the pre-paid addressed envelope enclosed within three weeks of receiving this letter. Please keep this study information sheet for your own records.

The flow diagram summarises what will happen if you choose to participate in this study.

Thank you for your time in reading this information sheet.

Flow diagram of the study



The University of Manchester

The Pennine Acute Hospitals NHS Trust

Physiotherapy Department A
North Manchester General Hospital
Delaunays Road
Crumpsall
Manchester
M8 5RB

Interview Appointment Form

Please return to the hospital with the consent form

Study Code

Title of the study: Exploring the Acceptability of the New Activity Pacing Questionnaire

If you decide to participate, Miss Deborah Antcliff (Senior Physiotherapist) will invite you to undertake a telephone interview which will last approximately 20 to 40 minutes. Please state below when you are free to undertake this interview. Please ensure that this is a day and time that you are available without being disturbed. If possible, please can we call you on a landline to reduce possible problems of a mobile phone connection.

1. Which days are most suitable for you to be contacted to undertake the interview?

_____

2. What time is best to contact you to undertake the interview?

_____

3. Please may we ask for your landline number, or mobile number if a landline is not available?

_____

Please now return this form together with the signed consent form in the prepaid envelope and we will contact you on your preferred date to undertake the interview.

With thanks for your participation in this interview design study.

Appendix 23. Interview outline

1. Introductory script

Good morning/afternoon Mr/Mrs/Miss ----------. My name is Deborah Antcliff and I am calling from the Pennine Acute Hospitals NHS Trust. I recently wrote to you to invite you to participate in a telephone interview to discuss the new activity pacing questionnaire which you completed in ----- 2012. I have received your consent form to say that you would be willing to participate in the interview, and I was wondering if it is convenient for us to do the interview today.

Before we start the interview can I ask if you are positioned in a comfortable, quiet place that is free from interruptions for approximately 20 to 40 minutes? Do you have the questionnaire booklet in front of you?

With your consent, I will record the interview on a tape. The purpose of using a tape recorder is to allow me to type up the interview without forgetting or changing anything that you have said. I will send you a copy of the typed version of the interview for you to check, sign and return to me in a prepaid envelope. Please can I reassure you that anything that you say will remain anonymous and confidential. However, if at any point you would like me to stop recording, I can stop the tape and we can continue the interview without the recorder, or we can stop the interview altogether.

2. Interview themes

2.1 Pacing as a construct

Examples of possible questions for this theme:

1. Please can you describe what you understand by the word "pacing"
2. Can you give examples of how you pace your activities?
3. What types of activities do you pace?

2.2 The new activity pacing questionnaire

2.2.1 Clarity of instructions

Examples of possible question for this theme:

1. In your opinion did the instruction box at the top of the new activity pacing questionnaire (on page 2) explain what you needed to do?
2. The new activity pacing questionnaire asked you to think about your activities over the past seven days. Do you think that this is a suitable amount of time to reflect on your activities?

2.2.2 Suitability of the questions

Examples of possible questions for this theme:

1. Did the new activity pacing questionnaire ask questions that were relevant to how you pace your activities? *If yes, please give examples*

2. Did the new activity pacing questionnaire give you new ideas about how to pace your activities? *If yes, please give examples*

3. In your opinion, are there any aspects of pacing that were missing from the new activity pacing questionnaire?

2.2.3 Ease of completion

Examples of possible questions for this theme:

1. You indicated in the questionnaire booklet that you returned that you found the new activity pacing questionnaire very difficult to complete/difficult to complete/neither difficult or easy to complete/easy to complete/very easy to complete *(read as appropriate).* Please can you explain what made the new activity pacing questionnaire very difficult to complete/difficult to complete/neither difficult or easy to complete/easy to complete/very easy to complete *(read as appropriate).*

2. Are there any questions in the new activity pacing questionnaire that you did not understand?

3. The new activity pacing questionnaire is scored using a five-point scale, with the labels '0=never did this', '1=rarely did this', '2=occasionally did this', '3=frequently did this' and '4=always did this'. Please explain how easy or difficult you found this scale to use.

2.2.4 Comments

Examples of questions

1. You made the following comment about the new activity pacing questionnaire: ….

Please can you explain this comment further.

2. Are there any other comments that you would like to make about the new activity pacing questionnaire?

2.3 Pacing Scale 1

2.3.1 Content

Example of a possible question for this theme:

1. Please now turn to the Pacing Scale 1 on page 5 of the questionnaire booklet. What is your opinion of the questions contained in this questionnaire?

