COMMUNITY MOBILITY AND PHYSICAL ACTIVITY PARTICIPATION IN INDIVIDUALS WITH MULTIPLE SCLEROSIS

by

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Abstract

This thesis incorporates five studies investigating physical activity and community mobility in individuals with multiple sclerosis (MS).

1. Pedometer step count accuracy was investigated whilst examining activity levels in individuals with neurological disease (n=43). The pedometers significantly under-estimated counts in this group.

2. The test-retest reliability of the Physical Activity Scale for the Elderly (PASE) was examined. People with MS (n=20) were found to have low activity levels with a test-retest reliability coefficient total PASE score of 0.934 (95% CI=0.62-0.97).

3. An observational study examined physical activity levels in individuals with MS using the PASE. Participants appeared to be less active than healthy individuals (69.6±50.11, 154.3±80.4 respectively).

4. A questionnaire (n=80) and focus group discussions (n=24) were used to gather user opinions regarding physical activity participation. Emerging themes were the desire to be active and the barriers and facilitators to participation.

5. A phase II RCT investigated the feasibility of a physical activity provision support system in people with MS (n=18). The approach successfully resulted in attendance at fitness centres and increased activity levels (but did not reach statistical significance).

The 5 studies each present new data in the field. The implications are discussed with suggestions for further research.

Dedication

To mummy and daddy, who have supported me tirelessly.

This is for you.

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1. Introduction

1.1 General Introduction to the thesis

Purpose of Thesis

This thesis will investigate the different aspects of physical activity within individuals with multiple sclerosis (MS), develop a physical activity provision support system (PAPSS) and, finally, assess the effects of a physical activity provision support system.

Specifically, this thesis aims to:

1) Investigate the physical activity of individuals with MS in a specified community setting.

2) Investigate factors that affect and prevent individuals with neurological conditions from participating in physical activity in the community.

3) Develop a physical activity provision support system. The development of the PAPSS will be directed according to the outcomes of aims 1 and 2.

4) Establish whether providing individuals with MS with this support system (PAPSS), increases physical activity participation and attendance at physical activity sessions in the community in a phase II randomised controlled trial.

There are many studies that report the importance of physical activity in day-to-day life, and the health benefits of a physically active lifestyle are well known. There is an increasing interest in physical activity in disabled populations, and as such there are an increasing number of studies reporting a reduction in community mobility and decreased physical activity in individuals with neurological conditions such as multiple sclerosis.

Definition, Prevalence and Cost of MS

Multiple sclerosis is a chronic, often progressive disease of the central nervous system. Its worldwide prevalence is estimated at 1–2.5 million cases (World Health Organisation, 2006) and it is the most common neurological condition among young adults in the UK, affecting approximately 85,000 people. It is possible for MS to occur at any age, but in most cases symptoms are first seen between the ages of 20 and 40. Women are almost twice as likely to develop MS as men. For individuals with MS a physically active lifestyle could improve everyday functioning, reduce disability and reduce the risk of secondary health problems. However, these individuals are typically less active than healthy individuals (Busse et al., 2004; Busse et al., 2006), and as a result the mean total cost to the NHS per patient per year in the UK in 2006 ranged from £16,300 (20,000 Euros) to £44,000 (54,000 Euros) (Kobelt et al., 2006). With an estimated 85,000 patients in the UK, this represents a large cost to the economy every year.

A recent study indicated that the UK has the second highest care costs in Europe (second only to Sweden, where high costs are due to individuals with

disability being provided with a full-time personal assistant), which is thought to be a consequence of a very high use of informal care services (indirect costs, services, informal care and direct healthcare), (Kobelt et al., 2006). According to the Multiple Sclerosis Society of Canada, early and easy access to MS treatment options has the potential to improve quality of life and significantly reduce healthcare costs (Pohar, 2007). A recent study (Pohar, 2007) shows that MS affects approximately 75,000 Canadians. The subsequent cost of MS to the Canadian economy is estimated to be more than $1 billion (Canadian dollars) per year and the annual lifetime cost of the disease is estimated at $1.6 million (Canadian dollars) per Person. Findings from this paper indicate that improving the health of Canadians with MS can reduce the societal cost of caring for them. This could include benefits derived from the use of existing treatments, but only if people with MS are given access to treatments early, before disability accumulates. Physical activity participation has previously been reported to be low in individuals with MS in the United Kingdom, if increased then one could hypothesise this may make a significant change in the service provision costs and requirements in the UK.

1.2 Thesis outline

Chapter 2 begins with an overview of epidemiology and aetiology of multiple sclerosis and continues by reviewing the current government policies surrounding physical activity in neurological conditions, and literature surrounding physical activity participation in adults with neurological conditions. Physical activity has been reported in healthy individuals to be important for well-being and health, so it was of interest to investigate the literature surrounding current research in individuals with MS.

Chapter 3 reviews the outcome measures that were selected to use within the main study discussed in this thesis.

Chapter 4 investigates the accuracy of pedometers in individuals with neurological conditions. A study was conducted in order to establish the suitability of their use in the studies within this thesis, specifically in adults with MS.

Chapter 5 assesses the reliability of the physical activity scale for the elderly (PASE) questionnaire in neurological populations. The PASE questionnaire is used as an outcome measure in two of the studies presented in this thesis.

Chapter 6 investigates mobility in individuals with MS in their daily lives. This chapter provides background information regarding current mobility levels and gives accurate weekly step counts in adults with MS. Chapter 6 uses a novel approach to investigate how effective these individuals' steps are in terms of their aerobic efficiency.

Chapter 7 investigates factors affecting physical activity, such as the barriers and facilitators to participation. Several focus group meetings were conducted within different neurological condition groups, such as muscular dystrophy, multiple sclerosis, parkinson's disease and motor neurone disease. A range of neurological conditions was investigated to give a better overview of individuals with complex conditions. The outcomes of these focus groups are presented in Chapter 7. As a result of the focus group meetings held, a questionnaire was developed to investigate the themes that emerged. The development and results of this questionnaire are also discussed in Chapter 7. Findings from this chapter directed the intervention that was trialled in Phase II RCT in Chapter 8.

The results of the questionnaire and focus group discussions reported in Chapter 7 were instrumental in developing the main Phase II RCT study reported in Chapter 8 of this thesis, the Long-term Individual Fitness Enablement (LIFE) study.

The LIFE study demonstrates the development of a unique support system, named the physical activity provision support system. This was developed to provide inclusive support to adults with MS aiming to increase their attendance at community-based fitness establishments. Chapter 8 reports the development of the PAPSS the main findings of this study.

2 Literature review

2.1 Introduction

Individuals with neurological conditions such as multiple sclerosis (MS) often present with functional effects that lead to immobility and secondary deconditioning. The level of severity and progression of MS may vary and individuals with neurological disorders may present a confusing picture with changes in their fitness and physical activity patterns, either due to the primary disease process or due to the secondary effect of enforced physical inactivity. There is increasing evidence to suggest that individuals with long-term neurological conditions do not participate in regular physical activity (Department of Health, 2005a).

Aim of the review

A review of the literature surrounding physical activity, physical fitness and exercise participation in individuals with multiple sclerosis was undertaken to determine the extent of the previous research in these areas and to check the value of the future research to be undertaken.

Chapter overview

This chapter commences with definitions of multiple sclerosis and information regarding its epidemiology and aetiology. This is followed by a section on the literature surrounding physical activity participation, physical fitness, exercise participation in individuals with multiple sclerosis and current government

policy. The literature surrounding resistance and aerobic training in individuals with multiple sclerosis will then be presented.

Search methods for identification of studies

All studies that were found to involve aspects of physical activity, physical fitness and exercise participation in individuals with multiple sclerosis were included in this review.

To identify studies that investigated aspects of physical activity, physical fitness and exercise participation in individuals with multiple sclerosis a systematic search of the literature was conducted. The sources for the electronic search included: PUBMED (1974-2008), MEDLINE (from 1966 to July 2008), CINAHL (from 1982 to July 2008) and AMED (from 1985 to July 2008). The search terms used were: “physical activity” or “physical fitness” or “exercise” or “mobility” or “resistance” or “aerobic”, AND with “multiple sclerosis” or “neurological conditions” or “progressive neurological condition”. The reference lists of identified articles were also searched.

2.2 Epidemiology and aetiology of multiple sclerosis

Multiple sclerosis is a chronic demyelinating disorder, with an estimated 100,000 patients in the UK (MS Society, 2009). Characteristically, axon insulation or myelin is lost from nerves in the central nervous system (CNS). The disease can affect various parts of the CNS, including the spinal cord, brainstem, cerebellum, cerebrum, and optical nerves, but the peripheral nerves are not affected (Thompson, 2001). Although the aetiology is unknown, an abnormal immune response against oligodendrocytes and

myelin is believed to contribute to the disease. The presence of lesions scattered throughout the CNS white matter causes multiple, varied symptoms and signs of neurological dysfunction (Warren, 2001). The essential feature of these lesions is loss of the myelin sheath with perivascular inflammation and relative sparing of the axons (Thompson, 2001). The presence of inflammation in MS lesions and of oligoclonal immunoglobulin bands suggest an autoimmune basis of the disease (Thompson, 2001). The major cause of negative symptoms during relapses (e.g. paralysis, blindness and numbness) is conduction block, caused mainly by demyelination and inflammation, and possibly by defects in synaptic transmission (Warren, 2001). MS is progressive, characterised by exacerbations and remissions. Nerve conduction alters with variations in sclerosis and inflammation. Symptoms and the rate of progression of the disease differ between people. At times there may be a plateau or slight improvement in symptoms due to reduced inflammation, whereas at other times a sudden deterioration may occur due to rapid demyelination. Recovery from symptoms during remissions is due mainly to the restoration of axonal function, either by remyelineasation, resolution of inflammation, or restoration of conduction to axons that persist in the demyelinated state (Thompson, 2001).

MS is often classified by its clinical course (Ebers, 2001). Benign MS is characterised by mild intermittent relapses with nearly complete resolution. Secondary progressive MS starts with a relapsing-remitting course with symptoms becoming more severe with less complete recovery of function after each exacerbation (Ebers, 2001). Patients may then enter a chronic

progressive phase, characterised by a step-like downhill course. MS that begins with a slow progression of signs and symptoms is classified as primary progressive MS (Ebers, 2001).

2.3 Physical activity, physical fitness and exercise participation among individuals with multiple sclerosis

Movement is fundamental to human existence and is required for engagement in activities of daily living, communication, occupation, exercise and leisure (Cott, 1995). In recent years much emphasis has been put on the importance of physical activity as a method of improving quality of life and promoting a healthier lifestyle. The body's ability to perform this depends on a set of attributes collectively termed physical fitness. These include cardio-respiratory endurance, muscle strength, body composition and flexibility. These attributes or components of physical fitness adapt to changes in physical activity and provide the focus for any comprehensive fitness training programme (American College of Sports Medicine, 1990; Saunders et al., 2004). In addition to the health related components of physical fitness, functional or goal-directed physical activity requires integration and control mechanisms appropriate to the task. Motor control, speed, power, co-ordination and balance can be referred to as skill-related components of physical activity.

A review of the impact of physical activity on health summarises the benefits by noting that adults who are physically active have a 20-30% reduced risk of premature death, and up to 50% reduced risk of developing major chronic diseases such as coronary heart disease, stroke, diabetes and cancer. In

addition, it is well established that physically active people feel happier and more satisfied with life (Department of Health, 2004). It has been suggested that the overall benefit of physical activity for persons with chronic diseases and disabilities is improved physical functioning but the health benefits of exercise, established in healthy individuals, also apply to those with chronic disease and long-term disability.

A recent study by Giacobbi et al (2008) investigated the opinions of highly active individuals with physical disabilities. The study revealed that individuals who use wheelchairs perceived a number of psychological, social, and health benefits associated with physical activity involvement. The participants' evaluations and descriptions of their physical activity experiences appeared to support self-efficacy beliefs, feelings of empowerment, and motivation for continued involvement and these individuals perceived physical activity behaviours to enhance the quality of their lives.

Health-related benefits of physical activity in healthy individuals extend beyond prevention of chronic disease. Physical activity is associated with improved mental health and increased feelings of well-being (Department of Health, 2004). Although mental health and the psychological benefits of physical activity are not investigated within this thesis, it is important to note that it has been previously shown that although there is evidence of general health benefits of regular physical activity for people with MS, information regarding the effect of psychological functioning is limited. There is an increasing recognition that aerobic exercise positively influences psychological well-being in individuals with MS (Sutherland and Andersen,

2001). Previous research (Taylor, 2005) has shown physical activity to elicit positive changes in overall physical self-worth as well as specific aspects of physical self perceptions such as body image, perceived fitness and strength. The degree to which changes in physical self-perceptions are accompanied by improvements in overall feelings of worth or general self esteem is variable (Fox, 2000).

Therapeutic exercises for treating the effects of disease or disability are a traditional and fundamental component of most physical rehabilitation interventions. However, in 2004 the chief medical officer's report (Department of Health, 2004) highlighted the increasing amount of evidence and the strong preventative effects of physical activity.

There is very little previous research conducted into the health-related benefits of physical activity in adults with neurological conditions, and as with many neurological conditions, there is no effective way to prevent multiple sclerosis.

Therefore, researchers and clinicians have examined methods for slowing the progression of MS and managing its symptoms. Physical activity is an important behavioural factor for improving and managing the physical demands of MS (Simmons, 2004; Stuifbergen, 1992) and has positive influences on symptom management through effects on fatigue, spasticity, mobility, depression, and pain (Schapiro, 2003). Nevertheless, individuals with MS are relatively inactive compared with non-diseased populations (Motl et al., 2008b; Motl et al., 2008c). The rate of inactivity in MS sufferers is of

concern given the accepted prevalence of sedentary lifestyles among healthy adults and adults with neurological disease in the United Kingdom (Department of Health, 2004), and is further investigated in Chapter 6.

Rimmer et al (2000a) investigated health promotion by providing a health promotion programme to 35 stroke survivors. The aims of the programme were: 1) to reduce secondary conditions; 2) maintain functional independence; 3) provide an opportunity for leisure and enjoyment; 4) enhance the overall quality of life by reducing environmental barriers to good health. Short-term results were encouraging, with significant treatment gains being observed for reduced total cholesterol and weight; increased cardiovascular fitness, strength, life satisfaction and ability to manage self-care needs; and decreased social isolation. While the benefits of physical activity alone for this group of stroke survivors would be unlikely to achieve significant results for all the health promotion aims, the results of the exercise programme that were reported separately showed significant improvements in fitness.

Health promotion and interventions aimed at increasing physical activity need to account for the barriers to participation experienced by many individuals, and engage these sedentary populations in increased levels of habitual physical activity, as evidence suggests the health-related benefits of physical activity decrease once physical activity participation is stopped.

As neurological conditions progress, the ability to perform activities of daily living (ADL) reduce (Mansson and Lexell, 2004). Limitations in ADL and

physical activity have a huge impact on independence, confidence and quality of life (Benito-Leon et al., 2003). When the ability to be physically active and mobile is compromised, independence is lost, and emotional well-being is reduced (McDonald, 2002).

Recent studies have investigated the low physical activity levels of individuals with MS (Dalgas, 2008; Motl, 2008; Motl et al., 2008b). These low levels of physical activity may cause decreases in aerobic capacity, muscular strength endurance, and flexibility, all of which have the potential for restricting functional independence and increasing the risk of secondary complications.

