

# IMPROVING THE CLINICAL EFFECTIVENESS OF PHYSIOTHERAPY IN PARKINSON'S DISEASE

by

CHARMAINE ELISE MEEK

A thesis submitted to the  
University of Birmingham  
for the degree of  
MASTER OF PHILOSOPHY

Rehabilitation Research Group  
Primary Care Clinical Sciences  
School of Health & Population Sciences  
College of Medical & Dental Sciences  
University of Birmingham  
September 2011

UNIVERSITY OF  
BIRMINGHAM

**University of Birmingham Research Archive**

**e-theses repository**

This unpublished thesis/dissertation is copyright of the author and/or third parties. The intellectual property rights of the author or third parties in respect of this work are as defined by The Copyright Designs and Patents Act 1988 or as modified by any successor legislation.

Any use made of information contained in this thesis/dissertation must be in accordance with that legislation and must be properly acknowledged. Further distribution or reproduction in any format is prohibited without the permission of the copyright holder.

## **ABSTRACT**

Parkinson's disease (PD) is a chronic progressive neurodegenerative experienced by 120,000 people in the UK and costing £3.3 billion per annum. Current treatment for PD predominantly centres on pharmacological therapy but patients still experience functional deterioration which has led to a multidisciplinary approach to care. Physiotherapy for PD aims to address impairments in function and activity, but the evidence base is still incomplete. This thesis aims to identify current attitudes and practices and demonstrate the improvement research has made to physiotherapy in PD. This was considered within three inter-related studies.

The first two studies utilise a questionnaire and modified Delphi technique to examine overall current and perceived best practice (Study One), and more specific issues surrounding outcome measurement (Study Two), within the physiotherapeutic management of PD, as perceived by 76 UK therapists. Study One aimed to gain an insight into current practice, particularly in relation to setting, structure and delivery of services, referral patterns to physiotherapy, and dose of treatment, via a closed-question questionnaire. The best practice element centred on identifying the reasons for physiotherapy provision, core areas of practice, effective treatment techniques and general issues surrounding outcome measurement through the ranking of agreement with a defined set of statements. Study Two focused specifically on the exploration of what assessment tools are currently used by physiotherapists when treating PD patients, and provided a more in depth analysis of the outcomes used in best practice.

Study One revealed the majority of therapy is provided in a patient's home or outpatient department, with referrals mainly coming from a PD Nurse Specialist. It identified that physiotherapy is mostly delivered within the context of a multidisciplinary team, but that the

format of therapy delivery varies greatly. A median dose of six sessions delivered over eight weeks was reported, with initial assessments lasting a median of 60 minutes and follow up sessions lasting a median of 45 minutes. This dose was comparable with that reported the decade previously. The best practice survey found high levels of agreement surrounding the reasons for delivering physiotherapy, resulting in the production of a framework for practice. It identified a focus on gait and mobility, balance and falls, transfers, posture, and physical conditioning and found best practice treatment provision to have a patient-centred approach. Strong levels of agreement existed for the efficacy treatment techniques for gait, balance, physical conditioning and transfers rehabilitation, but there was less certainty surrounding the rehabilitation of posture and the upper limb.

Study Two highlighted strong support for outcome assessment, with 82% of physiotherapists utilising outcome measures and a mean of 3.7 measures being listed per therapist. However, whilst some overlap existed between outcome measures used currently and those recommended in guidelines, there was wide variation in practice. For perceived best practice, consensus outlined a clear focus for assessment, the structure of measures, timing, and the uses of outcome measurement, but clear discrepancies were evident between expert generated guidelines and perceived achievable best practice by clinical therapists.

Study Three was a pilot randomised controlled trial of supported community exercise in people with PD. Participants were given access to a gym and co-created a three-month personalised, progressive exercise programme with the support of a fitness instructor. Physiotherapeutic input and financial assistance was also provided. The primary outcome measure was the Physical Activity Scale for the Elderly (PASE); a subjective measure of physical activity levels, whilst measures of step count, mobility speed and endurance,

strength, fatigue, cognition, falls and quality of life were also included. Outcome measures were assessed at baseline, three and six months.

The trial found the supported exercise programme to be both feasible in delivery and acceptable to patients; particularly evident from the high uptake of the intervention (87% of participants completed the programme). However, the number of gym visits varied widely, indicating that the programme did not optimally support all participants. Outcome measures were well completed, but some issues were noted regarding the seasonality of the PASE; an issue which would have to be further addressed if a larger scale trial were to be conducted.

Co-operation between researchers and practicing physiotherapists is needed to enhance the presence of achievable best practice and encourage multidisciplinary coordination of outcome measures. Furthermore, continued methodologically-sound research is needed to ascertain the long-term effect of physiotherapy for PD, optimal doses of treatment, and the efficacy of specific interventions.

## **ACKNOWLEDGEMENTS**

The author would like to thank her supervisors, Professor Cath Sackley and Professor Carl Clarke, for their knowledge and guidance. Many thanks to all of the patients and physiotherapists who were kind enough to participate in the studies reported within this thesis; their time and effort spent contributing to this research is greatly appreciated. The author would like to express her gratitude to the researchers she worked alongside on the exercise trial described within Study Three of this thesis, both at the University of Birmingham and Oxford Brookes University, and special thanks are due to Mrs Smitaa Patel for conducting the randomisation and analysis on this trial. The author would also like to convey her thanks to the West Midlands Strategic Health Authority and Parkinson's UK for providing financial support. Finally, the author would like to express her deepest gratitude to all of her family and friends for their love and support throughout.

## TABLE OF CONTENTS

1	Introduction .....	1
1.1	What is Parkinson’s Disease? .....	1
1.2	Aetiology and Pathophysiology .....	2
1.3	Epidemiology .....	3
1.4	Economic Burden .....	4
1.5	Medical Management .....	5
1.6	Multidisciplinary management .....	6
1.7	Physiotherapy for Parkinson’s Disease and the Need for Research .....	8
1.8	Objectives .....	10
2	Study One: Defining UK Physiotherapy Practice in Parkinson’s disease: A survey of current and perceived best practice .....	11
2.1	Introduction .....	11
2.2	Aims .....	14
2.3	Methods .....	14
2.3.1	Participants .....	14
2.3.2	Setting .....	16
2.3.3	Trial Design .....	16
2.3.4	Survey process .....	21
2.3.5	Research Governance and Ethics .....	22
2.4	Results .....	23
2.4.1	Response to Survey .....	23
2.4.2	Current Physiotherapy Practice for PD .....	23
2.4.3	Perceived Best Practice for Physiotherapy in PD .....	27
2.5	Discussion .....	40
2.5.1	Current Physiotherapy Practice for PD .....	40
2.5.2	Perceived Best Practice for Physiotherapy in PD .....	45
2.5.3	Limitations of the Study .....	52
2.6	Conclusion .....	53
3	Study Two: Outcome Measurement in Physiotherapy for Parkinson’s Disease: A Survey of Current and Perceived Best Practice in the UK .....	56
3.1	Introduction .....	56
3.2	Methods .....	58

3.2.1	Participants.....	58
3.2.2	Study Design.....	59
3.3	Results.....	61
3.3.1	Respondent Characteristics.....	61
3.3.2	Outcome Measures Currently Used in Practice.....	61
3.3.3	Perceived Best Practice for Outcome Measurement.....	64
3.4	Discussion.....	65
3.4.1	Current Practice.....	65
3.4.2	Perceived Best Practice.....	68
3.4.3	Limitations of the Study.....	71
3.5	Conclusions.....	72
4	Study Three: A pilot randomised controlled trial of supported community exercise in people with Parkinson’s disease.....	75
4.1	Introduction.....	75
4.2	Methods.....	77
4.3	Results.....	80
4.4	Discussion.....	86
4.5	Conclusions.....	89
5	Summary of Main Findings and Discussion.....	90
5.1	Summary of Main Findings.....	90
5.1.1	Study One: Defining UK Physiotherapy Practice in Parkinson’s disease- A survey of current and perceived best practice.....	90
5.1.2	Study Two: Outcome Measurement in Physiotherapy for Parkinson’s Disease- A Survey of Current and Perceived Best Practice in the UK.....	91
5.1.3	Study Three: A pilot randomised controlled trial of supported community exercise in people with Parkinson’s disease.....	93
5.2	Summary of Study Limitations.....	94
5.3	Implications for Clinical Practice.....	95
5.4	Implications for Research.....	96
6	References.....	100
7	Appendices.....	118



## LIST OF FIGURES

<i>Figure 1: Cumulative number of randomized and controlled clinical trials on the efficacy of physical therapy in PD (From Keus et al, 2009).....</i>	<i>14</i>
<i>Figure 2: Core Areas of Physiotherapy .....</i>	<i>30</i>
<i>Figure 3: Design of Study and Participant Flow Through .....</i>	<i>81</i>
<i>Figure 4: Results for Outcome Measurements .....</i>	<i>84</i>

## LIST OF TABLES

<i>Table 1: Practice Setting for Physiotherapy Delivery</i> .....	24
<i>Table 2: Health Care Professionals Referring to Physiotherapy</i> .....	25
<i>Table 3: Time of Referral to Physiotherapy</i> .....	26
<i>Table 4: Level of evidence</i> .....	28
<i>Table 5: Reasons for Physiotherapy</i> .....	28
<i>Table 6: Context of Treatment</i> .....	31
<i>Table 7: Rehabilitation of Gait</i> .....	34
<i>Table 8: Rehabilitation of Balance and the Prevention of Falls</i> .....	35
<i>Table 9: Rehabilitation of Transfers</i> .....	35
<i>Table 10: Rehabilitation of Posture</i> .....	36
<i>Table 11: Physical Conditioning</i> .....	36
<i>Table 12: Rehabilitation of the Upper Limb</i> .....	37
<i>Table 13: Additional Treatment Techniques</i> .....	38
<i>Table 14: Outcome Measurement</i> .....	39
<i>Table 15: Structure, Delivery and Use of Outcome Measurement</i> .....	40
<i>Table 16: Number of years qualified versus number of outcome measures</i> .....	62
<i>Table 17: Number of patients treated in last 12 months versus number of outcomes</i> .....	62
<i>Table 18: Summary Statistics of Selected Results at Baseline, 3 Months and 6 Months</i> .....	83

# 1 INTRODUCTION

## 1.1 What is Parkinson's Disease?

Parkinson's disease (PD) is a common chronic, progressive neurodegenerative condition (Jones and Playfer, 2004), second only to Alzheimer's disease in occurrence (Schapira, 2011). It is most often recognised as a movement disorder, as patients present with a triad of physical signs; resting tremor, rigidity on passive movement and akinesia (bradykinesia and hypokinesia) (Lang and Lozano, 1998, Clarke, 2007), often accompanied with postural instability (Jones and Playfer, 2004). These clinical features can present as a multitude of symptoms. These include gait disturbances: slow shuffling steps with a reduced stride length (Morris et al., 2010), start hesitation and freezing of gait (Morris et al., 2008), and impaired balance (Morris, 2000), leading to an increased likelihood of falls. Difficulties with self care tasks and activities of daily living are evident due to reduced dexterity and bradykinesia (Weiner and Singer, 1989), and the ability to communicate is impaired as a result of changes to the patient's voice (reduced loudness, monotony of pitch, altered prosody, imprecise articulation and a breathy voice) (Ramig et al., 2004, Pinto et al., 2004), reduced spontaneous facial expression (Spielman et al., 2003) and micrographia of handwriting (Weiner and Singer, 1989). The direct physical effects of PD often lead to secondary musculoskeletal complications, most notably the development of a stooped, forward flexed, kyphotic posture (Lusis, 1997). PD is also a complex disorder and, in addition to the motor problems, a wide range of non-motor symptoms are also frequently present including neuropsychiatric disorders (e.g. depression, dementia, hallucinations), sleep disturbances, autonomic symptoms (e.g. bladder and sexual dysfunction), gastrointestinal problems, sensory disturbances and a range of other symptoms (e.g. fatigue) (Chaudhuri et al., 2006).

Diagnosis of PD remains predominantly clinical, with physicians utilising the UK Parkinson's Disease Society Brain Bank Criteria to identify the inclusion and exclusion criteria for PD (Gibb and Lees, 1988). Whilst the presentation and progression of the condition is noted to be diverse and individualised (van der Marck et al., 2009), systems such as the Hoehn and Yahr scale (Hoehn and Yahr, 1967), Unified Parkinson's Disease Rating Scale (Fahn and Elton, 1987) and the MacMahon and Thomas's Clinical Scale (diagnosis, maintenance, complex and palliative) (MacMahon and Thomas, 1998) are used to chart disease progression and guide treatment. Normality of life expectancy has been noted for the first 10 years of PD, with the standardised mortality ratio increasing after this point, although life expectancy is known to be adversely affected by age of onset (Diem-Zangerl et al., 2009). Pneumonia is frequently recognised as the "terminal event" in the disease process (Pennington et al., 2010).

## **1.2 Aetiology and Pathophysiology**

The aetiology of PD remains relatively unknown, but is thought to be multifactorial with both genetic and environmental factors potentially playing a role (Bilney et al., 2003, Jones and Playfer, 2004). PD has classically been viewed a disease of the basal ganglia (Jones and Playfer, 2004), characterised primarily by damage to dopaminergic projections from the substantia nigra pars compacta to the basal ganglia's striatum (Samii et al., 2004), and accompanied by associated receptor destruction (Tapper, 1997). Dopamine depletion is most prominently noted within the putamen (Kish et al., 1988); a region recognised as the striatal motor area (Agid, 1991), resulting in the akinesia and rigidity seen within PD (Lang and Lozano, 1998). In addition, there is the hallmark presence of Lewy bodies within neuronal cytoplasm; spherical protein granules which may alter axonal function (Goldman et al., 1983),

resulting in connection loss between the pars compacta and striatum. However, this explanation has recently been challenged and a new six stage process has been proposed during which the olfactory nucleus, glossopharyngeal and vagal nerves are initially effected (stage 1), followed by changes in the lower brainstem (stage 2), both resulting in non-motor symptoms (Braak et al., 2003, Chaudhuri et al., 2006). This is thought to be followed by the changes in the midbrain (basal ganglia) and other areas of the cortex that present as motor signs (stages 3 and 4), and finally degeneration of the sensory association areas of the neocortex, prefrontal cortex, and premotor cortex (stages 5 and 6) (Braak et al., 2003, Chaudhuri et al., 2006).

### **1.3 Epidemiology**

PD is thought to affect around 120,000 people in the UK (Parkinson's UK, 2008b). The incidence and prevalence of PD increases with age, with a sharp increase following the mean age of onset between 60 and 65 years (Twelves et al., 2003, Jones and Playfer, 2004). Despite this, 10% of patients are known to be diagnosed before the age of 40; early onset PD (Giovannini et al., 1991). Average prevalence has been identified at between 0.2% and 0.3% for the entire population (de Lau and Breteler, 2006, Clarke, 2007), up to 1% in people over 60 years and between 3% and 4% for those aged 80 years and over (Nussbaum and Ellis, 2003, Clarke, 2007). Average incidence was reported at 16-19 per 100,000 in a systematic review by Twelves et al (2003); a figure comparable with the 8-18 per 100,000 noted by de Lau and Breteler (2006). At present, there is no concrete evidence for cross cultural variation in PD epidemiology (de Lau and Breteler, 2006), but a number of studies have identified a higher level of incidence in men, with an age-standardised sex ratio of 1.5 to 2.0 (Twelves et al., 2003).

## 1.4 Economic Burden

The cost of PD is known to be great, and is directly associated with the growing level of disability seen as the disease progresses (Findley, 2007). A UK study conducted between 1988 and 1989 by the Office of Health Economics identified NHS costs at around £126 million per annum (West, 1991). More recently, a cross-sectional survey investigated the direct economic burden of PD in the UK (Findley et al., 2003). This study identified the average direct cost as £5993 per patient per year (38% NHS costs, 35% social services costs and 27% private expenditure), but this varied substantially based on disease severity (£2,971 per patient per year at Hoehn and Yahr Stage I versus £18,358 at stage V). The rise in direct expenditure as the condition progressed was related to the increase in hospital inpatient and institutionalised care, with costs 4.5 times higher than for patients remaining at home. Surprisingly, drug costs were noted to remain the same throughout the course of the disease. The figures presented by Findley et al., (2003) are based on the provision of “standard” treatment. If the recommendations laid out in national guidelines were put into practice (increased access to nurse specialists, physiotherapy, occupational therapy and speech and language therapy), it is thought there would be an additional cost of £3.766 million per annum (National Institute for Health and Clinical Excellence, 2006).

When considering indirect costs, great variation has been identified depending on the methods of evaluation used, from £1668 per patient per annum based on lost productivity alone (a low figure due to the age of the average PD patient), through to over £27,000 per patient per year if considering replacing care given by family members with professional carers (Findley, 2007). Due to this variability, Findley (2007) set the total cost of PD within the UK at between £449 million and £3.3 billion per annum.

## 1.5 Medical Management

Current treatment for PD predominantly centres on pharmacological therapy (Deane et al., 2001e). In recent years, a number of trials have been conducted exploring the immediate commencement of drug therapy following diagnosis as a means of slowing disease progression via a neuroprotective effect (Fahn et al., 2004, Olanow et al., 2009). However, a recent meta-analysis has found there is still insufficient evidence to warrant implementation of this practice into current patient management (Clarke et al., 2011). In light of this, the provision of medication within clinical practice for PD is currently withheld until a patient's symptoms begin to interfere with their day to day life (Clarke, 2007). National guidelines recommend that the early pharmacological treatment of PD consists of dopaminergic medication (e.g. Sinemet, Madopar), dopamine-agonists (e.g. Pramipexole, Ropirinole) or monoamine-oxidase-B inhibitors (e.g. Selegiline, Rasagiline) (National Collaborating Centre for Chronic Conditions, 2006). As the disease progresses, motor complications become apparent due to the administration of levodopa therapy, and so adjuvant therapy is recommended in the form of a dopamine-agonist, monoamine-oxidase-B inhibitor, or catechol-O-methyltransferase inhibitors (e.g. Entacapone, Tolcapone) (National Collaborating Centre for Chronic Conditions, 2006). Within the advanced stages of PD, Amantadine and dopamine agonist Apomorphine may be introduced to manage further motor complications (Clarke, 2007).

Surgery is also considered within the advanced stages of PD when pharmacological therapy fails to control symptoms adequately. This most frequently consists of the lesioning or stimulation of three areas deep inside the brain; the thalamus, subthalamic nucleus and the globus pallidus (Pentland, 1999). A recent randomised controlled trial of surgery (stimulation or lesioning of either the subthalamic nucleus or globus pallidus) plus medication versus

medication alone in 366 advanced PD patients found surgery to have a significant effect on quality of life, but recommended strict selection of surgical candidates (Williams et al., 2010).

## **1.6 Multidisciplinary management**

Even when optimal medical management is in place, patients still experience deterioration of body functions, daily activities and participation (Nijkraake et al., 2007). For this reason, a multidisciplinary team approach is advocated, most commonly including the physician, a nurse specialist, physiotherapist, occupational therapist and speech and language therapist (Rubenis, 2007). A wide variety of other professions may also be employed based on the individual needs of the patient such as dieticians, social workers, sexologists and complementary therapists (Nijkraake et al., 2007, van der Marck et al., 2009).

The PD nurse specialist role involves the monitoring of symptoms and medication to ensure optimal medical management, and the provision of information, education and advice (National Collaborating Centre for Chronic Conditions, 2006). In addition, the nurse often takes on the role of key worker, facilitating the referral of patients to allied health professionals and other services (Rubenis, 2007). Whilst the PD nurse specialist is often advocated, actual evidence for the role is currently inconclusive (Reynolds et al., 2000, Jarman et al., 2002).

Allied health professionals predominantly aim to maximise the performance of activities of daily living and minimise any secondary complications (Montgomery, 2004, Nijkraake et al., 2007). National guidelines recommend access to physiotherapy, occupational therapy and speech and language therapy throughout the course of the disease (National Collaborating Centre for Chronic Conditions, 2006), although referral to these services is still variable and



often limited (Parkinson's UK, 2008b, Hu et al., 2011). The provision of physiotherapy will be outlined shortly.

Occupational therapy for PD is thought to focus on functional goals “centred on independence, safety and confidence” (Deane et al., 2003b). It aims to provide early intervention in order to prevent activities and roles being restricted or lost, and offer appropriate coping strategies, deliver individualised interventions to enhance participation in self-care, mobility, domestic and family roles, work and leisure, and optimise safety through consideration of environmental issues (Aragon and Kings, 2010). Occupational therapy sessions for people with PD are known to most frequently incorporate the provision of adaptive equipment and environmental adaptations, transfers, mobility and activities of daily living training, elements of review and discussion, and the teaching of techniques (e.g. cueing, compensational movement strategies) and provision of education (Meek et al., 2010). Published evidence for the effectiveness of occupational therapy in PD is currently limited, with a Cochrane review by Deane et al (2001a), and a subsequent update by Dixon et al (2007) noting there to be insufficient evidence to support or refute its provision.

Speech and language therapy within PD most commonly targets dysarthria and dysphagia. Problems with swallowing may be treated through exercises to support tongue motion and vocal fold adduction, verbal cueing, bolus modification and postural changes, but at present there are no randomised trials investigating the efficacy of such interventions (Bajjens and Speyer, 2009). Treatment for dysarthria falls into two categories; traditional therapy and Lee Silverman Voice Treatment. Traditional therapy may include interventions targeted at impairment level such as exercises for respiration and articulatory muscle function, and techniques for improving phonation intensity and coordination (Johnson and Pring, 1990), or treatments for optimising function and participation including behavioural techniques for

prosodic abnormality and speech rate (Scott and Caird, 1984, Johnson and Pring, 1990), and the use of augmentative and alternative communication strategies and devices (Hustad and Weismer, 2007). Lee Silverman Voice Treatment is a specific technique that aims to increase vocal loudness through improved vocal fold adduction, comprising of repeated maximum effort vocal drills and progressive speech production tasks delivered over four 50 minute sessions per week for four weeks (Ramig et al., 1995). As with occupational therapy, there is no definitive evidence to support either approach (Deane et al., 2001c, Deane et al., 2001d).

### **1.7 Physiotherapy for Parkinson's Disease and the Need for Research**

Physiotherapy for PD aims to “maximise functional ability and minimise secondary complications through movement rehabilitation within context of education and support for whole person” (Deane et al., 2001e). It focuses on optimising the patient's independence, safety and wellbeing, thereby enhancing quality of life (Keus et al., 2004a; Keus et al., 2007a). Physiotherapy is thought to target six core areas: gait, balance (and falls), transfers, body posture, reaching and grasping and physical capacity and (in)activity (Keus et al., 2007a). Therapy is individualised to suit the patient's needs and evolves over time; early intervention focuses on the prevention of inactivity and preservation/ improvement of physical capacity, mid-stage therapy aims to maintain and encourage activities of daily living, and late stage physiotherapy focuses on the prevention of complications (Keus et al., 2004b). The treatment strategies employed by physiotherapists may be wide ranging, from “traditional” techniques such as exercise (Goodwin et al., 2008), cueing (Nieuwboer et al., 2007), and cognitive movement strategies (Kamsma et al., 1995), through to more alternative methods including the Alexander technique (Stallibrass et al., 2002) and martial arts (Schmitz-Hubsch et al., 2006). However, guidelines particularly advocate the following: the

provision of cues for the treatment of gait, posture and transfers (short term effect only), the application of cognitive movement strategies for the rehabilitation of transfers, exercise to improve or maintain balance, and flexibility and strength training to maximise physical capacity (Keus et al., 2007a, Keus et al., 2009).

Between 1998 and 2000, a survey of specialist physiotherapists and case studies of best practice sites were conducted to explore current and perceived best practice for physiotherapy in the UK, and to provide a framework for service delivery (Plant et al., 2000, Ashburn et al., 2004). Shortly afterwards, two Cochrane reviews were published, but both found there to be insufficient evidence to support or refute physiotherapy for PD (Deane et al., 2001e), or to advocate one form of treatment over another (Deane et al., 2001b). In the years following the volume of higher quality research – randomised controlled trials (RCTs) and controlled clinical trials – has sharply increased (Keus et al., 2009), and more recent reviews and meta-analyses have found there to be growing evidence in favour of physiotherapy (Kwakkel et al., 2007) and exercise (Goodwin et al., 2008) for PD, although there have been no definitive updates of the Cochrane reviews published. These reviews have also identified a need for further methodologically sound trials, and have stated that research is required in neglected fields of rehabilitation, such as the use of exercise for physical fitness training (Kwakkel et al., 2007). In addition, profession-specific guidelines with evidence-based recommendations have been made available (Keus et al., 2004b, Ramaswamy et al., 2009). This may mean that the current and perceived best practice for physiotherapy in PD captured a decade ago has now changed. Therefore, further research is required in order to move the evidence base forward.

A series of linked studies have been undertaken to begin to fill the gaps identified above within the research, and therefore allow progression within physiotherapy practice for PD. In

order to influence practice through new research, it is vital to understand what current practice entails and what therapists perceive best practice to comprise of, uncovering any areas of uncertainty and any discrepancies between current practice, the evidence base and guideline recommendations. Therefore, two surveys (Study One and Study Two) have been undertaken to capture current and perceived best practice for overall physiotherapy and outcome measurement for PD in the UK. In light of the survey results, and the recommendations for further research outlined in published evidence synthesise, a phase II pilot randomised controlled trial of supported community exercise in people with PD has been conducted (Study Three), focusing primarily on improving physical activity levels within the population. This was identified as a key area requiring further evidence, as rehabilitation of physical conditioning was identified as a core area by physiotherapists within Study One, and it is central to maximising quality of movement, minimising secondary complications, and supporting self management and participation, but physiotherapists rarely measure physical fitness levels (as captured in Study Two), despite guideline recommendations.

This thesis aims to describe the three studies conducted.

## **1.8 Objectives**

This thesis aims to describe the following three studies:

1. A survey of current and perceived best practice physiotherapy for PD in the UK
2. A survey of current and perceived best practice outcome measurement in physiotherapy for PD in the UK
3. A pilot randomised controlled trial of supported community exercise in people with PD

## **2 STUDY ONE: DEFINING UK PHYSIOTHERAPY PRACTICE IN PARKINSON'S DISEASE: A SURVEY OF CURRENT AND PERCEIVED BEST PRACTICE**

### **2.1 Introduction**

Over the past ten years, the number and quality of trials investigating the effectiveness of physiotherapy interventions for people with Parkinson's disease (PD) has increased considerably; a growth which has been demonstrated visually in an overview of the evidence by Keus et al (2009) (see Figure 1). Despite this, questions still remain surrounding the optimal content, structure and delivery of physiotherapy practice for PD (Kwakkel et al., 2007, Goodwin et al., 2008) because, at present, RCTs fail to address these issues sufficiently. For this reason, we look to survey-based evidence to inform us of what best practice is perceived to entail, and to provide information on current service delivery.

Only a few studies have provided information on the structure, content and delivery of physiotherapy services for PD. A Dutch survey of 235 patients and 99 physiotherapists aimed to explore the quality and quantity of current physiotherapy care for PD patients in the Netherlands, and provided some information regarding the structure and content of physiotherapy delivered (Keus et al., 2004a). It reported that the majority of patients were referred to physiotherapy by a neurologist or general practitioner. The goals of physiotherapy treatment were identified to centre on the improvement of gait (including falls), general physical condition, posture, and balance (including falls). Treatment goals varied dependent on the severity of the patient's condition. Physiotherapy was mostly delivered in the therapist's practice (68% of cases) or the patient's home (20% of cases), and the majority of patients received therapy on a one-to-one basis (88%). Treatment was mainly reported to focus on active exercise (often utilising cardio fitness and strengthening equipment). However, other interventions were also employed including external auditory cues and

treadmill training for gait rehabilitation, the use of mirrors for posture correction, the application of massage for stiffness and pain relief, and hydrotherapy. Details of dose for a completed course of therapy, other than the median total treatment duration (31 weeks) and interval between two sessions (9.4 days), were not given.

More recently, another Dutch survey has been published detailing practice, based on findings from 217 patient questionnaires and 86 physiotherapist-completed questionnaires (Nijkraak et al., 2009). Along with targeting gait, transfers, posture and balance, it was reported that people with PD may also access physiotherapy to treat problems with upper limb function, and leisure and work activities.

Whilst both of these surveys provide useful information, it must be noted that these findings may not completely correlate with physiotherapy delivered within the UK.

Our understanding of physiotherapy for PD in the UK has been mostly informed by the PD: Physiotherapy Evaluation Project (PD: PEP) (Plant et al., 2000, Ashburn et al., 2004). The PD: PEP employed a Delphi method survey of 49 specialist physiotherapists and case studies of nine best practice sites (29 physiotherapists and 30 patients) to explore current and perceived best practice. The evaluation project uncovered that current physiotherapy practice was variable and early referral to physiotherapy services was rare. Therapy was delivered in either an individual or group format, once or twice weekly over a period of six to eight weeks.

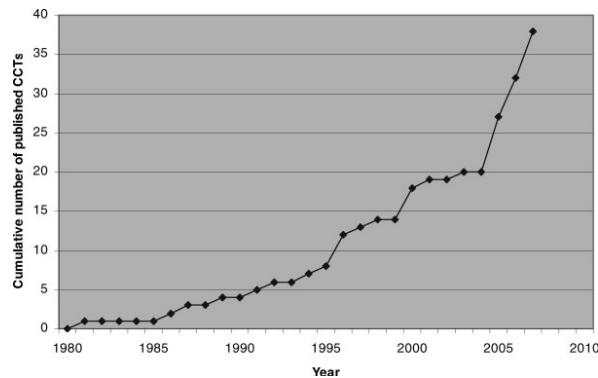
With regards to perceived best practice, the PD: PEP (Plant et al., 2000, Ashburn et al., 2004) reported high levels of consensus surrounding the context of physiotherapy delivery. Therapists felt that physiotherapy interventions could be maximised if treatment was delivered in the community as part of a multidisciplinary team effort, and coordinated by a key worker. Individual treatment sessions supplemented by group work were recommended. The use of standardised assessment forms was advocated, and therapists felt treatment goals

should be jointly agreed between patient and practitioner. Physiotherapists supported the initiation of physiotherapy on diagnosis, and reported that patient health could be optimised through the use of a long-term monitoring programme with frequent reviews (based on the patients' individual needs), and the option of patient or carer initiated re-referral. Involvement of the carer was noted to be of importance. When considering the purpose of therapy, there was a focus on maximising functional movement and general fitness, and minimising secondary complications, with specific consideration of gait, transfers, balance, and posture as the core areas to address. The importance of education delivery and support for patient and carer self-management was also apparent. For treatment, the use of a combination of approaches to treat individualised problems was advocated, although the delivery of exercise interventions and cueing strategies were specifically mentioned. The physiotherapists strongly supported the measurement of effect at the level of functional ability, but consensus was also reached for outcome measurement focused on the specific aims of treatment, quality of life, and subjective wellbeing.

The findings of the PD: PEP led to the construction of a much cited working definition of physiotherapy in PD; "The purpose of physiotherapy in Parkinson's disease is to maximise functional ability and minimise secondary complications through movement rehabilitation within the context of education and support for the whole person", and the production of the UK guidelines (Plant et al., 2001).

The PD: PEP, and the subsequently published guidelines, has provided guidance on the structure and delivery of best physiotherapy practice for PD in the UK for the past decade. However, since its completion the evidence base has moved forward significantly. National guidelines (National Collaborating Centre for Chronic Conditions, 2006) and international,

physiotherapy-specific, evidence-based guidance (Keus et al., 2004b) have been published. In light of this, the delivery of current practice and perceived best practice may have moved on.



**Figure 1:** Cumulative number of randomized and controlled clinical trials on the efficacy of physical therapy in PD (From Keus et al, 2009)

## 2.2 Aims

The main aim of this survey was to identify perceived best practice, as viewed by physiotherapists, for the physiotherapeutic management of people with PD in the UK, using a modified Delphi technique. In particular, it aimed to gain information on the perceived reasons for physiotherapy, core areas of physiotherapy, context of physiotherapy, effective treatment techniques and outcome measurement. In addition to this, the survey aimed to provide details on current practice with regards to service structure and delivery through an additional questionnaire.

## 2.3 Methods

### 2.3.1 Participants

The Delphi technique requires that an expert panel is recruited as the sample in the survey (Williams and Webb, 1994). However, note that there is little consensus as to what actually qualifies a person as an expert, and the dangers of simply equating expertise with knowledge or years of experience alone have been identified (Keeney et al., 2001, Baker et al., 2006). In



light of this, a rather broad definition of expert was used in this survey: a physiotherapist with an interest, or expertise, in the management of people with PD. The lack of any strict criteria helped to ensure that perceptions of best practice could be obtained from a range of therapists with varying levels of experience and from a diverse selection of settings, and that the full scope of current practice was captured. The use of heterogeneous samples within Delphi surveys has been advocated as a way of including the entire spectrum of opinion (Keeney et al., 2001) and providing a sample representative of the total population in terms of qualities exhibited. It is also associated with improving the validity of findings (Mead and Moseley, 2001, Baker et al., 2006).

Members of the survey panel were generated using non-random methods of sampling, in particular convenience and purposive/ judgemental sampling (Sim and Wright, 2000). These methods were utilised due to their economical and convenient nature, and their appropriateness in the conducting of surveys (Fink, 1995). In addition, the purposive aspect ensured that therapists with the correct characteristics were recruited (Bowling, 2002). Non-random sampling methods are often questioned in research, particularly due to the risk of producing a non-representative sample (Bowling, 2002, Hicks, 2004). However, a study by McKee et al (1991) found that consultant doctors who were willing to participate in expert panels for research actually displayed similar characteristic to those who did not participate. To support the generation of a representative sample, multiple recruitment strategies were employed. A database of physiotherapists who had previously expressed an interest in participating in research related to PD was accessed. The survey was advertised at rehabilitation and neurological conferences. Details of the survey were posted on the Interactive Chartered Society of Physiotherapy webpage, and participants were recruited via

personal correspondence. In a few cases, a snowballing technique was used (Hicks, 2004), with therapists already recruited to the survey introducing other colleagues to the study.

With regards to sample size, no agreement exists regarding the optimum size for an expert panel (Williams and Webb, 1994). The survey aimed to recruit at least the same number of participants as the PD: PEP (Ashburn et al., 2004). No upper limit was set, with the view that the more participants recruited the greater the reliability of the findings (Hicks, 2004).

### **2.3.2 Setting**

The survey was conducted within the UK, and included both the NHS and private practice. The survey was coordinated from the University of Birmingham.

### **2.3.3 Trial Design**

The survey was conducted utilising two different design methods. A modified Delphi technique was used to capture what the physiotherapists perceived to be best practice. A questionnaire was employed to obtain information on participants' characteristics and current clinical practice. Completion of the current practice questionnaire was optional, as it was felt that some therapists may not wish to disclose personal characteristics and details surrounding their current practice, and capturing current practice data was a secondary aim of the survey. Due to its focus on clinical practice, the questionnaire was only completed by therapists currently practising clinically.