2.3.2 Ease of completion

Examples of possible questions for this theme:

1. Pacing Scale 1 is scored by answering each question in terms of the number of days you did each item. Please explain how easy or difficult you found this scoring system to use.
2. You indicated in your questionnaire booklet that you found Pacing Scale 1 very difficult to complete/difficult to complete/neither difficult or easy to complete/easy to complete/very easy to complete *(read as appropriate)*. Please can you explain what made Pacing Scale 1 very difficult to complete/difficult to complete/neither difficult or easy to complete/easy to complete/very easy to complete *(read as appropriate)*.

2.4 Pacing Scale 2

2.4.1 Content

Example of a possible question for this theme:

1. Please now turn to the Pacing Scale 2 on page 6 of the questionnaire booklet. What is your opinion of the questions contained in this questionnaire?

2.4.2 Ease of completion

Examples of possible questions for this theme:

1. Pacing Scale 2 is scored on a scale of 0 to 5 where 0=you never did this and 5=you always did this. Please explain how easy or difficult you found this scoring system to use.
2. You indicated in your questionnaire booklet that you found Pacing Scale 2 very difficult to complete/difficult to complete/neither difficult or easy to complete/easy to complete/very easy to complete *(read as appropriate)*. Please can you explain what made Pacing Scale 2 very difficult to complete/difficult to complete/neither difficult or easy to complete/easy to complete/very easy to complete *(read as appropriate)*.

2.5 General comments

1. Are there any other comments that you would like to make?

3. Closing Script

I will stop recording the interview now. Thank you for your time in participating in the study. Your help is greatly appreciated. I will now type the interview recording and I will send you a copy in the post, together with a prepaid envelope. Please read the typed version of the interview and sign it if you agree that it reflects the interview that was conducted today. Please return the signed version of the interview in the prepaid envelope. If you wish to make any extra comments you can write these on the typed interview. With thanks again.

Appendix 24. Fieldnote exemplar

Participant RB108, 17/04/2013

Effect of co-morbidities: RB108 is currently unwell with other conditions (asthma, and recent asthma attack and gastroenteritis). This is having an effect on her activities, which is reported to be annoying. Therefore, her current levels and patterns of activity may be different to those if enquired on a different occasion. Interestingly, she commented that the doctor had told her to "take things easy". Therefore, there may be an influence of others/health professions. Of note, the participant additionally reported hearing difficulties and that her ears needed to be syringed. However, she could hear the questions and this should not affect the telephone interview.
(Relationships: co-morbidities and influence of others/other treatments)

Seven-day recall: RB108 mentioned that the seven day recall would usually be fine but it is not applicable at present due to co-morbidities.
(Relationships: co-morbidities and seven-day recall)

Age: This participant is 74 years old. Her activities therefore involve swimming and walking (but work is not applicable in this case). Furthermore, she reports that due to her age she is pacing more.
(Relationships: age and pacing; age and decreasing levels of activities)

Typology: Pacer, but some activity limitation/awareness of suitable activities e.g. swimming rather than zumba. Consistent levels of activity, not boom-bust. RB108 feels that pacing is a helpful strategy.
(Relationships: pacing, in particular consistency and better management of the condition)

Appendix 25. Progression of the themes emerging from the acceptability interviews

Appendix 25, Table 7.1 Initial themes (20/03/2013)

(These themes were considered before the first interview, and were included in the questions written for the semi-structured interviews)

Theme	Subtheme
Definitions of pacing	
Types of activities that require pacing	
APQ	Instructions Questions Scale Ease of completion
CPCI pacing subscale	Scale Questions Ease of completion
PARQ pacing subscale	Scale Questions Ease of completion

Appendix 25, Table 7.2 Emerging themes (17/06/2013)

Theme	Subtheme	Division of subtheme
Pacing knowledge		
Pacing themes	Activity limitation	
	Activity planning	
	Activity progression	
	Activity consistency	
	Activity acceptance	
Types of activities		
APQ	Ease of completion	
	Format	
	Instructions	Seven day recall
	Questions	Confusing questions
		Number of questions
		Relevant questions
	Scale	Number of options
		Word descriptors
CPCI pacing subscale	Questions	Number
		Relevance
	Scale	
PARQ pacing subscale	Questions	Number of questions
		Relevance
	Scale	
Boom-bust		
Memory recall in general		
Quota-contingent		
Symptom-contingent		
Researcher's influence		
Whole booklet comments		

Appendix 25, All nodes that were indexed and reorganised (10/07/2013)