Table 1: Summary of differences between MS patients and healthy subjects (Dalgas, 2008)

	MS patients versus healthy subjects Reference
Daily activity level	Decreased (KentBraun et al., 1997; Ng and KentBraun, 1997)
VO2/VO_2 max	Decreased (Mostert and Kesselring, 2002; Tantucci, 1996)
Blood pressure (rest)	
Systolic	No difference (Pepin et al., 1996)
Diastolic	No difference or increased (Pepin et al., 1996)
Resting heart rate	No difference or increased (Pepin et al., 1996; Tantucci, 1996)
Muscle strength	
Isokinetic strength	Decreased (Carroll et al., 2005; Lambert et al., 2001)
Isometric strength	Decreased (Carroll et al., 2005; Ng et al., 2004)
Rate of force development	No difference or decreased (Ng et al., 2004; Schwid et al., 1999)
Muscle mass (% FFM)	No difference or decreased (Formica, 1997; Lambert et al., 2002)
Muscle fibre area	No difference or decreased (Carroll et al., 2005; KentBraun et al., 1997)
Muscle activation	Decreased (Ng et al., 2004)
Function	Decreased (Morris, 2002; Savci et al., 2005)
CVD risk	Increased (Ponichtera et al., 1992)
BMD	Decreased (Formica, 1997)
Depression risk	Increased (Zorzon, 2001)
Fatigue	Increased (Krupp, 2003)
HRQoL	Decreased (Miller, 2006)

BMD: bone mineral density, CVD: cardiovascular disease, FFM: fat free mass, HRQoL: health-related quality of life, VO_2 max: maximum oxygen consumption

Ruiz et al (2008) demonstrate that participation in regular exercise and physical activity provides health benefits in healthy individuals. Their study conducted a prospective cohort study to examine prospectively the association between muscular strength and mortality from all causes, cardiovascular disease and cancer in men. A total of 8762 men aged between

20 and 80 were assessed between 1980 and 1989. They were then followed up until the date of death or 31st December 2003. This study found that muscular strength was significantly and inversely associated with risk of death from all causes and cancer. It also found that the death rate in men with high levels of both muscular strength and cardiovascular fitness was 60% lower ($p<0.001$) than the death rate in the group of unfit men with the lowest levels of muscular strength. These results highlight the importance of having at least moderate levels of both muscular strength and cardio-respiratory fitness to reduce risk of death from all causes and cancer. Muscular strength seems to add to the protective effect of cardio-respiratory fitness against the risk of death for men. This study emphasises the importance of physical activity in healthy individuals, however, there is increasing evidence that these health benefits would also benefit individuals experiencing disease (Bartlett, 1997; N.I.C.E, 2004; Santiago and Coyle, 2004; Singh, 2002b; van der Kooi et al., 2005a)

When considering how best to provide support to encourage activity, participation evidence from neurological populations shows that the current hospital-based approach to delivering therapeutic exercises and improving mobility is ineffective (Green et al., 2002). After stroke, only a third of mobile individuals get out in the community alone (Logan et al., 2004; Lord et al., 2004). This may be due to individuals finding it hard to transfer 'treatment' received as part of a medical model into active lifestyle changes. Interventions provided in the community setting have been shown to be effective in increasing mobility (Ansved, 2003b) and targeted support to initiate an activity

is more effective than advice alone (Pengel et al., 2007). This is heartening as therapeutic exercises, such as treadmill walking (Pohl et al., 2002b), muscle strengthening (Weiss et al., 2000a) and functional exercises (Duncan et al., 1998) have been shown to improve mobility in neurologically disabled populations and can be delivered effectively in the home or the community (Ada et al., 2003a).

Health concerns that affect the general population if sedentary may be more serious for those with disabilities (Hicks et al., 2003; Rimmer, 2005). It is therefore important to encourage increased physical activity. Interestingly, there is evidence that exercise support systems are beneficial for individuals after stroke, facilitate participation (Logan et al., 2004) and that an individual's motivation and confidence to exercise may be low if required to participate in physical activity unsupported (Cromwell and Adams, 2006). There is, however, limited evidence regarding positive facilitators to support exercise participation in the community setting for individuals with neurological conditions.

Reduced endurance and fatigue are characteristic impairments experienced by MS patients that will usually affect the performance of low-intensity activities such as walking or stair climbing (Florence and Hagberg, 1984; Phillips and Mastaglia, 2000; Taivassalo et al., 1999; Wright et al., 1996) and many activities of daily living, such as getting out of a chair, reaching above the head and manipulating objects with the hands (Phillips and Mastaglia, 2000). These symptoms, together with the advice of GPs and physiotherapists, often result in patients altering their lifestyle to a more

sedentary one, to avoid these activities (Florence and Hagberg, 1984; Phillips and Mastaglia, 2000). This decrease in physical activity leads to deconditioning and an even lower tolerance and incentive for physical activities, including work tasks. Consequently, two factors may contribute to a diminution in endurance: the first is the alteration of muscle function due to the disease process itself, while the second is deconditioning due to a sedentary lifestyle (Florence and Hagberg, 1984; Taivassalo et al., 1999; Wright et al., 1996).

There is very little evidence suggesting the patterns of exercise participation among adults with neurological disorders. This research is needed to further the understanding of issues related to the effect of physical activity on health and disease prevention among individuals with MS. However, Rimmer et al (2004b) found the barriers and facilitators to exercise participation were varied and complex. The barriers and facilitators were discussed around several key points, such as: the built and natural environment; economic issues, such as cost; emotional and psychological issues, such as confidence and embarrassment; and equipment barriers.

2.4 Resistance training in multiple sclerosis

Inactivity has previously been shown to further compromise muscle function, ambulatory ability and therefore physical fitness (Gutierrez et al., 2005), and in more recent years resistance training has started to become more routinely used in individuals with multiple sclerosis.

Muscle weakness and fatigue contribute to reduced daily activity in persons with MS (Gutierrez et al., 2005). Strength training is known to promote neural adaptations such as improved motor unit activation and synchronization of firing rates, which may deteriorate with periods of inactivity (Frontera et al., 2003; Gutierrez et al., 2005).

A review of previous studies on resistance training in individuals with MS found four articles (DeBolt and McCubbin, 2004; Gutierrez et al., 2005; Jones, 1999; White et al., 2004a; White et al., 2004b). DeBolt and McCubbin (2004) investigated the effect of an eight-week resistance exercise programme on balance, leg extension power and mobility. Thirty-six individuals were randomly assigned to an exercise (n=19) or control (n=17) group. Chair raises, forward lunges, step-ups, heel-toe raises and leg curls were some of the resistance exercises used. After the intervention a significant difference was found in leg extensor power.

Gutierrez et al (2005) evaluated the effect of an eight-week lower body resistance training programme on walking mechanics in eight individuals with MS. Individuals had gait kinematics assessed before and after an eight-week training intervention, which consisted in attending resistance training sessions

twice a week. Exercises focused on lower limbs, specifically knee flexion and extension, plantarflexion, trunk flexion and extension. The results from their study suggest that resistance training facilitates gait modification. After training, subjects had longer strides, spent more time in swing phase and less time in stance and double support phases. Significant differences were found in knee extension and plantarflexion strength.

Jones et al (1999) compared a mobility exercise programme with a weighted leg exercise training programme and with a control group receiving no exercise. Nineteen MS patients were randomly allocated into the three arms of the trial. Muscle strength (maximal voluntary contraction) of quadriceps and the functional activities of walking and transferring (timed walk and timed transfer) were measured. Although the weighted leg group improved significantly in time needed for chair transfers, no significant differences were found between the three groups for gait speed, ability to transfer and muscle strength.

White et al (2004b) evaluated the effect of an eight-week progressive resistance training programme on lower extremity strength, ambulatory function, fatigue and self-reported disability in individuals with MS. Results indicated that knee extension (7.4%), plantarflexion (52%) and stepping performance (8.7%) increased significantly ($p<0.05$). In general, these studies have examined only small sample sizes and only the studies by De Bolt and McCubbin (2004) and Jones et al (1999) applied an RCT design. The RCT design employed by DeBolt and McCubbin (2004) was not supervised. A non-supervised programme represents a very realistic training approach but the

methodological quality of the study, however, is lowered due to the unreliable nature of the self-report system. The other RCT study conducted by Jones et al (1999) is under-powered with only seven participants with MS included in the resistance training group.

Based on the existing studies it is difficult to draw solid conclusions regarding the effects of resistance training in subjects suffering from MS (Dalgas, 2008), although it is clear that a few clinically relevant findings are consistent across studies. All resistance training reported appears to be well tolerated by individuals with MS and none of these studies report any problems related to resistance training. Another important consistent finding is an improvement in muscle strength after resistance training.

Only a few studies have evaluated the application of resistance training among individuals with MS. In general, these studies are of low methodological quality, which makes it difficult to draw solid evidence-based conclusions regarding the true effects of resistance training and the intensity, dose and duration of resistance exercise most appropriate to these individuals. However it appears that resistance training of a moderate intensity seems to be well tolerated and to improve both muscle strength and some functional measures (Dalgas, 2008). The studies presented here have only evaluated training regimes of a moderate intensity and mild progression and this was tolerated well. If individuals with MS can tolerate a higher training intensity, a larger training volume and faster progression then it is thought that larger and faster improvements would be expected (Dalgas, 2008).

2.5 Aerobic training in Multiple Sclerosis

The effects of aerobic training have been studied more extensively in individuals with multiple sclerosis than resistance training, however, only the effects of aerobic training of low to moderate intensity have previously been evaluated in MS patients. MS patients having a Kurtzke expanded disability status scale (EDSS) scoring lower than seven have been studied and it has been shown that aerobic training is well tolerated (Dalgas, 2008). Endurance training induces improvements in aerobic capacity and in measures regarding health-related quality of life, mood and depression in MS patients (Dalgas, 2008). Inconsistent findings regarding the impact of aerobic training on fatigue might be related to the selected fatigue scale. Aerobic training of low to modest intensity has no or only a modest effect on functional capacity evaluated as gait velocity.

A recent review by Dalgas et al (2008) details 13 studies (Gehlsen, 1986; Gehlsen et al., 1984; Kileff and Ashburn, 2005; Mostert and Kesselring, 2002; Oken et al., 2004; Petajan et al., 1996; Ponichtera-Mulcare, 1997; Rasova et al., 2006; Rodgers et al., 1999; Schapiro, 1988; Schulz et al., 2004; Sutherland et al., 2001; van den Berg et al., 2006) that have evaluated aerobic training in individuals with MS. Eight of these studies used an RCT design, and bicycle ergometry, arm ergometry, aquatic exercise and treadmill training were used.

These eight studies found some clinically relevant findings: it is evident that individuals with MS tolerate aerobic training at low to moderate intensity, and

it was noted within the review that aerobic training has both a beneficial psychological and physiological effect on individuals with MS.

In the study by Petajan et al (1996), ambulatory patients with MS participated in a 15-week outpatient exercise training programme to improve measures of physical fitness and to determine its effects on ADL, mood and levels of fatigue. Forty-six patients participated. The exercise group showed statistically significant increases in maximal aerobic capacity (VO_2 max) and physical workload capacity (PWC) after the intervention period. Compared with baseline, the EX group demonstrated significant increases in VO_2, upper and lower extremity strength, and significant decreases in skinfolds. Exercise training resulted in improved fitness and had a positive impact on factors related to quality of life.

In 2003 Carter et al (2003) investigated the effect of a 12-week exercise training programme consisting of twice weekly supervised aerobic and flexibility training in 11 participants. A significant reduction was seen in the normalised physiological cost index scores after 12 weeks in the exercising group, but not in the non-exercising control group. When comparing the exercise with the non-exercise group, significant effects were observed for isometric strength in the hip flexors and knee flexors of both limbs, the knee extensors and the ankle dorsal flexors of the right limb, but not the ankle dorsal flexors or the knee extensors of the left limb.

Mostert and Kesselring (2002) studied 37 MS patients who took part in an inpatient rehabilitation programme and were randomly assigned to an aerobic

exercise training group or to a non-training group. The four-week aerobic training intervention consisted of five 30-minute sessions per week of bicycle exercise with individualised intensities. The exercise group demonstrated a significant improvement of the aerobic threshold, an improvement in Health related quality of life (HRQoL) as measured by the Short form 36 (SF-36) and an increase in activity levels.

A pilot study (van den Berg et al., 2006) investigated whether four weeks of aerobic treadmill training in individuals with MS improved mobility and reduced fatigue. Individuals with MS were recruited to this prospective, randomised controlled trial. Individuals were assessed at baseline, week 7 and week 12 with a 10-metre timed walk, a 2-minute walk, the Rivermead Mobility Index, and the Fatigue Severity Scale. Treadmill training consisted in four weeks of supervised aerobic exercise delivered over weeks 3 to 6 in the immediate group and weeks 8 to 11 in the delayed group. There was a significant difference in walking endurance between the delayed and immediate groups at baseline ($p<0.05$). On reassessment in week 7, decreases in 10-metre walk time were found in both groups, which was significant in the immediate group ($p<0.05$). The two-minute walk distance significantly increased in both groups ($p<0.05$). In the training group, reassessed at week 12 after training ceased, there was a return toward baseline scores. No significant changes in fatigue scores were found. This study showed that in less mobile individuals with MS, aerobic treadmill training is feasible and well tolerated. Further investigation would be warranted in individuals who are more disabled. This would indicate how well

individuals who are less mobile are able to tolerate exercise. Walking speed and endurance increased following training with no increase in reported fatigue.

Intensity, duration and frequency seem to be important factors in modifying treatment effects (Rietberg et al., 2005). Within the current literature there is a large diversity regarding the frequency and duration of training sessions, but intensity was poorly described. It is impossible to gain an understanding of the best 'dose' of treatment required for these patients to have the effective sessions. Within MS patients, the effect of duration and intensity of treatment sessions need further investigation. However, the American College of Sports Medicine (American College of Sports Medicine, 2003) suggest exercise guidelines of best practice based on limited evidence with regards to strength, endurance, flexibility and best mode of delivery. Currently these are the most appropriate guidelines available for fitness professionals when prescribing exercise for these individuals.

2.5.1 Conclusion

This section has shown that in these samples of individuals with MS aerobic training at a low to moderate intensity is tolerated well, the review by Dalgas (2008) noted that aerobic training can have a positive psychological effect on individuals with MS.

2.6 Department of Health (DoH) and government policies

To a certain extent, all individuals with neurological conditions such as multiple sclerosis rely on a provision of services from the National Health Service, whether its for medication, physiotherapy or occupational therapy amongst many others. It is therefore of interest to further examine how the government is advancing support for these individuals. The annual cost of MS to the government has been previously reported as high and a key way to start to reduce this cost would be to investigate and facilitate interventions that may alter service usage of individuals with MS (Kobelt et al., 2006; Pohar, 2007).

In January 2006, the Department of Health released the white paper entitled "Our Health, Our Care, Our Say: A new direction for community services" (Department of Health, 2005b). The aim of this detailed report was a discussion of the DoH's vision of high-quality support meeting individuals' aspirations for independence and greater control over their lives, with the intention of making services flexible and responsive to individual needs. Specifically, this paper detailed provision of increased support for people with long-term needs. The intention of the DoH is to provide support for people with long-term conditions with the view to aiding them to better manage their conditions themselves with the correct help from health and social care services. Currently, over half of individuals with long-term conditions are not aware of various support or treatment options and do not have a clear plan that could facilitate self-management of their condition. The DoH intends to support individuals by increasing investment in the Expert Patient Programme

(Department of Health, 2005b), by developing an ‘information prescription’ for people with long-term health and social care needs. Many people with a long-term condition have social care as well as health care needs.

This paper (Department of Health, 2005b) was released at the same time as the 2005 paper "Supporting People and integration with long-term conditions: An NHS and social care model to support local innovation". Care for many people with long-term conditions has traditionally been reactive, unplanned and episodic (Department of Health, 2005d). This has resulted in heavy use of secondary care services. The initiative aimed to: embed an effective, systematic approach to the care and management of patients with a long-term condition in local health and social care communities; reduce reliance on secondary care services; increase the provision of care in a primary, community or home environment; and ensure that patients with long-term conditions receive high-quality care personalised to meet their individual requirements.