#### *2.3.3.1 Current Practice Questionnaire*

The questionnaire was designed to capture participant characteristics and the following elements of current practice for PD: practice setting, referral patterns, the structure of services (working as part of a multidisciplinary team and care coordination), the delivery of physiotherapy (individual or group sessions), and the dose of therapy delivered.

The questionnaire was designed by the author, but certain aspects were informed by the therapist's questionnaire used in the Dutch survey by Keus et al (2004a), which had been obtained from the authors and translated. More specifically, questions relating to therapist expertise (postgraduate training), therapist interest in PD, referral of patients to therapy services by other professionals, practice setting, delivery of treatment via individual or group basis and dose of therapy (number of sessions and length of a course of therapy) were all modified from those used by Keus et al (2004a), who had approached their survey slightly differently; collating information based on case studies of the specific management of one patient per physiotherapist surveyed, as opposed to a more general view on therapist current practice. The questionnaire was constructed primarily of closed questions. This question format was chosen because it is recognised to produce more reliable and consistent question completion, and because it lends itself to statistical analysis and interpretation (Fink, 1995). However, some questions were designed to capture numerical data where more appropriate (e.g. number of patients treated over the last 12 months), and a few questions allowed for short free text answers (e.g. "other" options for practice setting and referral, and the naming of a key worker). Once a draft of the questionnaire had been completed, it was piloted on members of the University of Birmingham Primary Care Clinical Sciences Department, allowing feedback to be gained on the clarity of questionnaire (Hicks, 2004). Following this, adjustments were made and the questionnaire was finalised (see Appendix A for copy of questionnaire).

#### *2.3.3.2 Modified Delphi Survey*

A modified Delphi technique was used to capture what therapists perceived best practice to entail, focusing specifically on the reasons for physiotherapy, core areas of physiotherapy, effective treatment techniques and outcome measurement.

The Delphi technique is a consensus method which uses rounds of questionnaires, interspersed by controlled feedback, to create a convergence of opinion from an expert panel regarding a specific topic (Hasson et al., 2000, Powell, 2003). The original Delphi consisted of four rounds, but the number varies between studies (Mullen, 2003), and many include only two or three rounds (Keeney et al., 2001). The first round may be unstructured, producing an open response to a broad question (Powell, 2003). The results of this round then undergo qualitative analysis and statements are generated (Jones and Hunter, 1995). During subsequent rounds, participants rank their agreement with the statements (Powell, 2003). The researcher feeds back the results of previous rounds to the expert panel, supporting the movement towards a consensus of opinion (Jaraith and Weinstein, 1994, Powell, 2003). Rounds may be repeated until consensus is obtained (Jones and Hunter, 1995), although the time and cost associated must be considered and there is an associated risk of participant fatigue and attrition (Keeney et al., 2001, Powell, 2003). What constitutes an “acceptable level of consensus” is open to judgement; some believe a complete convergence of opinion is required (Williams and Webb, 1994, Hicks, 2004), whilst others advocate various pre-arranged definitions of agreement and disagreement (Powell, 2003, Black, 2006).

There are other consensus methods available, namely the Nominal Group Technique (NGT) and Consensus Development Conference. The NGT is a structured meeting, facilitated by a non-participant, during which a small group of relevant experts (usually up to 12 people) meet to provide information on a specific topic (Jones and Hunter, 1995). The stages involved in the NGT are similar to that of the Delphi technique (Black, 2006), but the face-to face meeting provides the opportunity for discussion between panel members throughout the rounds (Murphy et al., 1998, Bowling, 2002). For the Consensus Development Conference, a small group of experts attend an open, chaired meeting to discuss a particular topic (Bowling,

2002). These meetings may last a few days, during which time evidence on the chosen topic is presented to the panel by expert non-participants (Murphy et al., 1998). Following this, the expert panel enter a private discussion in an attempt to reach consensus in light of the evidence (Murphy et al., 1998). The face-to-face meetings associated with the NGT and Consensus Development Conference have been viewed as advantageous, allowing the process of consensus to be supported by verbal clarification and social interaction (Gallagher et al., 1993). However, this aspect can also be seen as a disadvantage, as physical group interaction may result in domination of opinions from powerful, higher status individuals (Murphy et al., 1998, Black, 2006). Additionally these methods (particularly Consensus Development Conference) have been recognised as expensive (Bowling, 2002), and the small numbers included may lead to questions over representativeness of the target population as a whole (Black, 2006). The Delphi technique removes geographical constraints (Fink et al., 1984), has greater reliability due to the larger sample size (Black, 2006), is time and cost efficient (Murphy et al., 1998, Powell, 2003), preserves the anonymity of respondents, and encourages all panel members to voice their opinion free from peer pressure (Williams and Webb, 1994). For these reasons, the Delphi method of consensus was chosen.

For the purposes of this survey, the Delphi technique was modified. In the first round, statements were generated utilising the current literature for physiotherapy in PD, including national and international guidelines and trial evidence. This was to ensure the statements were grounded in the evidence-base available. Databases MEDLINE, EMBASE and CINAHL were systematically searched up to the end of March 2009 combining terms and MeSH headings including physiotherapy, physical therapy, exercise, rehabilitation, parkinson, parkinson's disease, parkinsonism, and the six core areas of physiotherapy for PD identified in the Dutch guidelines (Keus et al, 2004b); gait, balance (and falls), transfers, posture,

reaching and grasping (upper limb function) and physical conditioning, to identify appropriate study literature. The objectives of the trials provided information on the reasons for physiotherapy provision, the findings of the studies helped identify potentially effective treatment techniques, and the focus of outcome assessment within the trials informed how measurement may take place. This information was cross-checked and merged with trial evidence-based recommendations laid out within the Dutch guidelines (Keus et al., 2004b) and national guidelines (National Collaborating Centre for Chronic Conditions, 2006) to generate the majority of first round statements, in particular regarding the reasons for physiotherapy, core areas of physiotherapy, treatment techniques and outcome measurement. The guidelines available, including UK guidance published following the PD: PEP (Plant et al., 2001), were then further checked for expert consensus recommendations, and these were also formulated into first round statements for completeness. This particularly contributed to statements regarding the context and overall nature of treatment delivery; an area in which little trial evidence was available.

Following statement generation from the evidence base, the draft of the first round questionnaire was sent to an advisory panel of seven researchers and clinical physiotherapists; six of whom were acting as part of an expert group on a multi-centre randomised controlled trial of therapy for PD and a final member who had previously conducted a Delphi survey. The advisory panel gave feedback on the overall structure of the Delphi questionnaire and the clarity of wording within the document. They also provided additional statements to be included based both on evidence and expert opinion, and on one occasion identified a statement that should be removed (cost-effectiveness had been included within the outcome measurement section, but it was highlighted that you cannot measure cost-effectiveness for

the individual patient only). Following this, the questionnaire was finalised ready for dissemination in the first round of ranking.

#### **2.3.4 Survey process**

The Delphi survey was conducted over two rounds, with the current practice questionnaire also being sent out during the first round. The survey documents were disseminated by email and returned by either email or post (by choice of the therapist).

The first round Delphi questionnaire included a total of 83 statements divided between the areas of interest as follows: reasons for physiotherapy (9 statements), core areas of physiotherapy (17), general issues around treatment (11), gait rehabilitation (12), balance rehabilitation (7), treatment of transfers (3), treatment of posture (2), physical conditioning (6), upper limb rehabilitation (4), and outcome measurement (12) (See Appendix A for questionnaire). Ranking of agreement for each statement was recorded on a five-point Likert scale: strongly agree, agree, undecided, disagree, strongly disagree (Bowling, 2002), in line with previous Delphi surveys (Deane et al., 2003a). Following each section of the survey, there was space to provide further free text information on additional aspects therapists felt important for consideration.

The first round of the survey was conducted between 24<sup>th</sup> June and the 12<sup>th</sup> August 2009 (seven weeks). Reminder emails were sent at two, four and six weeks. At the end of the first round, the Delphi questionnaires were checked for completion and clarity, and data queries were generated and answered. The responses of the current practice questionnaire were collated using Microsoft Access 2003. The information was summarised using the Access query function, and descriptive statistics were produced using Microsoft Excel 2003. The ranking of the Delphi statements was collated within Microsoft Excel 2003, and the percentage of respondents falling into each category on the Likert scale was calculated for all

statements. All free text was stored using QSR NVIVO Version 8 and content analysis was performed, allowing themes to be identified and categorised (Bowling, 2002). The findings of the content analysis were used to create additional Delphi statements to be added to the second round as follows: reasons for physiotherapy (3 statements), core areas of physiotherapy (1), general issues around treatment (6), gait rehabilitation (1), balance rehabilitation (1), treatment of transfers (3), treatment of posture (6), physical conditioning (7), upper limb rehabilitation (1), additional treatment techniques (6), complementary therapies (4), and outcome measurement (5) (see Appendix A for copy of second round survey).

For the second round, statements were ranked as in round one. Where statements had been included in the previous round, the panel's responses were incorporated into the survey document to inform agreement. No additional free text was collected. The second round was conducted between 9<sup>th</sup> September and the 22<sup>nd</sup> October 2009 (six weeks), with reminder emails at three and four weeks. On completion of the second round, the data was collated and analysed as in the first round and, in line with a previous Delphi survey of occupational therapy for PD (Deane et al., 2003a), consensus was set at agreement totalling 80% or more in the two adjacent agreement levels of the Likert scale (strongly agree and agree).

### **2.3.5 Research Governance and Ethics**

The University of Birmingham provided ethical review, and consent to participation in the study was assumed through returning the completed survey documents at each round. In line with the Medical Research Council's guidance for Good Clinical Practice (Medical Research Council, 1998), survey data was anonymised through allocation of participant identification numbers, and all study documents were stored securely in a locked filing cabinet.



## 2.4 Results

### 2.4.1 Response to Survey

A total of 107 physiotherapists were approached to participate in the study. 76 (71%) responded to the first round of the Delphi survey and 61 (80%) to the second round of the survey. In addition, 67 (63%) clinical therapists completed the current practice questionnaire.

### 2.4.2 Current Physiotherapy Practice for PD

#### 2.4.2.1 Participant Characteristics

Sixty three (83%) of the physiotherapists responding to the current practice questionnaire identified themselves as solely clinical therapists, whilst four participants (5%) worked both in research and clinical practice. The therapists had been qualified for a mean of 17.6 years (SD 9.5). Sixty four participants (96%) disclosed their pattern of working hours; 36 (54%) were employed full time and 28 worked part time (42%). The mode working hours reported, expressed as a percentage of whole time equivalent, was 100%. Fifty seven of the 67 physiotherapists (85%) identified themselves as having a specific interest in PD, and 40 of these therapists (60%) had received postgraduate training applicable to the management of PD. Of the 27 participants that had not undertaken postgraduate training, 24 (89%) felt that additional relevant training would be beneficial. A wide range was reported for the number of patients with PD treated by the physiotherapists over the last 12 months (3 to 250; range 247). The median number of patients treated was 25 and the interquartile range was 35. Three therapists reported treating over 100 patients with PD in the past year (100, 150 and 250 respectively).

#### 2.4.2.2 Practice Setting

Participants identified which setting(s) they delivered physiotherapy in. The findings regarding practice setting are presented in Table 1. The majority of therapists delivered physiotherapy in the patient's home (38 participants: 57%) or within an outpatients

department (26 participants: 39%). Only five therapists (8%) saw patients within an intermediate care setting. In addition to the options listed, 14 physiotherapists (21%) reported delivering treatment in other practice settings. Seven therapists (10%) provided treatment in other community settings, such as community centres and gymnasiums/ leisure centres. One physiotherapist (1%) delivered therapy within a hospital based gymnasium. Two participants (3%) practised within PD clinics. Two therapists (3%) worked in outpatient health centres, one physiotherapist (1%) treated patients at a day centre and another delivered treatment in a residential care setting. One physiotherapist (1%) worked in private practice and a final therapist ran a one week residential PD treatment holiday in Blackpool annually.

**Table 1: Practice Setting for Physiotherapy Delivery**

<b>Practice Setting</b>	<b>Yes : Number of participants (%)</b>	<b>No Number of participants (%)</b>
Hospital Inpatient	15 (22)	52 (78)
Hospital Outpatient	26 (39)	41 (61)
Day Hospital	15 (22)	52 (78)
Intermediate Care	5 (7)	62 (93)
Nursing Home	12 (18)	55 (82)
Rehabilitation Centre	8 (12)	59 (88)
Patient's home	38 (57)	29 (43)

#### *2.4.2.3 Referral to physiotherapy*

Physiotherapists were asked to identify which health care professionals referred to their services, ranking how often they referred patients to physiotherapy on a five point Likert scale. This scale was not numerically defined, potentially resulting in a blurring of boundaries between categories. For this reason, the “always” and “usually” categories, and the “often” and “occasionally” categories, were combined during the data analysis. The results are presented in Table 2. Of the five professions listed specifically in the question, participants identified the PD nurse specialist as the most likely to refer patients to their

services, with 42 (63%) of the therapists stating the PD nurse would “always” or “usually” refer” to physiotherapy. General practitioners were the least likely to refer to physiotherapy, with just 17 participants (25 %) ranking them as “always” or “usually” referring to their services.

Nineteen participants (28%) reported that other professionals referred to their services. Four physiotherapists (6%) identified referrals from other doctors, such as rehabilitation consultants. Five therapists (7%) reported referral from nurses other than PD specialists, such as district nurses and community matrons. Eight physiotherapists (12%) received referrals from social services; five (7%) specifically identified social workers as the professionals referring to their services. Four physiotherapists (6%) reported referrals from Parkinson’s UK; two (3%) specifically identified Parkinson’s UK support workers. One therapist (1%) occasionally received referrals from an unspecified case manager.

**Table 2: Health Care Professionals Referring to Physiotherapy**

<b>Professional</b>	<b>Always and usually: Number of participants (%)</b>	<b>Often and occasionally: Number of participants (%)</b>	<b>Never: Number of participants (%)</b>	<b>No Answer: Number of participants (%)</b>
Neurologist	28 (42)	34 (51)	2 (3)	3 (4)
Geriatrician	27 (40)	32 (48)	4 (6)	4 (6)
General Practitioner	17 (25)	41 (61)	5 (7)	4 (6)
PD Nurse Specialist	42 (63)	17 (25)	4 (6)	4 (6)
Allied Health Professionals	24 (36)	37 (55)	3 (4)	3 (4)

In addition to professional referral, patient and carer self referral into physiotherapy services was considered. Of the 66 participants that responded to questions regarding self referral, 30 therapists (45 %) reported that patients and carers could self refer as a way of initially

accessing physiotherapy. Fifty two physiotherapists (78%) stated that patients and carers could re-access therapy via self referral following the initial course of physiotherapy.

Participants were also asked to rank when patients were most likely to be referred to their services in terms of stage of PD, using the four stages from MacMahon and Thomas' Pragmatic Clinical Scale (1998). The findings regarding time of referral are presented in Table 3. The therapists identified that patients were most likely to be referred to physiotherapy for the first time during the maintenance phase of the condition (35 participants; 52%). Only 10 therapists (15%) reported that the initial referral occurred during the diagnosis stage of PD.

**Table 3: Time of Referral to Physiotherapy**

Stage of PD	Ranked 1: Number of participants (%)	Ranked 2: Number of participants (%)	Ranked 3: Number of participants (%)	Ranked 4: Number of participants (%)	No Answer: Number of participants (%)
Diagnosis	10 (15)	18 (27)	16 (24)	20 (30)	3 (4)
Maintenance	35 (52)	21 (31)	7 (10)	1 (1)	3 (4)
Complex	22 (33)	24 (36)	18 (27)	1 (1)	2 (3)
Palliative	1 (1)	3 (4)	18 (27)	43 (64)	2 (3)

#### 2.4.2.4 Structure of physiotherapy services

With regards to the structure of physiotherapy services, therapists were asked whether they practised within the context of a multidisciplinary team (MDT), and if patient care was coordinated by a key worker. Of the 64 participants answering the question, 50 (78%) worked as part of a MDT. Seventeen (26%) of the 65 therapists responding reported that a key worker coordinated the care of their PD patients. Ten physiotherapists (15%) listed which professional undertook the key worker role within their team (one listed two key workers); seven (11%) reported that a nurse was the patient key worker, five (7%) specifically stated the PD nurse specialist, two (3%) identified a physiotherapist as the care coordinator,

one participant (2%) stated that the consultant physician undertook the role, and the final therapist reported that the “most appropriate person” acted as key worker for each individual patient in their team.

Sixty five physiotherapists provided details of the format of treatment delivery. Twenty nine therapists (45%) delivered treatment on an individual basis, 1 (2%) participant provided group sessions only, and 35 physiotherapists (54%) combined both one to one and group sessions.

#### *2.4.2.5 Dose of Physiotherapy*

The number of sessions included in a single course of physiotherapy for a patient with PD was recorded by 59 participants. The median number of physiotherapy sessions reported was 6 (interquartile range: 2)

The median length of an initial physiotherapy assessment was 60 minutes with an interquartile range of 15 minutes (calculated from 64 responses), and the median length of a standard follow up session was 45 minutes, with an interquartile range of 15 minutes (calculated from 63 responses).

The median length for a course of physiotherapy was 8 weeks with an interquartile range of 4 (10 non respondents).

### **2.4.3 Perceived Best Practice for Physiotherapy in PD**

These results represent the findings following completion of the second round of the survey. The statements and their corresponding levels of consensus are presented in a series of tables and figures. The level of evidence supporting each statement is indicated through a ranking system adapted from The Intercollegiate Stroke Working Party (2004) National Clinical Guidelines for Stroke (see Table 4). Statements added by the expert panel and included in the second round only are recognised by the letters “EP”.

**Table 4: Level of evidence**

Level of evidence	Type of evidence
Ia	Meta-analysis of RCTs
Ib	At least one RCT
IIa	At least one controlled clinical trial but without randomisation
IIb	At least one quasi-experimental study
III	At least one non experimental descriptive study
IV	Expert committee reports, opinions and/ or experience of respected authorities

#### 2.4.3.1 Reasons for physiotherapy in PD

There was consensus for all 12 of the statements examining the purpose of providing physiotherapy for people with PD; six reached unanimous consensus, five achieved a high level of consensus (90% and above), and one statement was ranked at 82% consensus. The full statements and their levels of consensus are provided in Table 5. Together, they provide a framework for the overall focus of physiotherapy in PD: to maximise quality of movement, functional independence and general fitness, and minimise secondary complications whilst supporting self-management and participation, and optimising the safety of the individual.

**Table 5: Reasons for Physiotherapy**

Level of Consensus	The purpose of providing physiotherapy to people with Parkinson’s disease is to...
100%	<p>Improve, maintain, or minimise degeneration of a person’s quality of movement (100)  <i>Level of evidence: Ib</i></p> <p>Improve, maintain or minimise degeneration of functional independence, including mobility and activities of daily living (100)  <i>Level of evidence: Ib</i></p> <p>Improve, maintain, or minimise degeneration of general fitness, including aerobic capacity and physical activity levels (100)  <i>Level of evidence: Ib</i></p> <p>Provide education to the patient (and carer(s)) to stimulate and support self-management (100)  <i>Level of evidence: IV</i></p> <p>Empower patients and carers with sufficient knowledge about the disease process and benefits of sustained physical activity to encourage a positive attitude towards self-management. (100)  <i>Level of evidence: IV</i></p> <p>Improve, maintain or minimise degeneration of a patient’s balance, and minimise the risk of falls (100)</p>

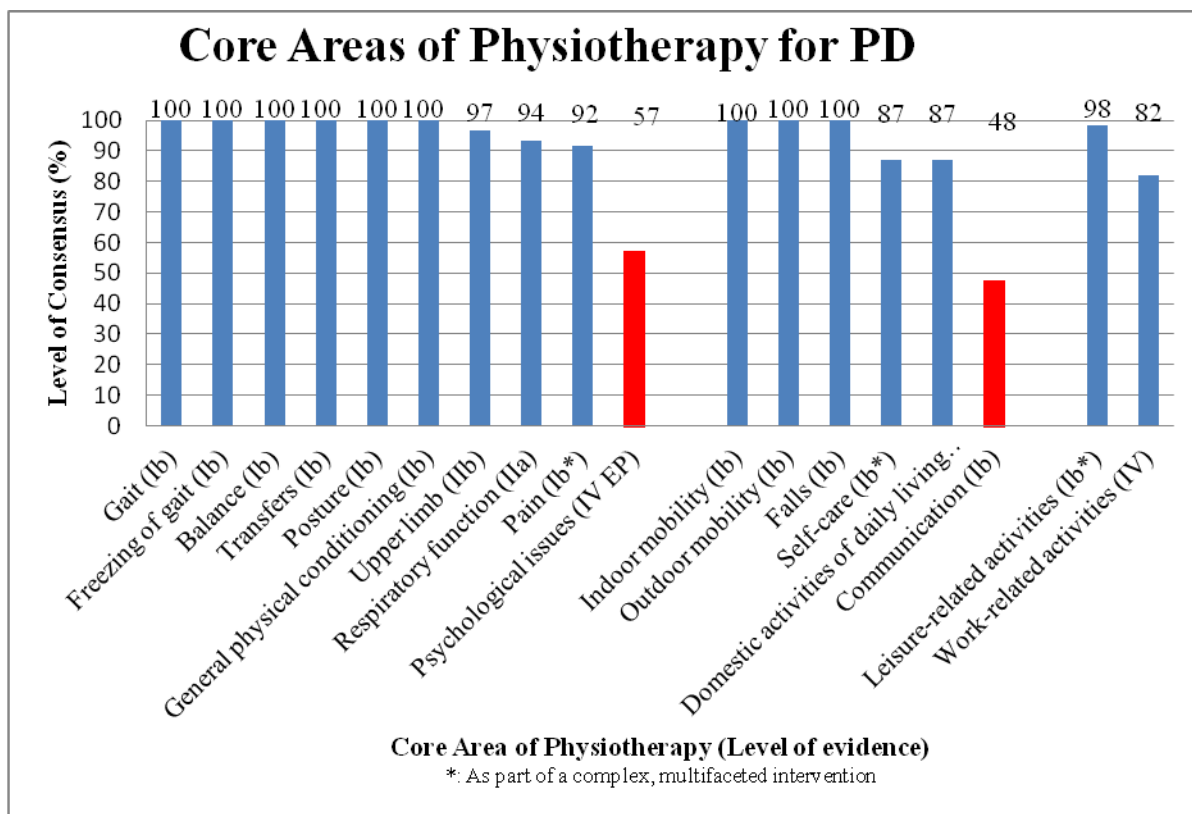
	<i>Level of evidence: Ib EP</i>
90-99%	Minimise the onset of musculoskeletal and cardiorespiratory secondary complications (98) <i>Level of evidence: Ib</i> Prevent fear of falling, and maintain a person's confidence in their ability to move safely (98) <i>Level of evidence: Ib</i> Support a patient's involvement in work and leisure activities (98) <i>Level of evidence: IV EP (Ib*)</i> Provide advice regarding safety in the home environment (97) <i>Level of evidence: III</i> Provide information to the patient (and carer(s)) regarding Parkinson's disease, issues surrounding therapy, and potential medical, social and financial support available (within their scope of practice) (95) <i>Level of evidence: IV</i>
80-89%	Provide treatment and strategies for managing pain (82) <i>Level of evidence: Ib* EP</i>
<80% (No Consensus)	-

\*: As part of a complex, multifaceted intervention

#### 2.4.3.2 Core areas of physiotherapy in PD

Findings regarding the core areas of physiotherapy for PD are presented in Figure 2.

Consensus was reached for 16 of the 18 statements, those areas that failed to reach consensus are marked in red. There was unanimous consensus for a focus on gait, freezing of gait, balance, transfers, posture, physical conditioning, indoor and outdoor mobility and falls. Consensus over 90% was reached for upper limb rehabilitation, respiratory function, pain management and leisure-related activities, whilst addressing self-care, domestic ADL and work-related activities just reached consensus (87%, 87% and 82% respectively). There was no consensus for addressing patient communication (57%) or psychological issues such as anxiety and depression (48%). The latter was the only area generated through free text from the physiotherapists' responses to round one.



**Figure 2: Core Areas of Physiotherapy**

#### 2.4.3.3 Treatment provision within physiotherapy for PD

Of the 17 statements considering the overall delivery of treatment, 12 reached consensus (see Table 6).

Patient-centredness was identified as central to physiotherapy provision through high consensus responses to a number of related statements. There was unanimous consensus for the use of patient-determined goals and individualised interventions, whilst 98% of participants noted that the treatment format (individual or group) and setting of therapy delivery should be chosen based on the needs of the individual. One hundred percent of the therapists also determined the appropriateness of including the carer in rehabilitation as patient specific. Consideration of the individual patient was further supported through unanimous consensus for the provision of sufficient time during rehabilitation to process and



query information, and the encouragement of problem-solving skills to support self management.

The importance of multidisciplinary team collaborative working within treatment provision was also identified through high levels of consensus.

**Table 6: Context of Treatment**

<b>Level of Consensus</b>	<b>Context of treatment</b> (% of consensus)
100%	<p>Physiotherapy for Parkinson’s disease should be patient specific, rather than based on a specific “named” approach (e.g. Bobath, Brunstrom) (100)  <i>Level of evidence: IV</i></p> <p>Rehabilitation is maximised if sufficient time is given for people with Parkinson’s disease to process information and plan a response to queries and instructions (100)  <i>Level of evidence: IV</i></p> <p>Rehabilitation is maximised if patients are encouraged to develop problem solving skills to encourage self-management of functional difficulties (100)  <i>Level of evidence: IV</i></p> <p>Rehabilitation is maximised if based on patient determined goals (100)  <i>Level of evidence: IV EP</i></p> <p>Involvement of the carer should be based on the individual needs of the patient, and the individual situation of the carer (100)  <i>Level of evidence: IV EP</i></p> <p>Rehabilitation is maximised if physiotherapists recognise when referrals to other multidisciplinary/ interdisciplinary team members are required (100)  <i>Level of evidence: IV EP</i></p>
90-99%	<p>The intervention package delivered, the treatment setting, and the treatment format (one to one session or group), should be based on the individual needs of the patients as determined by their initial assessment (98)  <i>Level of evidence IV EP</i></p> <p>Rehabilitation is maximised if physiotherapy interventions are task specific (97)  <i>Level of evidence: Ib</i></p> <p>Rehabilitation is maximised when physiotherapists work collaboratively within the multidisciplinary/ interdisciplinary team format (97)  <i>Level of evidence: IV EP</i></p> <p>Rehabilitation is maximised if carers are involved in the physiotherapy process (95)  <i>Level of evidence: IV</i></p> <p>Rehabilitation is maximised if physiotherapy is made available for people with Parkinson’s disease from diagnosis (94)  <i>Level of evidence: IV EP</i></p>
80-89%	<p>The effects of physiotherapy are maximised if rehabilitation is delivered as both individual and group sessions (82)  <i>Level of evidence: IV</i></p>
<80% (No Consensus)	<p>The effects of physiotherapy are maximised if rehabilitation is delivered in both the patient’s home and the hospital environment (77)  <i>Level of evidence: IV</i></p> <p>The effects of physiotherapy are maximised if rehabilitation is delivered in the patient’s home (57)  <i>Level of evidence: IV</i></p> <p>The effects of physiotherapy are maximised if rehabilitation is delivered as individual sessions (56)  <i>Level of evidence: IV</i></p> <p>The effects of physiotherapy are maximised if rehabilitation is delivered as group therapy (25)  <i>Level of evidence: IV</i></p> <p>The effects of physiotherapy are maximised if rehabilitation is delivered in the hospital environment (0)  <i>Level of evidence: IV</i></p>

#### 2.4.3.4 *Specific treatment interventions for PD*

Statements regarding specific treatment techniques were listed under the six core areas identified in the Dutch guidelines of physiotherapy for PD (Keus et al, 2004b). Additional treatment techniques identified by the therapists that were unrelated to these areas, were considered separately.

High levels of consensus were found for statements concerned with the rehabilitation of gait. Eleven of the 13 statements reached consensus, with five reaching unanimous consensus, and four over 90% consensus (see Table 7). Whilst a range of interventions were perceived to be effective by the therapists, unanimous consensus identified a focus on external cueing techniques (visual, auditory, sensory, and verbal instruction) and cognitive movement strategies. Therapists again also noted the importance of individualising gait rehabilitation through walking practice in the patient's own environment (100% consensus). There was no consensus on how to approach the issue of dual tasking.

For balance rehabilitation, only one statement failed to reach consensus, but no statements gained unanimous consensus. The eight statements for balance rehabilitation are presented in Table 8. The main focus of the therapists' responses indicated, in order to maximise outcome, treatment should be multifaceted and progressive, including a wide variety of interventions such as balance specific exercises (static, dynamic and functional training, with and without feedback), gait-related training, lower limb strength and range of motion exercises and the provision of strategies to prevent falls and fear of falling, and conducted in a diverse set of environments.

All statements regarding the rehabilitation of transfers reached a high level of consensus (see Table 9). Unanimous consensus signified that the use of external cueing techniques and cognitive movement strategies, and an assessment of the home environment were at the forefront of best practice transfers rehabilitation.

For postural rehabilitation, five of the eight statements reached consensus, and three were ranked at 90% consensus or above (see Table 10). The highest level of consensus was reached for the provision of education regarding correct posture (95%).

High levels of consensus were found for statements regarding physical conditioning, with 11 of the 13 statements reaching achieving 80% agreement or above (see Table 11). The therapists' responses highlighted that exercise with a specific focus is beneficial for the area being targeted (e.g. lower limb strengthening for improvement of the lower limb). Consensus also indicated that support for self management of physical conditioning rehabilitation should be at the forefront of treatment through appropriate education (97%), advice and referral to local leisure facilities (97%) and encouragement of recreational physical activity (100%).

Five statements concerning best practice for upper limb rehabilitation were included within the survey. As can be seen in Table 12, only two of the five statements reached consensus, both advocating an exercise-based approach to upper limb rehabilitation.

During the first round, therapists proposed other effective treatment techniques that did not fall under the six areas considered in depth. A further ten statements were created from this information and included in the second round survey. Six additional treatment techniques statements are listed in Table 13. Only one statement reached consensus, with 82% of therapists advocating the inclusion of breathing exercises for the management of secondary respiratory complications. Four statements were created specifically regarding the inclusion of complementary therapy techniques within physiotherapy best practice. None the statements reached consensus, with the interventions reaching the following levels of agreement: Alexander technique (48%), Pilates (67%), Tai Chi (76%), and Yoga (54%).