1. Activity limitation
2. Activity planning
3. Activity progression
4. Activity consistency
5. Activity acceptance
6. Other pacing themes
7. Pacing knowledge: *included within APQ ease of completion-APQ questions, activity consistency, activity progression, support from others, other coping strategies, research experience, typologies: boom-bust, effects of pacing*
8. Boom-bust
9. Avoidance
10. Persistence
11. Symptom-contingent
12. Quota-contingent
13. APQ Ease of completion
14. APQ format
15. APQ instructions
16. APQ questions
17. APQ scale
18. APQ stability
19. APQ stimulating ideas: *in research experience*
20. CPCI pacing subscale ease of completion
21. CPCI pacing subscale questions
22. CPCI pacing subscale format
23. PARQ pacing subscale ease of completion
24. PARQ pacing subscale questions
25. PARQ pacing subscale format
26. Comparing the three scales
27. Co-morbidities
28. Emotions
29. Pain focused: *included within symptom contingent, PARQ, comparing the three scales*
30. Deterioration in activity: *included within activity limitations and progression*
31. Flare up management: *combined with other coping strategies*
32. Other coping strategies
33. Essential activities: *contained within activity limitation*
34. Speed of activities: included in CPCI pacing subscale questions
35. Types of activities: *contained with APQ instructions*
36. Support from others: *contained within APQ questions, Activity limitation, progression, consistency, acceptance, and other coping strategies*
37. Effects of pacing
38. Seven day/memory recall: *contained within APQ seven day recall, comparing the scales*
39. Mental fatigue: *contained within APQ seven day recall and comparing the three scales*
40. Effect of pain when completing the questionnaire: *in research experience*
41. Aiming to please the researcher: *in research experience*
42. Research experience: *in reflexivity (discussion)*
43. Researcher's influence: *in research experience*
44. Remembering completing the questionnaire booklet: *in research experience*
45. Problems with telephone interviews: *in research experience*
46. Whole booklet comments: *with APQ ease of completion and research experience*

Appendix 25, Table 7.3 Final framework of themes from the acceptability telephone interviews

(Final themes and subthemes derived on 12/07/2013)

Theme	Subtheme	Division of subtheme	Subdivision
1. Pacing themes	Activity limitation	Essential activities	
	Activity planning		
	Activity progression	Deterioration	
	Activity consistency		
	Activity acceptance		
	Other pacing themes		
2. Pacing scales	APQ: ease of completion	Instructions	Types of activities
			Seven day recall
		Scale	Number of intervals
			Word descriptors
		Questions	Relevance
			Number
		Format	
		Stability of the APQ	
	CPCI: ease of completion	Instructions	Seven day recall
		Scale	
		Questions	Relevance
			Speed of activities
			Number
	PARQ: ease of completion	Scale	
		Questions	Relevance
			Number
	Comparing the three scales	Mental fatigue	
3. Co-morbidities	Other illnesses/age	External factor: weather	
	Effect of pain when completing the questionnaire		
	Emotions		
4. Coping strategies	Effects of pacing	Pacing knowledge	
	Other coping strategies	Support from others	Flare up management
5. Activity behaviour typologies	Quota-contingent		
	Symptom-contingent	Pain focused	
	Task avoidance	Avoidance	
	Task persistence	Persistence	
	Task fluctuation (boom-bust)	Boom-bust	
	Task modification (activity pacing)		

Appendix 26. Relationships between pacing themes, subthemes and behaviour typologies

Appendix 26, Table 7.4 Relationships between pacing themes, subthemes and behaviour typologies

	Activity limitation	Activity planning	Activity progression	Activity consistency	Activity acceptance
Pacing themes					
Activity limitation		✓	✓	✓	✓
Activity planning	✓		✓	✓	✓
Activity progression	✓	✓		✓	✓
Activity consistency	✓	✓	✓		✓
Activity acceptance	✓	✓	✓	✓	
Contingency					
Quota-contingent	✓	✓	✓	✓	
Symptom-contingent	✓	✓	✓	✓	✓
Typology					
Task avoidance	✓	✓		✓	✓
Task persistence			✓	✓	
Task fluctuation	✓		✓	✓	
Task modification	✓	✓	✓	✓	✓
Subthemes					
Boom-bust	✓		✓	✓	
Co-morbidities	✓	✓	✓	✓	✓
Condition status	✓	✓	✓	✓	✓
Emotions	✓		✓		✓
Flare-up management	✓	✓	✓	✓	✓
Pacing knowledge	✓	✓	✓	✓	✓
Support from others	✓			✓	✓
Speed of activities	✓		✓	✓	✓
Types of activities	✓	✓	✓	✓	✓