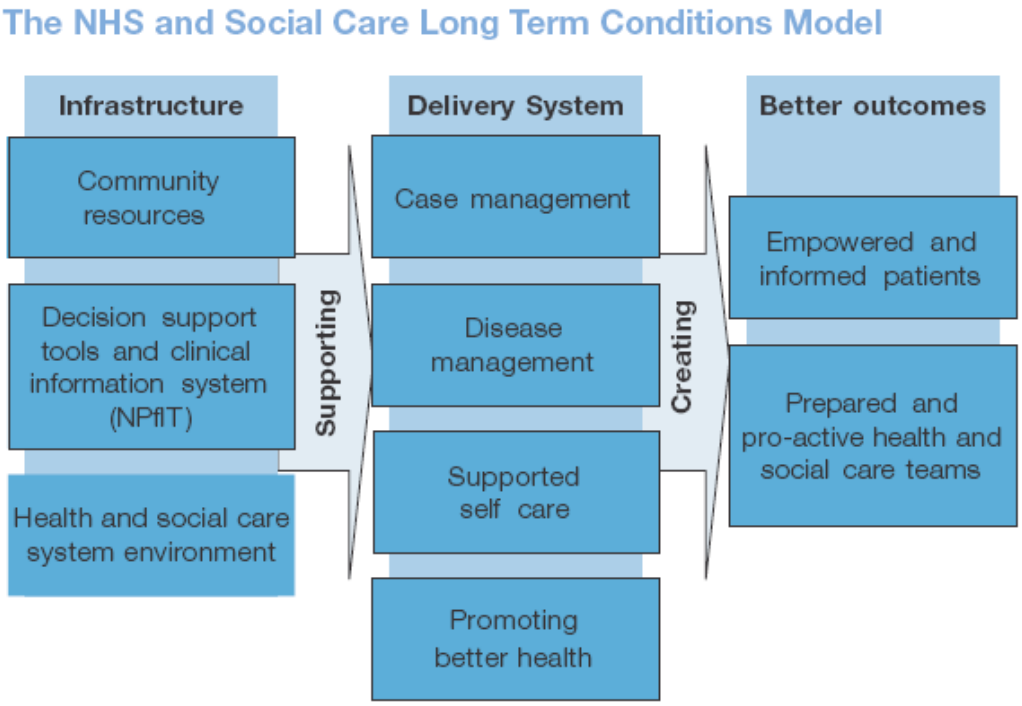


Figure 1: The NHS and Social Care Long-term Conditions Model (Department of Health, 2005a).

However, the needs of individuals with long-term neurological conditions are very different. This is highlighted in the publication by the DoH of "The National Service Framework (NSF) for Long-term Neurological Conditions: National Support for Local Implementation 2008" (Hopcutt, 2008). This paper gives an overview of resources, tools and initiatives that should be available to support local implementation of the National Service Framework for Long-Term (Neurological) Conditions (LTNCs).

The NSF was published in March 2005 (Department of Health, 2005a) with a 10-year implementation period. It sets 11 quality requirements for improving treatment, care, and support from diagnosis to the end of life for people with neurological conditions. It also underlines the need for appropriate, integrated

services planned and delivered around individual needs, and the provision of support to enable people to live independently with a good quality of life.

Very little is mentioned within the above government publications regarding independent fitness enablement for individuals with LTNCs. The need for this to be developed is highlighted in the most recent NSF for long-term neurological conditions publication (Hopcutt, 2008), which describes one of the National Underpinning Programmes (NUP). The NUP is trying to achieve a maximum 18-week wait from referral to treatment pathways for neurology. The stated aim of providing ‘treatment’, including physiotherapy services, after an 18-week wait sets an unsatisfactory time period in which to be getting individuals to be active.

It has previously been shown that individuals with long-term neurological conditions are nervous about participating in physical activity and exercise unless medical personnel such as physiotherapists are present. This indicates that from referral to delivery of the ‘treatment pathway’ it is likely that individuals will remain inactive for approximately 18 weeks.

It is important for individuals with neurological conditions to gain confidence in their ability to participate in physical activity independently. The NSF paper states its aim is to focus on "Promoting independence, empowering patients and allowing them to take control of their lives." The NSF for long-term conditions is an important step in the right direction for the future of fitness enablement.

2.7 Main aims of the study

This chapter has discussed factors surrounding physical activity in individuals with long-term neurological conditions, specifically multiple sclerosis. This thesis aims to establish how active individuals with MS actually are, investigate barriers to exercise and from these findings, develop and assess the feasibility of an exercise support provision service.

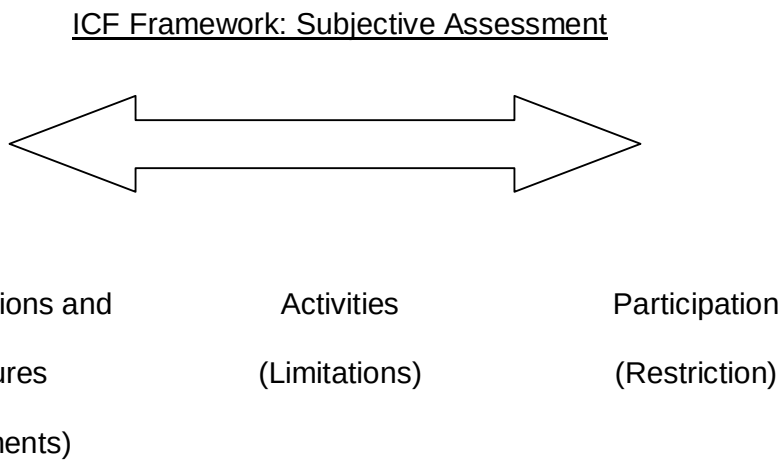
3 Outcome measures: mobility and strength

3.1 Introduction

It is widely accepted that physical activity is beneficial for continuing well-being and health (Heath and Fentem, 1997). Previous studies have indicated that mobility proficiency and degree of physical activity or community mobility are important measures of functional status. However, it is important to use appropriate tools for the population being investigated and the outcomes to be tested. Studies focusing on the relationship of physical activity to health and fitness have used a variety of objective methods for physical activity assessment, some of which will be discussed within this chapter

The World Health Organisation (WHO) (Salter et al., 2005a; Salter et al., 2005b; van der Ploeg et al., 2004) model for the International Classification of Functioning, Disability and Health (ICF), provides a framework in which to describe aspects of a person's health and health-related well-being. It proposes the description of function and disability under three headings: body function, activities and participation. This chapter discusses the outcome measures most suitable for measuring activity and participation.

Figure 2: ICF framework for subjective assessment.



Several measures, such as the rivermead mobility index (RMI) and the barthel (ADL) index, are used routinely in neurological populations both in clinical and research settings. However, there is a distinct need for the development of a technique to quantitatively and reliably measure the actual physical activity of these individuals continuously over an extended period of time. Objective assessment of physical activity and exercise are particularly important within these populations, as physical activity is a crucial aspect of day-to-day functioning, which if improved can have implications on quality of life and independence.

Research looking at the effect of exercise on individuals with neurological conditions is ongoing, but this area of research is underdeveloped and there is surprisingly little evidence in circulation regarding the effects of exercise in individuals with neurological conditions. This is of concern, as it is such an important area, specifically in the area of rehabilitation.

This chapter describes evaluation criteria and standards for outcome measures that can be used to describe activity and participation, as well as factors that may affect the ability to participate in activity and participation, such as cognition. Additionally, this chapter will review the outcome measures of mobility and functional activities used throughout this thesis.

3.2 Outcome measures and measurement properties

An outcome measure is defined as the "quantification of an observation against a standard" (Wade, 1992). The need to measure the outcome and effectiveness of rehabilitation is accepted as being essential to good practice. There are many factors to take into consideration when deciding upon the most appropriate instrument to use. Reliability, validity and administrative burden are properties of measurement instruments that affect the credibility of the measurement process and the reporting of research findings (Salter et al., 2005a; Salter et al., 2005b).

The Health Technology Assessment programme (Fitzpatrick et al., 1998) examined 413 articles that focused on methodological aspects of the use and development of patient-based outcome measures. The report recommended the use of eight validation criteria. Table 2 lists criteria that should be considered when deciding upon an appropriate measure to use. It gives a definition for each one and also lists a recommended standard for quantifying each criterion, and where appropriate, and how the ratings should be interpreted. The HTA programme produces independent research about the effectiveness of different healthcare treatments and tests for those who use, manage and provide care in the NHS. The HTA programme is managed by the NIHR Evaluation, Trials and Studies Coordinating Centre (NETSCC). This particular study by Fitzpatrick et al (1998) was commissioned and funded entirely by the HTA at a cost of £49,692.

Table 2: Evaluation criteria and standards (Salter et al., 2005a; Salter et al., 2005b)

Criterion	Definition	Standard
1. Appropriateness	*The match of the instrument to the purpose/question under study.* One must determine what information is required and what use will be made of the information gathered.	Depends upon the specific purpose for which the measurement is intended.
2. Reliability	*Refers to the reproducibility and internal consistency of the instrument.* • Reproducibility addresses the degree to which the score is free from random error. Test re-test and inter-observer reliability both focus on this aspect of reliability and are commonly evaluated using correlation statistics including ICC, Pearson's or Spearman's coefficients and kappa coefficients (weighted or unweighted). • • Internal consistency assesses the homogeneity of the scale items. It is generally examined using split-half reliability or Cronbach's alpha statistics. Item-to-item and item-to-scale correlations are also accepted methods.	*Test-retest or inter-observer reliability (ICC; kappa statistics):* Excellent: ≥0.75; Adequate: 0.4 – 0.74; Poor: ≤0.40 Note: Fitzpatrick et al (Fitzpatrick et al., 1998) recommend a minimum test re-test reliability of 0.90 if the measure is to be used to evaluate the ongoing progress of an individual in a treatment situation. *Internal consistency (split-half or Cronbach's a statistics):* Excellent: ≥0.80; Adequate: 0.70 – 0.79; Poor: <0.70 Note: Fitzpatrick et al. caution α values in excess of 0.90 may indicate redundancy. *Inter-item & item-to-scale correlation coefficients:* Adequate levels: inter-item - between 0.3 and 0.9; item-to-scale - between 0.2 and 0.9

3. Validity	*Does the instrument measure what it purports to measure?* • Forms of validity include face, content, construct, and criterion. Concurrent, convergent or discriminative, and predictive validity are all considered to be forms of criterion validity. However, they all depend on the existence of a 'gold standard' to provide a basis for comparison. If no gold standard exists, they represent a form of construct validity in which the relationship to another measure is hypothesized. • • Construct validity is a way of assessing validity by investigating if the measure really is measuring the required theoretical construct. If it is accepted that gait speed is affected by balance, then the results of a measure of balance should correlate with an independent measure of gait speed. Criterion-related validity is a way of assessing validity by comparing the results against a gold standard. The criterion can take many forms, e.g. Another measure of accepted validity (concurrent validity), the opinion of experts or the ability to predict the future (predictive validity). This type of validity is most important in screening tools and prognostic measures. Content validity refers to items included within a multi-item measure. The component items should not only relate to the construct being measured but also cover all aspects of that construct.	*Construct/convergent and concurrent correlations:* Excellent: ≥ 0.60, Adequate: 0.31 – 0.59, Poor: ≤ 0.30 *ROC analysis:* AUC - Excellent: ≥0.90; Adequate: 0.70 – 0.89; Poor: ≤0.70. • There are no agreed on standards by which to judge sensitivity and specificity as a validity index.
4. Responsiveness	*Sensitivity to changes in patients over time (which might be indicative of therapeutic effects).* • Responsiveness is most commonly evaluated through correlation with other change scores, effect sizes, standardised response means, relative efficiency, sensitivity and specificity of change scores and ROC analysis. Assessment of possible floor and ceiling effects is included as they indicate limits to the range of detectable change beyond which no further improvement or deterioration can be noted.	*Sensitivity to change:* Excellent: evidence of change in expected direction using methods such as standardised effect sizes (<0.5=small; 0.5 – 0.8=moderate; ≥0.8=large) Also, by way of standardized response means, ROC analysis of change scores (area under the curve, see above) or relative efficiency. Adequate: evidence of moderate/less change than expected; conflicting evidence. Poor: Weak, evidence based solely on p-values (statistical significance) *Floor/Ceiling Effects:* Excellent: no floor or ceiling effects. Adequate: floor and ceiling effects ≤20% of patients who attain either the minimum (floor) or maximum (ceiling)

		score. Poor: >20%
5. Precision	*Number of gradations or distinctions within the measurement.* E.g. Yes/no response vs. a 7-point Likert response set	Depends on the precision required for the purpose of the measurement (e.g. classification, evaluation, prediction).
6. Interpretability	• How meaningful are the scores? Are there consistent definitions and classifications for results? Are there norms available for comparison?	Jutai and Teasell (Jutai and Teasell, 2003) point out these practical issues should not be separated from consideration of the values that underscore the selection of outcome measures. A brief assessment of practicality will accompany each summary evaluation.
7. Acceptability	• How acceptable is the scale in terms of completion by the patient? Does it represent a burden? Can the assessment be completed by proxy if necessary?	
8. Feasibility	• Extent of effort, burden, expense and disruption to staff/clinical care arising from the administration of the instrument.	

Criticisms of current outcome measures used in rehabilitation are: a mismatch between the measurement tools and aims of interventions, lack of sensitivity to detect changes due to the specific interventions, a lack of information about the psychometric properties of the measurement tools and relevance to the patient group or ‘content validity’.

3.3 Review

A brief review of outcome measures was undertaken to identify valid and reliable measurement tools suitable for use in individuals with neurological conditions.

The measurement tools found were assessed against the criteria in Table 2. The following measurement tools measuring relevant questionnaires and mobility were identified in Table 3, below.

Search methods for identification of studies

To identify studies that used outcome measures that measured aspects of physical activity, physical fitness and exercise participation in individuals with multiple sclerosis a search of the literature was conducted.

The sources for the electronic search included: PUBMED, MEDLINE (from 1966 to July 2008), CINAHL (from 1982 to July 2008) and AMED (from 1985 to July 2008). The search terms were: “outcome measure”, “measures”, combined using AND with “physical activity” or “physical fitness” or “exercise” or “mobility” combined using AND with “multiple sclerosis” or “neurological disease”. The reference lists of identified articles were also searched.

All studies that were found to involve aspects of physical activity, physical fitness and exercise participation in individual with multiple sclerosis (MS) were included in this review.