**Table 7: Rehabilitation of Gait**

Level of Consensus	Rehabilitation of gait (% of consensus)
100%	<p>Visual, auditory and/ or sensory external cueing techniques may be effective in improving, maintaining, or minimising the degeneration of gait parameters (100)  <i>Level of evidence: Ib</i></p> <p>Cognitive movement strategies, such as the breaking down of complex movement sequences into simple steps and the use of self instruction, may be effective in improving, maintaining, or minimising the degeneration of gait parameters (100)  <i>Level of evidence: IIa (Ib*)</i></p> <p>Combining cognitive movement strategies with external cueing techniques may be effective in improving gait initiation (100)  <i>Level of evidence: Ib</i></p> <p>The use of verbal instruction to focus attention on specific aspects of gait may be effective in improving, maintaining, or minimising the degeneration of gait parameters (100)  <i>Level of evidence: Ib</i></p> <p>Walking practice utilising the patient’s own environment may be an effective treatment technique for the improvement, maintenance or minimisation of degeneration of gait (100)  <i>Level of evidence: IV</i></p>
90-99%	<p>Joint mobility/ limb mobilisation exercises, when combined with task-specific training, may effectively contribute to the improvement, maintenance, or minimisation of degeneration of gait parameters (98)  <i>Level of evidence: IIa (Ib*)</i></p> <p>The provision of, education on the use of, and practice in using walking aids may be an effective treatment technique for the improvement, maintenance or minimisation of degeneration of gait (98)  <i>Level of evidence: IV</i></p> <p>Lower limb strengthening exercises may be effective in improving, maintaining, or minimising the degeneration of gait parameters (97)  <i>Level of evidence: IIa (Ib*)</i></p> <p>Walking practice utilising functional conditions such as obstacles and turning may be an effective treatment technique for the improvement, maintenance or minimisation of degeneration of gait (97)  <i>Level of evidence: IIb</i></p>
80-89%	<p>The use of compensatory strategies, such as side stepping to negotiate narrow areas, may be effective in improving, maintaining, or minimising the degeneration of gait (82)  Level of evidence: IV EP</p> <p>The use of mental rehearsal prior to walking may be effective in improving, maintaining, or minimising the degeneration of gait (80)  Level of evidence: IIa</p>
<80% (No Consensus)	<p>Dual or multiple task training, which gradually increases in complexity, may be effective in improving, maintaining or minimising the degeneration of gait carried out under multiple task/ functional conditions (66)  <i>Level of evidence: IIb</i></p> <p>Dual tasking with another motor task, or cognitive task, should be avoided when walking (54)  <i>Level of evidence: IIb</i></p>

\*: As part of a complex, multifaceted intervention

**Table 8: Rehabilitation of Balance and the Prevention of Falls**

<b>Level of Consensus</b>	<b>Rehabilitation of balance and prevention of falls</b> (% of consensus)
100%	-
90-99%	<p>A balance rehabilitation programme should be multifaceted and progressive, including static, dynamic and functional balance training, gait training, lower limb strength training, range of motion exercises, and the provision of falls prevention strategies (98) <i>Level of evidence: Ib</i></p> <p>A combined, progressive exercise programme of lower limb strength training and balance training involving alteration of visual, vestibular and somatosensory feedback, may be effective in improving, maintaining, or minimising the degeneration of balance (93) <i>Level of evidence: Ib</i></p> <p>A balance rehabilitation programme should include training in outdoor, leisure, and work related conditions (93) <i>Level of evidence: IV</i></p> <p>Teaching a patient, and practising, how to get on and off the floor may be beneficial in reducing the fear to fall (93) <i>Level of evidence: IV</i></p>
80-89%	<p>Exercises focused on the control and coordination of axial movement and related muscle activity may be effective in improving, maintaining, or minimising the degeneration of balance (87) <i>Level of evidence: Ib</i></p> <p>External cueing techniques, provided for gait rehabilitation, may have a secondary beneficial effect on balance (82) <i>Level of evidence: Ib</i></p> <p>Cognitive movement strategies and external cueing techniques, provided for gait and transfer rehabilitation, may have a secondary beneficial effect on balance (80) <i>Level of evidence: Ib*</i></p>
<80% (No Consensus)	<p>Education on the importance of pelvic control and the interplay of the pelvis and trunk during movement, may be effective in improving, maintaining, or minimising the degeneration of balance (62) <i>Level of evidence: IV EP</i></p>

\*: As part of a complex, multifaceted intervention

**Table 9: Rehabilitation of Transfers**

<b>Level of Consensus</b>	<b>Rehabilitation of transfers</b> (% of consensus)
100%	<p>Cognitive movement strategies including mental rehearsal, the breaking down of complex movement sequences into simple steps, and the use of self instruction, may be effective in improving, maintaining, or minimising a person's difficulties in performing transfers (100) <i>Level of evidence: IIa</i></p> <p>Visual, auditory and/ or sensory external cueing techniques may be effective in improving, maintaining, or minimising a person's difficulties in performing transfers (100) <i>Level of evidence: Ib</i></p> <p>Inclusion of a home environment assessment to identify whether modifications would enhance a patient's ability to transfer may be useful to include within transfers rehabilitation (100) <i>Level of evidence: IV EP</i></p>
90-99%	<p>The provision of education and training to carers may be effective in facilitating a patient's ability to transfer (98) <i>Level of evidence: IV EP</i></p> <p>Transfers rehabilitation may be optimised by ensuring task specificity (e.g. practising transferring in the patient's car, in their own bed etc) (95) <i>Level of evidence: IV EP</i></p> <p>The provision of, education on the use of, and practice with equipment such as transfer boards may be helpful for performing transfers (92) <i>Level of evidence: IV</i></p>

80-89%	-
<80% (No Consensus)	-

**Table 10: Rehabilitation of Posture**

<b>Level of Consensus</b>	<b>Rehabilitation of posture</b> (% of consensus)
100%	-
90-99%	<p>Education regarding the importance of correct posture may be beneficial in improving, maintaining, or minimising the degeneration of posture (95) <i>Level of evidence: IV EP</i></p> <p>Exercises focused on the control and coordination of axial movement, and related muscle activity, may be effective in improving, maintaining, or minimising the degeneration of posture, and function related to posture (94) <i>Level of evidence: Ib</i></p> <p>The use of feedback such as verbal prompts and visual feedback from a mirror, may be effective in improving, maintaining, or minimising the degeneration of posture (92) <i>Level of evidence: IV</i></p>
80-89%	<p>Exercises focused on the strengthening of core muscles may be effective in improving, maintaining, or minimising the degeneration of posture (89) <i>Level of evidence: IV EP</i></p> <p>Passive and positional stretching, such as lying semi prone or supine on a bed, may be beneficial in improving, maintaining, or minimising the degeneration of posture (80) <i>Level of evidence: IV EP</i></p>
<80% (No Consensus)	<p>The hands on facilitation of body alignment may be effective in improving, maintaining, or minimising the degeneration of posture (71) <i>Level of evidence: IV EP</i></p> <p>The provision of, and education on the use of equipment and aids, such as a lumbar roll, may be effective in improving, maintaining, or minimising the degeneration of posture (66) <i>Level of evidence: IV EP</i></p> <p>The inclusion of manual techniques, such as mobilisations, may be effective in improving, maintaining, or minimising the degeneration of posture (54) <i>Level of evidence: IV EP</i></p>

**Table 11: Physical Conditioning**

<b>Level of Consensus</b>	<b>Physical Conditioning</b> (% of consensus)
100%	<p>An exercise programme which includes exercises focused on trunk strengthening may be effective in improving, maintaining, or minimising the degeneration of trunk strength (100) <i>Level of evidence: Ib</i></p> <p>To maximise the effectiveness of rehabilitation aimed at physical conditioning and fitness, physiotherapists should encourage the patient to engage in a recreational form of activity to support independence, adherence and self-management. (100) <i>Level of evidence: IV</i></p>

90-99%	<p>Utilisation of functional goals and task specific training may be effective in improving or maintaining a patient's level of physical activity (98) <i>Level of evidence: IV EP</i></p> <p>An exercise programme which includes lower limb strengthening may be effective in improving, maintaining, or minimising the degeneration of lower limb strength (98) <i>Level of evidence: Ib</i></p> <p>An exercise programme which includes exercises focused on joint mobility and flexibility may be effective in improving, maintaining, or minimising the degeneration of joint mobility and flexibility (98) <i>Level of evidence: Ib</i></p> <p>An exercise programme which includes upper limb strengthening may be effective in improving, maintaining, or minimising the degeneration of upper limb strength (97) <i>Level of evidence: Ib</i></p> <p>An exercise programme which includes exercises focused on cardiorespiratory training, may be effective in improving, maintaining, or minimising the degeneration of cardiorespiratory fitness (97) <i>Level of evidence: Ib</i></p> <p>Training for physical conditioning may have a secondary impact on the psychological health of a patient (97) <i>Level of evidence: IV EP</i></p> <p>Education on physical activity, such as what it entails and advice on how much should be carried out weekly, may be effective in improving or maintaining a patient's level of physical activity (97) <i>Level of evidence: IV EP</i></p> <p>Advice on, and referral to, local leisure facilities may be beneficial in improving or maintaining a patient's level of physical activity (97) <i>Level of evidence: IV EP</i></p>
80-89%	<p>The rehabilitation of posture may have a secondary effect on improving, maintaining, or minimising the degeneration of a patient's cardiorespiratory capacity (87) <i>Level of evidence; IV EP</i></p>
<80% (No Consensus)	<p>Positioning and passive stretching may be effective in improving, maintaining, or minimising the degeneration of a patient's physical condition (67) <i>Level of evidence: IV EP</i></p> <p>Manual techniques, such as mobilisations, may be effective in improving, maintaining, or minimising the degeneration of a patient's joint mobility and flexibility (54) <i>Level of evidence: IV EP</i></p>

**Table 12: Rehabilitation of the Upper Limb**

<b>Level of Consensus</b>	<b>Rehabilitation of the Upper Limb</b> (% of consensus)
100%	-
90-99%	<p>Exercises focused on upper limb strengthening and range of movement may be effective in improving, maintaining, or minimising degeneration of upper limb functional movement (95) <i>Level of evidence: IV</i></p>
80-89%	<p>Exercises focused on upper limb muscular coordination may be effective in improving, maintaining, or minimising degeneration of upper limb functional movement (84) <i>Level of evidence: IIa*</i></p>
<80% (No Consensus)	<p>Upper limb rehabilitation, focused on dexterity and coordination as applied to functional tasks (e.g. doing up buttons), may be effective in improving, maintaining, or minimising the degeneration of upper limb function (77) <i>Level of evidence: IV EP</i></p> <p>Internally generated cues or self instruction may be effective in improving, maintaining, or minimising degeneration of the parameters of reach to grasp (66) <i>Level of evidence: IIb</i></p> <p>External cueing techniques may be effective in improving, maintaining, or minimising degeneration of the parameters of reach to grasp (36) <i>Level of evidence: IIb</i></p>

\*: As part of a complex, multifaceted intervention

**Table 13: Additional Treatment Techniques**

Level of Consensus	Additional treatment techniques (% of consensus)
100%	-
90-99%	-
80-89%	The inclusion of breathing exercises may be effective in managing the secondary respiratory complications of Parkinson's disease (82) <i>Level of evidence: IIa EP</i>
<80% (No Consensus)	The provision of Transcutaneous Electrical Nerve Stimulation (TENS) may be effective in the management of pain (57) <i>Level of evidence: IV EP (Ib*)</i> The provision of acupuncture may be effective in the management of pain (48) <i>Level of evidence: IV EP (Ib*)</i> The inclusion of manual chest physiotherapy may be effective in managing the secondary respiratory complications of Parkinson's disease (38) <i>Level of evidence: IV EP</i> The provision of massage may be effective in the management of pain (36) <i>Level of evidence: IV EP</i> Prolonged stretching may be effective in the management of pain (28) <i>Level of evidence: IV EP</i>

\*: As part of a complex, multifaceted intervention

#### 2.4.3.5 Outcome measurement

The focus of outcome measurement, and the structure, delivery and use of outcome measures in best physiotherapy practice was considered in two separate sets of statements. These are listed, with their corresponding rankings of agreement, in Tables 14 and 15. Of the nine statements exploring the focus of outcome measures, six reached consensus, whilst six of the eight statements considering how outcome measurement should be carried out reached significant levels of agreement.

Consensus identified that the outcome measures used should be focused, measuring specifically the effect of treatment on the areas targeted (98%) and those closely related to this (100%). It also revealed a contradiction of focus, as the therapists' noted through unanimous consensus that health-related quality-of-life and wellbeing should be at the forefront of best practice outcome measurement, but only reached consensus for the measurement of outcome at the level of activity performance on the World Health Organisation International



Classification of Functioning, Disability and Health (WHO ICF) model (World Health Organization, 2001), and not for measurement at the level of body structure and function or participation.

The responses to second set of statements provides a framework for best practice outcome measurement, indicating that both subjective and objective measures should be employed, measurement should occur both at the beginning and end of a course of therapy, and throughout the treatment course if possible, and that findings of outcome measures should be used not only to monitor the disease progression of the individual, but should also be utilised to guide a physiotherapist's future practice for people with PD as a whole. There was no consensus for the timing of outcome measurement in relation to medical fluctuation (77%).

**Table 14: Outcome Measurement**

<b>Level of Consensus</b>	<b>Outcome measures should assess... (% of consensus)</b>
100%	The effect of the treatment delivered on areas related to those targeted specifically by the treatment (e.g. measuring the effect of balance rehabilitation on gait) (100) <i>Level of evidence: Ib</i> The effect of the treatment delivered on health-related quality-of-life and wellbeing (100) <i>Level of evidence: Ia</i>
90-99%	The specific aims of the treatment delivered (98) <i>Level of evidence: Ib</i> The effect of the treatment delivered on a person's overall physical functioning (94) <i>Level of evidence: Ia</i>
80-89%	The effectiveness of the treatment delivered at the level of activity performance, specific to the problem targeted (based on the ICF model) (87) <i>Level of evidence: Ib</i> The impact of the treatment delivered on a patient's carer(s) physical and psychological health, activity and participation (85) <i>Level of evidence: Ib</i>
<80% (No Consensus)	The effectiveness of the treatment delivered at the level of participation (based on the ICF model) (77) <i>Level of evidence: Ib</i> The effect of the treatment delivered on areas that can be indirectly influenced by the treatment (e.g. measuring the effect of cardiorespiratory training on mood/ depression) (61) <i>Level of evidence: Ib</i> The effectiveness of the treatment delivered at the level of the body structure or body function targeted (based on the ICF model) (59) <i>Level of evidence: Ib</i>

**Table 15: Structure, Delivery and Use of Outcome Measurement**

<b>Level of Consensus</b>	<b>Structure, delivery and use of outcome measurement</b> (% of consensus)
100%	Outcome measurement should include both subjective and objective measures to allow both patient self-report, and objective measurement of symptoms and the effects of treatment (100) <i>Level of evidence: Ib</i>
90-99%	Physiotherapists should use the findings of outcome measures when managing patients to influence their future practice (98) <i>Level of evidence: IV</i> Outcome measures should be recorded before commencing treatment, and at the end of the course of therapy (98) <i>Level of evidence: IV EP</i> Measurement of outcome measures over an extended period of time may be useful to monitor disease progression and change. (98) <i>Level of evidence: IV EP</i> Outcome measures should be recorded both pre-and post-treatment to allow change to be measured (90) <i>Level of evidence: IV</i>
80-89%	Outcome measures should be objective in nature (87) <i>Level of evidence: IV EP</i>
<80% (No Consensus)	Outcomes should be measures during both the “on” and “off” periods for a patient (77) <i>Level of evidence: IV EP</i> Outcome measures should be of a (patient) self-report, subjective nature (75) <i>Level of evidence: IV EP</i>

## 2.5 Discussion

### 2.5.1 Current Physiotherapy Practice for PD

The survey provided useful information on the setting, referral to, delivery and dose of current physiotherapy for PD, updating our knowledge of UK practice.

Physiotherapy was predominantly delivered within a primary care setting, with 57% of participants practising within the patient’s home, and 39% delivering physiotherapy in an outpatients department. This echoes the support provided for community-delivered care in the PD: PEP (Plant et al., 2000). Interestingly, it is also comparable with the findings of a Dutch survey which reported 88% of physiotherapy was delivered within primary care, although the majority of therapy within the Netherlands was delivered within the therapist’s practice, with only 20% being domiciliary (Keus et al., 2004a). This illustrates a clear move towards the primary care management of illness, something which has been specifically

supported for PD rehabilitation. Morris (2000) has advocated home-delivered physiotherapy as a way of identifying how the individual's movement disorder interacts with their own environment, and therefore optimising functional rehabilitation, whilst outpatient and leisure settings have been recommended specifically for physical activity training in PD (Keus et al., 2004b). However, the most important point to note is, at present, there is no evidence for an optimal treatment setting, and so where physiotherapy is currently delivered is as much dependant on resource and the local structure of therapy services, as it is the individual needs of a patient.

Current referral patterns to physiotherapy services were considered through a number of questions, with the results highlighting a number of developments in referral practices. The therapists' responses identified that the PD nurse specialist was the professional most likely to refer patients on to physiotherapy by far, with 63% of respondents rating the nurse as "always" or "usually" referring. This is in contrast with both the findings of the PD: PEP and the Dutch physiotherapy survey, which both noted consultants (Neurologists) and General Practitioners (GP) to be the main referrers (Plant et al., 2000, Keus et al., 2004a). Within the UK, the number of PD nurse specialists has grown substantially over the last decade (Robertson, 2003, Nursing Times, 2007), receiving support from national guidelines ((National Collaborating Centre for Chronic Conditions, 2006), Parkinson's UK (All Party Parliamentary Group for Parkinson's Disease, 2009), medical professionals and patients. One of the key roles of the PD nurse specialist is to create an integrated service through referral to other disciplines (Parkinson's UK, 2008a), and so this may explain the change seen in UK referral patterns. However, strong trial evidence confirming the clinical and cost effectiveness of the role is yet to be published (Reynolds et al., 2000, Jarman et al., 2002), and the specific effect on outcome of referral to other disciplines as part of the nurses role has not

been particularly explored. Jarman et al (2002) did not measure this element at all, whilst Reynolds et al (2000) included referral to other professionals as part of a patient satisfaction survey, but found no significant difference between nurse-led and consultant-led care.

Another development was the reporting of self and carer initial referral and re-referral; 45% of respondents stated patient self-referral could initiate treatment, whilst 78% had self-referral mechanisms in place for re-accessing care. Self-referral was not reported within the current practice element of the PD: PEP, although 87% of therapists included did associate the ability to self re-refer with optimised care (Plant et al., 2000). However, interest in self-referral has increased in recent years, resulting in pilot schemes of initial self-referral to musculoskeletal physiotherapy across the UK (Department of Health, 2008). The findings of these schemes have identified numerous benefits including high levels of service user satisfaction and confidence, increased empowerment to self-manage, higher levels of therapy attendance and completion, and lower costs to the NHS through reduced use of GP time and prescriptions (Department of Health, 2008). Whilst, the number of therapists reporting initial self-referral in this survey was below 50%, there does appear to be a movement towards improving access to services which, in light of the findings of these pilot schemes, may be beneficial to both the patient and the NHS as a whole.

One area of referral that appears to have remained unchanged is the timing of patient referral to physiotherapy services. The majority of referrals were reported to occur during the maintenance phase of PD; the stage during which care centres on the relief of morbidity and the prevention of complications (MacMahon and Thomas, 1998), with only 10 physiotherapists reporting referral to primarily occur in the diagnosis phase. It is difficult to compare this finding to previously reported practice as disease staging was not utilised before, but therapists had reported that early referral of patients to physiotherapy was rare

(Ashburn et al., 2004). There is clear support for the availability of physiotherapy throughout the duration of PD (National Collaborating Centre for Chronic Conditions, 2006), and it is thought that early intervention can act as a preventative measure, maintaining a patients' health and independence, as opposed to therapists intervening only when complications occur (All Party Parliamentary Group for Parkinson's Disease, 2009). Whilst this does appear to be a logical argument, evidence for early referral is predominantly limited to expert physiotherapist opinion (Morris, 2000, All Party Parliamentary Group for Parkinson's Disease, 2009). Few RCTs have been conducted that include patients from the early stages of PD (Pohl et al., 2003, Fisher et al., 2008), and a recent systematic review identified this as an area requiring further investigation (Kwakkel et al., 2007). Therefore, it may be that the current timing of referral has to be deemed adequate until strong, supportive evidence is available for early referral to physiotherapy.

The structure of current physiotherapy services was reported in terms of multidisciplinary team (MDT) working, the presence of a key worker and the format of treatment delivery. Collaborative working is advocated as the best way of approaching care in PD (Plant et al., 2000, National Collaborating Centre for Chronic Conditions, 2006) and was supported by therapists here through consensus in the best practice Delphi survey. However, the evidence for MDT rehabilitation in PD is actually limited (van der Marck et al., 2009), and the findings of RCTs investigating its effect on outcome have been variable (Wade et al., 2003, White et al., 2009, Guo et al., 2009). Despite this lack of evidence, 78% of therapists stated that they currently worked within the MDT format. In comparison, far fewer therapists reported coordination of patient care by a single professional in their team (26%), despite there being support for this method of practice (Plant et al., 2000, Robertson et al., 2008) The format of physiotherapy delivery was variable; 54% of therapists combined individual and group

sessions within their current practice, whilst 45% of respondents delivered treatment on an individual basis only. This variability echoes the most recent guidance on physiotherapy for PD, which identified that the format of treatment delivery will be governed by a number of factors including treatment goals, a patient's ability and external issues (Keus et al., 2004b). There is no evidence to support one form of delivery over another; this was noted in the UK guidelines published immediately following the PD: PEP (Plant et al., 2001) and still remains true today. Both formats offer different benefits with individual therapy allowing a patient's specific problems to be targeted (Keus et al., 2004b), and group therapy offering an element of social support which can improve adherence to treatment (O'Brien et al., 2008). At present though, as with practice setting, it may be speculated that the current format of physiotherapy delivery is as much guided by local service structure and resource availability as it is the individual patient's needs.

Therapists were asked to provide details of the average dose of therapy. Their combined findings indicated that a median of 6 physiotherapy sessions were delivered over 8 weeks, with the initial assessment lasting a median of 60 minutes, and subsequent sessions a median of 45 minutes. This shows little change from the practice reported over a decade ago (Ashburn et al., 2004). Practice between therapists was also highly variable, which may signify that the treatment delivered is being shaped by the needs of individual patients and their disease course (as recommended by the Dutch physiotherapy guidelines (Keus et al., 2004b), but also by the habitual practice of therapists. It could also be associated with the lack of evidence for an optimal dose of physiotherapy in PD, an issue which recent systematic reviews have highlighted as an area requiring exploration (Kwakkel et al., 2007, Keus et al., 2009).

### **2.5.2 Perceived Best Practice for Physiotherapy in PD**

The Delphi survey captured information regarding the focus and content of best practice physiotherapy for PD, as perceived by the physiotherapists. The first element considered was the reasons for providing physiotherapy. High levels of agreement were found, with all statements reaching consensus. These statements were then combined to provide the following framework for therapy:

*‘To maximise quality of movement, functional independence and general fitness, and minimise secondary complications whilst supporting self-management and participation, and optimising the safety of the individual.’*

This is similar to the reasons included in the definition created following the PD: PEP, which identified a focus on maximising functional ability and minimising secondary complications (Plant et al., 2000). It also draws comparisons with the objectives of physiotherapy outlined in the Dutch PD guidelines: “to improve the quality of life by maintaining or increasing the patient’s independence, safety and well-being... through prevention of inactivity and falls, improving functional activity and decreasing limitations in activities” (Keus et al., 2004b). A new concept that has been introduced within the framework is that of supporting self-management. Self-management is seen as an important and inescapable part of chronic disease (Bodenheimer et al., 2002), with Holman and Lorig (2000) identifying the patient as their own primary caregiver. Within the UK, support for patients taking ownership of their treatment has become more evident over the last decade and, in light of the limited resources in the NHS; an element of self management is inevitable and required. However, it is currently unclear how professional support for self-management in PD is best delivered, and whether it has any positive effect on outcome, although programmes focusing on self management rehabilitation (transferring clinic training into home and community routines) have recently begun to be evaluated (Tickle-Degnen et al., 2010).

There were also high levels of consensus for statements regarding the focus of physiotherapy in PD, with a wide range of core areas being identified. Those that reached unanimous consensus (gait and freezing of gait, indoor and outdoor mobility, balance and falls, transfers, posture, and physical conditioning) could all be linked to core areas identified within the Dutch guidelines (Keus et al., 2004b), indicating that these are viewed as the cornerstones of physiotherapy practice for PD universally. Other areas reaching high levels of agreement were respiratory function (94%), pain management (92%), leisure-related activities (98%) and upper limb function (97%). The first three had not previously been identified as core areas, but their inclusion may indicate they are addressed by therapists if relevant to the individual patient. It is, however, interesting that upper limb rehabilitation did not reach unanimous consensus, as this is the sixth core areas included in the Dutch guidance document (Keus et al., 2004b). Only two statements failed to reach agreement; the management of psychological issues (57%) and communication (48%), both falling well below the consensus threshold. Psychological issues such as depression have been considered through secondary outcome measures in a number of exercise trials for PD (Comella et al., 1994, Dereli and Yaliman, 2010), and physiotherapeutic rehabilitation of facial mobility (essential to communication), was evaluated in a RCT by Katsikitis and Pillowsky (1996). Despite this, the surveyed therapists indicated that these issues fell outside the scope of practice for most physiotherapists, highlighting the gap between research and therapist-perceived best practice.

Perhaps the most interesting finding from the core area statements is the consensus reached for physiotherapists addressing self care (87%), domestic ADL (87%) and work-related activities (82%). Although at a lower level of agreement, these areas are typically recognised as the concern of occupational therapy, and so their inclusion illustrates an overlapping of



boundaries between therapies. This has been discussed previously in the literature (Nancarrow, 2004), and is thought to occur due to a shared focus of physical and functional rehabilitation, and a similar approach to patient care (Smith and Roberts, 2005). Within the management of PD it may be proposed that this blurring of boundaries is actually necessary to ensure patients receive the treatment they need. Although therapy provision is thought to have increased in recent years – the most recent survey by Parkinson’s UK reported that 54% of respondents had received physiotherapy and 44% occupational therapy (Parkinson's UK, 2008b) – in comparison with the 27% and 17% accessing these services ten years before (Yarrow, 1999), these figures may be an overestimate. Services are still highly variable and suboptimal care is apparent in some areas of the UK. This has been highlighted in a recent community based study of 248 PD patients from Milton Keynes Primary Care Trust, which revealed that only 27.9% of the patients had received physiotherapy, and 18.2% occupational therapy (Hu et al., 2011). Therefore, an overlap of services may mean that patient’s problems are dealt with even if the therapist who traditionally addresses this issue is unavailable.

Overall treatment provision was explored through a series of statements. The findings here suggested patient-centred care was the central concept to physiotherapy in PD, with aspects such as patient-determined goals, and an individualised approach to the intervention content, setting and delivery being identified as best practice. This is perhaps unsurprising as the patient-centred approach is highly relevant in the treatment of PD due to its complex nature and individualised presentation in patients (van der Marck et al., 2009). This approach to care is a step away from the traditional “medical model”, as the practitioner works in partnership with the patient (Little et al., 2001, Bauman et al., 2003). There is opportunity for shared decision-making (Stewart, 2001) and a broader view is taken of patient management, with treatment decisions being informed by the patient’s individual experience of their illness and

its interaction with their life as a whole (Epstein, 2000, Stewart, 2001). Patients have identified a preference for this approach (Little et al., 2001, Cooper et al., 2008). There have also been reports of a positive effect on outcome, with some evidence suggesting that patient-centred care may lead to increased patient satisfaction, a better recovery, better emotional health and improved quality of life (Stewart et al., 2000, Bauman et al., 2003), although the strength of this evidence base has been questioned (Heaney, 2001). However, whilst elements of patient-centred practice relating to communication can be easily implemented, an individualised approach to physiotherapy setting and the format of delivery (individual or group treatment) may be more dependent on resources and the structure of therapy services, potentially leading to an unavoidable gap between perceived best practice and the treatment that can actually be delivered.

The efficacy of specific intervention techniques was considered primarily through statements focused on the six core areas identified by the Dutch guidelines. The results showed high levels of agreement for treatment techniques related to gait, balance, physical conditioning and the rehabilitation of transfers. The first three areas have all received a significant amount of attention in PD rehabilitation research, and it would appear that the therapists' decisions regarding best practice were often guided by the existence of high quality research, indicating evidence-based decision making (Muir-Gray, 1997). For example, the inclusion of external cueing techniques in gait rehabilitation reached unanimous consensus, and this has strong supportive evidence from a systematic review by Lim et al (2005) (auditory cueing only), and a large RCT by Nieuwboer et al (2007; n=153) (visual, auditory and sensory cueing). Similarly, the multifaceted and progressive approach advocated by the therapists for balance rehabilitation is supported by positive outcomes in a number of RCTs (Toole et al., 2000, Ashburn et al., 2007), and the efficacy of focused strength training for physical conditioning

is evident in a recent systematic review of exercise by Goodwin et al (2008). This link between evidence-base and therapist agreement is further supported by the lack of consensus where contradictory and low quality evidence exists. For gait rehabilitation, two statements were included exploring approaches to dual tasking; one supported avoidance of dual tasking in line with guidance recommendations (Keus et al., 2004b), whilst the other advocated dual task training in light of recent small pre-experimental trials (Canning, 2005, Baker et al., 2007). Both statements fell well below the consensus threshold (54.1% and 65.5% respectively). However, this explanation does not fit with all of the findings. A number of statements within these three areas that reached high levels of consensus, including walking practice within the patient's own environment and the importance of recreational activity in supporting self-management of physical conditioning, are all grounded in expert opinion. Similarly, three of the six statements regarding the rehabilitation of transfers were generated by the therapists through free text in round one, but all six statements reached consensus. This illustrates that the therapists' decisions on specific interventions for best practice were not only shaped by research evidence, but also their own individual clinical experience, and potentially their knowledge of patient's preferences for treatment techniques. These aspects are recognised as key to health care decision making (Sakala and Corry, 2001) and to evidence-based practice, with Sackett (1996) noting that "evidence can inform, but can never replace, individual clinical expertise".

There were lower levels of consensus for statements regarding the treatment of posture and upper limb function. For postural rehabilitation, as with transfers, there is a paucity of research. Only one statement was created from trial evidence, with exercise for axial coordination being supported through a RCT by Schenkman et al (1998; n=51). However, despite the panel generating a further six statements through free text, the levels of consensus

in this area failed to match those reported for the rehabilitation of transfers. It may be that practice for postural rehabilitation varies dependant on the practitioner, which is plausible given the number of different treatments suggested by the respondents. However, the lack of a clear approach is surprising given that posture was identified as a core area by all therapists in this survey. For upper limb rehabilitation, only two of the five statements reached consensus. This is known to be a neglected area of rehabilitation research in PD (Kwakkel et al., 2007), but therapists did not draw on their clinical experience to provide treatment solutions in light of this (only one relevant statement was generated from the free text). In combination with the lack of unanimous consensus for upper limb function as a core area of practice, it would appear that physiotherapists do not always address upper limb problems, perhaps due to prioritisation of other patient complaints or a view that other professionals may be better suited to treat these issues. For this reason, therapists do not have the same level of experience to draw when asked to identify best practice for upper limb rehabilitation.

Six additional treatment technique statements and four complementary therapy-related statements were included following free text suggestions by the therapists in round one. Only one reached consensus, but the level of agreement was low at 81.9% (see Table 12). The generation of so many extra statements, combined with the lack of consensus, illustrates an individualised scope of practice which is known to exist for physiotherapists due to the autonomous nature of the profession (Chartered Society of Physiotherapy, 2008).

The final aspect of practice considered in the Delphi survey was the use of outcome measures. Consensus highlighted that outcome measurement should be focused; targeting the specific aims of the treatment delivered (98%) and areas closely related to this (100%). This is in agreement with the views captured in the PD: PEP (Ashburn et al., 2004) and echoes the focus on task specificity advocated in a systematic review by Kwakkel et al

(2007). However, there was also an interesting contradiction of focus, with therapists advocating the measurement of quality of life and wellbeing, but then also stating that outcome measurement should only occur at the level of activity performance on the World Health Organization's International Classification for Functioning, Disability and Health (World Health Organization, 2001). Whilst a focus primarily on activity limitation is supported by the Dutch guidelines (Keus et al., 2004b), most recent UK guidance actually advocates a holistic approach, encompassing measures from all three domains of the WHO ICF model (Ramaswamy et al., 2009). Quality of life is recognised as particularly relevant to the management of PD due to the chronic, progressive nature of the condition (Global Parkinson's Disease Survey Steering Committee, 2002), and has long been identified as a key area of outcome measurement in best practice (Ashburn et al., 2004). Therefore, this finding perhaps highlights that the respondents' understanding of the WHO ICF model could be improved, which in turn would lead to increased clarity when reporting best practice.

With regards to structure of the outcome measurement process, there was unanimous consensus for the inclusion of subjective and objective measures - an approach that is thought to help ensure a full and comprehensive assessment occurs (Fitzpatrick, 2003). There was also consideration of the timing of outcome measurement, with therapists stating this should occur both at the beginning and end of a course of therapy, and throughout the treatment course if possible. This is in line with recommendations from UK guidelines (Plant et al., 2001). However, there was no consensus surrounding the timing of outcome measurement in relation to "on-off" fluctuations, despite clear guidance suggesting that measurement should be performed at the same time of day as the initial assessment (Keus et al., 2004b). Again, this indicates a gap between what is recommended and what therapists feel is achievable best practice.

### **2.5.3 Limitations of the Study**

There are a number of potential limitations with this study, both with the sample included and the design utilised. With regards to the representativeness of the sample, broad inclusion criteria was utilised in a bid to capture the full scope of practice. Despite this, the therapists included were actually highly experienced practitioners in terms of both years qualified (mean of 17.6 years), and the number of people with PD treated per annum (median of 25 patients). This level of expertise is comparable with the previous UK survey, but there the researchers purposely targeted senior therapists with a current PD caseload and at least two years of practising with this specific client group (Ashburn et al., 2004). For this reason, it could be presumed that the sample is not representative of the whole therapist population treating people with PD, a problem which may have arisen from the non-random sampling methods used in the study, the sample size and the number of dropouts between the first and second round. However, it must be noted that we do not know which physiotherapists usually treat people with PD in the UK, and it could be that the majority of patients are actually referred to senior therapists for treatment.

Further limitations may have arisen due to the modified Delphi design employed for the best practice survey. Firstly, a method was used in this study by which first round statements were drafted following a literature review before involving the expert panel, rather than the classical Delphi method which utilises responses to an open question from the panel to formulate statements (Powell, 2003). Whilst this method ensured the original statements were grounded in the evidence base, it has been criticised by Thompson (2009), who believes it imposes too rigid a starting point on the Delphi participants, constraining expert thinking and thereby weakening the methodology. Thompson (2009) goes on to state that this method should be described as a rating exercise rather than a Delphi process. However, it may be suggested that the present survey did try to preserve the role of the expert panel as therapists

had the opportunity within the first round to provide additional free text on any issues they felt had been omitted, which was then used to create further statements. A second potential issue arising from the Delphi survey is the type of expert panel included. We opted for a larger, heterogeneous sample in an attempt to maximise validity (Mead and Moseley, 2001). However, this does stray away from the classical Delphi concept, as the original Delphi study only employed seven experts on their panel (Baker et al., 2006). A study by Akins et al (2005) also suggests that the response characteristics of small panels of experts can be stable and good results produced, as long as the members are similarly trained and selected via strict inclusion criteria. Whilst this may bring into question the sample selected in the current study, it must be noted that if a small group of similarly trained experts are chosen, there is a risk that the consensus may be based around the training received rather than evidence and the wider practice delivered.

Other limitations may have resulted from the type of data collected; self-reported information rather than actual documented behaviour, leading to a risk of over-reporting and social-desirability bias (Abrams et al., 2006), and the structure and content of the survey documents, which may have failed to capture some potentially useful information. For example, an opportunity was lost to compare current and perceived best practice, as the current practice survey focused on the structure and delivery of physiotherapy services for PD as a whole, and the best practice Delphi element captured the content and focus of therapy delivered.

## **2.6 Conclusion**

This survey provided an insight into current practice and best practice physiotherapy, as perceived by physiotherapists, for people with PD. The current practice element revealed that

therapy is predominantly delivered in the patient's home or an outpatient department. The majority of referrals are sent from the PD Nurse Specialist, and referral usually occurs in the maintenance phase of the condition. Seventy-eight percent of therapists reported working as part of a multidisciplinary team, and the majority of physiotherapists delivered treatment on both an individual and group basis. The average dose of physiotherapy delivered for people with PD was comparable to that reported in the PD: PEP a decade ago (Ashburn et al., 2004), with a median of six sessions over eight weeks, an initial assessment lasting 60 minutes and subsequent sessions lasting 45 minutes each.

With regards to best practice, there was consensus for all statements considering the reasons for physiotherapy in PD, resulting in the following framework for practice: "to maximise quality of movement, functional independence and general fitness, and minimise secondary complications whilst supporting self-management and participation, and optimising the safety of the individual". Similarly, there was consensus for the majority of statements concerning the core areas of practice. Individualised treatment delivery was identified as best practice, whilst the level of consensus surrounding specific treatment techniques varied dependent on the problem being targeted. Finally, consensus revealed a focused approach to best practice outcome measurement in PD, and provided an insight into the optimal timing of measurement, the types of outcome measures that should be employed, and how the findings of outcome measures should be used.

Having established a framework for best practice in physiotherapy and identified core areas of practice, it is necessary to examine how these results are and should be gauged. In this study, consensus revealed a focused approach to best practice outcome measurement in PD, and provided an insight into the optimal timing of measurement, the types of outcome measures that should be employed, and how the findings of outcome measures should be



used. Study Two sought to extend these findings and assess the relevant focus of outcome measurement, factors affecting this measurement, and how it relates to current guidelines and achievable best practice.

### **3 STUDY TWO: OUTCOME MEASUREMENT IN PHYSIOTHERAPY FOR PARKINSON'S DISEASE: A SURVEY OF CURRENT AND PERCEIVED BEST PRACTICE IN THE UK**

#### **3.1 Introduction**

Outcome measurement, defined by Kendall (1997) as “a measure of change; the difference from one point in time to another”, is an important aspect of physiotherapy. Whilst the measurement of outcome has not historically featured as part of routine clinical practice (Herbert et al., 2005), it is now identified as a requirement of UK physiotherapists through the core standards of practice from the Chartered Society of Physiotherapy (CSP) (2005), and is directly associated with good clinical practice (Haigh et al., 2001). Within the physiotherapeutic management of Parkinson's disease (PD), outcome measurement is advocated within disease specific guidelines (Keus et al., 2004b, Ramaswamy et al., 2009).

The reasons behind the use of outcome measures in practice are multifaceted; they provide baseline information on a patient, support treatment planning and act as a tool for communicating feedback to the patient regarding the effect of treatment (Yoward et al., 2008). Within PD, it has been noted that outcome assessment may provide a mechanism to feedback treatment outcome to the referring physician (Keus et al., 2004b). This can potentially increase the physician's confidence in physiotherapy; an important concept when considering that referral rates have been historically low (Mutch et al., 1986, Yarrow, 1999), with a recent survey reporting that over 40% of service users have still never received physiotherapy (Parkinson's UK, 2008b). In addition, as the pressure to demonstrate effectiveness of physiotherapy to service commissioners and policy makers increases, outcome measurement is being looked to as a means of providing clear evidence of the benefits (Herbert et al., 2005).