Table 3: Summary of measurement tools

Outcome Measure	What is measured	Population/setting
MOBILITY		
Kurtzke Expanded Disability Scale (Vaney, 1996)	Impairment and disability, maximum walking distance and aids required.	Multiple sclerosis
Functional Ambulation Category (FAC)	Designed to give detail on the physical support given by patients who are walking.	Geriatric day hospital
2- or 6-min walk/15 sec (Brooks et al., 2001; Butland et al., 1982; Fisher and Gullickson, 1978; Harada et al., 1999; Rossier and Wade, 2001)	Gait endurance.	Stroke, community-dwelling, neurological centre, nursing home
Rivermead mobility index (RMI) (Collen et al., 1990; Collen et al., 1991; Forlander and Bohannon, 1998; Green et al., 2001; Rossier and Wade, 2001; Vaney, 1996)	Based on mobility-derived disability, ranging from ability to turn in bed to running.	Stroke, MS, neurological centre, adults with learning disability
Ambulation index (AI)	Semi-quantitative scale based on time to walk 25ft and use of aids.	MS
Functional independence measure (FIM)/Functional assessment measure (FAM) (Brock et al., 2002; Gosman-Hedstrom and Svensson, 2000; Mansson and Lexell, 2004; Salter et al., 2005b; Sangha et al., 2005; Svantesson et al., 1999)	Scale includes mobility and locomotion.	Various neurological conditions, hospital, nursing home
Physical activity scale for the elderly (PASE) (Allison and Keller, 2004; Chad et al., 2005; Dinger et al., 2004b; Martin et al., 1999; Schuit et al., 1997; Sunnerhagen et al., 2004; Washburn et al., 1993a)	Questionnaire investigating physical activity levels, at home, at work and socially.	Stroke, community-dwelling, hospital, healthy elderly, knee pain
Modified baecke questionnaire for older adults (MBQ) (Pereira et al., 1997; Pols et al., 1996)	Questionnaire assessing physical activity levels.	Elderly
Zutphan physical activity questionnaire (Z-PAQ) (Pereira et al., 1997)	Questionnaire assessing physical activity levels.	Elderly, community, neurological conditions
ACTIVITIES OF DAILY LIVING AND FATIGUE		
Barthel ADL index (Cohen and Marino, 2000; Collin et al., 1988; Green et al., 2001; Mahoney and Barthel, 1965; Sangha et al., 2005; Schlote et al., 2004; Wade and Hewer, 1987; Wolfe et al., 1991)	A self-report or observer-administered measure that consists of 10 items measuring Activities of Daily Living and mobility.	Various neurological conditions

Fatigue severity scale (FSS) (Flachenecker et al., 2002; Krupp et al., 1989; LaRocca et al, 1989)	Eight-item questionnaire investigating fatigue.	MS, elderly, community, hospital based. Neurological conditions
QUALITY OF LIFE		
Expanded disability status scale (EDSS) (Mansson and Lexell, 2004)	A method of quantifying disability in multiple sclerosis that quantifies disability in eight Functional Systems.	MS, hospital, community dwelling
Short form health survey (SF-36) (Taivassalo et al., 1999; Wenneberg et al., 2004)	A multi-purpose, short-form health survey with 36 questions. It yields an 8-scale profile of functional health and well-being.	Community-dwelling, nursing home, myopathies
Sickness impact profile (SIP) (Ellis et al., 2005)	A 136-item self- or interviewer-administered, behaviourally based, health status questionnaire.	Parkinson's disease (PD)
PHYSICAL ACTIVITY		
Physical performance test (PPT)	Overall functional ability of older adults, 7 or 9 items.	Community dwelling, nursing home
Nottingham health profile (Horemans et al., 2004)		MS, post-poliomyelitis community-dwelling
Resistance training (Gerben, 1972; Aitkens et al., 1993; Ansved, 2001; Drory et al., 2001; Hakkinen and Hakkinen, 1995; Jozsi et al., 1999; Kelm et al., 2001; Kilmer, 2002; Kilmer et al., 2001; Kilmer et al., 1994; Lindeman et al., 1999a; Lindeman et al., 1999b; Milnerbrown and Miller, 1988; Skelton et al., 1995; Weiss et al., 2000a)	Using weights or resistance to improve muscle strength or function.	Community, hospital, MS, elderly, muscular dystrophy (MD), stroke, PD, spinal cord injuries
Upper and lower limb ergometer (Bateman et al., 2001; Bizzarini, 2005; Eng et al., 2004; Hill et al., 2005; Orngreen et al., 2005; Phillips and Mastaglia, 2000)		Stroke, myopathies, elderly
Pedometers/accelerometers (Busse et al., 2004)	Total steps or displacement counts	Various neurological conditions
Gait analysis (Alton et al., 1998; Brandstater et al., 1983; Cerny et al., 1980; Dawson et al., 1996; De Quervain et al., 1996; Lindmark and Hamrin, 1995; Mansour et al., 1982; Nadeau et al., 1999; Olney et al., 1994; Olney et al., 1986; Ozgirgin et al., 1993; Roth et al., 1997; Sadeghi et al., 1997; Shiavi et al., 1987; Turnbull et al., 1995; Wagenaar and Beek, 1992; Wagenaar et al., 1990)	Temporal and spatial parameters used to assess gait.	Community, MS, MD, stroke, elderly
Stepping test	Measures speed of performing a dynamic standing task with the number of repeated steps in 15 seconds recorded.	Community dwelling,
Physical disability index (PDI) (Bateman et al., 2001; Cohen and Marino, 2000; Salter et al., 2005b; Suzuki et al., 1999)	An observer-administered measure consisting of 54 items that assess range of motion, strength, mobility and balance.	Nursing home

Step activity monitor (SAM) (Busse et al., 2004; Cavanaugh et al., 2007; Coleman et al., 1999; Foster et al., 2005; Haeuber et al., 2004)	An ankle-worn accelerometer, measuring long-term ambulatory activity.	Obese, healthy, children, elderly, Spinal Cord Injury
Actigraph (Bussmann and Stam, 1998; Corder et al., 2007; Davis and Fox, 2006b; Khemthong et al., 2006; McClain et al., 2007; Reilly et al., 2006)	Accelerometer-based device measuring energy expenditure, step counts and sleep levels.	Women, children, healthy, chronic pulmonary disorder, arthritis. Elderly, stroke, neurological, healthy
Pedometers (Bassett et al., 2000; Croteau, 2004; Crouter et al., 2003; Cyarto et al., 2004; Eakin et al., 2004; Elsworth et al., 2007; Foster et al., 2005; Le Masurier and Tudor-Locke, 2003; Macko et al., 2002; Melanson et al., 2004; Motl et al., 2005c)	Step counter.	Healthy, Alzheimer's
GPS (Schutz and Chambaz, 1997; Schutz and Herren, 2000; Shoval et al., 2008; Terrier et al., 2005; Troped et al., 2008)	Global positioning system.	Stroke, Alzheimer's, MS, Huntington's disease
COGNITIVE STATE		
Repeatable battery for the assessment of neuropsychological status (RBANS)	RBANS was developed to aid in identifying and characterizing abnormal cognitive decline in older adults and as a neuropsychological screening tool in younger patients.	

3.4 Discussion of selected measurements

The following measures were selected, from the measurement tools identified in the above review, as measures for baseline descriptors throughout the studies included in this thesis: fatigue severity scale, rivermead mobility index, Barthel Index, the repeatable battery for the assessment of neuropsychological status, 2-minute walk.

The following measures were selected as primary outcome measures throughout chapters within this thesis: physical activity scale for the elderly, step activity monitor.

These measures were selected for their reliability and sensitivity in neurological populations and, where possible, among individuals with multiple sclerosis.

The measurements selected for this thesis will be described and discussed in more detail in the following paragraphs. These measures have been chosen, as they are deemed suitable to measure actual physical activity and participation. Certain additional measures have been selected, as they are deemed appropriate to measure factors that may affect the individual's ability to participate and undertake physical activity.

3.5 Mobility

Rivermead Mobility Index

Test development

The rivermead mobility index (Appendix 1) was developed to measure mobility in patients with head injury or stroke. The RMI is a short and easy way of measuring a patient's level of mobility. The RMI is a Guttman Scale that comprises 14 questions and one direct observation covering a range of activities from turning over in bed to running. The subjects are asked the questions and a score of 1 is given to each question answered with 'yes'.

Based on the rivermead motor assessment (gross function section), it was designed to meet the Guttman scaling criteria and devised as a short, simple way of measuring specifically a patient's mobility. It is intended for clinical use, with neurologically impaired individuals being assessed in any setting (hospital or home) with the aim of measuring their levels of disability. The RMI primarily reflects patients' ability to move their own bodies and does not measure the use of a wheelchair or mobility assistance by another person. It is quick and easy to use, requiring no equipment as information is obtained by asking the patient or a carer (Collen et al., 1991).

Reliability

Collen et al (1991) reported inter-rater reliability to be high as they found that there was never more than a two-point difference in the total score. Green et al (2001) reported good test re-test reliability of the RMI in stroke patients by

conducting a randomised controlled trial designed to investigate the effectiveness of physiotherapy for patients with mobility problems one year post stroke. In Green's study 22 patients were tested twice with a one-week interval. The study showed that measurement of basic ADL and mobility is reliable when measured by the RMI, finding that there was little bias between total scores between assessments one and two and there was a reliability coefficient of 2.2 with 90% of patients' scores differing by two points or less. Forlander and Bohannon (1999) reviewed the use of the RMI in previous published studies. The RMI was described as reliable and well able to respond to changes over time (Forlander and Bohannon, 1999).

Validity

Concurrent validity was tested on subjects with head injury and stroke by measurement of mobility using gait speed and endurance, and standing balance (Collen et al., 1991). Reliability and validity were also found to be good.

Antonucci et al (2002) assessed the validity and item uni-dimensionality of the RMI by using Rasch analysis in different samples and on different occasions in 308 consecutive patients. Rasch measurement provides a model of expected responses based on the interactions between persons of differing abilities and items of varying difficulty. Each person and item is compared in terms of fitting a uni-dimensional continuum model. The model computes the probability of a response as a function of the person's estimated ability and the item's estimated difficulty associated with the transition between adjacent

response alternatives related to the item (Antonucci et al., 2002). In Antonucci's study, the Rasch analysis showed good validity of the RMI and found that the RMI is a uni-dimensional scale with a hierarchy of easy to hard questions. The test was found to be reliable and sensitive to change during hospital rehabilitation (Antonucci et al., 2002).

Measurement target population

Although the RMI was originally developed and validated for stroke patients, (Collen et al., 1991), its validity has been reported in a much broader range of pathologies. Vaney et al (1996) used the RMI, the expanded disability status scale and the ambulation index to assess levels of mobility in individuals with multiple sclerosis. Two hundred MS patients attending a rehabilitation centre were assessed at the beginning and the end of a four-week period using the RMI, EDSS, the 10-metre walk and Hauser's Ambulation Index. This study found the RMI to be the most sensitive measure for recording changes. It successfully measured changes in 39% of the participants and also validated the RMI against the AI.

Walk tests

Timed walk tests are usually administered in order to give gait speed, which is a robust gait parameter, and it is the most frequently cited of all mobility measures.

Walk tests are administered to monitor changes in walking performance. A variety of walking tests exist, including distance-based tests (e.g. the 10-metre and 2-kilometre walk tests) and time-based tests (e.g. 2, 5, 6, 9 and 12 minute walk tests).

Walking may be timed over a fixed distance or expressed as speed (m/s).

There are two types of timed measure, those timed over a short distance (2 – 20 metres) and those measured over a longer time (2 – 12 minutes), (Wade, 1992a). Walk tests below 10 metres have been found to be unreliable if measured with a stopwatch. This is due to the speed at which they are generally completed (Wade, 1992a).

Endurance is another important factor in mobility. It is commonly measured by asking patients to walk for a set amount of time and then recording the distance covered in that time. Three different times are generally used in clinical settings: 2, 6 and 12 minutes.

Two-minute timed walk test

Test development and method

Walking endurance is tested in the presented studies with the 2-minute timed walk test (Armand et al., 2005). Many previous studies have reported using the 6-minute walk test as a measure of endurance among individuals with MS. However, within these studies the 2-minute timed walk test was deemed more appropriate, owing to the fact that individuals with neurological conditions may find walking for longer than two minutes uncomfortable. Individuals were asked to walk at a self-selected walking speed around a predetermined 10-metre track signed with two cones in a quiet corridor. Patients were allowed to use their walking aid or orthosis if necessary. Timing with a stopwatch commenced when the patient started to walk. The distance walked was measured to the nearest tenth of a metre and the direction of walking (i.e. clockwise or anti-clockwise) was noted.

Reliability

Connelly et al (1996) reported that intra-rater and inter-rater reliability of the two-minute timed walk to be high in elderly patients and many studies have confirmed the reliability of the two-minute walk (Brooks et al., 2001; Brooks et al., 2004; Butland et al., 1982; Rossier and Wade, 2001).

Rossier and Wade (2001) established the reliability of the two-minute walk by assessing 46 individuals with neurological impairment twice with an interval of seven days. It was found that the two-minute walk was a valid, reliable measure of endurance that was the most relevant to patients. The ICC

between test occasions was found to be 0.97; this demonstrates high measure reliability.

Validity

Rossier and Wade (2001) established the reliability and concurrent validity of the RMI, 10-metre walk and two-minute walk in 46 neurologically impaired individuals. The measures showed significant inter-correlation, suggesting that all the measures were valid mobility measures. With r=0.97 for the two-minute walk between assessments and r=0.75 between the RMI and the two-minute walk.

3.6 Physical activity

Physical Activity Scale for the Elderly

There are few physical activity questionnaires that have been validated for use in clinical populations and the elderly. Two that are in regular use are the modified baecke questionnaire for older adults (MBQ) (Voorrips et al., 1991) and the slightly less well known Zutphen Physical Activity Questionnaire (Z-PAQ) (Caspersen et al., 1991). However, these questionnaires have limitations, the Z-PAQ does not include household activities and the MBQ does not include work-related activities. The physical activity scale for the elderly (Appendix 2), however, covers these topics and is a well-established questionnaire for use in elderly and clinical populations.

Test development

The PASE was developed in 1993 by Washburn et al (1993) to assess activities commonly engaged in by elderly populations. It is a self-report/interview based measure designed to capture and assess the occupational, household and leisure activities typically performed in day-to-day life by older or less physically able individuals. The time spent participating in each activity area is multiplied by a weighted value that reflects the amount of energy expended by an older person engaged in that activity.

Activities are reported retrospectively over a period of one week including the weekend, enabling detection of changes in activity over a relatively short period of time. The PASE does not estimate energy expenditure as most questionnaires do, but provides a final score with which subjects can be

compared. Subsequently it has been validated and evaluated in a number of studies (Schuit et al., 1997; Dinger et al., 2004b; Martin et al., 1999).

Reliability

Washburn et al (1993b) found the test re-test reliability to be 0.75 (CI=0.69-0.80) in a sample of 36 individuals aged between 65 and 85 years old, this was assessed over a 3-7 week interval. They also observed that the reliability for mail administration (r=0.84) was higher than for telephone administration (r=0.68). In a recent systematic review of physical activity questionnaires (Forsén et al, 2010) the PASE was found to have a positive rating on reliability, with a Pearson correlation coefficient of r = 0.84.

Validity

Washburn et al (1993b) established construct validity for the PASE by correlating PASE scores with health status and physiologic measures, as hypothesized PASE scores were positively associated with grip strength (r=0.37), static balance (r=0.33), leg strength (r=0.25) and negatively correlated with resting heart rate (r=-0.13), age (r=0.34) and perceived health status (r=-0.34).

Schuit et al (1997) investigated the validity of the PASE in 21 elderly men and women and the PASE score was compared with the doubly labelled water method. They found the correlation coefficient of the PASE score with the residuals from the regression analysis using total energy expenditure as dependent and resting metabolic rate, as independent variate was 0.58 (95%

CI=0.50-0.81).

Measurement target population

Martin et al (1999) validated the PASE questionnaire in older adults, regarding it as a valid and reliable tool to assess physical activity in their chosen population. Nine years after developing the PASE, Washburn et al developed the physical activity scale for individuals with physical disabilities (PASID) (Washburn, 2002). Similar to the PASE in terms of questions asked, the wording was altered to be more inclusive for those with physical disabilities. However, the PASE was found to be more appropriate for the population targeted within this thesis this is due to the fact that it is shorter in length than the PASID, making it more suitable to be used within patient assessment, and the questions were found to be more suitable to the clinical population being studied in this thesis.

Pedometers

Physical activity can be determined in many ways: behavioural observation; questionnaires (including diaries, recall questionnaires, and interviews); calorimetry; physiological markers such as heart rate; and motion sensors (Shepard, 2002; Westerterp, 1999a).

Historically researchers have relied on the use of self-reported measures in an attempt to quantify physical activity, such measures are the most convenient and cheap to administer and cover physical activities within the daily pattern (Westerterp, 1999a). The shortcomings of any self-reported data are widely acknowledged (Tudor-Locke, 2001). These include compliance

to completing activity logs or diaries in field research (Sallis, 2000); the difficulty in quantifying the relationship between physical activity and health (Eston, 1998); the inability to apply a measure universally to all subject categories and the fact that estimates of activity can be easily over- or under-estimated (Westerterp, 1999a).

There are many different measures of physical activity in use but one of the most common is the pedometer. Pedometers can be effective for increasing physical activity and one of the major limitations facing researchers is finding practical, cheap and easy-to-use methods of assessing physical activity in free-living conditions such as the community. As mentioned above, self report and dairies have been used in the past, but the limitations of these methods have been well documented, particularly the lack of sensitivity towards ambulatory or walking activities (Ainsworth, 1993). The attractiveness of the pedometer is the potential to provide a low-cost objective measure of walking behaviour that has low interference with day-to-day life, is convenient and easy-to-use (Dishman et al., 2005; Le Masurier, 2004; Tudor-Locke et al., 2002).

Reliability

Both step counters and pedometers are normally worn at the waist, where vertical movements increment a single register. In the case of pedometers, the increments are scaled according to a selected stride length setting. Accuracy has been reported to vary considerably between subjects and to be particularly questionable for those with gait disorders. Frequently reported

problems with both types of instrument include the assertion that the response is affected by factors such as movement style, walking speed, mode and location of attachment, and the amount of soft tissue at the attachment site. They were used in conjunction with accelerometers in the presented studies to investigate reliability and validity.

Validity

Within normal populations the Yamax Digiwalker SW-200 Pedometer (YX200) has been found to be a valid and reliable tool for measuring physical activity with respect to walking (Melanson et al., 2004; Schneider et al., 2004). Accuracy has been found to exceed 96% at faster speeds such as 3mph (Melanson et al., 2004). It is slightly less accurate at slower speeds, being 71% less accurate when the subject is walking below 2mph. The Yamax Digiwalker SW-200 is used in the studies presented in this thesis. Tudor-Locke et al (2002) reported the construct and concurrent validity of using pedometers to assess physical activity to be high, specifically between pedometer-determined physical activity and the six-minute walk test (median r=0.33).

Measurement target population

Crouter et al (2003) assessed the validity of 10 different electronic pedometers in normal, healthy individuals and found them to be a valid and reliable research tool. Following their investigation into pedometer accuracy in healthy individuals, Washburn et al (1980) concluded that the results of their study and others reported in the literature "offer little to recommend the use of

the mechanical pedometer." With this in mind, a manual count was taken when using pedometers in this thesis, to further assess the reliability within neurological populations.

Step Activity Monitors

Development

Many pedometer-type devices are commercially available and can be worn by anyone. Both step counters and pedometers are normally worn at the waist, where vertical movements increment a single register.

In 1991, Smith proposed the development of the step activity monitor in order to overcome the limitations of the previously available long-term activity monitors. The main development goals were for the device to be easy to use, highly accurate, unobtrusive for the wearer, capable of continuously recording data in short time intervals, and capable of withstanding the demands of field monitoring.

The SAM detects and counts steps for a wide variety of gait styles, ranging from a slow shuffle to a fast run. The monitor is approximately the size of a pager and was designed for long-term use without maintenance by the user.

To achieve maximum sensitivity for step detection, the SAM is worn just above the lateral malleolus on the right leg or the medial malleolus on the left leg. The device is secured to the leg by an elastic attachment strap (Coleman et al., 1999).

Accuracy

Coleman et al (1999) investigated the accuracy of the SAMs by observing 10 subjects with diabetes. Individuals were asked to walk in varying conditions, such as over-ground, on a treadmill, uphill and downhill, and up and down stairs. It was found that overall step-counting accuracy for normal walking was 99.7% and overall accuracy for walking on stairs was 96.2%.

Shepherd et al (1999) compared the accuracy of the SAM with that of an electronic pedometer. Twenty-nine healthy individuals were assessed while walking over 400 metres. They found the SAMs mean absolute error was 0.54%, whereas the pedometer was 2.82%.

Reliability

Test re-test reliability was assessed by Coleman et al (1999) with 45 subjects with diabetic peripheral neuropathy, both with and without amputation. Two accuracy trials over the same course were conducted for each subject, separated by a two-week monitoring period. For each subject, the same monitor with the same sensor settings was used for both accuracy trials and the intervening two-week monitoring period. During each trial the average deviation of the SAM count was 0.54% and 0.65% respectively.

Validity

Busse et al (2004) monitored ambulation for seven days using the SAM in 10 individuals with multiple sclerosis, 10 with Parkinson's, 10 with primary muscle disease and 10 healthy subjects. They reported ambulatory monitoring to be a valid tool (ICCs of 0.89 in healthy individuals and 0.86 in individuals with neurological conditions).

3.7 Activities of Daily Living

Barthel Index

Test development

Activities of daily living refer to the basic, physical functions, which underlie daily living, such as continence, going to the toilet, dressing and walking (Wade, 1992a). Measures of ADL record an individual's actual performance not their presumed potential ability. There are many researched, published ADL indices and Feinstein et al (1986) identified 43 with good reliability and validity.

The barthel ADL index (Appendix 3) has been used in the studies within this thesis, as it includes the ten most common areas included within ADL scales.

The barthel ADL index is a scale used to indicate the independence of subjects in activities of daily living and is a standardised measure of 10 activities of daily living that is delivered in a functional rating scale. The barthel index has been used since 1955 (Mahoney and Barthel, 1965). It was originally intended as a simple index of independence with which to quantify the ability of a patient with a neuromuscular or musculoskeletal disorder to care for his or herself. It is perhaps the most widely used measure of functional disability. Sangha et al (2005) investigated the frequency and patterns of use of the BI and the functional independence measure (FIM) in stroke rehabilitation trials. Their results indicated that the BI and the FIM were the most commonly used measures of disability used in RCTs examining

stroke rehabilitation. However, the BI was used more often than the FIM ($n=86$, $p<0.001$) and was cited in trials of superior quality ($p=0.005$).

The Barthel is very simple, consisting of 10 common ADL activities. The activities are given numerical scores depending on the level of support needed by the patient when performing these activities. It is scored visually and arbitrary weighting system. Total scores range from 0 to 100, with subjects being fully independent at a score of 100.

The BI can take as little as 5 minutes to do if completed by self-report and up to 20 minutes through direct observation (Salter et al., 2005b). It does not require training to administer and has been shown to be equally reliable when administered by skilled and unskilled individuals (Collin et al., 1988). Collin et al (1988) investigated different methods of obtaining the score. Self-report, asking a relative and skilled observer were compared and close correlations indicated no differences between these methods (Collin et al., 1988). The BI has been found to be a valid and reliable measure of disability.

Reliability

Green et al (2001) tested 22 patients one year post stroke twice, at an interval of one week using the BI. They reported >75% agreement on individual items assessed one week apart. This finding is supported by Wolfe at al (1991), who measured 50 patients with stroke two weeks apart using the BI. They reported test retest as 0.98. Cohen and Marino (2000) reported studies showing inter-observer reliability of $r=0.71 – 0.99$.

The BI has been found to be reliable and valid with its reliability having been studied in several different ways such as within a rehabilitation setting (Collin et al., 1988; Gosman-Hedstrom and Svensson, 2000).

Validity

The construct validity, also called parallel reliability, of the BI has been assessed by Gosman and Svensson, (2000). They found the concordance between the FIM and the BI on the item level to be strong, both according to the theoretical cut-off levels defined by the operational definitions and the empirical cut-off levels defined by the marginal distributions. Concurrent validity has been reported by Cohen and Marino (2000), who reported high correlations between the BI and the Katz Index (k=0.77).

Limitations

Perhaps the most common criticism of the BI is its relative insensitivity to change and a limited content validity, which is reflected in large reported ceiling and floor effects. Duncan et al (1997) showed that among patients recovering from mild stroke who scored 100 on the BI, there were deficits in health status, suggesting that the BI is not sufficiently sensitive to change among the least impaired stroke survivors (Salter et al., 2005b).

Measurement target population

The BI can be applied reliably by non-medical personnel, as investigated by Schlote et al (2004). Inter-rater and test-retest reliability was deemed to be good for all the items of the BI in stroke patients (Green et al., 2001; Schlote et al., 2004).

3.8 Fatigue

Fatigue Severity Scale

A large number of fatigue scales exist and there is no consensus on which fatigue measuring scales are most appropriate for use in assessment of fatigue in neurological diseases (Hjollund et al., 2007). Several studies have assessed several fatigue scales (Flachenecker et al., 2002; Kos et al., 2006) and found the FSS to positively correlate and be comparable to different scales (Dittner et al., 2004) .

Test development

The FSS (Appendix 4) is a widely used index of physical and emotional fatigue. It is a self-report scale consisting of nine items based on the relationship between fatigue and depressive symptoms. Subjects read nine statements on the questionnaire and choose a number from 1 to 7 that best describes their feelings towards each statement (1 = strongly disagree, 7 = strongly agree). The FSS score is obtained by computing the average rating (range 1-7), (Krupp et al., 1989).

Reliability

The FSS has been found to be a short, easy-to-administer and useful measure of fatigue (Schneider, 2004). Surakka et al (2004) found the FSS to have high test retest reliability. Leberge et al (2005) assessed the reliability of the epworth sleepiness scale (ESS), daytime sleepiness scale (DSS), chalder fatigue scale (CFS), and fatigue severity scale in patients with myotonic

dystrophy type 1 (DM1). Twenty-seven patients with neuromuscular conditions were administered the questionnaires on two occasions, with a two-week interval. Internal consistency and test retest reliability were measured using intra-class correlation coefficients (ICCs), and Cronbach's alpha, Cohen's kappa, and Goodman-Kruskal's gamma coefficients. Internal consistency of the CFS and FSS were adequate (alpha >0.70). Both daytime sleepiness and fatigue rating scales showed significant test retest reliability. Reliability of the FSS was high, indicating its use for individual patients with neuromuscular disorders. They concluded that fatigue rating scales such as the FSS, which are based on the behavioural consequences of fatigue, may constitute a more accurate and comprehensive measure of fatigue severity in populations of individuals with neuromuscular disorders.

Validity

Fatigue is commonly looked at as a response to stress whether mental, emotional or physical (Porock and Oliver, 2005). Flachenecker et al (2002) compared four widely used fatigue scales in multiple sclerosis patients. The fatigue severity scale appeared to be a sensitive and reliable measure to detect clinical changes, (Flachenecker et al., 2002).

3.9 Physical activity compliance

The studies presented use attendance at a leisure facility as a measure to further investigate attendance. This was recorded by participants on a session progress sheet (Appendix 5). Participants were asked to complete a new session progress sheet each time they visited the leisure facility. The date and time of each visit was required and there were four questions on the session progress sheet to be answered after each session in the gym. These were scored by participants using a six-point Likert scale.

Question one was "How enjoyable was the session?" (The enjoyment scale ranged from 1 to 6, with a score of 1 indicating a ‘very enjoyable’ session and 6 indicating that the session was ‘not at all enjoyable’.)

Question 2 was "How helpful were the staff?" (The staff helpfulness scale ranged from 1, indicating staff were ‘very helpful’, to 6, indicating staff were ‘not helpful at all’.)

Question 3 asked, "Did you encounter any problems with the equipment?" (The scale regarding problems encountered with equipment was also rated from 1 to 6, where 1 represented ‘no problems at all’ and 6 represented ‘major problems’).

The final scale individuals were asked to complete was taken from the SF-36 questionnaire. Individuals were asked "How happy are you with your life today?" Again the scale ranged from 1 to 6, where 1 indicated the individual was ‘very happy’, and 6 indicated the individual was ‘very dissatisfied’.

Individuals were asked to complete a self-report diary in which he or she will use a diary to note the date and time of attendance to the gym. Self-report systems of measurement are often used because of their acceptability, cost, practicality and low interference with day-to-day life (Motl et al., 2005a).

There are a number of concerns when using self-reporting for measuring physical activity. It is well documented that these systems can be notoriously unreliable and have many problems associated with them (Tudor-Locke, 2001), such as social desirability. Motl et al, (2005a) found evidence to suggest that social desirability might result in an over-reporting of physical activity. Self-reporting requires a high level of adherence, and may interfere with or influence physical activity. This is known as the Hawthorne Effect (Bassett et al., 2000; Mayo, 1933). The Hawthorne Effect refers to the phenomenon that causes people participating in a study to temporarily change their behaviour or performance.

Kozlow-Johnson and Matt (2004) reported that self report measures of activity appear to be more sensitive to the maximum rather than the frequency or duration of activity. This is due to the fact that it is likely that individuals will report maximum effort as opposed to average effort.

'Slice card' system

To assess the reliability of the self-report system and ensure accurate data, individuals will be asked to use the 'slice card' system in conjunction with the self-report activity diaries. The slice card system has been put in place by Oxfordshire City Council to monitor and promote gym attendance, and

therefore hopefully increase physical activity participation.

This system is used in leisure centres run by Oxfordshire City Council, to effectively monitor the use of the facility. At the entrance to each facility is a swipe system, through which the slice card must be passed before entrance is granted; each swipe is also registered with the facility's computer system.

It is by these means that attendance of the leisure facility will be monitored.

The slice card will provide an effective way of monitoring attendance to the leisure centre facility and therefore provide information on how often individuals are attending for physical activity sessions. If attendance increases this may reflect a concomitant increase in physical activity levels.

The slice card is a system provided by Oxford City Council to make access to city leisure centres more affordable and accessible to the public. Specifically, individuals with disabilities are eligible for a 'bonus' slice, which enables use of leisure centre facilities at a much-reduced rate.

This will be an essential way of monitoring physical activity as Pitta et al (2005) reported that individuals significantly over-estimated the amount of time engaged in physical activity (22 ±47 minutes, $p=0.04$). Individuals have reported many reasons for this, such as a desire to please the researcher and a desire to appear more active than reality would suggest.

3.10 Conclusion

This chapter discussed the outcome measures used within the studies presented in this thesis, and justifies their selection in comparison with other available measures and through a critique of their psychometric properties. Many of these measures are routinely used in clinical practice as well as research, demonstrating the ease-of-use and versatility of the measures chosen. The reported measures have been well used and documented in previous studies as valid, effective tools for use within neurological populations.

4 Pedometer step counts in individuals with neurological conditions

4.1 Introduction

Pedometers have been used successfully in a range of populations to encourage physical activity (PA) (Cyarto et al., 2004; Tudor-Locke et al., 2002). However, their ability to accurately assess PA within clinical populations (Beets et al., 2005) or at slow speeds (Crouter et al., 2003) has been an issue of concern. To date, there is little published data on the utility of pedometers in individuals with neurological conditions (Motl et al., 2005c) and currently no accepted 'gold standard' for self-monitoring of physical activity in neurological populations. There is, however, increasing evidence to suggest individuals with neurological conditions would benefit from increased activity levels (Le Masurier et al., 2003).

Mobility assessment tools such as step activity monitors (SAMs) have been shown to provide accurate and reliable assessment measures of cadence and total stride counts in hemiparetic stroke patients (Macko, 2001; Macko et al., 2002) and in neurological populations (Busse et al., 2004; Pearson et al., 2004b). Yet they are not suitable for widespread exercise prescription as they are expensive and provide more information than a clinician or patient requires. Pedometers are generally accepted as simple to use, inconspicuous and a relatively inexpensive device providing step count information that is useful for measuring physical activity.

Objective

In order to examine the validity of a pedometer for measuring step counts and everyday activity monitoring in individuals with a range of neurological conditions, we set out to assess the accuracy of a pedometer. Considering that previous studies have suggested that walking speed may be a factor that is related to pedometer accuracy we explored accuracy in individuals with a normal gait at both self-selected and slow walking speeds.

Aims

More specifically:

- we measured step counts in healthy and neurologically impaired individuals walking at a self-selected walking speed (SSWS) and
- healthy individuals who were asked to walk at both SSWS and a slow speed (SWS).

4.2 Methods

Participants

Adults with a stroke (at least six months post-onset), muscular dystrophy (MD), multiple sclerosis (MS), any similar neuro-muscular condition (n=43) and healthy individuals (n=13) were invited to take part in the study. No formal power calculation was carried out to determine optimal participant numbers. Participants were included if they were able to walk for at least two minutes without physical assistance from another person (aids permitted) and with no contraindications to walking, exercise participation, severe musculoskeletal or cardio-respiratory disease. Participants were excluded if they were unable to meet the inclusion criteria, or unwilling or unable to undertake the test. Healthy individuals were recruited from a sample known to researchers and participants were recruited from the local community, via a researcher visiting local disease support groups, and consultant neurologists in the Oxfordshire area and investigated at a rehabilitation centre. Study participants were provided with information on the study and were only included in the study if they provided informed consent. Ethical approval was obtained prior to participation as part of a community ambulatory study (Ethics study number: 05/Q1605/95).