Despite these reasons, the use of outcome measures in physiotherapy appears variable with recent reports ranging from 48% (Jette et al., 2009) to 91% (Yoward et al., 2008) of physiotherapists employing standardised outcome assessments within their current practice. Within PD, evidence exploring outcome measurement within physiotherapy is limited to the findings of the PD: Physiotherapy Evaluation Project (PEP) – a UK survey of 49 specialist therapists and case study of nine best practice sites conducted between 1998 and 2000 (Plant et al., 2000, Ashburn et al., 2004). The survey contained seven statements focused on best practice outcome assessment, with therapists ranking their agreement for each statement. There was consensus around the focus of outcomes on functional ability, the aims of treatment, and the importance of measuring quality of life and wellbeing, but uncertainty surrounding the use of cost-effectiveness measures. Away from physiotherapy, research has been conducted into outcome measurement within speech and language therapy and occupational therapy for PD. In a survey of 169 UK occupational therapists, 46 % utilised standardised scales and only 34% reported assessing response to a course of therapy (Deane et al., 2003b). Cognition was most frequently assessed, although a few therapists also measured activities of daily living, Parkinsonian disability and quality-of-life. When considering best practice, 85% of therapists advocated the use of standardised measures, 82% identified that re-assessment should occur after every course of therapy, and 99% felt assessment should focus on the gap between present and desired function (Deane et al., 2003a). In speech and language therapy, 82% of 187 UK therapists surveyed reported using outcome measures when treating people with PD (Miller et al., 2010). Assessment primarily focused on the measurement of speech, language and swallowing, although a small number of therapists also included measures of cognition, mood and quality-of-life.

There is a clear lack of research exploring outcome measurement for physiotherapy in PD. With this in mind, when a survey to establish UK physiotherapy practice in PD was conducted between June and October 2009, the issue of outcome measurement was included. This chapter aims to highlight the outcome measures currently used by UK physiotherapists when treating people with PD as reported in this survey. Additionally, whilst recommendations for best practice outcome measurement had been detailed within the Dutch guidelines (Keus et al., 2004b), at the time of this survey UK guidance had not been published. Best practice is, at least partially, shaped by the society in which it is delivered (Stoll, 1989), and so what is achievable best practice within the Dutch health system may not translate to the UK National Health Service. In light of this, the survey also captured what therapists perceived as (achievable) best practice outcome measurement and these results are also presented here. Both current and best practice findings will then be explored in the context of current guidance for outcome measurement and practice reported for other disciplines within the management of PD.

## **3.2 Methods**

### **3.2.1 Participants**

For the purposes of this survey, the same participant sample was used, at the same time, as for Study One. To summarise, participants for the survey panel were generated using convenience and purposive methods of sampling. The target population of the study was clinical physiotherapists within the UK who expressed an interest in the treatment of people with PD. A database of physiotherapists who had previously expressed an interest in participating in research related to PD was accessed. In addition, the survey was advertised at rehabilitation and neurological conferences, and on the Interactive CSP webpage. Participants were also recruited through personal correspondence.

### **3.2.2 Study Design**

The survey was conducted between the 24<sup>th</sup> June and 22<sup>nd</sup> October 2009 over two rounds.

During the first round, details of current physiotherapy practice were collated as therapists were asked to list any outcome measures they currently used when treating people with PD (see Appendix B). Information related to the level of experience of the responding physiotherapists was also collected, including the number of years qualified, number of people with PD treated in the last 12 months, and relevant postgraduate training. The former two therapist attributes (years qualified and number of patients treated) in particular were recorded as a simple way of identifying level of expertise within the sample, as extensive experience and professional development within a specific field of practice have been directly associated with expertise (Higgs and Bithell, 2001, Smith, 2010). The findings of the current outcome measurement practice were summarised and descriptive statistics produced, with the number and type of outcome measures (i.e. the spread across the WHO ICF model (World Health Organization, 2001)) being stratified against both number of years practice and number of people with PD treated within the past year. It was felt that the number of outcome measures, and type of measurement tools used, may have some correlation with the experience of the physiotherapist, as reflective practice (inclusive of patient evaluation) is another recognised attribute of the expert therapist (Jensen et al., 1992, Jensen et al., 2000).

The best practice element of the survey was investigated over both rounds using a modified Delphi technique; a method which involves members of an expert panel ranking their agreement with statements on a particular topic, over a number of rounds, in order to reach consensus (Powell, 2003). A draft of the statements was created from the current evidence base for physiotherapy in PD. This document was then sent to an advisory panel of seven researchers and clinical physiotherapists; six of whom were acting as part of an expert group on a multi-centre randomised controlled trial of therapy for PD and a final member who had

previously conducted a Delphi survey. The advisory panel gave feedback on structure and content to finalise the statements for the first round.

The best practice survey disseminated during the first round included 12 statements relating to what outcome measures should assess and how outcome measurement should be conducted (see Appendix B). Ranking of agreement for each statement was recorded on a five-point Likert scale (strongly agree, agree, undecided, disagree, strongly disagree). The survey panel were also given the opportunity to provide further free text information on additional aspects of outcome measurement they felt important for consideration.

Following completion of the first round, the statement responses were collated, data queries conducted, and descriptive statistics produced using Microsoft Access and Excel 2003. The free text information provided by the responding therapists was stored using QSR NVIVO Version 8 and underwent qualitative analysis. In light of the findings, a further five statements were produced to represent their opinion for the second round of ranking (see Appendix B).

For the second round, statements were ranked as in round one. Where statements had been included in the previous round, the panel's responses were incorporated into the survey document to inform agreement. No additional free text was collected. On completion of the second round, the data was collated and analysed as in the first round and, in line with the best practice Delphi survey of occupational therapy for PD (Deane et al., 2003a), consensus was set at agreement totalling 80% or more in the two adjacent agreement levels of the Likert scale (strongly agree and agree).

The survey documents were disseminated via email and returned by email or post. Participants were given seven weeks to complete the first round of the survey, with reminder emails being sent out at two, four and six weeks. The second round was completed over a six week period, with reminder emails at three and four weeks.

The University of Birmingham provided ethical review, and consent to participation in the study was assumed through returning the completed study documents at each round.

### **3.3 Results**

A total of 103 physiotherapists were provided with information regarding the study; 72 (70%) responded to the first round of the survey and 57 (79% of the respondents) to the second round.

#### **3.3.1 Respondent Characteristics**

Of the 72 respondents, 67 provided details related to their level of experience and expertise in the management of PD. These therapists had been qualified for a mean of 17.6 years (SD 9.5). Eighty-five percent of the therapists identified themselves as having a special interest in PD, and 60% reported receiving post-graduate training applicable to the management of people with PD. A wide range was reported for the number of PD patients treated by the physiotherapists over the last 12 months (3 to 250; range 247). The median number of patients treated was 25 and the interquartile range was 35. Three therapists reported treating over 100 patients with PD in the past year (100, 150 and 250 respectively).

#### **3.3.2 Outcome Measures Currently Used in Practice**

Of the 72 clinical therapists responding to the first round of the survey, 60 (83%) listed outcome measures used currently in practice. The physiotherapists reported using a mean of 3.7 outcome measures (SD 2.8) when treating patients with PD. When considering the number of outcome measures listed in light of the therapists' characteristics, there was little difference in the number reported by therapists with a specific interest in PD (mean 3.8; SD 2.7), compared with those without (mean 3.2; SD 3.2). This was also true when comparing physiotherapists who had or hadn't received relevant postgraduate training, with a mean of

4.0 (SD 2.9) and 3.4 (SD 2.5) outcomes being reported for each group respectively. Similarly, the number of years qualified and number of PD patients treated in the last 12 months had little effect on the mean number of outcome measures reported (see Tables 16 and 17).

**Table 16: Number of years qualified versus number of outcome measures**

Time qualified: years	Number of therapists: /67	Number of outcome measures: mean (SD)	Spread of measures across WHO ICF model: mean		
			Body function and structure	Activities	Participation
0-5	6	3.8 (4.4)	1.0	5.3	0.3
6-10	17	3.6 (1.4)	0.2	3.2	0.1
11-15	5	3.0 (2.1)	0.8	3.5	0.0
16-20	10	3.9 (2.2)	0.5	3.2	0.1
21-25	17	3.8 (3.4)	0.7	4.5	0.1
26-30	6	4.8 (4.3)	1.4	4.2	0.2
31-35	4	3.0 (2.2)	0.8	3.0	0.5
36-40	2	2.5 (2.1)	0.0	2.5	0.0

**Table 17: Number of patients treated in last 12 months versus number of outcomes**

Number of PD patients treated in last 12 months	Number of therapists: /60	Number of outcome measures: mean (SD)	Spread of measures across WHO ICF model: mean		
			Body function and structure	Activities	Participation
0-10	8	2.1 (1.8)	0.2	2.7	0.0
11-20	18	4.1 (2.7)	0.6	3.8	0.1
21-30	8	2.6 (2.1)	0.5	2.8	0.2
31-40	8	5.1 (3.7)	1.0	4.7	0.0
41-50	9	3.7 (3.4)	0.5	3.6	0.1
51-60	2	2.5 (2.1)	0.0	2.5	0.0
61-70	3	5.0 (2.6)	1.0	4.3	0.3
71-80	1	4.0 (n/a)	0.0	4.0	0.0
81-90	0	N/A	N/A	N/A	N/A



91-100	0	N/A	N/A	N/A	N/A
100+	3	4.3 (1.5)	1.0	4.0	0.7

A total of 62 different outcome measures were listed by the physiotherapists (see Appendix B). The measures most frequently reported were the Berg Balance Scale (40 respondents; 67%), Timed Up and Go (28; 47%), timed walk (most frequently the 10 metre walk test) (28; 47%), Lindop Parkinson’s Disease Mobility Assessment (LPA) (25; 42%), and the Performance Oriented Mobility Assessment (POMA) – Tinetti (14; 23%). The largest number of outcome measures, including all five of those most frequently reported, focused upon gait, balance and general mobility, with 23 different outcome measures being listed and outcomes related to this area being reported a total of 197 times by the therapists.

The outcome measures listed were also viewed in light of the World Health Organisation’s International Classification of Functioning, Disability and Health model (WHO ICF) (World Health Organization, 2001). Whilst the outcomes listed by therapists covered all three levels of the model; there was a strong preference for assessment of activity performance, as measures focusing on this area were reported a total of 231 times. Outcome measures which considered impairment of body function and structure were reported 36 times, whilst those focusing on participation were only reported 10 times. This preference for measures of activity limitation was unaffected by the level of experience of therapists (see Table 16) or the number of patients treated (see Table 17).

Of all of the outcome measures reported, five were PD specific; the LPA, Freezing of Gait questionnaire, Unified PD Rating Scale, PD Quality of life questionnaire and the PDQ-39.

### **3.3.3 Perceived Best Practice for Outcome Measurement**

Fifty seven physiotherapists (79%) completed both rounds of the best practice survey and their responses are presented here.

From the 17 statements regarding perceived best practice for outcome measurement (12 statements included in the first round and an additional five in the second round following the therapists' suggestions), 12 reached consensus, with 10 reaching high levels of consensus (90% and above) and four reaching unanimous consensus (see Appendix B).

Most therapists (98%) identified that outcome measures should focus on the specific aims of the treatment delivered, and 100% of the participants felt measurement should consider aspects related to those areas specifically targeted (such as measuring balance for gait rehabilitation). There was no consensus regarding the measurement of outcomes that could be indirectly influenced by the treatment delivered (such as the effect of physical capacity training on mood).

When considering outcome assessment in the context of the WHO ICF model (World Health Organization, 2001), 86% of therapists felt that measures should be aimed at the level of activity performance, whilst measurement at the levels of body function/ structure and participation failed to reach consensus. Despite this, a holistic approach was favoured, with 93% of physiotherapists supporting the inclusion of measures relating to overall physical functioning, and all participants advocating measurement of patient health-related quality-of-life. Eighty-six percent of physiotherapists also felt that measures relating to carer quality of life should be employed for best practice.

With regards to the type and structure of outcome measurement, there was unanimous consensus for the inclusion of both subjective and objective measures in patient management. However, 90% of therapists also felt best practice could be achieved through the use of objective measures alone. Ninety-one percent of physiotherapists supported the measurement

of outcome pre- and post treatment session, whilst 100% felt measures should be predominantly recorded before initiating treatment and at the end of a course of therapy. All of the therapists viewed outcome measurement as useful in charting disease progression for the individual patient, whilst 98% felt best practice involved using the findings of these measures to inform future practice. There was no consensus surrounding the timing of outcome measures in relation to on-off motor fluctuations.

### **3.4 Discussion**

#### **3.4.1 Current Practice**

The majority (83%) of physiotherapists responding to this survey reported using outcome measures within their current practice for PD. This figure is higher than the 48% quoted for the general therapist population by Jette et al (2009), and much closer to the 91% reported in a survey of 269 physiotherapists with a special interest in neurology (Yoward et al., 2008). When compared to other surveys within allied health care for PD, the number of therapists identified as using outcome measures is much higher than that reported by Deane et al (2003b) for occupational therapists (46%), although this is perhaps unsurprising as the survey was conducted nearly 10 years ago and so practice across all professions has inevitably moved on. The figure is much more in line with recent evidence for speech and language therapy, which found 82% of therapists were utilising standardised assessments (Miller et al., 2010). From this evidence, and our findings, it appears that current outcome measure use by healthcare professionals treating people with PD is fairly high. With regards to the number of measures used, a mean of 3.7 outcome measures was listed per therapist. This level of outcome assessment again shows great advances on practice reported in the previous decade; for example, in a survey of physiotherapy for stroke rehabilitation, only 10 of the 91 respondents reported using what they perceived as standardised assessments and only one

therapist utilised a published assessment (Sackley and Lincoln, 1996). In light of literature discussed earlier within this chapter, this change in outcome measurement practice is encouraging as it may result in improved patient-practitioner communication, support future referral to physiotherapy by physicians, and even help to commission further therapy services.

It must be noted that the number of outcome measures used by therapists remained relatively unchanged by the number of years qualified or number of patient seen in the last 12 months. This may be due to the fact that the development of expertise is a complex and multidimensional process, which combines many more factors than just reflective practice through patient evaluation and therapist experience alone (Jensen et al., 2000). For this reason, the actual link between physiotherapist experience and outcome measurement may be far more tenuous than initially anticipated, providing explanation for the lack of effect of stratification.

A total of 62 different outcome measures were listed. This level of variety has been seen before, with Yoward et al (2008) reporting 89 different measures within their survey of neurological physiotherapists. Although differences in practice can be expected, dependent on service policies and practice settings, this level of variety may indicate a lack of consensus surrounding the most appropriate measures to use. This is of particular concern as guidance was available at the time of the survey in the form of the Dutch guidelines (Keus et al., 2004b), bringing into question the physiotherapists' familiarity with the evidence.

Only five PD specific outcome measures were reported. Whilst disease-specific assessments are useful for their focus on domains most relevant to the condition (Testa and Simonson, 1996), aspects other than disease specificity are equally important, including validity and reliability (Herndon and Cutter, 2006). Although only one of the top five outcome measures listed was disease specific (the LPA), all five have been tested for reliability and validity

within the PD population (Schenkman et al., 1997, Morris et al., 2001, Qutubuddin et al., 2005, Kegelmeyer et al., 2007, Pearson et al., 2009), indicating that the therapists are utilising appropriate outcome measures.

Of the measures listed, the largest number (and top five assessments) focused on gait, balance and mobility. These areas are central to neurological physiotherapy and, in particular PD rehabilitation, as therapists play a significant role in managing the gait deficits and postural instability that are often unresponsive to dopaminergic medication (Bloem et al., 1996, Sethi, 2008). This highlights that physiotherapists prefer to use profession-specific measures. Despite this focus, therapists did list assessments covering all core areas detailed within the Dutch physical therapy guidelines (Keus et al., 2004b) and all levels of the WHO ICF model (World Health Organization, 2001). However, whilst the outcome measures named were diverse, therapists were primarily concerned with capturing activity limitation (regardless of their level of experience and expertise), with only a few physiotherapists reporting measures of body function/ structure and participation. In contrast, current speech and language therapy practice for PD is known to centre on the measurement of impairment of body function and structure (Miller et al., 2010). Occupational therapists are also reported to focus their assessment at this level, as a survey of current practice found cognition to be most frequently measured (although this evidence is now almost a decade old) (Deane et al., 2003b). When comparing the actual outcome measures named by the physiotherapists with those listed by other health professionals for PD, there is minimal overlap. A small number of speech and language therapists have reported using the Mini-Mental Status Examination (MMSE), Hospital Anxiety and Depression Scale, SF-36 and PDQ-39 but, as with physiotherapy, they primarily favoured profession-specific measures focused upon speech, language and swallowing (Miller et al., 2010). A few occupational therapists have also

reported using the MMSE, PDQ-39, and the Barthel ADL index for people with PD (Deane et al., 2003b). All of these measures were identified by physiotherapists within this survey, but they were infrequently reported with only one or two therapists listing each measure. The sharing of outcome measures would increase communication between teams and potentially improve the overall quality-of-care delivered, but at present there are disparities between how therapists from different professions approach outcome measurement, and therapists have a preference for using profession-specific assessments as opposed to more global measures. It may be hypothesised that the sharing of assessments across teams could be facilitated by the publication of multidisciplinary guidelines that directly address outcome measurement in PD.

When comparing the measures reported to those advocated in guidelines, only four overlapped with the ten listed in the Dutch guidelines (Timed Up and Go, ten metre walk, six minute walk test and Freezing of Gait Questionnaire) (Keus et al., 2004b). Again, this brings into question therapists' access to the guidelines and indicates that further steps to support dissemination may be required. Four different measures matched to the seven identified in the UK guidance document published since completion of the survey (Falls Efficacy Scale, EuroQol-5D, PDQ-39 and tragus to wall measure) (Ramaswamy et al., 2009). Interestingly, the therapists did not report any measures of physical activity, despite both guidelines advocating this. This identifies a difference in priorities between guidelines based on evidence and expert consensus, and what therapists feel is appropriate for clinical practice.

### **3.4.2 Perceived Best Practice**

The therapists' ranking of the Delphi statements gave an insight into their perception of best practice for outcome measurement in the physiotherapy management of PD within the UK.

When considering the focus of outcome measurement, the physiotherapists' responses were mixed; sometimes agreeing with guidelines, published research and their own current

practice, and at other times going against this. Ninety-eight percent of the therapists felt outcome measurement should focus on the specific aims of treatment. This is in agreement with the views captured in the PD: PEP (Plant et al., 2000, Ashburn et al., 2004) and echoes the focus on task specificity advocated in a systematic review by Kwakkel et al (2007). There was also complete agreement on the use of measures closely related to the specific areas treated (for example including measurements of balance when gait rehabilitation has been performed), but there was no consensus regarding the measurement of outcomes that may be indirectly affected by treatment. It is common practice within rehabilitation research to employ an extensive battery of outcome measures during patient assessment. However, the measurement conducted within research cannot always be replicated in practice (Higginson and Carr, 2001) and it is reasonable that best clinical practice should assume a more focused approach.

The therapists also gave their opinion on the focus of outcome measurement in relation to the WHO ICF model (World Health Organization, 2001). They reported that best practice should include measures aimed at the level of activity performance, with no consensus surrounding measurement at the levels of body function and structure, and participation. This is supported by the Dutch guidelines (Keus et al., 2004b), and is in agreement with the focus of current practice. However, the most recent UK guidelines advocate a holistic approach, recommending assessments that cover all domains of the model (Ramaswamy et al., 2009). For example, the document details the tragus-to-wall assessment (a measure of body function and structure), the Phone FITT questionnaire (an assessment of activity), and the PDQ-39 which considers aspects from all domains. This focus on activity limitation is also contradicted by the consensus reported for the inclusion of patient and carer quality of life measures. Quality of life is particularly relevant to the management of PD due to the chronic,

progressive nature of the condition (Global Parkinson's Disease Survey Steering Committee, 2002) and has long been identified as a key area of outcome measurement in best practice (Plant et al., 2000), with UK guidelines advocating the aforementioned PDQ-39 and the EuroQol-5D (Ramaswamy et al., 2009). However, by nature quality of life measures are broad in approach and often include categories that cover all of the WHO ICF domains (Cieza and Stucki, 2005). This finding indicates that the physiotherapists' understanding of the WHO ICF model, which has been identified as a framework that can be used to assist the decision making surrounding outcome measurement (Unsworth, 2000), could perhaps be improved. In turn, this would lead to increased clarity when reporting best practice.

The wider reasons for conducting outcome assessment were considered. There was unanimous consensus for the use of outcome measures in charting disease progression – a view supported by the Dutch physiotherapy guidelines (Keus et al., 2004b) and in agreement with the findings of the best practice survey for occupational therapy in PD (Deane et al., 2003a) – and 98% felt the findings of outcome measures could inform future practice. This is unsurprising due to the emphasis on reflective practice in physiotherapy (Clouder, 2000).

The survey included three statements related to the construct of outcome measures. All therapists felt that both subjective and objective outcome measures should be employed, but 90% also reported that best practice could be achieved through objective measures alone. The use of subjective measures in isolation failed to reach consensus (77%). Objective outcome measurement is important for giving an unbiased view of the physical aspects of a condition, and it is prevalent in current physiotherapy practice; the top five outcome measures reported in this survey were objective in nature. However, subjective measures, and in particular patient-reported outcome measures, are vital for gaining a fuller understanding of the condition and the effects of treatment. Deane and Playford (2003) recognise that patients are



often more accurate in the assessment of their symptoms than health professionals. In relation to reporting the effects of treatment, Edwards et al (2002) suggests only patients can fully understand the benefits of rehabilitation, and physician-reported outcome measures are actually likely to underestimate this. For this reason, clinician completed subjective and objective measures, and patient-reported outcome measures should be used in combination to gain a comprehensive assessment of the treatment delivered (Hobart et al., 1996, Fitzpatrick, 2003).

Finally, the therapists were asked to rank agreement in relation to the timing of outcome measurement. In agreement with the survey of best practice for occupational therapy in PD (Deane et al., 2003a), there was unanimous consensus for recording measures prior to initiating treatment and at the end of a course of therapy. Ninety-one percent felt best practice also constituted the measurement of outcome pre- and post treatment session. There is no recent guidance on the timing of outcome measurement in relation to treatment, although guidelines created following completion of the PD: PEP did advocate measurement before and after a course of treatment and throughout the treatment course to help determine the length of therapy delivery (Plant et al., 2001). Interestingly, there was no consensus surrounding the timing of outcome measurement in relation to “on-off” fluctuations, despite clear guidance from the Dutch guidelines suggesting that measurement should be performed at the same time of the day as the initial assessment (assuming the patient takes their medication at the same time each day) (Keus et al., 2004b). This indicates, again, a gap between what is recommended and what clinical therapists feel is achievable best practice.

### **3.4.3 Limitations of the Study**

The main limitations of this study have arisen because of the sampling methods. Responders had an interest in PD and best practice, therefore it is likely that the respondents reflect a

higher degree of specialism than may be found in general work force. The mean length of time since qualification (17.6 years) indicates a degree of seniority in this sample; however, this would also be true of earlier studies.

Other limitations occurred due to the content and phrasing of the questions and statements included. For example, both the current questionnaire and best practice survey failed to capture how outcome assessment changes (or should change) over time. This is a particularly important factor in PD which, as a degenerative condition, goes through a number of phases throughout the disease process, each requiring a different approach to its management. It would have also been useful to include outcome measures listed within guidelines within the best practice survey in order to further ascertain the therapists' knowledge of the evidence, and also to identify any gaps between recommended best practice and what is perceived as best practice by clinicians. Whilst a systematic, structured approach was utilised to develop the Delphi statements for best practice, it may be that important issues warranting inclusion were missed. Finally, whilst the survey documents were piloted, there is still always a slight risk of limitation through the phrasing utilised in the questions and statements.

### **3.5 Conclusions**

This study found that the majority of physiotherapists surveyed did use outcome measures within their current practice when treating people with PD, and a similar number was used regardless of level of experience or expertise. This suggests that therapists are aware of the importance of outcome measurement. The outcome measures listed by the therapists were wide ranging, although there was a focus primarily on gait, balance and mobility, and measurement of outcome at the level of activity performance was preferred. The top five outcome measures listed were the Berg Balance Scale, Timed Up and Go, timed walk, LPA and the Tinetti POMA. When compared with the outcome assessments used by other health

professions for PD, minimal overlap was apparent, reducing the opportunity for sharing between teams. Multidisciplinary guidelines that specifically address outcome measurement may help to encourage the use of global measures in favour of profession-specific assessments, supporting communication between teams to optimise care. Some of the measures reported could be identified within disease specific guidelines, but differences between practice and these documents existed, highlighting the need for further support for guideline dissemination.

With regards to the Delphi statements, consensus provided an insight into the therapists' perceptions of best practice in relation to the focus of outcome measurement, the structure of measures to be used, timing in relation to treatment, and the uses of outcome measures. Although agreement with guidelines and current practice was evident for certain aspects, contradictions were also apparent, particularly when considering outcome measurement in the context of the WHO ICF framework. There was also a lack of agreement surrounding the timing of outcome measurement and clinical fluctuation, despite guidance being available on this issue. This highlights a gap between expert generated guidelines and the perceptions of achievable best practice by clinical therapists. Future guidance should build on the implementation advice documented previously, detailing outcome measurement procedures that both constitute best practice and are also practically viable.

Support for outcome measures was strong with physiotherapists agreeing on most aspects of their focus and application. In light of this support, and the numerous outcome measures being utilised, it is important that physiotherapists consider and investigate the feasibility and acceptability of the measures they use and understand the role research projects can play in facilitating this. Study Three, a pilot randomised controlled trial investigating an

individualised exercise programme, demonstrates how both interventions and outcome measures can be assessed for their suitability in certain situations.

## **4 STUDY THREE: A PILOT RANDOMISED CONTROLLED TRIAL OF SUPPORTED COMMUNITY EXERCISE IN PEOPLE WITH PARKINSON'S DISEASE**

### **4.1 Introduction**

As discussed in Chapter 1, Parkinson's disease (PD) is a common neurodegenerative condition, thought to affect around 120,000 people in the UK alone (Parkinson's UK, 2008b). The management of PD usually centres on the provision of pharmacological therapy (Deane et al., 2001e), but even with optimal medical treatment in place, impairments, activity limitations and restriction of participation can develop (Keus et al., 2009). For this reason, additional management strategies are employed.

Exercise is often recommended for people with PD (Reuter and Engelhardt, 2002). From a physiological perspective, it is thought to stimulate dopamine synthesis, resulting in reduced symptoms in PD (Sutoo and Akiyama, 2003). Animal models have also suggested that exercise may have a neuroprotective effect, enhancing the survival of remaining dopaminergic neurones (Yoon et al., 2007). With regards to the reported benefits of exercise in people with PD, a paucity of evidence was noted for a long time and initial systematic reviews of the literature (Deane et al, 2001b; 2001e) failed to draw conclusions with regards to efficacy due to the limited methodological quality, small sample sizes, and the possibility of publication bias in published studies. However, within the last decade the evidence base has increased and moved forward. More recent trials have found the positive effects of exercise to be wide-ranging, from improvements in overall physical functioning and health-related quality of life (Goodwin et al., 2008), to reports of increased efficacy in administered Levodopa (Muhlack et al., 2007). Furthermore, the beneficial effects of exercise directly map onto the framework for physiotherapy in PD identified in Study One. A positive effect on *quality of movement* has been noted through multiple RCTs, particularly exemplified in

relation to gait by an increase in speed and stride length, and a reduction in cadence (Miyai et al., 2002, Protas et al., 2005). Improvement in the muscle strength aspect of *general fitness* have been confirmed through a meta-analysis of the existing literature (Goodwin et al., 2008), and increased endurance levels has been noted within a number of randomised trials (Stozek et al., 2003, Kurtais et al., 2008). Furthermore, exercise embodies the *self-management* advocated within physiotherapy for PD, and may actively support social *participation*. However, whilst two systematic reviews recently published have both identified the positive effects of exercise in PD, they have still noted that improvements could be made within the evidence base, particularly with regards to trial methodological quality and the reporting of research (Kwakkel et al, 2007; Goodwin et al, 2008). This signifies a need for further research if the place of exercise in the management of PD is to be confirmed.

Whilst exercise may be beneficial to people with PD, the physical activity levels exhibited within this population are known to be lower than those of healthy age-matched controls (Fertl et al., 1993). A number of barriers to participation in exercise have been reported by people with neurological conditions, including those with PD, such as inaccessible facilities, the costs of exercise and travel, a lack of relevant knowledge held by fitness professionals resulting in uneducated advice, and insufficient support (Elsworth et al., 2009). It has been hypothesised that by addressing these barriers via a community support system, people with neurological conditions may be encouraged to participate in physical activity (Elsworth et al., 2009), but at present there has been no research conducted regarding the application of supportive mechanisms to exercise interventions in this population. In light of this, there is a clear need for a research trial investigating a supported exercise programme within people with PD.

This chapter reports on a pilot study that aimed to assess the feasibility and acceptability of delivering an individualised exercise programme, supported by a Physical Activity Support System (PASS) with physiotherapeutic input, within community leisure centres for people with PD. This study was conducted as part of a larger exercise trial in people with long-term neurological conditions (Elsworth et al., 2011).

## 4.2 Methods

The study was conducted between November 2007 and July 2009 as an exploratory randomised controlled trial (RCT). The design of the study is illustrated in Figure 3.

Patients with PD were recruited from outpatient neurology clinics across Oxfordshire and the West Midlands, local Parkinson's UK support groups and the Dementias and Neurodegenerative Diseases Research Network (DeNDRoN). Patients were deemed eligible to participate if they were aged eighteen years or over, had a confirmed diagnosis of idiopathic PD (Gibb and Lees, 1988), were able to walk 10 metres using any aid or assistance as required, and had no cognitive, sensory or psychological impairments that could prevent participation in the study or put the participant at risk (as judged by the patient's physician).

Participants who consented to participate were then randomised to receive either the exercise programme (intervention group) or continue with their usual care (control group). Randomisation occurred at the level of the individual and participants were stratified by level of activity limitation through completion of the Barthel Activities of Daily Living (ADL) Index (Mahoney and Barthel, 1965) at baseline assessment. Participants were stratified as presenting with some, or significant, limitations on the Barthel ADL index (scoring 16-20/20 and 1-15/20 respectively), and randomisation occurred using computer generated random

block sizes of four. The group allocation was revealed to the treating physiotherapist, but concealed to the assessor.

Participants randomised to the exercise programme began the intervention immediately following randomisation. This consisted of a gym induction followed by exercise sessions delivered at community leisure centres across Oxfordshire and Birmingham. The exercise programme was personalised to address each individual's own needs and driven by participant-led goals. During their gym inductions, participants were familiarised with the environment, equipment and staff. They were assessed by their fitness instructor and, through collaboration, a fitness programme was designed. Whilst the intervention was created to specifically address each individual's own requirements and goals, programmes typically included components of endurance, muscle strength, flexibility and cardiovascular fitness, and were designed to progress over the course of the intervention period. The intensity, duration and frequency of exercise were also decided at this point. Following the induction, participants attended the gym for a three month period, with the number and length of sessions being determined by the individual. An example of an exercise programme undertaken by a participant within this trial is given in Appendix C.

The PASS was delivered alongside the intervention to reduce any barriers to exercise. Full details can be found at <http://www.brookes.ac.uk/lifesci/lifepass> and have been published elsewhere (The Long-term Individual Fitness Enablement (LIFE) group, 2011). In summary, the PASS took into consideration the support required from fitness professionals, the importance of the exercise setting, and any financial assistance. The exercise intervention was delivered within local authority gymnasiums with Inclusive Fitness Initiative (IFI) or pending IFI status. These centres make exercise accessible by providing a suitably adapted environment, physically accessible equipment, and trained fitness staff with knowledge of a



range of health conditions (<http://www.inclusivefitness.org/>). Physiotherapeutic support was available to participants and fitness professionals for the duration of the exercise programme, with therapists providing information, practical advice and physical support as required. Financial assistance was made available for gym and transport costs.

Participants allocated to the control group continued with their usual care for the three months following randomisation in order to provide a comparison for the intervention group. Following this, participants were offered the exercise intervention described above and all accepted it.

Participants were assessed at baseline (before randomisation), three months (immediately following the intervention) and six months (follow up). The primary outcome measure was the Physical Activity Scale for the Elderly (PASE); a seven day self-report questionnaire recalling community-based activity and mobility (Washburn et al., 1993). Secondary outcome measures included average step count recorded via an ankle attached Step Activity Monitor (SAM) (Resnick et al., 2001), mobility speed and endurance recorded through the ten metre and two minute walk tests respectively (Kersten, 2004), lower limb muscle strength and hand grip strength, fatigue as measured by the Fatigue Severity Scale (FSS) (Krupp et al., 1989), cognition as recorded through the Short Orientation Memory Concentration test (SOMC) (Wade and Vergis, 1999), and quality of life measured through the Parkinson's Disease Questionnaire-39 (PDQ-39) (Peto et al., 1995). Number of falls was recorded as an adverse event, and other adverse events were also monitored (e.g. cardiovascular events). Baseline demographics for age, sex, body mass index, and the Barthel Activities of Daily Living Index score (Mahoney and Barthel, 1965) were also collected, and following completion of the exercise programme, participants were asked to provide feedback via an optional questionnaire.