Measures

The following data were obtained at assessment: Gender and age; anthropometrical data [height (cm), weight (kg)]; presenting pathology; Independence in activities of daily living (ADL), barthel index (BI) (Wade,

1992b); and mobility as determined by the rivermead mobility index (RMI) (Collen et al., 1991).

Procedure

Participants were fitted with the Yamax digi-walker (Model SW-200, Yamax corporation, Tokyo, Japan) midway between their iliac crest and umbilicus over the right leg in line with the midline of their thigh (Bassett et al., 1996) as described in previous studies and in line with the manufacturer's instructions. It was not possible to calibrate the Yamax digi-walker (Ryan, 2006)

Participants were asked to walk along a 10-metre walkway (2 meters wide), in a quiet corridor in the rehabilitation centre, at their normal self-selected walking speed and using walking aids if required for a period of two minutes. A 10-metre walkway was used in this study, as this was the available space for use by the researchers. Participants walked round a set of cones. Healthy/control participants were then asked to repeat the test and walk at a slower walking speed, or a speed that they felt was slower than their normal walking speed.

An observer simultaneously manually recorded participants step counts using the manual step counter (MTC-001, ENM, UK). Manual step count and pedometer counts were recorded at the end of the trial along with total distance covered.

4.2.1 Statistical analysis

Differences between pedometer and manually measured counts were analysed using student t-test and bias (average difference). The level of error was calculated by random error (95% confidence intervals of the standard deviation of the differences), intra-class correlation coefficient (ICC) and percentage variability (absolute difference/mean value of pedometer and measured count). Statistical significance was accepted at $p<0.05$. Curve estimation was performed to investigate the relationship between walking speed and error difference between actual and measured counts. Residuals from regression analysis were examined for normality, independence and constant variance. The line of best fit was determined from visual inspection and examination of both R and R^2 values and strength of the association from ANOVA. All statistical analysis was carried out using SPSS v14. Alpha was set at 0.05.

4.3 Results

Healthy adults n=13, age: mean 29, *s*=12, and 43 adults with neurological conditions (n=20 stroke, n=16 multiple sclerosis, n=5 muscular dystrophy, n=1 spinal cord injury (SCI), n=1 traumatic brain injury (ABI)); age: mean ± sd, 54 ± 13, consented to participate. Demographic details are recorded in Table 4.

Table 4. Demographic data for control and neurological conditions.

	Mean ± sd				**Median (range)**		
	Height (cm)	Weight (kg)	BMI (kg m^{-2})	Age (yrs)	RMI (0-15)	BI (0-20)	Gender (m:f)
Control (13)	171 ±10	70 ±14	22 ±7	29 ±12	15	20	6:7
Neurological (43)	171 ±9	77 ±13	26 ±4	54 ±13	13	19	26:17
MD (5)	171 ±9	76 ±16	26 ±4	47 ±8	14	18	3:2
MS (16)	168 ±8	72 ±11	26 ±4	54 ±10	13	19	4:12
Stroke (20)	171 ±8	79 ±14	27 ±5	56 ±16	13	19	17:3
SCI (1)	195	86	28	52	11	19	m
ABI (1)	186	23	23	22	13	19	m

Table 5: Actual and Pedometer counts

	Pedo-meter	**Actual counts**	**t test, dependent, equal variance, 2 tailed**		**λ Bias (Random error)**	**φ % variability**	**ICC [3, 1]**	**Walking Speed m s^{1}**	**Cubic regression (speed/bias)**	
	Mean ± sd	Mean ±sd	p				Mean (95% CI)	Mean ±sd	R^2	F (P)
Normal adults SSWS n=13	229 ± 13	226 ±11	0.113		-3	3	0.84	1.3 ±0.3		
							0.55 - 0.95			
					13					
Normal adults slow n=10	155 ±25	165 ±17	0.080		10	8	0.73	0.8 ±0.4		
							0.23 - 0.93			
					31					
Neurological n=43	138 ±85	165 ±48	0.003	*	27	30	0.66	0.57 ±0.24	0.29	5.25
							0.46 - 0.80			(0.00)
					111					
Muscular dystrophy n=5	177 ±111	184 ±28	0.866		7.2	35	0.38	0.49 ±0.16	0.74	2.85
							-0.62 - 0.91			(0.26)
					176					
Multiple sclerosis n=16	124 ±83	146 ±59	0.044		23	24	0.84	0.49 ±0.23	0.44	3.12
							0.60 - 0.94			(0.07)
					81					
Stroke n=20	145 ±81	176 ±37	0.026	*	31	29	0.58	0.64 ±0.25	0.33	2.61
							0.20 - 0.81			(0.09)
					113					
Spinal cord injury n=1	9	139						0.42		
Acquired brain injury n=1	162	167						0.92		

Table 5 shows the pedometer data and analysis. In healthy individuals there were no significant differences between pedometer and measured tally counts at both self-selected walking speed and slow walking speed (Table 5).

In contrast to healthy individuals the pedometers significantly under-estimated counts in participants with neurological conditions when compared to measured tally counts. When examining the level of bias, this was greater for all neurological conditions when compared to both slow and fast walking in healthy groups. The level of error as shown by ICCs, % variability and random error was highest in the stroke group and higher in the neurological groups than the healthy group.

When examining the relationship between walking speed and difference between measured and pedometer counts in the neurological participants, it was observed that although the stroke group had the fastest average walking speed they had the highest degree of under-counting by the pedometer (bias) and overall variability (random error). On further examination, the relationship between walking speed and error between pedometer and measured counts in neurological gait was weak and non-linear. This relationship was cubic for all groups but only reached significance when the relationship was explored in the neurological group as a whole. The strength of the relationship is reported in Table 5. We observed that only a small degree of the error (<30%) in pedometer counts could be explained by walking speed.

4.4 Discussion

The pedometer model used in this study has been validated in two studies (Crouter et al., 2003; Schneider et al., 2004) and found to be consistently accurate under both controlled and free-living conditions. The findings from this study agree with this data, with accurate step counts obtained with healthy individuals walking at both SSWS and SWS but not in people with neurological conditions. Importantly the level of accuracy when explored in people with neurological conditions was not related to walking speed.

Within healthy populations pedometers have been shown to be a valid way of measuring physical activity demonstrating construct validity and convergent validity with measures of physical activity, including accelerometers (r=0.66-0.98) (Macko et al., 2002) and self-reported physical activity questionnaires (r=0.67) (Speck and Looney, 2006). Using a pedometer to work towards a goal of a number of recommended steps per day (Tudor-Locke and Bassett, 2004) provides a simple framework for self-exercise prescription and monitoring. Using a pedometer in a neurological population offers a possible method for motivating physical activity and is aligned with current rehabilitation goal setting targets.

There is limited previous research, but Cyarto et al (2004) investigated the impact of walking speed and gait disorders on the accuracy of waist mounted pedometers in older adults residing in a nursing home. Cyarto's study showed that the Yamax Digiwalker SW-200 pedometer underestimated steps by 74% at slow walking speeds, 55% at normal walking speeds and 46% at fast

walking speed. He concluded that gait disorders significantly compromise pedometer accuracy. This study's findings agree with this research, as although pedometers have been shown to be reliable and accurate at measuring step counts in healthy individuals (Melanson et al., 2004) their accuracy at measuring steps and thus physical activity in adults with neurological conditions was variable. In most cases the pedometers significantly under-counted steps. Importantly, walking speed was only weakly related to the level of inaccuracy in pedometer readings and therefore speed cannot be used to predict utility. Pedometers may not be an accurate method of counting steps in this group and the level of accuracy does not appear to be predicted by walking speed.

Limitations

This was a small study and perhaps recruited a small amount of numbers due to the nature of the disease and the small recruitment areas

Clinicians should therefore determine pedometer suitability on an individual basis for each patient**.** The stability of the level of error over time could be examined in a future study as error, if consistent, may be corrected and converted to actual steps.

4.5 Conclusion

Pedometers may be an inaccurate tool in individuals with neurological populations and people with neurological conditions should be assessed on an individual basis to ensure that the level of error is within acceptable limits prior to their use as an exercise prescription tool.

Walking speed did not predict the level of inaccuracy in the pedometer. Further study using larger sample sizes is warranted to highlight characteristics for use of such a tool in all settings and to explore the possibility of predicting gait characteristics that relate to the level of inaccuracy.

5 The test-retest reliability of the Physical Activity Scale for the Elderly (PASE) on assessing mobility in individuals with multiple sclerosis

5.1 Introduction

Reliability refers to the quality of a measure at demonstrating reproducibility (Batterham and George, 2003). Reproducibility is the degree to which a measure produces the same scores when applied repeatedly in the same circumstances (Nelson, 1997). A degree of error or lack of agreement is present between scores in all measurements (Batterham and George, 2003). This error can derive from error associated with the measurement tool or procedure, error from biological variation and a combination of the two. Error can be classified as either random error or systematic error. Random error refers to the 'noise' in the measurement (Batterham and George, 2003), whereas systematic error refers to consistently different results introducing a bias to the measurement (Kirtley, 2006). Whilst the reproducibility of measures taken by different individuals can be explored, in this study test-retest reliability of an individual using a measure is being explored. This assesses the consistency of a measure from one time to another.

This chapter aims to assess the reliability of the physical activity scale for the elderly (Appendix 2) when used with individuals with multiple sclerosis (MS). Many physical activity questionnaires have been tested for reliability over time in individuals with disabilities, such as the physical activity scale for individuals with physical disabilities (van der Ploeg et al., 2007) but few have been

validated in individuals with neurological conditions, and specifically in people with MS.

There are a limited number of physical activity questionnaires that have been validated for use in clinical populations and the elderly. Two that are in regular use are the modified baecke questionnaire for older adults (MBQ) (Voorrips et al., 1991) and the slightly less well known zutphen physical activity questionnaire (Z-PAQ) (Caspersen et al., 1991). However, these questionnaires have limitations, the Z-PAQ does not include household activities and the MBQ does not include work-related activities. The physical activity scale for the elderly covers these topics and is a well-established questionnaire for use in elderly populations. The questionnaires discussed above have not been validated for use in individuals with neurological conditions. There is no questionnaire validated for use in people with multiple sclerosis.

The PASE was developed in 1993 by Washburn (1993) to assess activities commonly engaged in by the elderly populations. It is a self-report/interview-based measure designed to capture and assess the occupational, household and leisure activities typically performed in day to day live by older or less physically able individuals.

Activities are reported retrospectively over a period of 1 week including the weekend, theoretically enabling detection of changes in activity over a relatively short period of time. The PASE does not estimate energy expenditure, but provides a final score with which subjects can be compared.

This scoring method has face validity for people with multiple sclerosis where energy expenditure for everyday tasks varies between individuals and may differ from the elderly population (Newman et al, 2007)

The PASE has previously been reported to be a reliable and valid tool in various populations (Dinger et al., 2004b; Martin et al., 1999; Schuit et al., 1997; Washburn et al., 1993b), such as the elderly and the physically disabled. Martin et al (1999) validated the PASE questionnaire in older adults, regarding it a valid and reliable tool to assess physical activity in their chosen population.

Objective

This study set out to explore the test-retest reliability of this tool in individuals with MS.

5.2 Methods

5.2.1 Study Design

A Cross sectional survey design was employed for this study.

5.2.2 Setting and Procedure

The study was conducted in hospital rehabilitation clinic, due to the availability of private space in which it was possible to administer the questionnaire.

On arrival, the procedure was explained to individuals who were then invited to give informed consent. The PASE questionnaire was then administered by researcher. Twenty subjects completed both baseline and follow-up questionnaires at a hospital clinic over a three-week interval period.

5.2.3 Participants and Recruitment

Twenty individuals took part in this study. All individuals had a diagnosis of multiple sclerosis and gave written informed consent prior to participation, in accordance to the declaration of Helsinki (World Health Organisation., 1996). Individuals were identified by consultant referral. Exclusion criteria for individuals were an unstable medical condition (e.g. uncontrolled cardiovascular disease or uncontrolled diabetes). Descriptive details of participants are found in Table 6.

Reliability was evaluated by determining the extent to which PASE scores were stable over two repeated administrations taken within one week.

5.2.4 Measure

The physical activity scale for the elderly is a self-report/interview based measure designed to capture and assess the occupational, household and leisure activities typically performed in day-to-day life by older or less physically able individuals. The time spent participating in each activity area is multiplied by a weighted value that reflects the amount of energy expended by an older person engaged in that activity. The PASE was developed in 1993 by Washburn et al (1993) to assess activities commonly engaged in by elderly populations and disabled populations.

5.2.5 Statistical analysis

Data was imported into SPSS v 11.0 (SPSS inc, Chicago, USA) software for statistical analysis. To assess the reliability of the parameters measured, the differences between test-retest measurements and their means were calculated and compared (Bland and Altman, 1996). To test whether the measurement contained any systematic error, bias was calculated as the mean of the differences between tests. Upper and lower limit 95% CI were also calculated. These limits provide an estimate of how small or large the true systematic bias may be. If the limits include the value of zero it also indicates no significant difference between test means (Batterham and George, 2003). To determine the relative agreement between tests, ICC 3:1 were used with 95% CI to determine the range of the true reliability (Batterham and George, 2003). Friedman chi squared, Cochran's Q and ANOVA F tests were performed on the component scores and the total score.

5.3 Results

Table 6: Participants' descriptive information

	N	Age (years)	Mass (kg)	Height (m)	RMI (0-15) Median	RMI IQR
Male	5	57 ±5.3	80.8 ±5.5	1.77 ±0.7	7	4.5 - 10.5
Female	15	54 ±9	70 ±11	1.64 ±0.1	13	9 - 13
All	20	53 ±9.6	74.5 ±10.2	1.62 ±0.07	12	6 - 13

Mean ± sd

Results for selected parameters and statistical tests are found in Table 7.

Table 7: PASE scores at time one and time two.

PASE parameter	T1 mean ±sd	T2 mean ±sd	Bias	Mean ICC (Lower - Upper bound)
Social	15.2 ±17.6	16.6 ±11.7	-1.5	0.56 -0.05 – 0.8
Home	35.8 ±36.06	27.5 ±39.3	8.4	0.77 0.37 - 0.94
Work	12.5 ±17.7	14 ±19.8	-1.5	0.99 0.95 - 0.99
PASE total	63.5 ±48.9	58.1 ±58.7	-1.6	0.89 0.62 - 0.97

sd - Standard deviation
Results given are PASE scores (max = 400)
T1 - Test 1
T2 - Test 2

The statistical analysis (reported in Table 8) performed on the data reported in Table 7 shows there were no significant differences between tests in any of the parameters reported in any group. No systematic bias was found in any direction. ICCs ranged from 0.64 in the home category to 0.99 in the work section. ICC was good (Cohen, 1998) in the total PASE score at 0.84.

Table 8: Statistical data for PASE components.

	Cronbach's Alpha Score	95% Confidence interval		Correlation	Test Score	Significance level (p=0.05)
		Lower	Upper			
Social	0.738	-0.057	0.871	0.585	0.048*	0.827
Home	0.915	0.372	0.945	0.844	2.19**	0.138
Work	0.997	0.955	0.997	0.994	2.0*	0.157
PASE	0.942	0.624	0.972	0.934	2.719***	0.134

* Friedman's Chi-Squared ANOVA test performed
** Cochran's Q ANOVA test performed
*** ANOVA F test performed

The Friedman's chi squared ANOVA test was performed on the social and work domains due to the repeated non-parametric nature of the data. The Cochran's Q ANOVA test was used on the data from the social subscale, as the data was binomial. After combining the scores from the three separate domains to determine the total PASE score, this was analysed using the ANOVA F-test as the total becomes parametric.