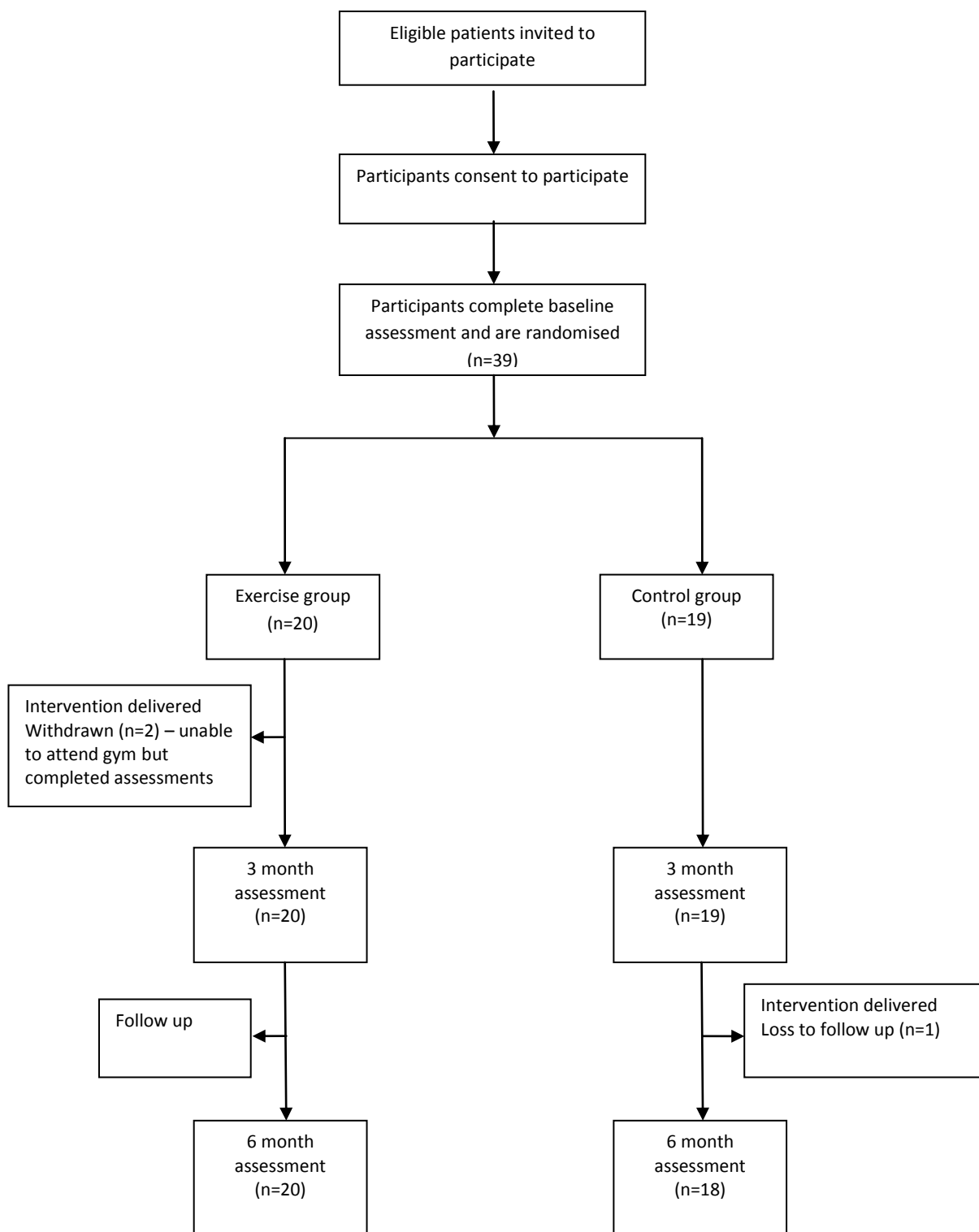
An exploratory intention to treat analysis was conducted for the demographic data and outcome measures. The two arms of the trial (intervention and control groups) were compared using the t-test at each time point.

Ethical approval (plus local site specific approval) for this study was granted by Oxfordshire Research Ethics Committee (07/H0606/81).

### 4.3 Results

Figure 3 shows the flow of participants through the study. Thirty-nine participants with PD were recruited, of which 20 were randomly assigned to the exercise group and 19 to the control group. There was one loss to follow up during the study in the control group. This occurred following the three month assessment and was due to medical reasons unrelated to the trial. Two patients from the exercise group completed the assessments but withdrew from the intervention, and one participant from the control group did not attend the gym during their allocated period (between three and six months) but still completed the assessments.

Assessments occurred on time and completion of the outcome measures was good. The primary outcome measure, the PASE, was reported for all participants at baseline, 38 out of 39 (97%) participants at three months, and 35 out of 38 (92%) active participants at six months. Data completion for all other outcome measures across the assessment time points ranged from 92% to 100% for the self-report questionnaires, and 76% to 100% for the objective measures recorded.



**Figure 3: Design of Study and Participant Flow Through**

Uptake of the intervention was good, with 34 out of the 39 participants (87%) carrying out the exercise programme. Gym attendance data was available for 32 out of the 39 participants and the median gym attendance was 12 visits, with an interquartile range of 12 and a range of 2 to 31 visits.

The demographic characteristics of the intervention and control groups were similar, with no significant differences between the two. In the intervention group the mean age was 63 years (5 female/ 15 male) and mean body mass index was 27.3 kg/m<sup>2</sup>. In the control group the mean age was 65 years (3 female/ 16 male) and mean body mass index was 28.2 kg/m<sup>2</sup>. The mean durations of disease were 5.1 years and 4.7 years in the intervention and control groups respectively, and the mean Barthel Index Score was 19/20 for both groups.

Data was collected for the outcome measures at baseline, three months and six months in each group, and the mean differences between the groups were calculated at each time point. Data collected at the baseline and three month assessments allowed for comparison between the group receiving the intervention immediately post randomisation, and the control group. Data collected at 6 months illustrated the carry over within the intervention group at follow up, and the immediate effect of the exercise programme on the control group. Statistical analysis revealed that there was no significant difference between the groups for any of the outcome measures or at any of the time points. Results for the PASE, two minute walk test, PDQ-39 and SAMs are summarised in Table 18, and illustrated graphically in Figure 4.

**Table 18: Summary Statistics of Selected Results at Baseline, 3 Months and 6 Months**

Measure		Immediate Exercise		Delayed Exercise (Control)		Mean Difference (95% CI)
		N	Mean (SD)	N	Mean (SD)	
PASE	Baseline	20	121.1 (55.4)	19	110.7 (56.4)	10.4 (-25.9 to 47.9)
	3 months	19	128.5 (38.3)	19	134.9 (75.9)	-6.4 (-46 to 33.1)
	6 months	20	116.8 (54.2)	15	91.5 (50.7)	25.3 (-10.6 to 61.2)
2-min walk	Baseline	19	133.5 (26.2)	18	134.8 (39.0)	-1.4 (-23.4 to 20.7)
	3 months	20	139.6 (36.4)	19	135.5 (38.4)	4.1 (-20.2 to 28.4)
	6 months	20	142.8 (31.2)	18	139.0 (39.4)	3.8 (-19.4 to 27.1)
PDQ-39 (SI)	Baseline	19	27.6 (16.1)	17	27.6 (17.9)	-0.09 (-11.6 to 11.5)
	3 months	20	25.0 (15.1)	19	24.5 (16.9)	0.47 (-9.9 to 10.9)
	6 months	20	25 (18.6)	17	26.2 (19.6)	-1.2 (-13.9 to 11.6)
SAMS	Baseline	18	3785.7 (1880.0)	16	3599.0 (2340.0)	186.7 (-1289 to 1662)
	3 months	16	3139.7 (2014.3)	16	3030.4 (1948.0)	59.3 (-1371 to 1490)
	6 months	16	3829.5 (1371)	13	3749.8 (3099.3)	79.8 (-1686 to 1846)

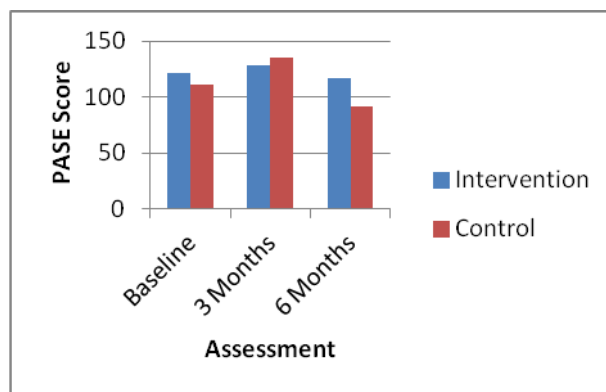


Figure 4a: Comparison of average PASE score at each time point  
PASE (Patient Activity Scale for the Elderly): Range: 0 – 400+ (bad – good)

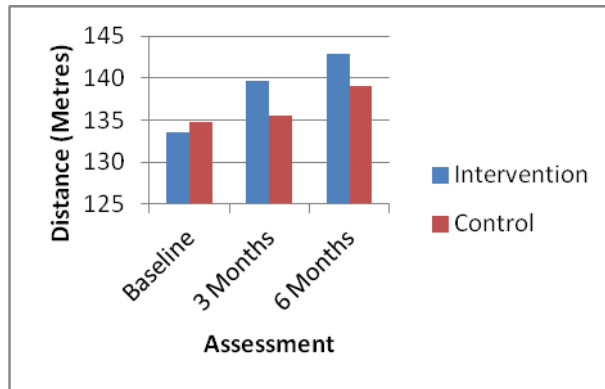


Figure 4b: Comparison of average Two minute walk test scores at each time point  
Higher score= positive

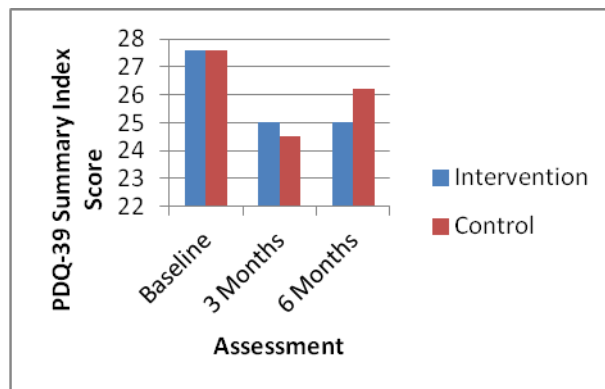


Figure 4c: Comparison of average PDQ-39 summary scores at each time point  
PDQ-39 (Parkinson's Disease Questionnaire-39): Range: 0 – 100 (good – bad)

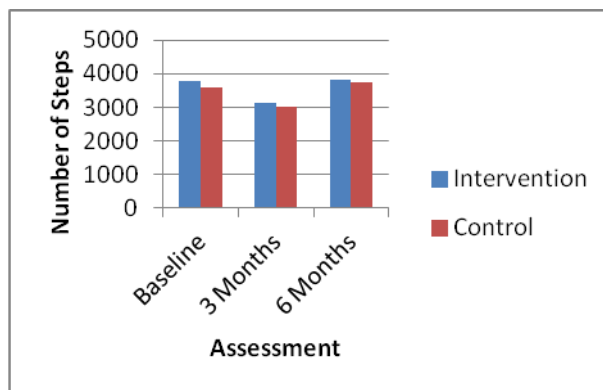


Figure 4d: Comparison of average step count at each time point  
Higher score= positive

**Figure 4: Results for Outcome Measurements**

Because both groups received the intervention, the data from outcome measures was pooled to allow statistical analysis of the whole study sample before and after treatment. Again, there was no significant difference between the means for the pooled before and after data for any measure. Four participants reported falls at each time point in the intervention group, although the number of falls per patient decreased following the intervention. The number of fallers increased following delivery of the exercise programme to the control group after the three month assessment. No other adverse events were reported.

Participant feedback following completion of the exercise programme was largely positive. It identified that good gym access, the attitudes of staff, the type of equipment available, and support from the fitness professional and physiotherapist were all important factors in the success of the exercise programme. Most participants reported that they were confident to exercise following the intervention, with the majority ranking this as 8/10 or above. Encouragingly, most participants also stated that they would continue to exercise following completion of the trial, with one participant even stating that “exercise is, without doubt, the way forward to maintain a more flexible frame”. When asked to identify any aspects of the exercise experience that could be improved, participants highlighted that a slightly more structured and varied programme may be useful, and that more input regarding progress throughout the programme would be beneficial. One participant also felt they would be encouraged to exercise harder if a competitive element was introduced, and a number of participants indicated that the exercise experience would be improved if the gym facilities were closer to their home.

#### 4.4 Discussion

As a pilot study, this trial aimed to test the feasibility and acceptability of the exercise programme, and other elements such as the control intervention used and the outcome measures employed. Due to the small size of the study, there were an insufficient number of patients to test the actual effectiveness of the intervention, and so it is unsurprising that there were no significant differences between the groups for any of the outcome measures.

Delivery of the exercise intervention with the PASS, and within the community leisure centre setting, was proved to be feasible through completion of the trial, whilst its acceptability was confirmed by participants' uptake of the programme. Eighty-two percent of participants (32 out of 39) randomised to the trial were confirmed to have completed the intervention through the availability of gym attendance data. Whilst this data was lost for three participants during a database system switchover, analysis of the PASE questionnaires for these participants uncovered that two of the three did attend the gym during their allocated time period. Therefore, a total of 87% of participants undertook the exercise programme. This is higher than the 61 and 71% reported in a RCT of a physical activity intervention in 424 older adults (Pahor et al., 2006), and much higher than the uptake of 35% recorded in a trial of primary care delivered physical activity for sedentary, healthy adults (Stevens et al., 1998). Support for the exercise intervention within our trial was further evident through the positive feedback from participants at the end of the programme, and the reported confidence to exercise following completion of the intervention. However, the number of gym attendances by participants was variable, with the number of visits per participant ranging from 2 to 31. This may indicate that, whilst the PASS supported some participants in a very effective manner, for others additional barriers and personal circumstances could have impacted on their ability to regularly exercise. This was particularly apparent from the reasons given by participants for withdrawing from the intervention. One participant was still



in full time employment and working shift pattern hours which led to difficulties fitting the gym programme into their daily schedule, whilst the other participant already exercised regularly and felt the programme was unable to enhance their current physical activity regime. This indicates that the exercise programme and its associated supportive system may have to be developed and modified if it were to be tested further, and finally implemented in practice.

Other elements of the trial also proved to be feasible and acceptable. The usual care comparator was accepted by participants, with only one participant dropping out (for unrelated medical reasons). The randomisation to no exercise may have been helped by the fact that participants could then receive the exercise programme following the three month assessment, as this crossover design has led to minimal loss to follow up in previous RCTs in PD (Nieuwboer et al., 2007).

The outcome measures used within the trial were also confirmed to be feasible and acceptable through their high completion rates. With regards to the types of measures included within the battery of assessments, they were broad in approach. In relation to the WHO ICF model (World Health Organization, 2001) discussed within Studies One and Two, the measures included within this trial can be seen to cover all domains. For example, body function and structure was examined through the measurement of muscle strength and inclusion of the SOMC, activities was measured through the PASE, step count, mobility speed, and mobility endurance, and participation was considered within questions included in the FSS and PDQ-39 (although it must be noted that the PDQ-39 covers all levels of the model). Despite this holistic approach, there was a large focus upon activity limitation, as exemplified by the use of the PASE as primary outcome measure. This is in agreement with the focus of physiotherapists noted within Study Two, and the recommendations outlined within the Dutch guidelines (Keus et al., 2004b). Whilst many of the assessments utilised

within this trial could be seen to be largely physiotherapy specific, the inclusion in particular of the PDQ-39 opens the findings of the study up to all members of the multidisciplinary team, encouraging the sharing of measures across professions that was advocated in Study Two. A further positive may be seen in the use of a patient rated assessment as the primary outcome measure; in Study Two this was identified as a means of capturing the true effect of an intervention due to the potential under-reporting of effect by clinicians (Edwards et al, 2002). However, some issues were noted, particularly with the PASE questionnaire. Whilst this measure has been previously tested for validity and reliability (Washburn et al., 1993), the questionnaire does include elements such as “walking outside the home”, “lawn work” and “outdoor gardening”. These activities may be affected by season, particularly due to weather in the UK, and so their inclusion may counteract any increases seen due to participation in exercise. If the study was to be repeated in a larger group of PD patients, alternative physical activity questionnaires may be considered.

The trial had several limitations. The sample size was small and participants within the trial were all of a high functioning nature (indicated through the high Barthel index scores). Therefore, the sample was not representative of the highly variable PD population. The trial design did not allow for any comparison of carryover from the intervention with a control group receiving no care, and additional factors outside the intervention (such as physiotherapy and medication) were not controlled or monitored and so could have potentially impacted on the intervention. Despite these limitations, the study provided important information as, although the area of exercise and physiotherapy research in PD has grown substantially over the last decade (Keus et al., 2009), and previous trials have included physical activity levels as one of their outcome measurements (Keus et al., 2007b), no trial had focused on the delivery of an exercise intervention primarily for improving physical activity levels in this population.

Since completion of this study, a large, multicentre RCT of 586 people with PD has commenced investigating a different, multifaceted behavioural intervention for improving physical activity levels (van Nimwegen et al., 2010). Due to the large numbers of patients within this trial, the findings should give a clearer indication of the clinical effectiveness of an intervention for improving physical activity levels in people with PD.

#### **4.5 Conclusions**

This trial has confirmed the feasibility and acceptability of an individualised and supported exercise intervention, delivered within community leisure centres for people with PD, illustrated through the high uptake of the exercise programme. In order to confirm the effectiveness of this intervention, a full scale trial is now required.

## **5 SUMMARY OF MAIN FINDINGS AND DISCUSSION**

In this Section the main findings are summarised and put into context, highlighting the original findings and their relationship to existing studies. The section also outlines the limitations to the studies, both methodological and others that arose because of time and funding limitations. Finally, the implications to clinical practice and research are sign posted and discussed.

### **5.1 Summary of Main Findings**

#### **5.1.1 Study One: Defining UK Physiotherapy Practice in Parkinson's disease- A survey of current and perceived best practice**

- The modified Delphi study of 76 physiotherapists found that current physiotherapy practice was predominantly delivered within a primary care setting; an aspect that echoes the findings of previous surveys (Plant et al, 2000) Referral was most likely to occur from the PD Nurse Specialist, although a movement towards self-referral for initiating treatment and re-accessing physiotherapy could be seen. The majority of referrals occurred during the maintenance phase of PD, despite support within the literature for access throughout the course of the disease and, in particular, early referral in order to prevent deterioration. The majority of physiotherapists worked as part of a multidisciplinary team, but very few reported that the care delivered was coordinated by a single key worker. The delivery of current practice physiotherapy for PD was variable, with therapists utilising both individual and group sessions with patients. Regarding dose, a median of six sessions was reportedly delivered over eight weeks, with a median assessment length of 60 minutes, and a median follow up session length of 45 minutes.

This is comparable with physiotherapy practice reported a decade ago, which reported an average dose of one to two sessions weekly over a period of six to eight weeks (Ashburn et al., 2004).

- The best practice element of this study found high levels of agreement surrounding the reasons for delivering physiotherapy, leading to the formulation of the following framework for physiotherapy in PD: “to maximise quality of movement, functional independence and general fitness, and minimise secondary complications whilst supporting self-management and participation, and optimising the safety of the individual”. Ranking of the core areas of physiotherapy identified a focus on gait and freezing of gait, indoor and outdoor mobility, balance and falls, transfers, posture, and physical conditioning, through unanimous consensus, and there were also lower levels of consensus for addressing self care, domestic ADL and work-related activities, highlighting a blurring between the boundaries of physiotherapy and occupational therapy. Best practice treatment provision was thought to have a patient-centred approach. When considering the efficacy of specific interventions, there were high levels of consensus for treatment techniques related to gait, balance, physical conditioning and the rehabilitation of transfers, but less certainty surrounding the rehabilitation of posture and the upper limb; this was believed to be affected by the evidence available to guide practice and the clinical experience of the therapist (the latter often being shaped by the need to prioritise patient complaints due to time constraints).

### **5.1.2 Study Two: Outcome Measurement in Physiotherapy for Parkinson’s Disease- A Survey of Current and Perceived Best Practice in the UK**

- Utilisation of outcome measures within current practice was found to be high, with the majority of therapists identifying assessments used with PD patients and reporting an

average of 3.7 outcome measures per therapist. This shows great improvement on practice reported in the previous decade – for example, in a survey of physiotherapy for stroke rehabilitation, only 10 of the 91 respondents reported using what they perceived as standardised assessments and only one therapist utilised a published assessment (Sackley and Lincoln, 1996). In comparison with other allied health professions treating PD, the current level of outcome measurement was in line with that reported for speech and language therapists, but there was minimal overlap between the types of outcome measures used by physiotherapists, occupational therapists and speech therapists, leaving little opportunity to share measures between teams. Some overlap existed between outcome measures used in current physiotherapy practice and those recommended in guidelines, but the assessments utilised by therapists varied widely, highlighting potential issues with the dissemination of this guidance.

- For perceived best practice, consensus outlined a clear focus for assessment, the structure of measures, timing, and the uses of outcome measurement, but was less clear regarding assessment and the World Health Organisation International Classification of Functioning, Disability and Health model (WHO ICF model) (World Health Organisation, 2001), and outcome measurement and clinical fluctuation. Contradictions could be seen between perceived best practice, current practice, and the recommendations for outcome measurement laid out in guidelines. For example, the therapists identified that best practice outcome measurement should be aimed at the level of activity limitation only on the WHO ICF model, but also stated that measures of health-related quality-of-life should be used (an aspect which often covers all domains of the WHO ICF model), and listed measures of structure/ function

impairment and participation within their current practice. Equally, the most recent UK guidelines identify that best practice physiotherapy for PD should utilise measures from all three levels of the framework (Ramaswamy et al, 2009).

### **5.1.3 Study Three: A pilot randomised controlled trial of supported community exercise in people with Parkinson's disease**

- This small pilot trial (n=39) found an exercise programme (with a physical activity support system and physiotherapeutic support) was both feasible and acceptable, with 87% of the participants completing the programme; a figure much higher than those previously reported for physical activity interventions within adults. This was further supported by qualitative evidence from the feedback received from individual participants. However, although gym attendance was good (median 12 visits) there was variability, indicating that the programme did not optimally support all participants. This was further evident from the reasons given by participants for withdrawing from the intervention. One participant was still in full time employment and working shift pattern hours which led to difficulties fitting the gym programme into their daily schedule, whilst the other participant already exercised regularly and felt the programme was unable to enhance their current physical activity regime. This indicates that the exercise programme and its associated supportive system may have to be developed and modified if it were to be tested further, and finally implemented in practice. The trial also found the usual care comparator to be an effective control, with minimal loss to follow up reported, and the outcome measures utilised were also proven to be acceptable through high completion rates, although difficulties were noted with the primary outcome measure: the PASE.

## 5.2 Summary of Study Limitations

- For Studies One and Two, limitations may have arisen due to the sample of therapists that participated. Despite using broad inclusion criteria and recruiting participants from multiple sources, the therapists included were actually highly experienced practitioners in terms of both years qualified and the number of people with PD treated per annum; a product potentially of the non-random sampling methods used, the sample size and the number of dropouts between the first and second round.
- Further limitations for these two studies may have occurred due to the modification of the Delphi methodology (the utilisation of a literature search to create statements instead of a free text first round from the expert panel), as this could have constrained the therapists' responses or caused important issues to be missed. There is also always a slight risk of limitation through the phrasing utilised within questionnaires and survey documents, although a piloting phase was used to minimise the effect of this.
- The final limitation for Studies One and Two occurred due to the content of the survey, as it failed to allow close comparison between current and perceived best practice (as the current practice survey focused on the structure and delivery of physiotherapy services, and the best practice Delphi element captured the content and focus of therapy delivered). The survey was also unable to capture how therapists alter their practice throughout the course of the disease to accommodate the individual, specific needs of the patient.
- For the trial of community based exercise in PD (Study Three), one of the main limitations arose from the sample included, as the sample size was small and participants were all high functioning, reducing the representativeness the sample and generalisability of the findings. The limitations of funding and the time available led



to the small sample size. The bias towards people with high levels of function may, to some extent, be due to the availability of accessible gym places (particularly in Birmingham) and the opening time limitations of the few that were adapted. For example, one was based within a school and only open to the public outside school hours.

- Study Three was also limited through the trial design, which did not allow for any comparison of longer term follow up of the intervention against a control group receiving no care. This was because of the requirements of the ethical reviewers to make the intervention available to the control group as soon as the primary time point was reached. Issues were also noted with the primary outcome measure, as the content of the PASE questionnaire led to a seasonal effect, potentially counteracting any increases seen in self-reported physical activity levels due actual to participation in exercise.

### **5.3 Implications for Clinical Practice**

- The findings of the best practice elements of Studies One and Two may be used to help shape physiotherapy practice, providing therapists with a framework for the focus, content and delivery of care in order to improve the quality of patient management. This would especially be true in areas where strong evidence currently does not exist (e.g. the delivery of specific treatment techniques for the rehabilitation of transfers). However, it must be noted that the findings of these surveys are based on therapist opinion rather than strong evidence, and so their application to practice would have to be approached with caution.

- The survey discussed within Studies One and Two also highlighted issues with therapist access to published guidelines, and this identified a need for further support for document dissemination within clinical practice. The studies also indicated the need for further guidance to be published for clinical practice, particularly to support the practical implementation of recommendations and to encourage allied health professionals to share outcome measures in order to improve communication and optimise patient care.
- Finally, Study One highlighted the emergence of self/ carer referral to physiotherapy within the management of PD, and this may be something to be supported in clinical practice to help optimise access to therapy for this population.
- The findings of Study Three are currently unsuitable for translation into practice, as the trial conducted was only a phase II pilot study, aimed at assessing the feasibility and acceptability of the exercise programme, control comparator and outcome measures, rather than the effectiveness of the intervention.

#### **5.4 Implications for Research**

- As identified within Section 5.2, the therapists surveyed within Studies One and Two were highly experienced practitioners, which may have led to a biased illustration of current and perceived best practice physiotherapy and outcome measurement for PD. Therefore, it may be useful for further, similar surveys to be conducted which either purposely target more junior therapists to provide a comparative sample for the survey already carried out, or simply a larger sample of physiotherapists could be surveyed with the hope of capturing a more diverse population simply by increasing sample size. The chance of contacting a wider range of physiotherapists may potentially be

strengthened by approaching therapists via governing bodies such as the Chartered Society of Physiotherapy and the Health Professions Council.

- If the survey described in Study One was to be repeated, it would provide an opportunity for more close comparison between current and perceived best practice, through slight amendment of the survey documents. By introducing questions focused on capturing the content of current physiotherapy treatment for PD, or by requesting details of a patient case study as carried out in the Dutch survey by Keus et al (2004a), the findings could then be compared directly to what therapists perceive best practice treatment to include. The current practice questionnaire and best practice Delphi statements could also be further modified to capture useful information on how therapists alter practice throughout the duration of the disease.
- It may be noted that the survey of current and perceived best practice for physiotherapy in PD (Study One) also identified numerous areas that require further trial-based research if physiotherapy practice for PD is to become truly evidence based. At present there is no evidence for the best time for referral to physiotherapy, or for the optimal content, dose, setting or delivery of therapy. The survey helped to identify core areas within physiotherapy for PD which will require further robust evidence to determine effective treatment techniques (e.g. the rehabilitation of transfers, posture and upper limb).
- In addition, Study One indicated a move towards self-referral and self-management; both elements need further RCT-based investigation if they are to be effectively incorporated into practice.
- The pilot exercise trial provided information on feasibility and acceptability. However, if Study Three was to be further developed into a Phase III trial, limitations noted

within this study would have to be addressed. Further research conducted would either require a broader sample in terms of participant level of functioning and duration of disease, to ensure trial findings could be applied to the widely varying PD population, or another pilot study could be conducted, specifically targeting people within the later stages of PD, to assess if the interventions and outcome measures were also feasible and acceptable within this population. Equally, the content of the individualised exercise programme would require refining and expanding, and other exercise settings may need to be considered (e.g. other community leisure facilities), as the type of exercises included were found to be insufficient for some participants that already exercised, and the use of IFI gyms only was restrictive due to location and opening times. Any further trials would also need to include a longer term follow up to assess the sustained effect of the exercise programme, and it would be beneficial to utilise additional physical activity measures, due to seasonal limitations noted for the PASE. For example, the Phone FITT and General Practice Physical Activity Questionnaire have been specifically recommended in recent UK guidelines for physiotherapy practice in PD (Ramaswamy et al, 2009).

- In order to develop Study Three into a Phase III trial, a much larger sample size would be required to accurately assess the effectiveness of the intervention. A sample size calculation has already been completed using the data generated from the primary outcome measure within the study (the Physical Activity Scale for the Elderly - PASE), and the clinically significant difference of 5% utilised within a previous sample size calculation for an exercise trial within stroke (Krarup et al., 2008). To detect a 5% difference in PASE score (20 points), assuming a standard deviation of 58.8 at a 5% level of significance and a 90% power, 183 patients would be required

per arm (366 in total). Assuming a 10% drop out rate, 201 patients would be required per arm, resulting in an overall sample size of 402 participants for a full scale trial.

## 6 REFERENCES

- Abrams, D., Davidson, M., Harrick, J. et al. (2006). Monitoring the change: current trends in outcome measure usage in physiotherapy. **Manual Therapy**, 11, 1, 46-53.
- Agid, Y. (1991). Parkinson's disease: pathophysiology. **Lancet**, 337, 8753, 1321-4.
- Akins, R.B., Tolson, H. and Cole, B.R. (2005). Stability of response characteristics of a Delphi panel: application of bootstrap data expansion. **BMC Medical Research Methodology**, 5, 37.
- All Party Parliamentary Group for Parkinson's Disease (2009). **Please mind the gap: Parkinson's disease services today**. London: Parkinson's UK.
- Aragon, A. and Kings, J. (2010). **Occupational therapy for people with Parkinson's: Best practice guidelines**. London: Parkinson's UK & College of Occupational Therapists.
- Ashburn, A., Fazakarley, L., Ballinger, C. et al. (2007). A randomised controlled trial of a home based exercise programme to reduce the risk of falling among people with Parkinson's disease. **Journal of Neurology, Neurosurgery & Psychiatry**, 78, 7, 678-84.
- Ashburn, A., Jones, D., Plant, R. et al. (2004). Physiotherapy for people with Parkinson's Disease in the UK: An exploration of practice. **International Journal of Therapy and Rehabilitation**, 11, 4, 160-167.
- Baijens, L.W.J. and Speyer, R. (2009). Effects of therapy for dysphagia in Parkinson's disease: systematic review. **Dysphagia**, 24, 1, 91-102.
- Baker, J., Lovell, K. and Harris, N. (2006). How expert are the experts? An exploration of the concept of 'expert' within Delphi panel techniques. **Nurse Researcher**, 14, 1, 59-70.
- Baker, K., Rochester, L. and Nieuwboer, A. (2007). The immediate effect of attentional, auditory, and a combined cue strategy on gait during single and dual tasks in Parkinson's disease. **Archives of Physical Medicine & Rehabilitation**, 88, 12, 1593-600.
- Bauman, A.E., Fardy, H.J. and Harris, P.G. (2003). Getting it right: why bother with patient-centred care? **Medical Journal of Australia**, 179, 5, 253-6.

- Bilney, B., Morris, M.E. and Denisenko, S. (2003). Physiotherapy for people with movement disorders arising from basal ganglia dysfunction. **New Zealand Journal of Physiotherapy**, 31, 2, 94-100.
- Black, N. (2006). Consensus development methods. *In*: Pope, C. and Mays, N. (eds.) **Qualitative research in health care**. 3rd ed. Oxford: Blackwell Publishing LTD, 132-141.
- Bloem, B.R., Beckley, D.J., van Dijk, J.G. et al. (1996). Influence of dopaminergic medication on automatic postural responses and balance impairment in Parkinson's disease. **Movement Disorders**, 11, 5, 509-21.
- Bodenheimer, T., Lorig, K., Holman, H. et al. (2002). Patient self-management of chronic disease in primary care. **JAMA**, 288, 19, 2469-75.
- Bowling, A. (2002). **Research Methods in Health: Investigating Health and Health Services**, 2nd ed, Maidenhead: Oxford University Press.
- Braak, H., Del Tredici, K., Rub, U. et al. (2003). Staging of brain pathology related to sporadic Parkinson's disease. **Neurobiology of Aging**, 24, 2, 197-211.
- Canning, C.G. (2005). The effect of directing attention during walking under dual-task conditions in Parkinson's disease. **Parkinsonism & Related Disorders**, 11, 2, 95-9.
- Chartered Society of Physiotherapy (2005). **Core Standards of Physiotherapy Practice**. London: Chartered Society of Physiotherapy.
- Chartered Society of Physiotherapy (2008). **The Scope of Practice of Physiotherapy**. London: Chartered Society of Physiotherapy.
- Chaudhuri, K.R., Healy, D.G., Schapira, A.H.V. et al. (2006). Non-motor symptoms of Parkinson's disease: diagnosis and management. **Lancet Neurology**, 5, 3, 235-45.
- Cieza, A. and Stucki, G. (2005). Content comparison of health-related quality of life (HRQOL) instruments based on the international classification of functioning, disability and health (ICF). **Quality of Life Research**, 14, 5, 1225-37.
- Clarke, C.E. (2007). Parkinson's disease. **BMJ**, 335, 7617, 441-5.

- Clarke, C.E., Patel, S., Ives, N. et al. (2011). Should Treatment for Parkinson's Disease Start Immediately on Diagnosis or Delayed until Functional Disability Develops? **Movement Disorders**, 26 7, 1187-1193.
- Clouder, L. (2000). Reflective Practice: Realising its potential. **Physiotherapy**, 86, 10, 517-522.
- Comella, C.L., Stebbins, G.T., Brown-Toms, N. et al. (1994). Physical therapy and Parkinson's disease: a controlled clinical trial. **Neurology**, 44, 3 Pt 1, 376-8.
- Cooper, K., Smith, B.H. and Hancock, E. (2008). Patient-centredness in physiotherapy from the perspective of the chronic low back pain patient. **Physiotherapy**, 94, 244-252.
- de Lau, L.M.L. and Breteler, M.M.B. (2006). Epidemiology of Parkinson's disease. **Lancet Neurology**, 5, 6, 525-35.
- Deane, K., Ellis-Hill, C., Dekker, K. et al. (2003a). A Delphi Survey of Best practice Occupational Therapy for Parkinson's Disease in the United Kingdom. **British Journal of Occupational Therapy**, 66, 6, 247-254.
- Deane, K.H., Ellis-Hill, C., Playford, E.D. et al. (2001a). Occupational therapy for patients with Parkinson's disease. **Cochrane Database of Systematic Reviews**, 3, CD002813.
- Deane, K.H., Jones, D., Playford, E.D. et al. (2001b). Physiotherapy for patients with Parkinson's Disease: a comparison of techniques. **Cochrane Database of Systematic Reviews**, 3, CD002817.
- Deane, K.H., Whurr, R., Playford, E.D. et al. (2001c). A comparison of speech and language therapy techniques for dysarthria in Parkinson's disease. **Cochrane Database of Systematic Reviews**, 2, CD002814.
- Deane, K.H., Whurr, R., Playford, E.D. et al. (2001d). Speech and language therapy for dysarthria in Parkinson's disease. **Cochrane Database of Systematic Reviews**, 2, CD002812.
- Deane, K.H.O., Ellis-Hill, C., Dekker, K. et al. (2003b). A Survey of Current Occupational Therapy Practice for Parkinson's Disease in the United Kingdom. **British Journal of Occupational Therapy**, 66, 5, 193-200.



- Deane, K.H.O., Jones, D., Playford, E.D. et al. (2001e). Physiotherapy versus placebo or no intervention in Parkinson's disease. **Cochrane Database of Systematic Reviews**, 3, CD002817.
- Deane, K.H.O. and Playford, D. (2003). Non-pharmacological Therapies. *In*: Playford, D. (ed.) **Neurological Rehabilitation of Parkinson's Disease**. London: Martin Dunitz, 49-82.
- Department of Health (2008). **Self-referral pilots to musculoskeletal physiotherapy and the implications for improving access to other AHP Services**. London: Department of Health.
- Dereli, E.E. and Yaliman, A. (2010). Comparison of the effects of a physiotherapist-supervised exercise programme and a self-supervised exercise programme on quality of life in patients with Parkinson's disease. **Clinical Rehabilitation**, 24, 4, 352-62.
- Diem-Zangerl, A., Seppi, K., Wenning, G.K. et al. (2009). Mortality in Parkinson's disease: a 20-year follow-up study. **Movement Disorders**, 24, 6, 819-25.
- Dixon, L., Duncan, D., Johnson, P. et al. (2007). Occupational therapy for patients with Parkinson's disease. **Cochrane Database of Systematic Reviews**, 3, CD002813.
- Edwards, S.G.M., Playford, E.D., Hobart, J.C. et al. (2002). Comparison of physician outcome measures and patients' perception of benefits of inpatient neurorehabilitation. **BMJ**, 324, 7352, 1493.
- Elsworth, C., Dawes, H., Sackley, C. et al. (2009). A study of perceived facilitators to physical activity in neurological conditions. **International Journal of Therapy and Rehabilitation**, 16, 1, 17-24.
- Elsworth, C., Winward, C., Sackley, C. et al. (2011). Supported community exercise in people with Long-term Neurological Conditions: a phase II randomised controlled trial. **Clinical Rehabilitation**, 25, 7, 588-598.
- Epstein, R.M. (2000). The Science of Patient-Centred Care. **The Journal of Family Practice**, 49, 9, 805-807.
- Fahn, S. and Elton, R. (1987). UPDRS Development Committee. Unified Parkinson's Disease Rating Scale. *In*: Fahn, S., Marsden, C., Calne, D. et al. (eds.) **Recent Developments in Parkinson's Disease**. Florham Park, NJ.: Macmillan Health Care Information, 153-163, 293-304.