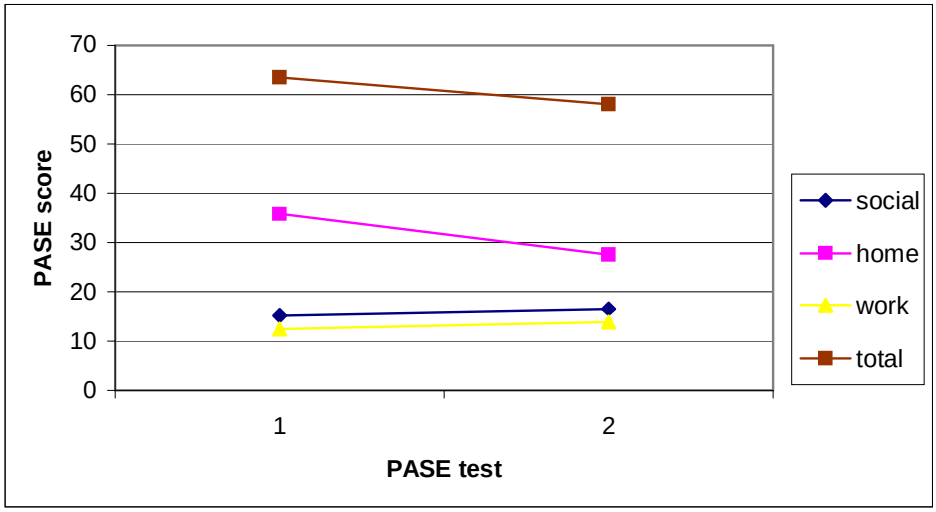


Figure 3: Mean PASE scores across two trials.

The calculation of the mean value for each of the three trials permits an initial screen for any systematic bias.

The following results are based on the components of the PASE questionnaire as well as the total scores. There are three components to the questionnaire, these determine physical activity levels in three different domains, social life, home life and work life.

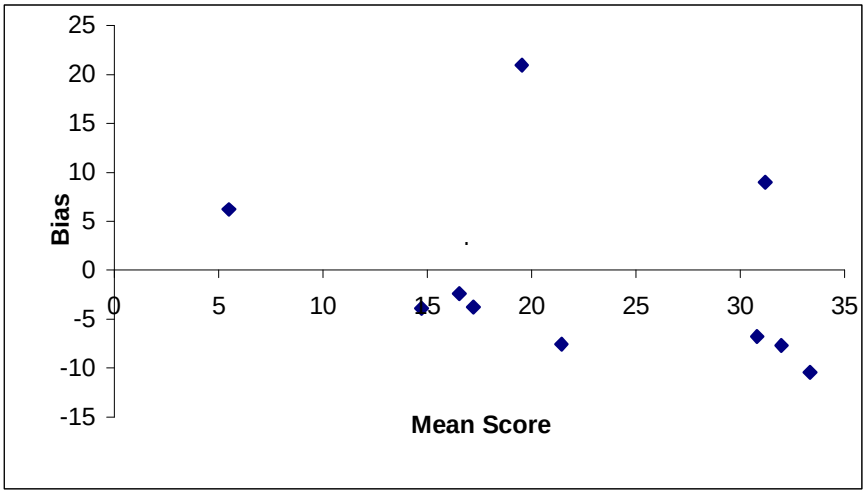


Figure 4: Variability in the social domain of the PASE questionnaire

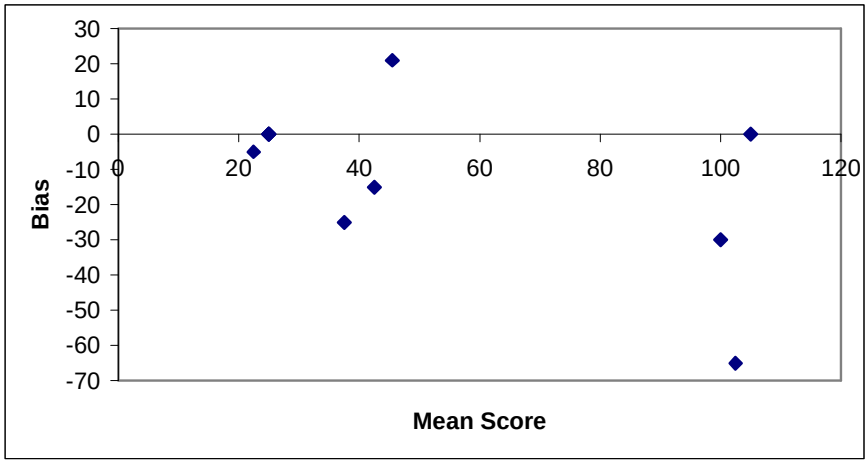


Figure 5: Variability in the Home domain of the PASE questionnaire

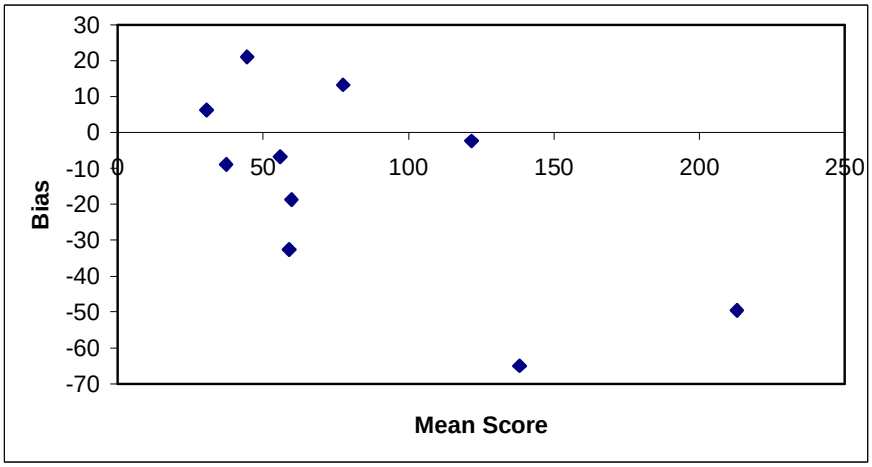


Figure 6: Variability of the total PASE scores.

It can be seen from the above graphs there is much variability within the total scores and whilst there is a tendency to a higher level of bias at higher scores, there was no significant correlation between absolute values of the bias scores and mean scores, and thus no hetroscedacity is present.

5.4 Discussion

This chapter aimed to establish the reliability of the PASE questionnaire, specifically before it was used throughout other studies within this thesis. The PASE questionnaire was found to be reliable and easy to administer. The ICCs were found to be good and there was no bias from test one to test two was found within the results.

This study found the PASE questionnaire to be highly feasible to use in this population the researcher who administered the questionnaire reported that it took less than five minutes to complete and individuals tolerated it well.

Reliability and validity of the PASE questionnaire has been previously established in healthy older adults and older adults with knee pain (Dinger et al., 2004b; Martin et al., 1999; Schuit et al., 1997; Washburn et al., 1993a). However, no previous studies have investigated the reliability of the three different domains used within the physical activity scale for the elderly (social, home and work).

The test - retest reliability coefficient for the total PASE score was 0.934 (95% CI=0.62-0.97), indicating a strong correlation between the two test scores. A correlation coefficient of 0.934 would be described as a very high correlation, according to Cohen (1998). This is slightly higher than the test - retest reliability of 0.75 (95% CI = 0.69-0.80) found by Washburn et al (1993b). To further assess reliability, mean differences were taken and compared. No significant difference was found between the means, which indicates the total

PASE score is reliable and stable.

There was no significant difference in the test means within the different domains and in the total score; therefore systematic bias within was negligible. The results for the PASE questionnaire were split into two sections: the total score reliability and the questionnaire domain reliability.

The PASE total score between time one and time two shows good correlations with a Cronbach's Alpha of 0.966 and an inter-item correlation of 0.934. The F-test within the ANOVA showed no significant difference between the scores. Total PASE score results in Table 7 indicate a slight increase in physical activity in the social activity domain at time point two. This may be associated with the observed decrease in home-time physical activity. If individuals were participating in increased social activity, it is possible this would decrease their home activity levels due to increased fatigue.

Figure 3 shows the lack of systematic bias and variance in this data. This is demonstrated by a high ICC of 0.89 and a bias of -1.6.

As previously mentioned, the PASE questionnaire is split into three domains: social, home and work. The mean ±sd score for the social domain at time one was 15.2 ±17.6, on the second assessment it was 16.6 ±11.7 and no significant difference was observed. These mean scores are lower than those reported by Washburn and Ficker (1999), who assessed physical activity in the elderly. Nine healthy individuals under the age of 70 and 11 healthy individuals over the age of 70 scored a mean ±sd of 29.6 ±22.9 and 33.1 ±23.7 respectively. The difference in score between Washburn's study and

the one presented in this chapter may be attributed to the diagnosis of multiple sclerosis in the individuals participating.

Bias within the social domain was reported to be -1.5, indicating relatively small systematic bias with no significant trend observed. There was a test retest correlation of 0.56 (95% CI=-0.057–0.871). No previous studies have reported test retest data of the separate domains.

The mean ±sd at time one and time two for the home domain of the PASE questionnaire are higher than those in the social domain, being 35.8 ±36.05 and 27.5 ±39.3 respectively. This indicates higher levels of physical activity in the home environment. Washburn and Ficker (1999) found the mean ±sd PASE score in the home domain in individuals below the age of 70 (n=9) to be 78.8 ± 41.5 and in those individuals over the age of 70 (n=11) the mean ±sd was reported to be 73.6 ± 45.6. This is substantially higher than the results reported in the presented study. However, it is interesting to note that in both studies the PASE score at home was higher than the PASE social score.

The higher scores reported in both domains, by Washburn and Ficker (1999), may be attributed to the sample of healthy individuals investigated. Healthy individuals have previously been reported to be more active than individuals with MS (Busse et al., 2006).

5.4.1 Limitations

The sample of individuals included in this study appeared to be very mobile. This may have affected the results and not given a true sample of those with MS as it is well known that individuals with MS range widely in their levels of mobility. However when considering the reported activity levels they were still inactive compared to elderly population.

Previous power calculations have revealed that a sample of 30 individuals would reveal a true indication, if the sample were significant. Within this study only 20 individuals were sampled. This was due to the time constraints of the study recruitment and the limited resources available.

5.5 Conclusion

This study demonstrates the reliability of the PASE questionnaire when measured over a three week period. The PASE appears to be a brief, easily scored, reliable and valid instrument for the assessment of physical activity in individuals with multiple sclerosis. People sampled in this study had generally low activity levels with most activity occurring in the home.

6 Mobility and physical activity levels in the community in individuals with multiple sclerosis

6.1 Introduction

Walking is a key component of many physical activities necessary for independent living (Guralnik et al., 2001) and serves as the most accessible form of exercise for many elderly and impaired individuals (Bijnen et al., 1998; Cavanaugh et al., 2007). Difficulty in walking is associated with neurological disease, and loss of mobility is an activity of daily living in which many individuals place the most value (Chiou and Burnett, 1985; Pearson et al., 2004b). Past studies (Motl et al., 2005b; Motl et al., 2006) have found individuals with multiple sclerosis (MS) to be more sedentary than the general population (McAuley et al., 2007), increasing their propensity for secondary disorders of inactivity and reducing their functional ability, mobility and participation in activities of daily living. Ng and Kent-Braun (1997), for example, examined the physical activity of individuals with MS versus sedentary and active controls using an accelerometer and self-report physical activity recall measures. Based on the accelerometer data, individuals with MS were less physically active than the group of sedentary controls. However, past studies including this one have not investigated individuals daily activity profiles by examining the domains in which individuals are active and for which period of time individuals are most active (Motl et al., 2005b; Motl et al., 2006). Activity domains were investigated throughout this chapter using the physical activity scale for the elderly (PASE) (Appendix 2). As previously

stated in Chapter 5, the PASE has been previously reported to be a valid and reliable questionnaire to use as a measure of physical activity (Dinger et al., 2004b).

Being physically active and maintaining a physically active lifestyle in the community is an important element of independent living for individuals with progressive neurological conditions. However, previous studies have shown that commonly there is a reduction of both community and household mobility with increasing age and decline in functional capacity (Geertzen, 2005; Davies, 2003). The issues affecting walking and mobility in the community are multifaceted, involving a range of social, emotional, physical and psychological factors.

The importance of a physically active lifestyle is well documented and the many associated health benefits in healthy individuals are well known (Department of Health, 2004). There is increasing evidence for the health benefits of a physically active lifestyle for individuals with MS (Dalgas, 2008; White and Dressendorfer, 2004) yet there are many studies suggesting that people with MS are not active enough (Busse et al., 2006) and are participating in less physical activity than healthy individuals.

Before an intervention is considered, it is important to note that there is very little previous research on which domain of daily life individuals with MS are most active, such as, in the home, in the workplace or during leisure/social time.

There is little research available that investigates the reasons why these

individuals are inactive. Previous studies have found (Becker and Stuifbergen, 2004; Rimmer and Rowland, 2008; Rimmer et al., 2004a) that the main barriers to participation include cost, difficulty in finding a means of transport to their fitness centre, lack of knowledge of where to go to exercise and no knowledge of how to exercise appropriately for their condition.

Individuals with neurological conditions are reported to be less mobile in the community (Busse et al., 2004). Busse et al (2006) investigated community walking activity in healthy individuals and those with neurological conditions using a step activity monitor and found that physical activity levels are lower in individuals with neurological disorders.

Whilst investigating how active individuals with MS are, it was of interest not only to observe how many steps were taken over the course of eight days, but to more fully describe physical activity. To do this, the frequency, intensity and duration of their steps taken were further investigated.

It was of particular interest to further investigate these factors, as it has been previously reported that when walking at a self-selected walking speed, individuals utilise 40% of their VO_2 max (Kinsman, 1975), therefore making walking at a self-selected speed an aerobically efficient activity.

Several studies have previously shown that gait initiation takes approximately three steps until steady state walking speed is reached (Bishop et al., 2006;, Hase, 1998; Sparrow, 2005; Stein, 1999).

If walking at a self-selected walking speed for long enough then there will be

health benefits associated with walking at this intensity, this is why it is increasingly important to investigate the intensity at which these individuals are walking in their day to day life.

6.1.1 Purpose of study

This chapter aims to take a 'snapshot' of individuals' community mobility and, by using step counts, determine how active individuals within this population actually are in their daily lives, as well as investigating in which domains of daily life individuals are more active.

6.1.2 Research questions

How many steps do individuals with MS take per day over a seven-day period, as measured by the step activity monitor (SAM)?

How active do individuals report to be as measured by the self-report PASE questionnaire?

Is there a relationship between these two (SAM and PASE) measures of physical activity?

How active are these individuals in different domains of their daily lives (home, work and leisure) as described by the PASE questionnaire?

How many minutes per week do individuals walk at an intensity high enough to elicit an aerobic treatment effect?

6.2 Methods

6.2.1 Participants

Patient-identifiable data was used to record baseline pathology and suitability for the study, but any details were recorded on assessment sheets that were coded for the study and therefore not identifiable.

6.2.2 Subject recruitment

Consultant neurologists in the Oxfordshire area identified suitable individuals and those who met the inclusion/exclusion criteria received an invitation letter containing information regarding the study. Individuals who returned the reply slip were asked to give their phone number and to indicate an appropriate time that they might be contacted by a researcher by phone. The researcher then contacted individuals to confirm that they were suitable to participate and this provided participants with the opportunity to ask any questions before giving consent. At this time it was made clear that individuals would be free to leave the study at any time without reason and that their decision to participate or not participate would not affect their normal care in any way. An appointment was given at the physiotherapy gym and written informed consent obtained at the first assessment. The individuals were given a letter containing the study information and were given an opportunity to ask questions before giving consent.

The first assessment session was arranged and on arrival the consent form was signed in the presence of the researcher and a witnessing member of

staff at the Oxford Centre for Enablement.