- Fahn, S., Oakes, D., Shoulson, I. et al. (2004). Levodopa and the progression of Parkinson's disease. **New England Journal of Medicine**, 351, 24, 2498-508.
- Fertl, E., Doppelbauer, A. and Auff, E. (1993). Physical activity and sports in patients suffering from Parkinson's disease in comparison with healthy seniors. **Journal of Neural Transmission - Parkinsons Disease & Dementia Section**, 5, 2, 157-61.
- Findley, L., Aujla, M., Bain, P.G. et al. (2003). Direct economic impact of Parkinson's disease: a research survey in the United Kingdom. **Movement Disorders**, 18, 10, 1139-45.
- Findley, L.J. (2007). The economic impact of Parkinson's disease. **Parkinsonism & Related Disorders**, 13 Suppl, S8-S12.
- Fink, A. (1995). **The Survey Handbook**, London: Sage Publications.
- Fink, A., Kosecoff, J., Chassin, M. et al. (1984). Consensus methods: characteristics and guidelines for use. **American Journal of Public Health**, 74, 9, 979-83.
- Fisher, B.E., Wu, A.D., Salem, G.J. et al. (2008). The effect of exercise training in improving motor performance and corticomotor excitability in people with early Parkinson's disease. **Archives of Physical Medicine & Rehabilitation**, 89, 7, 1221-9.
- Fitzpatrick, R. (2003). Evaluating the outcome of rehabilitation interventions. *In*: Playford, D. (ed.) **Neurological Rehabilitation of Parkinson's Disease**. London: Martin-Dunitz, 105-117.
- Gallagher, M., Hares, T., Spencer, J. et al. (1993). The nominal group technique: a research tool for general practice? **Family Practice**, 10, 1, 76-81.
- Gibb, W.R. and Lees, A.J. (1988). The relevance of the Lewy body to the pathogenesis of idiopathic Parkinson's disease. **Journal of Neurology, Neurosurgery & Psychiatry**, 51, 6, 745-52.
- Giovannini, P., Piccolo, I., Genitrini, S. et al. (1991). Early-onset Parkinson's disease. **Movement Disorders**, 6, 1, 36-42.
- Global Parkinson's Disease Survey Steering Committee (2002). Factors impacting on quality of life in Parkinson's disease: results from an international survey. **Movement Disorders**, 17, 1, 60-7.

- Goldman, J.E., Yen, S.H., Chiu, F.C. et al. (1983). Lewy bodies of Parkinson's disease contain neurofilament antigens. **Science**, 221, 4615, 1082-4.
- Goodwin, V.A., Richards, S.H., Taylor, R.S. et al. (2008). The effectiveness of exercise interventions for people with Parkinson's disease: a systematic review and meta-analysis. **Movement Disorders**, 23, 5, 631-40.
- Guo, L., Jiang, Y., Yatsuya, H. et al. (2009). Group education with personal rehabilitation for idiopathic Parkinson's disease. **Canadian Journal of Neurological Sciences**, 36, 1, 51-9.
- Haigh, R., Tennant, A., Biering-Sorensen, F. et al. (2001). The use of outcome measures in physical medicine and rehabilitation within Europe. **Journal of Rehabilitation Medicine**, 33, 6, 273-8.
- Hasson, F., Keeney, S. and McKenna, H. (2000). Research guidelines for the Delphi survey technique. **Journal of Advanced Nursing**, 32, 4, 1008-15.
- Heaney, D. (2001). Patient-centredness in Primary Care. **BMJ** [Online], 322. Available from: [http://www.bmj.com/content/322/7284/444.full/reply#bmj\\_el\\_13257](http://www.bmj.com/content/322/7284/444.full/reply#bmj_el_13257) [Accessed 3 September 2011].
- Herbert, R., Jamtvedt, G., Mead, J. et al. (2005). Outcome measures measure outcomes, not effects of intervention. **Australian Journal of Physiotherapy**, 51, 1, 3-4.
- Herndon, R.M. and Cutter, G. (2006). Introduction to clinical neurological scales. *In*: Herndon, R.M. (ed.) **Handbook of Neurologic Rating Scales**. New York: Demos Medical Publishing, 1-7.
- Hicks, C. (2004). **Research Methods for Clinical Therapists: Applied Project Design and Analysis**, 4th ed, London: Churchill Livingstone.
- Higginson, I.J. and Carr, A.J. (2001). Measuring quality of life: Using quality of life measures in the clinical setting. **BMJ**, 322, 7297, 1297-300.
- Higgs, J. and Bithell, C. (2001). Professional expertise. *In*: Higgs, J. and Titchen, A. (eds.) **Practice Knowledge and Expertise in the Health Professions**. 1st ed. Oxford: Butterworth-Heinemann, 59-68.

- Hobart, J.C., Freeman, J.A. and Lamping, D.L. (1996). Physician and patient-oriented outcomes in progressive neurological disease: which to measure? **Current Opinion in Neurology**, 9, 6, 441-4.
- Hoehn, M. and Yahr, M. (1967). Parkinsonism: onset, progression and mortality. **Neurology**, 17, 5, 427-442.
- Holman, H. and Lorig, K. (2000). Patients as partners in managing chronic disease. Partnership is a prerequisite for effective and efficient health care. **BMJ**, 320, 7234, 526-7.
- Hu, M.T.M., Butterworth, R., Kumar, V. et al. (2011). How common and what are the determinants of sub-optimal care for Parkinson's disease patients: The Milton Keynes community study. **Parkinsonism & Related Disorders**, 17, 3, 177-181.
- Hustad, K.C. and Weismer, G. (2007). A continuum of interventions for individuals with dysarthria: compensatory and rehabilitative treatment approaches. *In*: Weismer, G.G. (ed.) **Motor Speech Disorders: essays for Ray Kent**. 1st ed. San Diego, CA: Plural Publishing Inc, 261-303.
- Intercollegiate Stroke Working Party (2004). **National Clinical Guidelines for Stroke**. Second ed. London: Royal College of Physicians.
- Jarath, N. and Weinstein, J. (1994). The Delphi methodology: a useful administrative approach. **Canadian Journal of Nursing Administration**, 7, 29-42.
- Jarman, B., Hurwitz, B., Cook, A. et al. (2002). Effects of community based nurses specialising in Parkinson's disease on health outcome and costs: randomised controlled trial. **BMJ**, 324, 7345, 1072-5.
- Jensen, G.M., Gwyer, J., Shepard, K.F. et al. (2000). Expert Practice in Physical Therapy. **Physical Therapy**, 80, 1, 28-43.
- Jensen, G.M., Shepard, K.F., Gwyer, J. et al. (1992). Attribute Dimensions that Distinguish Master and Novice Physical Therapy Clinicians in Orthopedic Settings, Physical Therapy. **Physical Therapy**, 72, 10, 711-722.
- Jette, D.U., Halbert, J., Iverson, C. et al. (2009). Use of standardized outcome measures in physical therapist practice: perceptions and applications. **Physical Therapy**, 89, 2, 125-135.

- Johnson, J.A. and Pring, T.R. (1990). Speech therapy and Parkinson's disease: a review and further data. **British Journal of Disorders of Communication**, 25, 2, 183-94.
- Jones, D. and Playfer, J. (2004). Parkinson's Disease. *In*: Stokes, M. (ed.) **Physical Management in Neurological Rehabilitation**. 2nd ed. London: Elsevier Mosby, 203-220.
- Jones, J. and Hunter, D. (1995). Consensus methods for medical and health services research. **BMJ**, 311, 7001, 376-80.
- Kamsma, Y.P.T., Brouwer, W.H. and Lakke, J.P.W.F. (1995). Training of compensational strategies for impaired gross motor skills in Parkinson's disease. **Physiotherapy Theory and Practice**, 11, 209-229.
- Katsikitis, M. and Pilowsky, I. (1996). A controlled study of facial mobility treatment in Parkinson's disease. **Journal of Psychosomatic Research**, 40, 4, 387-96.
- Keeney, S., Hasson, F. and McKenna, H.P. (2001). A critical review of the Delphi technique as a research methodology for nursing. **International Journal of Nursing Studies**, 38, 2, 195-200.
- Kegelmeyer, D.A., Kloos, A.D., Thomas, K.M. et al. (2007). Reliability and validity of the Tinetti Mobility Test for individuals with Parkinson disease. **Physical Therapy**, 87, 10, 1369-78.
- Kendall, N. (1997). Developing outcome assessments: A step-by-step approach. **New Zealand Journal of Physiotherapy**, 25, 11-17.
- Kersten, P. (2004). Principles of physiotherapy assessment and outcome measures. *In*: Stokes, M. (ed.) **Physical Management in Neurological Rehabilitation**. 2nd ed. London: Elsevier Mosby, 29-46.
- Keus, S.H.J., Bloem, B.R., Hendriks, E.J.M. et al. (2007a). Evidence-based analysis of physical therapy in Parkinson's disease with recommendations for practice and research. **Movement Disorders**, 22, 4, 451-60.
- Keus, S.H.J., Bloem, B.R., van Hilten, J.J. et al. (2007b). Effectiveness of physiotherapy in Parkinson's disease: the feasibility of a randomised controlled trial. **Parkinsonism & Related Disorders**, 13, 2, 115-21.

- Keus, S.H.J., Bloem, B.R., Verbaan, D. et al. (2004a). Physiotherapy in Parkinson's disease: utilisation and patient satisfaction. **Journal of Neurology**, 251, 6, 680-7.
- Keus, S.H.J., Hendriks, H.J.M., Bloem, B.R. et al. (2004b). KNGF Guidelines for physical therapy in patients with Parkinson's disease. **Dutch Journal of Physiotherapy**, 114, Supplement 3.
- Keus, S.H.J., Munneke, M., Nijkrake, M.J. et al. (2009). Physical therapy in Parkinson's disease: evolution and future challenges. **Movement Disorders**, 24, 1, 1-14.
- Kish, S.J., Shannak, K. and Hornykiewicz, O. (1988). Uneven pattern of dopamine loss in the striatum of patients with idiopathic Parkinson's disease. Pathophysiologic and clinical implications. **New England Journal of Medicine**, 318, 14, 876-80.
- Krarup, L.H., Gluud, C., Truelsen, T. et al. (2008). The ExStroke Pilot Trial: rationale, design, and baseline data of a randomized multicenter trial comparing physical training versus usual care after an ischemic stroke. **Contemporary Clinical Trials**, 29, 410-417.
- Krupp, L.B., LaRocca, N.G., Muir-Nash, J. et al. (1989). The fatigue severity scale. Application to patients with multiple sclerosis and systemic lupus erythematosus. **Archives of Neurology**, 46, 10, 1121-3.
- Kurtais, Y., Kutlay, S., Tur, B.S. et al. (2008). Does Treadmill Training Improve Lower-Extremity Tasks in Parkinson's Disease? A Randomised Controlled Trial. **Clinical Journal of Sports Medicine**, 18, 3, 289-291.
- Kwakkel, G., de Geode, C.J.T. and van Wegen, E.E.H. (2007). Impact of physical therapy for parkinson's disease: A critical review of the literature. **Parkinsonism & Related Disorders**, 13, Supplement 3, S478-S487.
- Lang, A.E. and Lozano, A.M. (1998). Parkinson's disease. First of two parts. **New England Journal of Medicine**, 339, 15, 1044-53.
- Lim, I., van Wegen, E., de Goede, C. et al. (2005). Effects of external rhythmical cueing on gait in patients with Parkinson's disease: a systematic review. **Clinical Rehabilitation**, 19, 7, 695-713.
- Little, P., Everitt, H., Williamson, I. et al. (2001). Preferences of patients for patient centred approach to consultation in primary care: observational study. **BMJ**, 322, 7284, 468-72.

- Lusis, S.A. (1997). Pathophysiology and management of idiopathic Parkinson's disease. **Journal of Neuroscience Nursing**, 29, 1, 24-31.
- MacMahon, D.G. and Thomas, S. (1998). Practical approach to quality of life in Parkinson's disease: the nurse's role. **Journal of Neurology**, 245 Suppl 1, S19-22.
- Mahoney, F.I. and Barthel, D.W. (1965). Functional Evaluation: The Barthel Index. **Maryland State Medical Journal**, 14, 61-5.
- McKee, M., Priest, P., Ginzler, M. et al. (1991). How representative are members of expert panels? **Quality Assurance in Health Care**, 3, 2, 89-94.
- Mead, D. and Moseley, L. (2001). The use of the Delphi as a research approach. **Nurse Researcher**, 8, 4, 4-23.
- Medical Research Council (1998). **MRC Guidelines for Good Clinical Practice in Clinical Trials**. London: Medical Research Council.
- Meek, C., Morgan, E., Walker, M.F. et al. (2010). Occupational therapy to optimise independence in Parkinson's disease: the designing and recording of a randomised controlled trial intervention. **British Journal of Occupational Therapy**, 73, 4, 178-185.
- Miller, N., Deane, K.H.O., Jones, D. et al. (2010). National survey of speech and language therapy provision for people with Parkinson's disease in the United Kingdom: therapists' practices. **International Journal of Language and Communication Disorders**, 46, 2, 189-201.
- Miyai, I., Fujimoto, Y., Yamamoto, H. et al. (2002). Long-term effect of body weight-supported treadmill training in Parkinson's disease: a randomized controlled trial. **Archives of Physical Medicine & Rehabilitation**, 83, 10, 1370-1373.
- Montgomery, E.B., Jr. (2004). Rehabilitative approaches to Parkinson's disease. **Parkinsonism & Related Disorders**, 10 Suppl 1, S43-7.
- Morris, M.E. (2000). Movement disorders in people with Parkinson disease: a model for physical therapy. **Physical Therapy**, 80, 6, 578-97.
- Morris, M.E., Iansek, R. and Galna, B. (2008). Gait festination and freezing in Parkinson's disease: pathogenesis and rehabilitation. **Movement Disorders**, 23 Suppl 2, S451-60.

- Morris, M.E., Martin, C.L. and Schenkman, M.L. (2010). Striding out with Parkinson's disease: Evidence-based physical therapy for gait disorders. **Physical Therapy**, 90, 2, 280-288.
- Morris, S., Morris, M.E. and Iansek, R. (2001). Reliability of measurements obtained with the Timed "Up & Go" test in people with Parkinson disease. **Physical Therapy**, 81, 2, 810-8.
- Muhlack, S., Welnic, J., Woitalla, D. et al. (2007). Exercise improves efficacy of levodopa in patients with Parkinson's disease. **Movement Disorders**, 22, 3, 427-430.
- Muir-Gray, J.A. (1997). **Evidence-based Healthcare: How to make health policy and health management decisions**, London: Churchill Livingstone.
- Mullen, P.M. (2003). Delphi: myths and reality. **Journal of Health Organization & Management**, 17, 1, 37-52.
- Murphy, M.K., Black, N.A., Lamping, D.L. et al. (1998). Consensus development methods, and their use in clinical guideline development. **Health Technology Assessment (Winchester, England)**, 2, 3, i-iv.
- Mutch, W.J., Strudwick, A., Roy, S.K. et al. (1986). Parkinson's disease: disability, review, and management. **BMJ**, 293, 6548, 675-7.
- Nancarrow, S. (2004). Dynamic role boundaries in intermediate care services. **Journal of Interprofessional Care**, 18, 2, 141-51.
- National Collaborating Centre for Chronic Conditions (2006). **Parkinson's Disease: National clinical guideline for diagnosis and management in primary and secondary care**. London: Royal College of Physicians.
- National Institute for Health and Clinical Excellence (2006). **Parkinson's disease: diagnosis and management in primary and secondary care: National cost-impact report**. London: National Institute for Health and Clinical Excellence.
- Nieuwboer, A., Kwakkel, G., Rochester, L. et al. (2007). Cueing training in the home improves gait-related mobility in Parkinson's disease: the RESCUE trial. **Journal of Neurology, Neurosurgery and Psychiatry**, 78, 2, 134-40.



- Nijkraak, M.J., Keus, S.H., Kalf, J.G. et al. (2007). Allied health care interventions and complementary therapies in Parkinson's disease. **Parkinsonism & Related Disorders**, 13, Suppl 3, S488-94.
- Nijkraak, M.J., Keus, S.H.J., Oostendorp, R.A.B. et al. (2009). Allied health care in Parkinson's disease: referral, consultation, and professional expertise. **Movement Disorders**, 24, 2, 282-6.
- Nursing Times (2007). Reducing the toll of Parkinson's. **Nursing Times**, 103, 45.
- Nussbaum, R.L. and Ellis, C.E. (2003). Alzheimer's disease and Parkinson's disease. **New England Journal of Medicine**, 348, 14, 1356-64.
- O'Brien, M., Dodd, K.J. and Bilney, B. (2008). A qualitative analysis of a progressive resistance exercise programme for people with Parkinson's disease. **Disability & Rehabilitation**, 30, 18, 1350-7.
- Olanow, C.W., Rascol, O., Hauser, R. et al. (2009). A double-blind, delayed-start trial of rasagiline in Parkinson's disease. **New England Journal of Medicine**, 361, 13, 1268-78.
- Pahor, M., Blair, S.N., Espeland, M. et al. (2006). Effects of a physical activity intervention on measures of physical performance: Results of the lifestyle interventions and independence for Elders Pilot (LIFE-P) study. **Journals of Gerontology Series A-Biological Sciences & Medical Sciences**, 61, 11, 1157-65.
- Parkinson's UK (2008a). **Competencies: A competency framework for nurses working in Parkinson's disease management**, 2nd ed, London: Parkinson's UK.
- Parkinson's UK (2008b). **Life with Parkinson's today - room for improvement**. London: Parkinson's UK.
- Pearson, M.J.T., Lindop, F.A., Mockett, S.P. et al. (2009). Validity and inter-rater reliability of the Lindop Parkinson's Disease Mobility Assessment: a preliminary study. **Physiotherapy**, 95, 2, 126-133.
- Pennington, S., Snell, K., Lee, M. et al. (2010). The cause of death in idiopathic Parkinson's disease. **Parkinsonism & Related Disorders**, 16, 7, 434-7.

- Pentland, B. (1999). The nature and course of Parkinson's disease. *In*: Percival, R. and Hobson, P. (eds.) **Parkinson's Disease: Studies in Psychological and Social Care**. Leicester: BPS Books, 1-12.
- Peto, V., Jenkinson, C., Fitzpatrick, R. et al. (1995). The development and validation of a short measure of functioning and well being for individuals with Parkinson's disease. **Quality of Life Research**, 4, 3, 241-8.
- Pinto, S., Ozsancak, C., Tripoliti, E. et al. (2004). Treatments for dysarthria in Parkinson's disease. **Lancet Neurology**, 3, 9, 547-56.
- Plant, R., Jones, D., Walton, G. et al. (2001). **Guidelines for Physiotherapy Practice in Parkinson's Disease**. Newcastle upon Tyne and London: Institute of Rehabilitation and Parkinson's Disease Society.
- Plant, R., Jones, D., Walton, G. et al. (2000). **Physiotherapy for People with Parkinson's disease: UK Best Practice**. Institution of Rehabilitation, University of Northumbria.
- Pohl, M., Rockstroh, G., Ruckriem, S. et al. (2003). Immediate effects of speed-dependent treadmill training on gait parameters in early Parkinson's disease. **Archives of Physical Medicine & Rehabilitation**, 84, 12, 1760-6.
- Powell, C. (2003). The Delphi technique: myths and realities. **Journal of Advanced Nursing**, 41, 4, 376-82.
- Protas, E.J., Mitchell, K., Williams, A. et al. (2005). Gait and step training to reduce falls in Parkinson's disease. **Neurorehabilitation**, 20, 3, 183-190.
- Qutubuddin, A.A., Pegg, P.O., Cifu, D.X. et al. (2005). Validating the Berg Balance Scale for patients with Parkinson's disease: a key to rehabilitation evaluation. **Archives of Physical Medicine & Rehabilitation**, 86, 4, 789-92.
- Ramaswamy, B., Jones, D., Goodwin, V. et al. (2009). **Quick Reference Cards (UK) and Guidance Notes for physiotherapists working with people with Parkinson's disease**. London: Parkinson's UK.

- Ramig, L.O., Countryman, S., Thompson, L.L. et al. (1995). Comparison of two forms of intensive speech treatment for Parkinson disease. **Journal of Speech & Hearing Research**, 38, 6, 1232-51.
- Ramig, L.O., Fox, C. and Shapir, S. (2004). Parkinson's Disease: Speech and Voice Disorders and Their Treatment with the Lee Silverman Voice Treatment. **Seminars in Speech and Language**, 25, 2, 169-180.
- Resnick, B., Nahm, E.S., Orwig, D. et al. (2001). Measurement of activity in older adults: reliability and validity of the Step Activity Monitor. **Journal of Nursing Measurement**, 9, 3, 275-90.
- Reuter, I. and Engelhardt, M. (2002). Exercise Training and Parkinson's Disease: Placebo or Essential Treatment? **The Physician and Sportsmedicine**, 30, 3, 43-50.
- Reynolds, H., Wilson-Barnett, J. and Richardson, G. (2000). Evaluation of the role of the Parkinson's disease nurse specialist. **International Journal of Nursing Studies**, 37, 4, 337-49.
- Robertson, D. (2003). Developing and delivering services. *In*: Playford, D. (ed.) **Neurological Rehabilitation of Parkinson's Disease**. London: Martin Dunitz, 83-104.
- Robertson, D., Aragon, A., Moore, G. et al. (2008). Rehabilitation and the interdisciplinary team. *In*: Playfer, J. and Hindle, J. (eds.) **Parkinson's Disease in the Older Patient**. 2nd ed. Oxford: Radcliffe Publishing LTD, 291-313.
- Rubenis, J. (2007). A rehabilitational approach to the management of Parkinson's disease. **Parkinsonism & Related Disorders**, 13, Suppl 3, S495-7.
- Sackett, D.L., Rosenberg, W.M., Gray, J.A. et al. (1996). Evidence based medicine: what it is and what it isn't. **BMJ**, 312, 7023, 71-2.
- Sackley, C.M. and Lincoln, N.B. (1996). Physiotherapy treatment for stroke patients: A survey of current practice. **Physiotherapy Theory and Practice**, 12, 2, 87-96.
- Sakala, C. and Corry, M.P. (2001). What is evidence-based health care? **Journal of Midwifery and Women's Health**, 46, 3, 127-128.
- Samii, A., Nutt, J.G. and Ransom, B.R. (2004). Parkinson's disease. **Lancet**, 363, 9423, 1783-93.

- Schapira, A.H.V. (2011). The management of Parkinson's disease - what is new? **European Journal of Neurology**, 18 Suppl 1, 1-2.
- Schenkman, M., Cutson, T.M., Kuchibhatla, M. et al. (1997). Reliability of impairment and physical performance measures for persons with Parkinson's disease. **Phys Ther**, 77, 1, 19-27.
- Schenkman, M., Cutson, T.M., Kuchibhatla, M. et al. (1998). Exercise to improve spinal flexibility and function for people with Parkinson's disease: a randomized, controlled trial. **Journal of the American Geriatrics Society**, 46, 10, 1207-16.
- Schmitz-Hubsch, T., Pyfer, D., Kielwein, K. et al. (2006). Qigong exercise for the symptoms of Parkinson's disease: a randomized, controlled pilot study. **Movement Disorders**, 21, 4, 543-8.
- Scott, S. and Caird, F.I. (1984). The response of the apparent receptive speech disorder of Parkinson's disease to speech therapy. **Journal of Neurology, Neurosurgery & Psychiatry**, 47, 3, 302-4.
- Sethi, K. (2008). Levodopa unresponsive symptoms in Parkinson disease. **Movement Disorders**, 23 Suppl 3, S521-33.
- Sim, J. and Wright, C. (2000). **Research in Health Care: Concepts, Designs and Methods**, Cheltenham: Nelson Thornes.
- Smith, M., Higgs, J. and Ellis, E. (2010). Effect of experience on clinical decision making by cardiorespiratory physiotherapists in acute care settings. **Physiotherapy Theory and Practice**, 26, 2, 89-99.
- Smith, S. and Roberts, P. (2005). An investigation of occupational therapy and physiotherapy roles in a community setting. **International Journal of Therapy and Rehabilitation**, 12, 1, 21-29.
- Spielman, J.L., Borod, J.C. and Ramig, L.O. (2003). The effects of intensive voice treatment on facial expressiveness in Parkinson disease: preliminary data. **Cognitive & Behavioral Neurology**, 16, 3, 177-88.
- Stallibrass, C., Sissons, P. and Chalmers, C. (2002). Randomized controlled trial of the Alexander Technique for idiopathic Parkinson's disease. **Clinical Rehabilitation**, 16, 7, 695-708.

- Stevens, W., Hillsdon, M., Thorogood, M. et al. (1998). Cost-effectiveness of a primary care based physical activity intervention in 45-74 year old men and women: a randomised controlled trial. **British Journal of Sports Medicine**, 32, 3, 236-41.
- Stewart, M. (2001). Towards a global definition of patient centred care. **BMJ**, 322, 7284, 444-5.
- Stewart, M., Brown, J.B., Donner, A. et al. (2000). The impact of patient-centered care on outcomes. **Journal of Family Practice**, 49, 9, 796-804.
- Stoll, B. (1989). Best medical practice: viewpoint of a UK oncologist. **International Journal of Health Planning and Management**, 4, 3, 221-234.
- Stozek, J., Rudzinska, M., Longawa, K. et al. (2003). The effect of the complex rehabilitation on posture and gait in Parkinson disease. **Neurologia I Neurochirurgia Polska**, 37, Suppl. 5, 67-81.
- Sutoo, D.E. and Akiyama, K. (2003). Regulation of brain function by exercise. **Neurobiology of Disease**, 13, 1, 1-14.
- Tapper, V.J. (1997). Pathophysiology, assessment, and treatment of Parkinson's disease. **The Nurse Practitioner**, 22, 7, 76-95.
- Testa, M.A. and Simonson, D.C. (1996). Assessment of quality-of-life outcomes. **New England Journal of Medicine**, 334, 13, 835-40.
- The Long-term Individual Fitness Enablement (LIFE) group (2011). Supporting community based exercise in long-term neurological conditions: experience from the long-term individual fitness enablement (LIFE) project. **Clinical Rehabilitation**, 25, 7, 579-587.
- Thompson, M. (2009). Considering the implication of variations within Delphi research. **Family Practice**, 26, 5, 420-4.
- Tickle-Degnen, L., Ellis, T., Saint-Hilaire, M.H. et al. (2010). Self-management rehabilitation and health-related quality of life in Parkinson's disease: a randomized controlled trial. **Movement Disorders**, 25, 2, 194-204.

- Toole, T., Hirsch, M.A., Forkink, A. et al. (2000). The effects of a balance and strength training program on equilibrium in Parkinsonism: A preliminary study. **Neurorehabilitation**, 14, 165-174.
- Twelves, D., Perkins, K.S.M. and Counsell, C. (2003). Systematic review of incidence studies of Parkinson's disease. **Movement Disorders**, 18, 1, 19-31.
- Unsworth, C. (2000). Measuring the outcome of occupational therapy: Tools and resources. **Australian Occupational Therapy Journal**, 47, 4, 147-158.
- van der Marck, M.A., Kalf, J.G., Sturkenboom, I.H.W.M. et al. (2009). Multidisciplinary care for patients with Parkinson's disease. **Parkinsonism & Related Disorders**, 15 Suppl 3, S219-23.
- van Nimwegen, M., Speelman, A.D., Smulders, K. et al. (2010). Design and baseline characteristics of the ParkFit study, a randomized controlled trial evaluating the effectiveness of a multifaceted behavioral program to increase physical activity in Parkinson patients. **BMC Neurology**, 10, 70.
- Wade, D.T., Gage, H., Owen, C. et al. (2003). Multidisciplinary rehabilitation for people with Parkinson's disease: a randomised controlled study. **Journal of Neurology, Neurosurgery & Psychiatry**, 74, 2, 158-62.
- Wade, D.T. and Vergis, E. (1999). The Short Orientation-Memory-Concentration Test: a study of its reliability and validity. **Clinical Rehabilitation**, 13, 2, 164-70.
- Washburn, R.A., Smith, K.W., Jette, A.M. et al. (1993). The Physical Activity Scale for the Elderly (PASE): development and evaluation. **Journal of Clinical Epidemiology**, 46, 2, 153-62.
- Weiner, W.J. and Singer, C. (1989). Parkinson's disease and nonpharmacologic treatment programs. **Journal of the American Geriatrics Society**, 37, 4, 359-63.
- West, R. (1991). **Parkinson's disease**. London: Office of Health Economics.
- White, D.K., Wagenaar, R.C., Ellis, T.D. et al. (2009). Changes in walking activity and endurance following rehabilitation for people with Parkinson disease. **Archives of Physical Medicine & Rehabilitation**, 90, 1, 43-50.

- Williams, A., Gill, S., Varma, T. et al. (2010). Deep brain stimulation plus best medical therapy versus best medical therapy alone for advanced Parkinson's disease (PD SURG trial): a randomised, open-label trial. **Lancet Neurology**, 9, 6, 581-91.
- Williams, P. and Webb, C. (1994). The Delphi technique: a methodological discussion. **Journal of Advanced Nursing**, 19, 180-186.
- World Health Organization (2001). **International Classification for Functioning, Disability and Health**. Geneva: World Health Organization.
- Yarrow, S. (1999). Members' 1998 survey of the Parkinson's Disease Society of the United Kingdom. *In*: Percival, R. and Hobson, P. (eds.) **Parkinson's Disease: Studies in Psychological and Social Care**. Leicester: The British Psychological Society, 79-92.
- Yoon, M.-C., Shin, M.-S., Kim, T.-S. et al. (2007). Treadmill exercise suppresses nigrostriatal dopaminergic neuronal loss in 6-hydroxydopamine-induced Parkinson's rats. **Neuroscience Letters**, 423, 1, 12-17.
- Yoward, L.S., Doherty, P. and Boyes, C. (2008). A survey of outcome measurement of balance, walking and gait amongst physiotherapists working in neurology in the UK. **Physiotherapy**, 94, 2, 125-132.

**7 APPENDICES**  
**APPENDIX A: STUDY ONE SURVEY DOCUMENTS**

**DEFINING UK PHYSIOTHERAPY PRACTICE IN PARKINSON'S DISEASE:  
CURRENT PRACTICE QUESTIONNAIRE**

The following short questionnaire aims to identify therapist expertise, and the structure, dose and setting of physiotherapy currently delivered for Parkinson's disease. Please note that completion of this questionnaire is optional.

To complete the questionnaire, please mark the appropriate boxes with ☒. This can be done by copying this symbol ☒ and replacing the appropriate box for each question.

**Physiotherapist expertise**

1. Are you a clinical or research physiotherapist?

Clinical physiotherapist

Research physiotherapist

Both

If you are solely a research physiotherapist, you do not need to complete this questionnaire any further.

2. How many years have you been a qualified physiotherapist?

\_\_\_\_\_years

3. Do you have a special interest in treating patients with Parkinson's disease (PD)?

Yes

No

4. Have you received any post graduate training/ courses specifically on the subject of PD, or that is directly applicable to the treatment of patients with PD?

Yes, the following:

---

---



No

5. If you answered no to question 3, do you feel you would benefit from additional training?

Yes

No

6. How many patients with PD have you treated over the last 12 months?

\_\_\_\_\_patients

### **Practice Setting**

1. In which setting do you treat patients? If more than one setting is utilised then number the settings, with 1 equalling the most used setting (leave blank if a setting is not used).

Hospital - Inpatient.

Hospital – Outpatient.

Hospital – Day hospital.

Intermediate care.

Nursing home.

Rehabilitation centre.

Patient's home

Other, please state: \_\_\_\_\_

### **Structure of physiotherapy service delivered**

#### **Working hours**

1. Do you work full time or part time?

Full time – 100% WTE

Part time – please state the percentage of WTE \_\_\_\_\_

**Referral to physiotherapy**

2. Which clinicians refer PD patients to your service?

	Always	Usually	Often	Occasionally	Never
	Refer	Refer	Refer	Refer	Refer
Neurologist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Geriatrician	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
G.P.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
PD Nurse Specialist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Allied Health Professional	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other, please state:					
_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

3. Are patients with PD able to access your service through direct self/ carer

referral?

Yes.

No

4. At what stage of the disease are PD patients most often referred to your service?

Please rank 1 to 4 (1 = most often, 4 = least often)

Diagnosis phase \_\_\_\_\_

Maintenance phase \_\_\_\_\_

Complex phase \_\_\_\_\_

Palliative phase \_\_\_\_\_

5. Are patients able to re-access your service through direct self/ carer referral,  
without the assistance of a clinician?

Yes.

No.

#### **Context of physiotherapy within the multidisciplinary team**

6. Do you practice as part of a coordinated multidisciplinary team?

Yes.

No.

7. Is patient care coordinated by a key worker?

Yes \_\_\_\_\_

No.

#### **Delivery of physiotherapy**

8. Is treatment delivered on an individual or group basis?

Individual.

Group.

Both.

**“Dose” of physiotherapy service delivered**

1. On average, how many sessions do you deliver during a single “course” of physiotherapy for a PD patient?

\_\_\_\_\_sessions

2. On average, how long is your initial assessment of the PD patient?

\_\_\_\_\_mins

3. On average, how long are subsequent physiotherapy sessions for PD patients?

\_\_\_\_\_mins per session

4. On average, over how long a period is the complete “course” of physiotherapy delivered over?

\_\_\_\_\_weeks

**DEFINING UK PHYSIOTHERAPY PRACTICE IN PARKINSON’S DISEASE: DELPHI STATEMENTS ROUND 1**

Throughout the survey, please mark the appropriate box for each statement with an “X”. There is space for additional comments at the end of each section.

**1. REASONS FOR PHYSIOTHERAPY PROVISION**

- ❖ The statements below have been constructed using evidence from national and international guidelines, clinical studies, and textbooks.

**The purpose of providing physiotherapy to people with Parkinson’s disease is to...**

	<b>Strongly agree</b>	<b>Agree</b>	<b>Undecided</b>	<b>Disagree</b>	<b>Strongly disagree</b>
Improve, maintain, or minimise degeneration of a person’s quality of movement					
Improve, maintain or minimise degeneration of functional independence, including mobility and activities of daily living					
Improve, maintain, or minimise degeneration of general fitness, including aerobic capacity and physical activity levels					
Minimise the onset of musculoskeletal and cardiorespiratory secondary complications					
Prevent fear of falling, and maintain a person’s confidence in their ability to move safely					
Provide advice regarding safety in the home environment					
Provide information to the patient (and carer(s)) regarding Parkinson’s disease, issues surrounding therapy, and potential medical, social and financial support available (within their scope of practice)					
Provide education to the patient (and carer(s)) to stimulate and support self-management					
Empower patients and carers with sufficient knowledge about the disease process and benefits of sustained physical activity to encourage a positive attitude towards self-management.					

**Additional comments**

Please record any additional comments regarding the reasons for physiotherapy provision:

---



---



---

## 2. CORE AREAS OF PHYSIOTHERAPY

- ❖ The statements below have been constructed using evidence from national and international guidelines, clinical studies, and textbooks.

The core areas addressed by physiotherapists in people with Parkinson's disease are...

		Strongly agree	Agree	Undecided	Disagree	Strongly disagree
<b>Body functions and structures</b>	Gait					
	Freezing of gait					
	Balance					
	Transfers					
	Posture					
	Physical conditioning (including muscle strength, range of movement/ flexibility, and cardiorespiratory fitness)					
	Upper limb function					
	Respiratory functioning					
	Pain management					
<b>Activities</b>	Indoor mobility					
	Outdoor mobility					
	Falls					
	Self-care					
	Domestic activities of daily living					
	Communication					
<b>Participation</b>	Leisure-related activities					
	Work-related activities (including non-paid work such as voluntary work, and caring for others)					

### Additional comments

Please record any additional comments regarding the core areas of physiotherapy:

---



---



---

### 3. TREATMENT WITHIN PHYSIOTHERAPY PROVISION

- ❖ The statements below have been constructed using evidence from systematic reviews, clinical studies. In the absence of trial evidence, expert consensus has been utilised.

#### GENERAL STATEMENTS

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Rehabilitation is maximised if physiotherapy interventions are task specific					
The effects of physiotherapy are maximised if rehabilitation is delivered in the hospital environment					
The effects of physiotherapy are maximised if rehabilitation is delivered in the patient's home					
The effects of physiotherapy are maximised if rehabilitation is delivered in both the patient's home and the hospital environment					
The effects of physiotherapy are maximised if rehabilitation is delivered as individual sessions					
The effects of physiotherapy are maximised if rehabilitation is delivered as group therapy					
The effects of physiotherapy are maximised if rehabilitation is delivered as both individual and group sessions					
Physiotherapy for Parkinson's disease should be patient specific, rather than based on a specific "named" approach (e.g. Bobath, Brunstrom)					
Rehabilitation is maximised if carers are involved in the physiotherapy process					
Rehabilitation is maximised if sufficient time is given for people with Parkinson's disease to process information and plan a response to queries and instructions					
Rehabilitation is maximised if patients are encouraged to develop problem solving skills to encourage self-management of functional difficulties.					

#### Additional comments

Please record any additional general comments regarding treatment within physiotherapy:

---



---



---

## SPECIFIC STATEMENTS

The following sections explore possible treatment techniques within the specific areas of rehabilitation physiotherapists may be involved in when treating people with Parkinson’s disease. The treatments outlined are not meant to be prescriptive or applicable to all patients. Similarly, the interventions are not meant to stand alone, and it is recognised that therapists would employ a number of the techniques when managing a patient with Parkinson’s disease. Instead, the techniques covered by the statements are meant to act as a menu for physiotherapists treating people with Parkinson’s disease.

## EFFECTIVE TREATMENT TECHNIQUES FOR GAIT REHABILITATION

	<b>Strongly agree</b>	<b>Agree</b>	<b>Undecided</b>	<b>Disagree</b>	<b>Strongly disagree</b>
Visual, auditory and/ or sensory external cueing techniques may be effective in improving, maintaining, or minimising the degeneration of gait parameters					
Cognitive movement strategies, such as the breaking down of complex movement sequences into simple steps and the use of self instruction, may be effective in improving, maintaining, or minimising the degeneration of gait parameters					
Combining cognitive movement strategies with external cueing techniques may be effective in improving gait initiation					
The use of verbal instruction to focus attention on specific aspects of gait may be effective in improving, maintaining, or minimising the degeneration of gait parameters					
The use of mental rehearsal prior to walking may be effective in improving, maintaining, or minimising the degeneration of gait					
Lower limb strengthening exercises may be effective in improving, maintaining, or minimising the degeneration of gait parameters					
Joint mobility/ limb mobilisation exercises, when combined with task-specific training, may effectively contribute to the improvement, maintenance, or minimisation of degeneration of gait parameters					
Walking practice utilising functional conditions such as obstacles and turning may be an effective treatment technique for the improvement, maintenance or minimisation of degeneration of gait					
Walking practice utilising the patient’s own environment may be an effective treatment technique for the improvement, maintenance or minimisation of degeneration of gait					
Dual tasking with another motor task, or cognitive task, should be avoided when walking					



Dual or multiple task training, which gradually increases in complexity, may be effective in improving, maintaining or minimising the degeneration of gait carried out under multiple task/ functional conditions					
The provision of, education on the use of, and practice in using walking aids may be an effective treatment technique for the improvement, maintenance or minimisation of degeneration of gait					

**Additional comments**

Please record any additional comments regarding effective treatment techniques for gait rehabilitation:

---



---

**EFFECTIVE TREATMENT TECHNIQUES FOR BALANCE REHABILITATION AND THE MANAGEMENT OF FALLS**

	<b>Strongly agree</b>	<b>Agree</b>	<b>Undecided</b>	<b>Disagree</b>	<b>Strongly disagree</b>
A combined, progressive exercise programme of lower limb strength training and balance training involving alteration of visual, vestibular and somatosensory feedback, may be effective in improving, maintaining, or minimising the degeneration of balance					
A balance rehabilitation programme should be multifaceted and progressive, including static, dynamic and functional balance training, gait training, lower limb strength training, range of motion exercises, and the provision of falls prevention strategies					
A balance rehabilitation programme should include training in outdoor, leisure, and work related conditions					
Exercises focused on the control and coordination of axial movement and related muscle activity may be effective in improving, maintaining, or minimising the degeneration of balance					
External cueing techniques, provided for gait rehabilitation, may have a secondary beneficial effect on balance					
Cognitive movement strategies and external cueing techniques, provided for gait and transfer rehabilitation, may have a secondary beneficial effect on balance					
Teaching a patient, and practising, how to get on and off the floor may be beneficial in reducing the fear to fall					

**Additional comments**

Please record any additional comments regarding effective treatment techniques for balance and falls rehabilitation:

---



---



---

**EFFECTIVE TREATMENT TECHNIQUES FOR TRANSFERS REHABILITATION**

	<b>Strongly agree</b>	<b>Agree</b>	<b>Undecided</b>	<b>Disagree</b>	<b>Strongly disagree</b>
Cognitive movement strategies including mental rehearsal, the breaking down of complex movement sequences into simple steps, and the use of self instruction, may be effective in improving, maintaining, or minimising a person's difficulties in performing transfers.					
Visual, auditory and/ or sensory external cueing techniques may be effective in improving, maintaining, or minimising a person's difficulties in performing transfers.					
The provision of, education on the use of, and practice with equipment such as transfer boards may be helpful for performing transfers					

**Additional comments**

Please record any additional comments regarding effective treatment techniques for transfers rehabilitation:

---



---

**EFFECTIVE TREATMENT TECHNIQUES FOR POSTURE REHABILITATION**

	<b>Strongly agree</b>	<b>Agree</b>	<b>Undecided</b>	<b>Disagree</b>	<b>Strongly disagree</b>
Exercises focused on the control and coordination of axial movement, and related muscle activity, may be effective in improving, maintaining, or minimising the degeneration of posture, and function related to posture					
The use of feedback such as verbal prompts and visual feedback from a mirror, may be effective in improving, maintaining, or minimising the degeneration of posture					

**Additional comments**

Please record any additional comments regarding effective treatment techniques for posture rehabilitation:

---

---

**EFFECTIVE TREATMENT TECHNIQUES FOR PHYSICAL CONDITIONING**

	<b>Strongly agree</b>	<b>Agree</b>	<b>Undecided</b>	<b>Disagree</b>	<b>Strongly disagree</b>
An exercise programme which includes lower limb strengthening may be effective in improving, maintaining, or minimising the degeneration of lower limb strength					
An exercise programme which includes upper limb strengthening may be effective in improving, maintaining, or minimising the degeneration of upper limb strength					
An exercise programme which includes exercises focused on trunk strengthening may be effective in improving, maintaining, or minimising the degeneration of trunk strength					
An exercise programme which includes exercises focused on joint mobility and flexibility may be effective in improving, maintaining, or minimising the degeneration of joint mobility and flexibility					
An exercise programme which includes exercises focused on cardiorespiratory training, may be effective in improving, maintaining, or minimising the degeneration of cardiorespiratory fitness					
To maximise the effectiveness of rehabilitation aimed at physical conditioning and fitness, physiotherapists should encourage the patient to engage in a recreational form of activity to support independence, adherence and self-management.					

**Additional comments**

Please record any additional comments regarding effective treatment techniques for physical conditioning:

---

---

## EFFECTIVE TREATMENT TECHNIQUES FOR THE REHABILITATION OF UPPER LIMB FUNCTION

	<b>Strongly agree</b>	<b>Agree</b>	<b>Undecided</b>	<b>Disagree</b>	<b>Strongly disagree</b>
External cueing techniques may be effective in improving, maintaining, or minimising degeneration of the parameters of reach to grasp					
Internally generated cues or self instruction may be effective in improving, maintaining, or minimising degeneration of the parameters of reach to grasp					
Exercises focused on upper limb muscular coordination may be effective in improving, maintaining, or minimising degeneration of upper limb functional movement					
Exercises focused on upper limb strengthening and range of movement may be effective in improving, maintaining, or minimising degeneration of upper limb functional movement					

### **Additional comments**

Please record any additional comments regarding effective treatment techniques for the rehabilitation of upper limb function:

---



---

### **Additional treatment techniques**

Please record any techniques which you view as effective in treating other areas/ problems addressed by physiotherapists in people with Parkinson's disease:

---



---

## **4. Outcome measurement during physiotherapy provision**

- ❖ The statements below have been constructed using clinical experimental evidence, and findings from systematic reviews.

OUTCOME MEASURES SHOULD ASSESS...

	<b>Strongly agree</b>	<b>Agree</b>	<b>Undecided</b>	<b>Disagree</b>	<b>Strongly disagree</b>
The specific aims of the treatment delivered					

The effect of the treatment delivered on areas related to those targeted specifically by the treatment (e.g. measuring the effect of balance rehabilitation on gait)					
The effect of the treatment delivered on areas that can be indirectly influenced by the treatment (e.g. measuring the effect of cardiorespiratory training on mood/ depression)					
The effectiveness of the treatment delivered at the level of the body structure or body function targeted (based on the ICF model)					
The effectiveness of the treatment delivered at the level of activity performance, specific to the problem targeted (based on the ICF model)					
The effectiveness of the treatment delivered at the level of participation (based on the ICF model)					
The effect of the treatment delivered on a person's overall physical functioning					
The effect of the treatment delivered on health-related quality-of-life and wellbeing					
The impact of the treatment delivered on a patient's carer(s) physical and psychological health, activity and participation					

General statements regarding outcome measures during physiotherapeutic provision:

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Outcome measurement should include both subjective and objective measures to allow both patient self-report, and objective measurement of symptoms and the effects of treatment					
Outcome measures should be recorded both pre-and post-treatment to allow change to be measured.					
Physiotherapists should use the findings of outcome measures when managing patients to influence their future practice					

**Additional comments**

Please record any additional comments regarding outcome measurement during the physiotherapy process below:

---



---

## DEFINING UK PHYSIOTHERAPY PRACTICE IN PARKINSON'S DISEASE: DELPHI STATEMENTS ROUND TWO

This is the second round of the survey. For each statement, please mark the appropriate box with an "X". To help inform your decision when ranking, the percentage of agreement/ disagreement with each statement from round one has been included. Those statements that have no percentages listed next to them are new statements developed from the free text generated in round one.

### 2. REASONS FOR PHYSIOTHERAPY PROVISION

- ❖ The statements below have been constructed using evidence from national and international guidelines, clinical studies, textbooks and expert consensus

**The purpose of providing physiotherapy to people with Parkinson's disease is to...**

	Strongly agree	% R1	Agree	% R1	Undecided	% R1	Disagree	% R1	Strongly disagree	% R1
Improve, maintain, or minimise degeneration of a person's quality of movement		82.9		14.5		1.3		1.3		0
Improve, maintain or minimise degeneration of functional independence, including mobility and activities of daily living		98.7		1.3		0		0		0
Improve a patient's balance and minimise the risk of falls		—		—		—		—		—
Improve, maintain, or minimise degeneration of general fitness, including aerobic capacity and physical activity levels		76.3		22.4		1.3		0		0
Minimise the onset of musculoskeletal and cardiorespiratory secondary complications		68.4		27.6		3.9		0		0
Provide treatment and strategies for managing pain		—		—		—		—		—
Prevent fear of falling, and maintain a person's confidence in their ability to move safely		81.6		18.4		0		0		0
Provide advice regarding safety in the home environment		47.4		48.7		3.9		0		0
Provide information to the patient (and carer(s)) regarding Parkinson's disease, issues surrounding therapy, and potential medical, social and financial support available (within their scope of practice)		48.7		44.7		6.6		0		0
Provide education to the patient (and carer(s)) to stimulate and support self-management		84.2		15.8		0		0		0
Empower patients and carers with sufficient knowledge about the disease process and benefits of sustained physical activity to encourage a positive attitude towards self-management.		88.2		11.8		0		0		0

Support a patient's involvement in work and leisure activities		—		—		—		—		—
--	--	---	--	---	--	---	--	---	--	---

### 3. CORE AREAS OF PHYSIOTHERAPY

- ❖ The statements below have been constructed using evidence from national and international guidelines, clinical studies, textbooks, and expert consensus.

The core areas addressed by physiotherapists in people with Parkinson's disease are...

		Strongly agree	% R1	Agree	% R1	Undecided	% R1	Disagree	% R1	Strongly disagree	% R1
<b>Body functions and structures</b>	Gait		98.7		1.3		0		0		0
	Freezing of gait		85.5		14.5		0		0		0
	Balance		90.8		9.2		0		0		0
	Transfers		88.2		11.8		0		0		0
	Posture		93.4		5.3		0		0		0
	Physical conditioning (including muscle strength, range of movement/ flexibility, and cardiorespiratory fitness)		75.0		25.0		0		0		0
	Upper limb function		48.7		40.8		9.2		1.3		0
	Respiratory functioning		35.5		48.7		14.5		1.3		0
	Pain management		34.2		51.3		10.5		3.9		0
	Psychological issues (such as anxiety and depression)		—		—		—		—		—
<b>Activities</b>	Indoor mobility		94.7		5.3		0		0		0
	Outdoor mobility		92.1		7.9		0		0		0
	Falls		92.1		7.9		0		0		0
	Self-care		25.0		59.2		10.5		5.3		0
	Domestic activities of daily living		22.4		53.9		14.5		9.2		0
	Communication		7.9		43.3		30.3		17.1		1.3
<b>Participation</b>	Leisure-related activities		38.2		59.2		2.6		0		0
	Work-related activities (including non-paid work such as voluntary work, and caring for others)		25.0		55.3		14.5		5.3		0

## 5. TREATMENT WITHIN PHYSIOTHERAPY PROVISION

- ❖ The statements below have been constructed using evidence from systematic reviews, clinical studies and expert consensus.

### GENERAL STATEMENTS

	Strongly agree	% R1	Agree	% R1	Undecided	% R1	Disagree	% R1	Strongly disagree	% R1
Rehabilitation is maximised if physiotherapy interventions are task specific		50		40.8		9.2		0		0
Rehabilitation is maximised if based on patient determined goals		—		—		—		—		—
Rehabilitation is maximised if physiotherapy is made available for people with Parkinson's disease from diagnosis		—		—		—		—		—
The effects of physiotherapy are maximised if rehabilitation is delivered in the hospital environment		0		3.9		27.6		48.7		19.7
The effects of physiotherapy are maximised if rehabilitation is delivered in the patient's home		17.1		30.3		35.5		17.1		0
The effects of physiotherapy are maximised if rehabilitation is delivered in both the patient's home and the hospital environment		25		35.5		27.6		11.8		0
The effects of physiotherapy are maximised if rehabilitation is delivered as individual sessions		13.2		34.2		39.5		13.2		0
The effects of physiotherapy are maximised if rehabilitation is delivered as group therapy		5.3		21.1		52.6		21.1		0
The effects of physiotherapy are maximised if rehabilitation is delivered as both individual and group sessions		40.8		36.8		19.7		2.6		0
The intervention package delivered, the treatment setting, and the treatment format (one to one session or group), should be based on the individual needs of the patients as determined by their initial assessment		—		—		—		—		—
Physiotherapy for Parkinson's disease should be patient specific, rather than based on a specific "named" approach (e.g. Bobath, Brunstrom)		73.7		25.0		1.3		0		0
Rehabilitation is maximised if carers are involved in the physiotherapy process		57.9		38.2		3.9		0		0
Involvement of the carer should be based on the individual needs of the patient, and the individual situation of the carer		—		—		—		—		—
Rehabilitation is maximised if sufficient time is given for people with Parkinson's disease to process information and plan a response to queries and instructions		80.3		19.7		0		0		0
Rehabilitation is maximised if patients are encouraged to develop problem-solving skills		75.0		22.4		2.6		0		0



to encourage self-management of functional difficulties.										
Rehabilitation is maximised if physiotherapists recognise when referrals to other multidisciplinary/ interdisciplinary team members are required		—		—		—		—		—
Rehabilitation is maximised when physiotherapists work collaboratively within the multidisciplinary/ interdisciplinary team format		—		—		—		—		—

### SPECIFIC STATEMENTS

The following sections explore possible treatment techniques within the specific areas of rehabilitation physiotherapists may be involved in when treating people with Parkinson’s disease. **The treatments outlined are not meant to be prescriptive or applicable to all patients. Similarly, the interventions are not meant to stand alone, and it is recognised that therapists would employ a number of the techniques when managing a patient with Parkinson’s disease. Instead, the techniques covered by the statements are meant to act as a menu for physiotherapists treating people with Parkinson’s disease.**

### EFFECTIVE TREATMENT TECHNIQUES FOR GAIT REHABILITATION

	Strongly agree	% R1	Agree	% R1	Undecided	% R1	Disagree	% R1	Strongly disagree	% R1
Visual, auditory and/ or sensory external cueing techniques may be effective in improving, maintaining, or minimising the degeneration of gait parameters		68.4		31.6		0		0		0
Cognitive movement strategies, such as the breaking down of complex movement sequences into simple steps and the use of self instruction, may be effective in improving, maintaining, or minimising the degeneration of gait parameters		61.8		34.2		3.9		0		0
Combining cognitive movement strategies with external cueing techniques may be effective in improving gait initiation		57.9		40.8		1.3		0		0
The use of verbal instruction to focus attention on specific aspects of gait may be effective in improving, maintaining, or minimising the degeneration of gait parameters		48.7		47.4		2.6		1.3		0
The use of mental rehearsal prior to walking may be effective in improving, maintaining, or minimising the degeneration of gait		36.8		36.8		26.3		0		0
The use of compensatory strategies, such as side stepping to negotiate narrow areas, may be effective in improving, maintaining, or minimising the degeneration of gait		—		—		—		—		—
Lower limb strengthening exercises may be effective in improving, maintaining, or minimising the degeneration of gait parameters		40.8		46.1		13.2		0		0

Joint mobility/ limb mobilisation exercises, when combined with task-specific training, may effectively contribute to the improvement, maintenance, or minimisation of degeneration of gait parameters		42.1		48.7		6.6		2.6		0
Walking practice utilising functional conditions such as obstacles and turning may be an effective treatment technique for the improvement, maintenance or minimisation of degeneration of gait		47.4		43.4		7.9		0		1.3
Walking practice utilising the patient's own environment may be an effective treatment technique for the improvement, maintenance or minimisation of degeneration of gait		50.0		40.8		7.9		1.3		0
Dual tasking with another motor task, or cognitive task, should be avoided when walking		18.4		32.9		25.0		15.8		7.9
Dual or multiple task training, which gradually increases in complexity, may be effective in improving, maintaining or minimising the degeneration of gait carried out under multiple task/ functional conditions		22.4		35.5		35.5		6.6		0
The provision of, education on the use of, and practice in using walking aids may be an effective treatment technique for the improvement, maintenance or minimisation of degeneration of gait		36.8		55.3		5.3		2.6		0

**EFFECTIVE TREATMENT TECHNIQUES FOR BALANCE REHABILITATION AND THE MANAGEMENT OF FALLS**

	<b>Strongly agree</b>	<b>% R1</b>	<b>Agree</b>	<b>% R1</b>	<b>Undecided</b>	<b>% R1</b>	<b>Disagree</b>	<b>% R1</b>	<b>Strongly disagree</b>	<b>% R1</b>
A combined, progressive exercise programme of lower limb strength training and balance training involving alteration of visual, vestibular and somatosensory feedback, may be effective in improving, maintaining, or minimising the degeneration of balance		51.3		40.8		7.9		0		0
A balance rehabilitation programme should be multifaceted and progressive, including static, dynamic and functional balance training, gait training, lower limb strength training, range of motion exercises, and the provision of falls prevention strategies		67.1		31.6		1.3		0		0
A balance rehabilitation programme should include training in outdoor, leisure, and work related conditions		32.9		52.6		10.5		2.6		1.3
Exercises focused on the control and coordination of axial movement and related muscle activity may be effective in improving, maintaining, or minimising the degeneration of balance		27.6		44.7		25.0		1.3		1.3

Education on the importance of pelvic control and the interplay of the pelvis and trunk during movement, may be effective in improving, maintaining, or minimising the degeneration of balance		—		—		—		—		—
External cueing techniques, provided for gait rehabilitation, may have a secondary beneficial effect on balance		22.4		43.4		32.9		1.3		0
Cognitive movement strategies and external cueing techniques, provided for gait and transfer rehabilitation, may have a secondary beneficial effect on balance		23.7		44.7		30.3		0		1.3
Teaching a patient, and practising, how to get on and off the floor may be beneficial in reducing the fear to fall		56.6		34.2		7.9		1.3		0

### EFFECTIVE TREATMENT TECHNIQUES FOR TRANSFERS REHABILITATION

	Strongly agree	% R1	Agree	% R1	Undecided	% R1	Disagree	% R1	Strongly disagree	% R1
Cognitive movement strategies including mental rehearsal, the breaking down of complex movement sequences into simple steps, and the use of self instruction, may be effective in improving, maintaining, or minimising a person's difficulties in performing transfers.		57.9		31.6		9.2		0		0
Visual, auditory and/ or sensory external cueing techniques may be effective in improving, maintaining, or minimising a person's difficulties in performing transfers.		47.4		40.8		9.2		1.3		0
Inclusion of a home environment assessment to identify whether modifications would enhance a patient's ability to transfer may be useful to include within transfers rehabilitation		—		—		—		—		—
Transfers rehabilitation may be optimised by ensuring task specificity (e.g. practising transferring in the patient's car, in their own bed etc)		—		—		—		—		—
The provision of, education on the use of, and practice with equipment such as transfer boards may be helpful for performing transfers		31.6		42.1		21.1		3.9		1.3
The provision of education and training to carers may be effective in facilitating a patient's ability to transfer		—		—		—		—		—

### EFFECTIVE TREATMENT TECHNIQUES FOR POSTURE REHABILITATION

	Strongly agree	% R1	Agree	% R1	Undecided	% R1	Disagree	% R1	Strongly disagree	% R1
Exercises focused on the control and coordination of axial movement, and related muscle activity, may be effective in improving, maintaining, or minimising the degeneration of posture, and function related to posture		50.0		36.8		13.2		0		0
Exercises focused on the strengthening of core muscles may be effective in improving, maintaining, or minimising the degeneration of posture		—		—		—		—		—
Passive and positional stretching, such as lying semi prone or supine on a bed, may be beneficial in improving, maintaining, or minimising the degeneration of posture		—		—		—		—		—
The hands on facilitation of body alignment may be effective in improving, maintaining, or minimising the degeneration of posture		—		—		—		—		—
The inclusion of manual techniques, such as mobilisations, may be effective in improving, maintaining, or minimising the degeneration of posture		—		—		—		—		—
The use of feedback such as verbal prompts and visual feedback from a mirror, may be effective in improving, maintaining, or minimising the degeneration of posture		34.2		48.7		15.8		1.3		0
Education regarding the importance of correct posture may be beneficial in improving, maintaining, or minimising the degeneration of posture		—		—		—		—		—
The provision of, and education on the use of equipment and aids, such as a lumbar roll, may be effective in improving, maintaining, or minimising the degeneration of posture		—		—		—		—		—

### EFFECTIVE TREATMENT TECHNIQUES FOR PHYSICAL CONDITIONING

	Strongly agree	% R1	Agree	% R1	Undecided	% R1	Disagree	% R1	Strongly disagree	% R1
An exercise programme which includes lower limb strengthening may be effective in improving, maintaining, or minimising the degeneration of lower limb strength		55.3		40.8		3.9		0		0
An exercise programme which includes upper limb strengthening may be effective in improving, maintaining, or minimising the degeneration of upper limb strength		50.0		43.4		5.3		0		0
An exercise programme which includes exercises focused on trunk strengthening may be effective in improving, maintaining, or		51.3		47.4		1.3		0		0

minimising the degeneration of trunk strength										
An exercise programme which includes exercises focused on joint mobility and flexibility may be effective in improving, maintaining, or minimising the degeneration of joint mobility and flexibility		57.9		39.5		2.6		0		0
An exercise programme which includes exercises focused on cardiorespiratory training, may be effective in improving, maintaining, or minimising the degeneration of cardiorespiratory fitness		42.1		51.3		6.6		0		0
The rehabilitation of posture may have a secondary effect on improving, maintaining, or minimising the degeneration of a patient's cardiorespiratory capacity		---		---		---		---		---
Positioning and passive stretching may be effective in improving, maintaining, or minimising the degeneration of a patient's physical condition		---		---		---		---		---
Manual techniques, such as mobilisations, may be effective in improving, maintaining, or minimising the degeneration of a patient's joint mobility and flexibility		---		---		---		---		---
Training for physical conditioning may have a secondary impact on the psychological health of a patient		---		---		---		---		---
Utilisation of functional goals and task specific training may be effective in improving or maintaining a patient's level of physical activity		---		---		---		---		---
Education on physical activity, such as what it entails and advice on how much should be carried out weekly, may be effective in improving or maintaining a patient's level of physical activity		---		---		---		---		---
To maximise the effectiveness of rehabilitation aimed at physical conditioning and fitness, physiotherapists should encourage the patient to engage in a recreational form of activity to support independence, adherence and self-management.		75.0		23.7		1.3		0		0
Advice on, and referral to, local leisure facilities may be beneficial in improving or maintaining a patient's level of physical activity		---		---		---		---		---

### EFFECTIVE TREATMENT TECHNIQUES FOR THE REHABILITATION OF UPPER LIMB FUNCTION

	Strongly agree	% R1	Agree	% R1	Undecided	% R1	Disagree	% R1	Strongly disagree	% R1
External cueing techniques may be effective in improving, maintaining, or minimising degeneration of the parameters of reach to grasp		14.5		34.2		48.7		2.6		0
Internally generated cues or self instruction may be effective in improving, maintaining, or minimising degeneration of the parameters of reach to grasp		21.1		42.1		35.5		1.3		0
Exercises focused on upper limb muscular coordination may be effective in improving, maintaining, or minimising degeneration of upper limb functional movement		22.4		52.6		23.7		0		0
Exercises focused on upper limb strengthening and range of movement may be effective in improving, maintaining, or minimising degeneration of upper limb functional movement		32.9		50.0		17.1		0		0
Upper limb rehabilitation, focused on dexterity and coordination as applied to functional tasks (e.g. doing up buttons), may be effective in improving, maintaining, or minimising the degeneration of upper limb function		—		—		—		—		—

### ADDITIONAL EFFECTIVE TREATMENT TECHNIQUES WITHIN PARKINSON'S DISEASE

	Strongly agree	% R1	Agree	% R1	Undecided	% R1	Disagree	% R1	Strongly disagree	% R1
The inclusion of manual chest physiotherapy may be effective in managing the secondary respiratory complications of Parkinson's disease		—		—		—		—		—
The inclusion of breathing exercises may be effective in managing the secondary respiratory complications of Parkinson's disease		—		—		—		—		—
The provision of acupuncture may be effective in the management of pain.		—		—		—		—		—
The provision of Transcutaneous Electrical Nerve Stimulation (TENS) may be effective in the management of pain.		—		—		—		—		—
The provision of massage may be effective in the management of pain		—		—		—		—		—
Prolonged stretching may be effective in the management of pain		—		—		—		—		—

## COMPLEMENTARY AND ALTERNATIVE THERAPIES AS AN ADJUNCT TO PHYSIOTHERAPY

	Strongly agree	% R1	Agree	% R1	Undecided	% R1	Disagree	% R1	Strongly disagree	% R1
The physiotherapy management of people with Parkinson's disease may be enhanced by the inclusion of the Alexander technique		—		—		—		—		—
The physiotherapy management of people with Parkinson's disease may be enhanced by the inclusion of Pilates		—		—		—		—		—
The physiotherapy management of people with Parkinson's disease may be enhanced by the inclusion of Tai Chi		—		—		—		—		—
The physiotherapy management of people with Parkinson's disease may be enhanced by the inclusion of Yoga		—		—		—		—		—

### 6. Outcome measurement during physiotherapy provision

- ❖ The statements below have been constructed using clinical experimental evidence, findings from systematic reviews, and expert consensus.

#### OUTCOME MEASURES SHOULD ASSESS...

	Strongly agree	% R1	Agree	% R1	Undecided	% R1	Disagree	% R1	Strongly disagree	% R1
The specific aims of the treatment delivered		56.6		38.2		3.9		1.3		0
The effect of the treatment delivered on areas related to those targeted specifically by the treatment (e.g. measuring the effect of balance rehabilitation on gait)		57.9		40.8		1.3		0		0
The effect of the treatment delivered on areas that can be indirectly influenced by the treatment (e.g. measuring the effect of cardiorespiratory training on mood/ depression)		15.8		46.1		32.9		3.9		1.3
The effectiveness of the treatment delivered at the level of the body structure or body function targeted (based on the ICF model)		17.1		43.4		36.8		2.6		0
The effectiveness of the treatment delivered at the level of activity performance, specific to the problem targeted (based on the ICF model)		31.6		47.4		19.7		0		0
The effectiveness of the treatment delivered at the level of participation (based on the ICF model)		25.0		39.5		31.6		3.9		0
The effect of the treatment delivered on a person's overall physical functioning		43.4		48.7		7.9		0		0
The effect of the treatment delivered on health-related quality-of-life and wellbeing		40.8		51.3		5.3		2.6		0
The impact of the treatment delivered on a patient's carer(s) physical and psychological		28.9		47.4		17.1		6.6		0

health, activity and participation										
------------------------------------	--	--	--	--	--	--	--	--	--	--

General statements regarding outcome measures during physiotherapeutic provision:

	Strongly agree	% R1	Agree	% R1	Undecided	% R1	Disagree	% R1	Strongly disagree	% R1
Outcome measures should be of a (patient) self-report, subjective nature		—		—		—		—		—
Outcome measures should be objective in nature		—		—		—		—		—
Outcome measurement should include both subjective and objective measures to allow both patient self-report, and objective measurement of symptoms and the effects of treatment		69.7		26.3		3.9		0		0
Outcomes should be measures during both the “on” and “off” periods for a patient		—		—		—		—		—
Outcome measures should be recorded both pre- and post-treatment to allow change to be measured.		73.7		22.4		3.9		0		0
Outcome measures should be recorded before commencing treatment, and at the end of the course of therapy		—		—		—		—		—
Measurement of outcome measures over an extended period of time may be useful to monitor disease progression and change.		—		—		—		—		—
Physiotherapists should use the findings of outcome measures when managing patients to influence their future practice		63.2		31.6		3.9		1.3		0



## APPENDIX B: STUDY TWO

### OUTCOME MEASURES LISTED BY THERAPISTS

Outcome measure	Number of times recorded	Outcome measure	Number of times recorded
<b>Area: Gait</b>		<b>Area: Upper limb</b>	
Timed walk (e.g. 10 metre walk test)	28	Nine Hole Peg Test	5
Walking distance (e.g. 6 minute walk test)	6	Grip strength	1
Walk and talk	3	Ipswich tap test motor function	1
Freezing of Gait questionnaire	3	<b>Area: Physical activity/ fitness</b>	
Stride length	1	One repetition maximum	1
Dynamic Gait Index	1	<b>Area: Motor fluctuations</b>	
Physiological Cost Index	1	Modified dyskinesia scale	1
<b>Area: Balance</b>		<b>Area: Physical functioning</b>	
Berg Balance Scale	40	Unified PD Rating Scale	6
Timed Up and Go/ Get Up and Go	28	Barthel ADL index	2
Functional reach	9	Functional Independence Measure	1
360 degree turn	7	Canadian Occupational Performance Measure	1
180 degree turn	6	<b>Area: Pain</b>	
Timed Unsupported Steady Stand	4	Pain Self Efficacy questionnaire	1
One Leg Stance Test	3	Short form McGill pain questionnaire	1
CONFbal scale	3	Pain score (self-report out of 10 – “home-grown”)	1
Lateral reach	2	<b>Area: Psychological/ cognitive</b>	
Frailty and Injuries: Cooperative Studies of Intervention Techniques scale (FICSIT-4)	1	Hospital Anxiety and Depression Scale	1
Rombergs test	1	Mini Mental Status Examination	1
Step test	1	<b>Area: Quality of life</b>	
<b>Area: Combined gait/ balance/ mobility</b>		PDQ-39	3
Lindop PD mobility Assessment	25	Measure Yourself Medical Outcome Profile	2
Performance Oriented Mobility Assessment (Tinetti)	14	PD Quality of Life questionnaire	1
Elderly Mobility Scale	9	SF-12	1
Rivermead Mobility Index	1	EuroQol-5D	1
<b>Area: Transfers</b>		Quality of life score (“home-grown”)	1
Time of transfers	6	<b>Area: Carer</b>	
<b>Area: Posture</b>		Carer Strain Index	1
Tragus to wall standing	6	<b>Area: Goal attainment</b>	
Change in height	1	Goal attainment scale	5
Observation of posture	1	Patient goal setting and measurement of attainment (non-specific measure – “home-grown”)	3
<b>Area: Trunk</b>		<b>Area: Service evaluation</b>	
Trunk impairment scale (also measures balance)	1	Patient satisfaction questionnaire (“home-grown”)	2
Trunk control test (also measures transfers)	1	<b>Area: Other</b>	
<b>Area: Falls</b>		Visual Analogue Scale (no specific focus given)	3
Falls Efficacy Scale	1	Range of movement	2
<b>Area: Disease Status</b>		Bagley (full title unconfirmed)	1
Hoehn and Yahr	1	Nordic Musculoskeletal Questionnaire	1
		Unspecified timed measures	1

Total respondents listing outcome measures: 60/72

## DELPHI STATEMENTS AND LEVELS OF CONSENSUS

### Outcome measures should assess...

- The specific aims of the treatment delivered (98%)
- The effect of the treatment delivered on areas related to those targeted specifically by the treatment (e.g. measuring the effect of balance rehabilitation on gait) (100%)
- The effect of the treatment delivered on areas that can be indirectly influenced by the treatment (e.g. measuring the effect of cardiorespiratory training on mood/ depression) (60%)
- The effectiveness of the treatment delivered at the level of the body structure or body function targeted (based on the ICF model) (58%)
- The effectiveness of the treatment delivered at the level of activity performance, specific to the problem targeted (based on the ICF model) (86%)
- The effectiveness of the treatment delivered at the level of participation (based on the ICF model) (77%)
- The effect of the treatment delivered on a person's overall physical functioning (93%)
- The effect of the treatment delivered on health-related quality-of-life and wellbeing (100%)
- The impact of the treatment delivered on a patient's carer(s) physical and psychological health, activity and participation (86%)
  
- Outcome measures should be of a (patient) self-report, subjective nature (77%)
- Outcome measures should be objective in nature (90%)
- Outcome measurement should include both subjective and objective measures to allow both patient self-report, and objective measurement of symptoms and the effects of treatment (100%)
- Outcomes should be measures during both the "on" and "off" periods for a patient (77%)
- Outcome measures should be recorded both pre-and post-treatment to allow change to be measured (91%)
- Outcome measures should be recorded before commencing treatment, and at the end of the course of therapy (100%)
- Measurement of outcome measures over an extended period of time may be useful to monitor disease progression and change. (100%)
- Physiotherapists should use the findings of outcome measures when managing patients to influence their future practice (98%)

Week	1	2	3	4	5	6	7	8	9	10	11	12	
<b>Visits per week</b>	2	3	3	3	3	3	3	2	2	3	2	2	
<b>Cardiovascular/ Warm Up</b>													
<b>Treadmill: Minutes</b>	Not added until week 7						6	6	6	10	10	10	
Comfortable walking speed, with gradual increase (participant determined)													
<b>Cross trainer: Minutes</b>	10	10	12	15	20	20	25	25	25	20	20	20	
<b>Strength Training</b>													
<b>Chest press: Sets/ repetitions</b>	3/8	3/8	3/8	3/8	3/9	3/9	3/9	3/9	3/9	3/10	3/10	3/10	
Load in kilograms	50	50	50	50	50	50	50	50	50	50	50	50	
<b>Seated row: Sets/ repetitions</b>	3/8	3/8	3/8	3/8	3/10	3/10	3/10	3/10	3/9	3/10	3/10	3/10	
Load in kilograms	62.5	62.5	62.5	62.5	62.5	62.5	62.5	62.5	62.5	62.5	62.5	62.5	
<b>Lat pull down:</b>	Not added until week 4			3/8	3/8	3/9	3/9	3/10	3/10	3/10	3/10	3/10	
Sets/ repetitions	Not added until week 4			3/8	3/8	3/9	3/9	3/10	3/10	3/10	3/10	3/10	
Load in kilograms	Not added until week 4			62.5	62.5	62.5	62.5	62.5	62.5	62.5	62.5	62.5	
<b>Leg press: Sets/ repetitions</b>	Not added until week 3		3/8	3/8	3/9	3/9	3/10	3/10	3/10	3/10	3/10	3/10	
Load in kilograms	Not added until week 3		35	35	35	35	35	35	35	35	35	35	
<b>Strength/ Flexibility Training</b>													
<b>Abdominal crunches:</b>													
Sets/ repetitions	2/10	2/12	2/12	2/12	2/15	2/15	2/15	2/20	2/20	2/20	2/20	2/20	
<b>Back extensions:</b>													
Sets/ repetitions	2/10	2/12	2/12	2/12	2/15	2/15	2/15	2/20	2/20	2/20	2/25	2/25	
<b>Med ball twists:</b>													
Sets/ repetitions	2/10	2/12	2/12	2/15	2/15	2/15	2/15	2/20	2/20	2/20	2/25	2/25	
<b>Upper Limb Coordination</b>													
<b>Arm bike: Minutes</b>	Not added until week 6					5	6	6	6	Disliked by participant, so removed			
<b>Cardiovascular/ Cool down</b>													
<b>Exercise bike: Minutes</b>	5	5	5	6	7	8	Replaced by treadmill						
<b>Treadmill: Minutes</b>	Not added until week 7						6	6	7	10	10	10	
Comfortable walking speed, with gradual decrease (participant determined)													

## APPENDIX D: ASSOCIATED PUBLICATIONS

World Parkinson Congress 2010 Abstracts: *Movement Disorders*, 25(Suppl 3): S712

P35.03

### Defining UK Physiotherapy in Parkinson's Disease: A Modified Delphi Survey

*C. Meek, C.M. Sackley, C.E. Clarke, S. Shah (University of Birmingham, United Kingdom)*

**Introduction:** Physiotherapy is viewed as an essential component in the management of Parkinson's disease (PD), advocated by both patients and professionals. Its inclusion in the care of people with PD is supported by national guidelines, and there is a growing body of evidence suggesting its efficacy. However, our understanding of what physiotherapy entails for this population is limited.

**Aims:** To explore best practice physiotherapy for people with PD as perceived by therapists, and to obtain information on the current structure and delivery of physiotherapy services in the UK.

**Methods:** A two round, modified Delphi survey was conducted to generate information on the reasons for providing physiotherapy, the core areas of physiotherapy, perceived effective treatment techniques, and the measurement of outcome. In addition, an optional closed-questionnaire was disseminated to gain information on the characteristics of responding therapists, and the current structure and delivery of physiotherapy in the UK. Members of the Delphi panel consisted of researchers and practicing physiotherapists with an interest/ expertise in the management of people with PD, and were recruited through personal correspondence, postings on the interactive Chartered Society of Physiotherapy web page, and advertisement at conferences. The survey was conducted from Primary Care Clinical Sciences at the University of Birmingham and disseminated to members of the Delphi panel via email.

**Results:** From a database of 107 therapists, 76 (71%) responded to the first round of the Delphi survey and 61 (57%) to the second round of the Delphi survey. In addition, 70 therapists completed the optional questionnaire. Full results to follow.

**Conclusion:** The findings of this survey will be used to provide a framework for the physiotherapeutic intervention delivered within a multi-centre randomised controlled trial investigating the clinical and cost effectiveness of physiotherapy and occupational therapy for people with PD: PD REHAB, and to inform clinical practice.

## APPENDIX D: ASSOCIATED PUBLICATIONS

World Parkinson Congress 2010 Abstracts: *Movement Disorders*, 25(Suppl 3): S713

### P35.04

#### **Long-Term Individual Fitness Enablement (LIFE) for Parkinson's Disease: A Feasibility Study**

*C. Meek,<sup>1</sup> C.M. Sackley,<sup>1</sup> C.E. Clarke,<sup>1</sup> A.A. Soundy,<sup>1</sup> C. Winward,<sup>2</sup> P. Esser,<sup>2</sup> S. Patel,<sup>1</sup> H. Dawes<sup>2</sup> (<sup>1</sup>University of Birmingham, United Kingdom; <sup>2</sup>Oxford Brookes University, United Kingdom)*

**Background:** Exercise is a potentially important component within the management of Parkinson's disease (PD). Habitual levels of physical activity are known to be lower for people with PD than age-matched healthy adults. Packages to support individualised community-based physical activity have not been investigated.

**Aims:** To investigate the feasibility and acceptability of an individualised community exercise programme, supported by a physical activity support system, for people with idiopathic PD. Also, to assess the feasibility of outcome measures and to provide estimates of the effects of the intervention to inform further studies.

**Methods:** The study was conducted as a phase II randomised controlled trial (RCT) with blinded assessment at baseline and post-intervention (3-months). Adults with mild to moderate idiopathic PD were recruited from consultant-led outpatient neurological clinics. Participants randomised to the intervention group collaborated with fitness instructors to design a 3-month individualised, progressive exercise programme. The intervention was delivered in community leisure centres within Oxfordshire and Birmingham, and physiotherapy support was provided throughout. The control group received standard care. The primary outcome measure was the Physical Activity Scale for the Elderly (PASE). Secondary outcome measures included accelerometer monitored physical activity (using Step Activity Monitors), the 10-metre and 2-minute walk tests, lower limb muscle strength and grip strength, the Fatigue Severity Scale, the Parkinson's Disease Questionnaire-39 and falls.


**Results:** Thirty-nine participants with PD were recruited. Twenty were randomly assigned to the intervention group (5 female; mean age 63 years) and 19 to the control group (3 female; mean age 65 years). Assessments were carried out on time and outcome measures were completed well, with between 92.1% and 100% of participants completing the primary outcome measure at each time point. Uptake of the intervention was good (87% of participants – N=34) and the gym was attended well (mean number of 15 visits). There were no significant changes in any of the outcome measures. No adverse events were reported.

**Conclusions:** The trial confirmed the feasibility and acceptability of an individualised, supported exercise intervention, delivered in the community, for people with PD. In order to confirm the effectiveness of this intervention, a phase III RCT is now required.

## APPENDIX E: ASSOCIATED CONFERENCE POSTERS AND PRINTED ABSTRACTS

### Presented at:


- Parkinson's UK Research Conference (2010)
  - 2<sup>nd</sup> World Parkinson Congress (2010)
  - West Midlands Nurses, Midwives and Allied Health Professions Research Training Awards 2009 Celebratory Event (2010)
  - South West Society for Academic Primary Care Conference (2010)
- (See Appendix E for full details of conferences)



**UNIVERSITY OF BIRMINGHAM**

### Defining UK Physiotherapy Practice In Parkinson's Disease: A Modified Delphi Survey

Meek, C.1, Sackley, C.M.1, Clarke, C.E.2, Shah, S.1  
Primary Care Clinical Sciences<sup>1</sup>, School of Clinical and Experimental Medicine<sup>2</sup>, University of Birmingham



**Background:**  
Physiotherapy is viewed as an essential component in the management of Parkinson's disease (PD). Its inclusion in the care of people with PD (PwPD) is supported by national guidelines<sup>1</sup>, and there is a growing body of evidence suggesting its efficacy<sup>2</sup>. Despite this, our actual understanding of what physiotherapy entails for this population is limited and there are few surveys exploring physiotherapy as delivered for PwPD.

Our knowledge of UK practice is largely based on the findings of the PD: Physiotherapy Evaluation Project (PD: PEP); a Delphi survey of 72 specialist physiotherapists and case studies of the 9 best practice sites<sup>3,4</sup>. This highlighted:

- The focus of treatment: gait, balance, posture and transfers
- The structure of treatment delivery: individual and/or group format
- The average dose of treatment: once or twice weekly over a period of 6-8 weeks

It also acknowledged that treatment strategies utilised were individualised for the patient's needs and eclectic in nature.

The PD: PEP has provided a working definition of physiotherapy for PwPD in the UK for the past decade. However, the evidence base has now progressed, and physiotherapy specific evidence-based guidelines have been published. For these reasons, practice may have changed and so appropriate measures should be taken to update our understanding.

**Design:**  
A two round modified Delphi survey with an additional closed-question questionnaire.

**Participants:**  
Clinical or research physiotherapists with an interest/expertise in the management of PwPD.

**Setting:**  
The survey was conducted from Primary Care Clinical Sciences at the University of Birmingham and disseminated to members of the Delphi panel via email.

**Delphi Process**

**Generation of the Delphi statements**

Literature search conducted to uncover relevant evidence  
Literature analysed and graded for strength  
Delphi statements generated under the headings of: reasons for physiotherapy, core areas of physiotherapy, effective treatment approaches, outcome measures

**First round of Delphi**

Panel members scored agreement or disagreement with statements on a Likert scale. Responses analysed for agreement and consensus.  
In addition, optional closed question questionnaire were completed to gain information on expertise of therapists, and the setting, structure and dose of physiotherapy currently delivered.

**Second round of Delphi**

Delphi survey was repeated, incorporating the group's first round response.  
Panel members re-rated the statements in light of the first round response.

**Analysis of results for consensus**

Consensus for a statement reached if 80% or more respondents present in agreement on the Likert Scale.

**Report findings**

**Progress to date**  
Both rounds of the Delphi survey have been completed. From a database of 107 therapists, 76 (72%) responded to the first round, and 61 (60%) to the second round. In addition, 70 therapists completed the optional questionnaire. Full results to follow.


**Research Aims**  
The aims of this survey are:

To explore best practice physiotherapy for PwPD as perceived by physiotherapists and, more specifically, to uncover what therapists identify as:

- The reasons for providing physiotherapy
- The core areas of physiotherapy
- Perceived effective treatment techniques and modalities
- The outcomes that should be measured when managing PwPD

Also, to obtain information regarding the current structure and delivery of physiotherapy services within the UK.

The findings of this survey will be used to provide a framework for the physiotherapeutic intervention to be delivered within the multi-centre randomised controlled trial PD RENAB, and to inform clinical practice.



**References:**

1. NICE. Parkinson's disease: diagnosis and management in primary and secondary care. The Royal College of Physicians; 2006.
2. Kwakkel G et al. Impact of physical therapy for Parkinson's disease: a critical review of the literature. *Parkinsonism & Related Disorders*. 2007;13 Suppl. 3:S478-87.
3. Plant R et al. Physiotherapy for People with Parkinson's disease: UK Best Practice: Institution of Rehabilitation, University of Northumbria; 2000.
4. Ashburn A et al. Physiotherapy for people with Parkinson's Disease in the UK: An exploration of practice. *International Journal of Therapy and Rehabilitation*. 2004; 11(4):100-7.



**Funding:** This research is funded by the West Midlands Strategic Health Authority  
**Contact Details:** Charmaine Meek, Primary Care Clinical Sciences, University of Birmingham, Edgbaston, Birmingham, B15 2TT. Tel: 0121 414 2054. Email: c.meek@bham.ac.uk

# APPENDIX E: ASSOCIATED CONFERENCE POSTERS AND PRINTED ABSTRACTS

## Presented at:

- Parkinson's UK Research Conference (2010)
  - 2<sup>nd</sup> World Parkinson Congress (2010)
- (See Appendix E for full details of conferences)

**Long-term Individual Fitness Enablement (LIFE) for Parkinson's Disease:  
A Feasibility Study**

Meek C.<sup>1</sup>, Sackley CM.<sup>1</sup>, Clarke CE.<sup>1</sup>, Soundy A.<sup>1</sup>, Winward C.<sup>2</sup>, Esser P.<sup>2</sup>, Patel S.<sup>1</sup>, Dawes H.<sup>2</sup>  
University of Birmingham<sup>1</sup>, Oxford Brookes University<sup>2</sup>

### Background:

Exercise is recognised to have potentially wide-ranging benefits for people with Parkinson's disease (PD)<sup>1</sup>. Despite this, physical activity levels exhibited by people with PD are known to be lower than those of healthy age-matched controls<sup>2</sup>. Within a community-based setting, a number of barriers have been identified that may influence physical activity levels<sup>3</sup>. A system for supporting exercise in the community has been developed, which may be useful in improving physical activity levels and other health outcomes.

### Research Aims:

- To assess the feasibility and acceptability of an individualised exercise programme, delivered within community leisure centres and supported by a physical activity support system (PASS).
- To provide estimates of the effect of the intervention on physical activity levels and other health outcomes to inform a sample size calculation for a phase III trial.

### Methods:

#### Design

- A phase II randomised controlled trial (RCT) with blinded assessment and concealed allocation.

#### Inclusion criteria

- Over 55 years of age
- Diagnosis of idiopathic PD
- Ability to walk 10 metres using any aid or assistance as required
- No cognitive, sensory or psychological impairments that may preclude participation.

#### Exclusion criteria

- Patients unable to meet the inclusion criteria
- Additional impairments restricting mobility or any contraindications to exercise.

#### Setting

- Community leisure centres across Birmingham and Oxfordshire.

#### Intervention group

Participants collaborated with fitness instructors to design a 12-week progressive exercise programme. This was based on participants' own goals, but typically included elements of endurance, muscle strength, flexibility and cardiovascular fitness. The number and length of exercise sessions was determined by the individual.

The PASS was delivered alongside the exercise programme to reduce barriers. This included:

- Delivery of the exercise programme at gyms with a physically accessible environment and suitable equipment
- Ongoing support from a fitness professional with knowledge of PD
- Support throughout for the participants and fitness instructors from a physiotherapist
- Payment of gym and transport costs.

#### Control

- The control group received standard care.

#### Assessments

Assessments were carried out at baseline and immediately post-intervention (12 weeks).

- Primary outcome measure: Physical Activity Scale of the Elderly (PASE).
- Secondary outcome measures: accelerometer monitored physical activity (using a Step Activity Monitor), 10-metre walk test, two-minute walk test, lower limb muscle strength, grip strength, Fatigue Severity Scale (FSS), Short Orientation Memory Concentration (SOMC) test, Parkinson's Disease Questionnaire-39 (PDQ-39), Short Form Health Survey (SF-36), and number of falls.



Table 1: Baseline characteristics

Baseline Characteristics	Exercise group	Control group
Gender (N/P)	10/8	10/3
Mean age (years) (SD)	62 (8.7)	65 (9.8)
Mean Body Mass Index (kg/m <sup>2</sup> ) (SD)	27.3 (6.7)	26.2 (9.8)
Mean duration of disease (years) (SD)	5.1 (4.5)	4.7 (5.4)
Mean Number Activities of Daily Living Index (SD)	18	18

### Results:

- Thirty nine participants were recruited between the 15<sup>th</sup> November 2007 and the 30<sup>th</sup> January 2009.
- Twenty participants were randomised to the intervention group and 19 to the control group.
- There were no losses to follow up between assessments.
- Assessment occurred on time and completion of outcome measures was good (see Table 2).
- Uptake of the intervention was good with 18 out of 20 participants in the exercise group completing the intervention.
- The mean gym attendance was 17 visits (range 4 to 31).
- There were no significant differences between the two groups for any of the participant characteristics or outcome measures at baseline or post-intervention (see Tables 1 and 2).
- No adverse events were reported.

Table 2: Summary statistics for outcome measures

Measure		Exercise group	Control group	Mean difference		
		n	Mean (SD)	n	Mean (SD)	(95% CI)
PASE	Baseline	20	121.1 (26.4)	18	113.7 (26.4)	7.4 (-29.0 to 47.0)
	3 months	18	128.2 (28.2)	18	134.8 (25.8)	-6.4 (-48.0 to 35.1)
		20	132.8 (26.4)	18	135.8 (26.4)	4.7 (-21.2 to 28.4)
Sixm-walk	Baseline	18	133.3 (25.2)	18	134.8 (26.2)	-1.4 (-23.4 to 20.7)
	3 months	20	132.8 (26.4)	18	135.8 (26.4)	4.7 (-21.2 to 28.4)
		20	132.8 (26.4)	18	135.8 (26.4)	4.7 (-21.2 to 28.4)
Tenm-walk	Baseline	20	7.2 (1.8)	18	8.1 (1.6)	-0.90 (-2.1 to 1.3)
	3 months	20	7.2 (2.4)	18	7.6 (2.6)	-0.14 (-1.7 to 1.5)
		20	7.2 (2.4)	17	4.2 (1.3)	3.12 (-1.1 to 7.37)
FSS	Baseline	20	4.0 (1.3)	18	4.2 (1.3)	-0.20 (-1.0 to 0.60)
	3 months	20	3.8 (1.2)	18	3.7 (1.3)	0.09 (-0.8 to 0.92)
		20	38.8 (2.8)	18	38.2 (3.8)	0.58 (-1.5 to 2.6)
SOMC	Baseline	20	28.8 (2.8)	18	27.1 (2.5)	1.7 (-0.5 to 3.9)
	3 months	20	35.2 (2.8)	18	27.1 (2.5)	8.05 (5.8 to 10.3)
		18	27.8 (2.1)	17	27.8 (2.1)	0.00 (-1.8 to 1.8)
PDQ-39	Baseline	18	27.8 (2.1)	17	27.8 (2.1)	0.00 (-1.8 to 1.8)
	3 months	20	35.2 (2.8)	18	27.1 (2.5)	8.05 (5.8 to 10.3)
		18	31.6 (2.1)	18	33.0 (2.4)	1.4 (-0.8 to 3.6)
SAMS	Baseline	18	27.8 (2.1)	17	27.8 (2.1)	0.00 (-1.8 to 1.8)
	3 months	20	35.2 (2.8)	18	27.1 (2.5)	8.05 (5.8 to 10.3)
		18	31.6 (2.1)	18	33.0 (2.4)	1.4 (-0.8 to 3.6)
Falls	Baseline	20	4 patients reported falls	18	4 patients reported falls	0
	3 months	20	1.5 per patient reported falls	18	1 per patient reported falls	0
		20	4 patients reported falls	18	4 patients reported falls	0

PASE (Physical Activity Scale for the Elderly) Range 0 - 100 (poor - good)  
 FSS (Fatigue Severity Scale) Range 1 - 7 (good - bad)  
 SOMC (Short Orientation Memory Concentration) Range 0 - 30 (poor - good)  
 PDQ-39 (Parkinson's Disease Questionnaire) Range 0 - 100 (poor - best)  
 SAMS (Short Form Health Survey)

### Conclusions:

- The trial confirmed the feasibility and acceptability of an individualised, supported exercise intervention, delivered within community leisure centres for people with PD.
- In order to confirm the effectiveness of this intervention, an adequately powered phase III RCT is now required.

### References:

1. GOODYEAR N, et al (2004) The effectiveness of exercise interventions for people with Parkinson's disease: a systematic review and meta-analysis. *Alzheimer's Quarterly*, 33, 50-65.
2. REIS, R, et al (2002) Physical activity and sports in patients suffering from Parkinson's disease: comparison with healthy persons. *Journal of Neurological Rehabilitation*, Parkinson's Disease & Movement Disorders, 6, 127-31.
3. ELISABETH S, et al (2008) A study of barriers/benefits to physical activity in neurological conditions. *International Journal of Therapy and Rehabilitation*, 15, 17-20.



This trial was funded by the Department of Health and Parkinson's UK  
 Contact Details: Charmaine Meek, Primary Care Clinical Sciences, University of Birmingham, Edgbaston, Birmingham, B15 2TT, Tel: 0121 414 2664, Email: c.meek@bham.ac.uk

## APPENDIX E: ASSOCIATED CONFERENCE POSTERS AND PRINTED ABSTRACTS

### Presented at:

- Southampton Neurorehabilitation Conference (2008)

(See Appendix E for full details of conference)

**Long term Individual Fitness Enablement (LIFE); Parkinson's Disease. An ongoing RCT.**

*H Dawes<sup>1</sup>, CE Clarke<sup>2</sup>, P Esser<sup>1</sup>, CE Meek<sup>2</sup>, S Patel<sup>2</sup>, CM Sackley<sup>2</sup>, AA Soundy<sup>2</sup>, C Winward<sup>1</sup>.*

1. Oxford Brookes University, Oxford UK. 2. University of Birmingham, Birmingham UK.

Correspondence to: [c.meek@bham.ac.uk](mailto:c.meek@bham.ac.uk)

### BACKGROUND

Exercise is a potentially important component within the management of Parkinson's disease (PD). Habitual levels of physical activity are known to be lower for people with PD than age-matched healthy adults. Packages to support individualised community-based physical activity have not been investigated.

### AIM

To investigate the feasibility and acceptability of an individualised, supported community exercise programme in improving physical activity levels and mobility within individuals with idiopathic PD.

### METHODS

Design: A phase II RCT with blind assessment at baseline and post-intervention (3-months).

Setting: Community leisure centres within Oxfordshire and Birmingham.

Participants: Adults with mild to moderate idiopathic PD, recruited from consultant-led outpatient neurological clinics.

Interventions: Participants in the intervention group collaborate with fitness instructors to design a 3-month individualised, progressive exercise programme containing cardiovascular and strength training. Physiotherapeutic support is provided throughout. The control group receive standard care.

Primary measure: Physical Activity Scale for the Elderly (PASE).

Secondary measures: Accelerometer monitored physical activity, 10-metre walk test, 2-minute walk test and number of falls.

### RESULTS

17 participants recruited at present (12 men; mean age 62). Baseline data collected for all outcome measures. The mean PASE score is 93 (SD51.8). Accelerometers have recorded 3607 (SD2185) steps per day. The mean 10-metre walk time is 8 seconds (SD4.5). The mean 2-minute walk distance is 137 metres (SD38.2). Six participants reported falls (mean 2 each).

### CONCLUSIONS

The community-based exercise intervention is feasible and has been well received. The outcome measures are easy to complete and appear to be acceptable to the participants.

### LAY SUMMARY

People with Parkinson's disease (PD) have lower physical activity levels than healthy older people and suffer the consequences of reduced mobility. Yet, sufferers report that access to exercise and advice is restricted.

This study aims to investigate if an individualised exercise programme, delivered in local leisure centres (adapted for easy access) and supported by trained fitness instructors and a physiotherapist, can result in health gains.

Neurologists in Oxford and Birmingham ask people with PD to take part. Participants receive either the 3-month exercise programme, or standard care. Mobility and physical activity levels are compared before and after the programme.



## **APPENDIX E: ASSOCIATED CONFERENCE POSTERS AND PRINTED ABSTRACTS**

### **Presented at:**

- South West Society for Academic Primary Care Annual Conference (2010)  
(See Appendix E for full details of conference)

### **Poster Number: 24**

### **Defining UK Physiotherapy In Parkinson's Disease: A Modified Delphi Survey**

Charmaine Meek, Cath Sackley, Carl Clarke, Sonal Shah  
*University of Birmingham, Birmingham, United Kingdom*

### **Objectives**

Physiotherapy is viewed as an essential component in the management of Parkinson's disease (PD). However, our understanding of what physiotherapy entails for this population is limited.

The aim of this survey was to explore best practice physiotherapy for patients with PD as perceived by therapists, and to obtain information on the current structure and delivery of physiotherapy in the UK.

### **Method**

A two round, modified Delphi survey was conducted to generate information on the reasons for providing physiotherapy, the core areas of physiotherapy, perceived effective treatment techniques, and the measurement of outcome. In addition, an optional closed-question questionnaire was disseminated to provide information on the characteristics of responding therapists, and the current structure and delivery of physiotherapy in the UK. Members of the Delphi panel consisted of researchers and practicing physiotherapists with an interest/ expertise in the management of people with PD, and were recruited through personal correspondence, postings on the ICSP web page, and advertisement at conferences. The survey was conducted from Primary Care Clinical Sciences at the University of Birmingham and disseminated to members of the Delphi panel via email.

### **Results**

From a database of 107 therapists, 76 (72%) responded to the first round Delphi survey and 61 (80.3%) to the second round Delphi survey. In addition 69 therapists completed the optional questionnaire. Full results to follow.

### **Conclusions**

The findings of this survey will be used to provide a framework for the physiotherapeutic intervention delivered within the PD REHAB trial, and to inform clinical practice.

## APPENDIX E: ASSOCIATED CONFERENCE POSTERS AND PRINTED ABSTRACTS

### Presented at:

- Parkinson's UK Research Conference (2010)  
(See Appendix E for full details of conference)

### Poster abstracts

P79

#### Defining UK physiotherapy in Parkinson's disease: a modified Delphi survey

Meek C, Sackley C, Clarke C and Shah S  
University of Birmingham

**Objective:** To explore best practice physiotherapy for people with Parkinson's disease (PD) as perceived by therapists, and to obtain information on the current structure and delivery of physiotherapy services in the UK.

**Background:** Physiotherapy is viewed as an essential component in the management of PD, advocated by both patients and professionals. However, our understanding of what physiotherapy entails for this population is limited.

**Methods:** A two round, modified Delphi survey was conducted to generate information on the reasons for providing physiotherapy, the core areas of physiotherapy, perceived effective treatment techniques, and the measurement of outcome. In addition, an optional closed-question questionnaire was disseminated to gain information on the characteristics of responding therapists, and the current structure and delivery of physiotherapy in the UK. Members of the Delphi panel consisted of researchers and practicing physiotherapists with an interest/expertise in the management of people with PD, and were recruited through personal correspondence, postings on the interactive Chartered Society of Physiotherapy web page, and advertisement at conferences. The survey was conducted from Primary Care Clinical Sciences at the University of Birmingham and disseminated to members of the Delphi panel via email.

**Results:** From a database of 107 therapists, 76 (71%) responded to the first round of the Delphi survey and 61 (80%) to the second round of the Delphi survey. In addition, 70 therapists completed the optional questionnaire. Full results to follow.

**Conclusions:** The findings of this survey will be used to provide a framework for the physiotherapeutic intervention delivered within a multi-centre randomised controlled trial investigating the clinical and cost effectiveness of physiotherapy and occupational therapy for people with PD: PD REHAB, and to inform clinical practice.

P80

#### Long-term Individual Fitness Enablement (LIFE) for Parkinson's disease: A feasibility study

Meek C<sup>1</sup>, Sackley C<sup>1</sup>, Clarke C<sup>1</sup>, Soundy A<sup>1</sup>, Winward C<sup>2</sup>, Esser P<sup>2</sup>, Patel S<sup>1</sup> and Dawes H<sup>2</sup>

<sup>1</sup>University of Birmingham, <sup>2</sup>Oxford Brookes University

**Objective:** To investigate the feasibility and acceptability of an individualised, supported community exercise programme for people with Parkinson's disease (PD).

**Background:** Exercise is a potentially important component within the management of PD. Habitual levels of physical activity are often lower for people with PD than age-matched healthy adults. Packages to support individualised community-based physical activity have not been investigated.

**Methods:** The study was conducted as a phase II RCT with blinded assessment at baseline and post-intervention. Adults with mild to moderate idiopathic PD were recruited. Participants randomised to the intervention group collaborated with fitness instructors to design a three-month individualised, progressive exercise programme. The intervention was delivered in leisure centres, and physiotherapy support was provided throughout. The control group received standard care. The primary outcome measure was the Physical Activity Scale for the Elderly (PASE). Secondary outcome measures included accelerometer monitored physical activity, the 10-metre and two-minute walk tests, Fatigue Severity Scale, Parkinson's Disease Questionnaire-39 and falls.

**Results:** Thirty-nine participants were recruited. Twenty were randomly assigned to the intervention group (five female; mean age 63 years) and 19 to the control group (three female; mean age 65 years). Uptake of the intervention was good (87% of participants: N=34) and the gym was attended well (mean number of 15 visits). There were no significant changes in any of the outcome measures. No adverse events were reported.

**Conclusions:** The trial confirmed the feasibility and acceptability of an individualised, supported exercise intervention, delivered in the community, for people with PD. In order to confirm the effectiveness of this intervention, a phase III RCT is now required.

## APPENDIX F: SUMMARY OF OUTPUT FROM STUDIES

### Publications

- The Long-term Individual Fitness Enablement (LIFE) group, (2011) Supporting community based exercise in long-term neurological conditions: experience from the Long-term Individual Fitness Enablement (LIFE) project. **Clinical Rehabilitation**, 25(7): 579-587
- Elsworth, C., Winward, C., Sackley, C., et al (2011) Supported community exercise in people with long-term neurological conditions (LTNC): a randomised controlled trial. **Clinical Rehabilitation**, 25(7): 588-598
- Meek, C., Sackley, C.M., Clarke, C.E., et al (2010) Defining UK physiotherapy in Parkinson's disease: a modified Delphi survey. **Movement Disorders**, 25(S3): S712
- Meek, C., Sackley, C.M., Clarke, C.E., et al (2010) Long-term Individual Fitness Enablement (LIFE) for Parkinson's disease: A feasibility study. **Movement Disorders**, 25(S3): S713

The following papers have been submitted for publication:

- Meek, C., Sackley, C.M., Patel, S., et al (2011) A pilot randomised controlled trial of supported community exercise in people with Parkinson's disease, Submitted to **Ageing and Health**
- Meek, C., Clarke, C.E., Sackley, C.M. (2011) Outcome Measurement in Physiotherapy for Parkinson's Disease: A Survey of Current and Perceived Best Practice in the UK, Submitted to **International Journal of Therapy and Rehabilitation**

### Presentations

- Parkinson's UK Research Conference (2010) C Meek on behalf of Meek C, Sackley CM, Clarke CE, Shah S; Defining UK physiotherapy in Parkinson's disease: a modified Delphi survey [poster presentation], York
- Parkinson's UK Research Conference (2010) C Meek on behalf of Meek C, Sackley CM, Clarke CE, Soundy AA, Winward C, Esser P, Patel S, Dawes H; Long-term Individual Fitness Enablement (LIFE) for Parkinson's disease: A feasibility study [poster presentation], York
- 2<sup>nd</sup> World Parkinson Congress (2010) C Meek on behalf of Meek C, Sackley CM, Clarke CE, Soundy AA, Winward C, Esser P, Patel S, Dawes H; Long-term Individual Fitness Enablement (LIFE) for Parkinson's disease: A feasibility study [poster presentation], Glasgow
- 2<sup>nd</sup> World Parkinson Congress (2010) – C Meek on behalf of Meek C, Sackley CM, Clarke CE, Shah; Defining UK physiotherapy in Parkinson's disease: a modified Delphi survey [poster presentation], Glasgow
- PD REHAB Collaborators Meeting (2010) – C Meek on behalf of the PD REHAB study group; Exploring physiotherapy for Parkinson's disease: A Delphi survey [oral presentation], Birmingham
- Celebrating Success: West Midlands Nurses, Midwives and Allied Health Professions Research Training Awards 2009 Celebratory Event (2010) – C Meek on behalf of Meek C, Sackley CM, Clarke CE, Shah S; Defining UK Physiotherapy In Parkinson's Disease: A Modified Delphi Survey [poster presentation], Birmingham
- South West Society for Academic Primary Care Conference (2010) - C Meek on behalf of Meek C, Sackley CM, Clarke CE, Shah S; Defining UK Physiotherapy In Parkinson's Disease: A Modified Delphi Survey [poster presentation], Oxford
- PD REHAB Launch meeting (2009) – C Meek on behalf of the PD REHAB study group; Development of an individualised, community-delivered physiotherapy intervention: A Delphi survey [oral presentation], Birmingham

- West Midlands Association of Chartered Physiotherapists Interested in Neurology: A Study Day in Parkinson's Disease (2009) – C Meek on behalf of the PD REHAB study group; Development of an individualised, community-delivered physiotherapy intervention: A Delphi survey [oral presentation], Birmingham
- Southampton Neurorehabilitation Conference (2008) - C Meek on behalf of Dawes H, Clarke CE, Esser P, Meek CE, Patel S, Sackley C, Soundy AA, & Winward C. (2008). Long term Individual Fitness Enablement (LIFE); Parkinson's Disease. An ongoing RCT [oral presentation], Southampton