Informed Consent

All individuals that read the information sheet and indicated to researchers that they wished to take part were invited to attend the Oxford Centre for Enablement for the study. On arrival at their first assessment ample opportunity to ask questions was given. The named researchers read through the consent form with participants and made sure they understood what the research involved. Participants were informed that they were free to withdraw at any stage of the study, without any detriment to their usual medical care, and that no reason for withdrawal from the study was required.

Consent was recorded by a signature on the two copies of the study consent form. The original was retained by the patient and the other copy was held on file in a locked cabinet by the lead researcher.

Sponsorship and Ethical Approval

Oxford Brookes University acted as research sponsor for this study, under the terms of the Department of Health's Research Governance Framework. Ethical approval of this study was granted by Oxfordshire Research Ethics Committee (05/Q1605/95).

Inclusion Criteria:

Individuals were aged between 18 and 70 years old.

Individuals had a confirmed diagnosis of multiple sclerosis.

Individuals had no known psychiatric disorders as determined by the referring consultant.

Exclusion Criteria:

Unable to meet the inclusion criteria, or those unwilling or an inability to undertake the programme.

6.2.3 Procedure

Testing was conducted in a physiotherapy gymnasium, due to the availability of space, portability of equipment and safety. On arrival, the planned testing procedure was explained to individuals who were then invited to give informed consent (as detailed above).

After participants had given consent the assessment commenced with the questionnaires (see 6.2.4). Once the questionnaires had been thoroughly completed by the participant, the step activity monitor was provided and instructions for use were discussed by the researcher (please refer to section 3.6 for further details on the SAM). An instruction sheet was also provided with the researcher's contact details, should the participant wish to ask any further questions (Appendix 6).

The participant then completed a two-minute walk (please refer to section 3.5 for further detail on the two-minute walk) round a 10-metre track in the physiotherapy gymnasium. Below is an image of the actual walkway used; the red cones were used as markers as to where the individual needed to turn. If individuals didn't reach the end of the track when two minutes was finished then the researcher would measure the distance from the end of the track to where they stopped after two minutes and therefore be able to calculate the actual distance walked.

After the two-minute walk, the assessment was complete.

6.2.4 Measures

The following baseline measures were obtained from all individuals during their assessment: gender, age, (American College of Sports Medicine, 2002), together with anthropometrical data - height (m), weight (kg) and leg length (anterior superior iliac crest to medial malleolus, in cms).

Presenting pathology and past medical history were acquired and the following information obtained using standard questionnaires and tests:

Questionnaires

Within this study four questionnaires were used, these included:

The rivermead mobility index (standard version, 0-15) (Collen, 1991) was used to assess individuals mobility.

Barthel Index (standard 0-20 version) (Mahoney and Barthel, 1965) was used to assess individuals activities of daily living.

Fatigue: The fatigue severity scale (modified version, 0-6) (LaRocca et al., 1989).

Physical activity: physical activity scale for the elderly (0-400) (Washburn et al., 1993b). A detailed description and methods of application has been detailed previously in Chapter 3.

Walking measures

Step activity monitor: counts made over an eight-day period, the SAM being worn just above the right lateral malleolus (Crouter et al., 2003; Cyarto et al., 2004; Shepherd et al., 1999). During the initial configuration of the Stepwatch Activity Monitor, the software calibrates the Monitor automatically, no manual calibration was necessary.

Endurance: 2-minute walk (see Chapter 3 for method) (Rossier and Wade, 2001).

6.2.5 Analysis

Step Activity Monitor measures

Sustained activity - Max 1, 5, 20 and 30

Each of the 'sustained activity' measures referred to – Max 1, 5, 20, and 30 – is derived by scanning a specified time of a day with a 'window' of the designated width (1, 5, 20, or 30 minutes) and extracting the maximum number of steps achieved at any continuous interval of that duration. That maximum is then divided by the duration of the interval to give the average steps per minute of that best performance.

For example, for the 60-minute sustained activity calculation, the steps between 12:00 midnight and 1:00 AM are summed. Then the steps between 12:01 midnight and 1:01 AM are summed. That process is continued for the entire day (or entire included time), and the maximum sum is divided by 60 to

give the 60-minute score for the day.

Total step count

Two sets of results are reported for the total step counts. The total steps (right) count is the total number of steps taken as reported by the SAM software, this represents the total steps taken with the right leg, as this is where the SAM is worn. To observe actual total step counts, total right step counts must be doubled

One-minute, 30-second and 15-second activity counts

The two-minute step count was taken for each individual, as measured by a manual tally counter, and was divided by two to give the number of steps walked in one minute.

The sustained activity counts given obtained by the step activity monitor software are described above. These counts reflect the number of one-minute periods in which the individual was walking continuously. However, an alternative method has been employed within this study when reporting the activity counts in Table 11.

The one-minute, 30-second and 15-second sustained activity counts reported in Table 11 were calculated as described above. However, instead of scanning the raw data in Excel for the maximum number of steps taken in those time periods (1, 5, 20, 30 minutes, as described above), the two-minute step counts taken from the two-minute walk at the baseline assessment was used to investigate whether individuals were walking at their self-selected

walking speed.

The one-minute step count was calculated by dividing the two-minute step count by two, it was then used to determine the 30-second step count (one minute step count divided by two) and the 15-second step count (one minute step count divided by four). The raw SAM data was then scanned using these step counts to determine how often individuals walked at their SSWS for a sustained period of one minute, 30 seconds and 15 seconds.

Descriptive statistics

Descriptive statistics were calculated for demographic characteristics and for components of the PASE questionnaires and SAMs.

To investigate the relationship between PASE scores and mean seven-day step counts, as measured by SAMs, scatterplots were produced and correlations calculated using Spearman's rank correlation coefficient (r) for all normally distributed variables. The descriptors of the correlation coefficient given by Munro (1993) were used for analysis (i.e. 0.00-0.025: little, if any; 0.26-0.49: low; 0.50-0.69: moderate; 0.70-0.89: high and 0.90-1.00: very high). 95% confidence intervals were calculated around the correlation coefficients using the method described by Munro (1993).

6.3 Results

Table 9: Descriptive data for all participants.

All data reported as: mean ±sd	Age (Years)	Height (Metres)	Weight (Kilograms)	2-minute walk * (m)	Barthel Index (0-20)	Rivermead Mobility Index (0-15)	RBANS (%)
Male n=6	55.3 ±6.2	1.77 ±0.6	78.7 ±7	48.2 ±33.5	16.1 ±3	8.7 ±4.3	15.8 ±15.7
Female n=17	55.1 ±8.5	1.63 ±0.07	68.3 ±10.8	53 ±22.5	17.2 ±3.9	10.2 ±3.8	23.4 ±21
All n=23	55.2 ±7.8	1.67 ±0.1	71.3 ±10.8	51.7 ±24.7	16.9 ±3	9.8 ±4	21.2 ±20

- RBANS - Repeatable Battery for the Assessment of Neuropsychological Status.
- * - 6 individuals were not able to walk, so not included in this result.

Mean ±sd - standard deviation.

Table 10 (hereafter) shows the mean total daily step count to be 1435 ± 141.3, with 900.3 ± 749.5 of these were reported to be low activity steps, 460.2 ± 614.5 were reported as medium activity steps and 73.8 ± 190.1 were high activity steps. A substantial proportion of these individuals' steps are thus taken at low intensity.

6.3.1 Physical activity within the community as reported by the SAM

Table 10: Step counts as reported by the step activity monitor.

Subject	Step count (right)	Total steps	Steps low	Steps medium	Steps high	Max 60	Max 20	Max 5	Max 1
1	944	1888	926	17	0	2.9	4.9	7.6	15
2	30	60	30	0	0	0.3	0.6	1.5	3.4
3	3772	7544	1980	1017	774	14.8	23.4	40	50.4
4	3305	6610	1609	1430	265	11.2	17.4	34.2	45.6
5	1702	3404	1341	356	5	4.9	8	14.5	27.8
6	2543	5086	1503	1024	15	10.9	15.3	24.3	38.5
7	1219	2438	847	371	0	5.1	8.2	13.6	26.8
8	1095	2190	815	268	11	3.8	6.2	15.1	30.5
9	2233	4466	1403	625	204	10	15.6	27.3	34.9
10	235	470	235	0	0	1	2.1	4.4	8.9
11	3145	6290	2158	965	22	8	11.6	20	36.1
12	215	430	187	28	0	1.4	2.8	6.3	12.2
13	4193	8386	2074	2108	10	12.1	18.2	28.5	37
14	181	362	171	10	0	1.2	3	8.9	14.6
15	82	164	82	0	0	0.4	0.8	1.6	5.1
16	292	584	227	40	24	1.9	4.5	11.6	16.8
17	185	370	170	14	0	1	2	4.8	12
18	459	918	448	10	0	1.6	2.9	7.1	12.4
19	2821	5622	1765	1056	0	10	15	20.3	31.7
20	2911	5822	1444	863	603	14.2	24.7	41.1	54.5
21	152	304	144	7	0	1.1	1.8	4	9.1
22	264	528	260	3	0	1.1	2.1	5.3	14
Mean	1453	2906	900.86	464	87.86	5.4	8.6	15.5	24.4
± sd	± 1398	± 2731	± 742	± 591.7	± 207.7	± 4.9	± 7.6	± 12.3	± 15.1

- Step count (right) - Step counts reported by SAM software, right leg steps only.
- Total steps - Right step count doubled to give total steps taken.
- Steps low - Count refers to total steps accumulated during the time included for analysis at step counts between and inclusive of 1 and 15 steps per minute.
- Steps medium - Count refers to total steps accumulated during the time included for analysis at step counts between and inclusive of 16 steps per minute and 40 steps per minute.
- Steps high - Count refers to the total steps accumulated during the time included for analysis at step counts greater than 41 steps per minute.
- Max 60, 20, 5 and 1 - Each of these measures is derived by scanning the included time of a day with a ‘window’ of the designated width (1, 5, 20, 30 or 60 minutes) and extracting the maximum number of steps achieved at any continuous interval of that duration. That maximum is then divided by the duration of the interval to give the average steps per minute of that best performance.

Table 11: Sustained activity counts at 1 minute, 30 seconds and 15 seconds

Subject	2-minute step count	1-minute step count	Sustained activity count		
			1 min.	30 sec.	15 sec.
1	86	43	0	0	26
2	49	24	0	0	0
3	218	109	0	70	182
4	203	101	0	0	199
5	130	65	0	4	148
6	192	96	0	0	132
7	192	66	0	2	112
8	191	95.5	0	0	40
9	150	75	0	40	175
10	149	74.5	0	6	1154
11	159	79.5	0	11	436
12	129	64.5	0	0	3
13	53	26.5	0	8	24
14	127	63.5	0	0	0
15	162	81	0	0	64
16	230	115	0	11	145
Mean	151.25	73.68	0	9.5	177.5
±sd	±54.35	±26.73	0	±19	±282.9

- 2-minute step count - Measured using a manual tally counter during the 2-minute walk.
- 1-minute step count – 2-minute step count / 2.
- Sustained activity count: Mean number of minutes spent taking 1-minute steps divided by the time scale.
- 30 sec.: 1-minute step count / 2 to give mean steps taken in 30 seconds at self-selected walk speed. Raw data then analysed to give the number of 30-second periods per week that individuals walked for a sustained period at their 30-second step count.
- 15 sec.: 30-second step count / 2 to give mean steps taken in 15 seconds at self-selected walk speed. Raw data then analysed to give the number of minutes per week that individuals walked for a sustained period at their 15-second step count

Table 11 shows the mean number of times individuals walked for the specified time periods (one minute, 30 second and 15 seconds) at their self-selected walk speed cadence each week. Individuals wore the SAM for seven days. Interestingly, over the seven -day period none of the individuals walked at the self-selected walking speed that had previously been measured using step counts in the baseline assessment. Individuals walked for (mean ±sd) 9.5 ±19

minutes over a seven-day period at their 30-second self-selected walking speed. However, over the course of seven days, individuals spent (mean ±sd) 177.5 ±282.9 minutes where walking activity was sustained to the 15-second step count, and (mean ±sd) 9.5 ±19 minutes where walking activity was sustained to the 30-second step count.

6.3.2 Activity reported by the Physical Activity Scale for the Elderly

Table 12: Displays the physical activity scale for the elderly index scores for all participants.

Gender		Social	Home	Work	PASE Total*
Male	n=6	20 ±15.8	44.17 ±40.3	0±0	66.93±54.13
Median		14.54	52.5	0	71.43
Female	n=16	24.62±18.4	44.06±35.4	5±19.36	70.69±50.37
Median		24.03	25	0	52.41
All	n=23	22.06±16.9	42.3±35.8	3.75±16.7	69.6±50.11
Median		17.74	25	0	53.06

- *Total PASE score is calculated out of 400
- mean±sd

Table 12 demonstrates that women show a trend of higher activity in the social and work domain but the differences in PASE scores between males and females are not significant.

6.3.3 Relationship between the two measures of physical activity

Table 13: Spearman's rank correlation coefficients between PASE scores and mean total step count.

	Leisure	Home	Work	Total PASE score
Mean total step count	0.428	0.565 *	0.26	0.569 *

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

Correlation coefficients established using Spearman's rank. Correlations between the PASE questionnaire scores and the mean weekly total step counts taken from the SAMs are shown in Table 13. There is a significant correlation between the total PASE score and the mean total step count as measured by the SAM. A significant correlation was also found between mean total step count and the home activity component of the PASE questionnaire.

Figures 7, 8, and 9: SAM mean seven-day step counts and PASE scores,

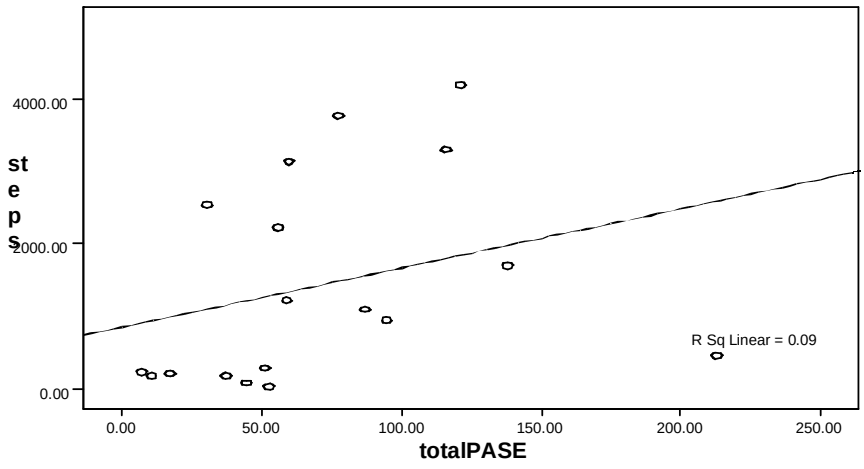


Figure 7

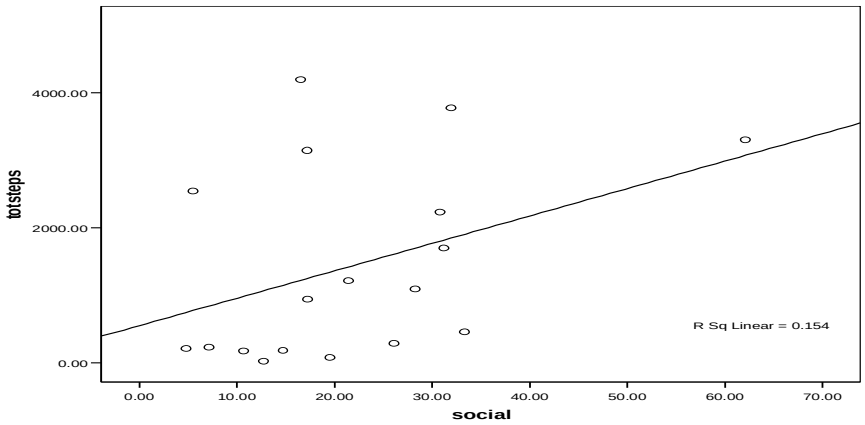


Figure 8

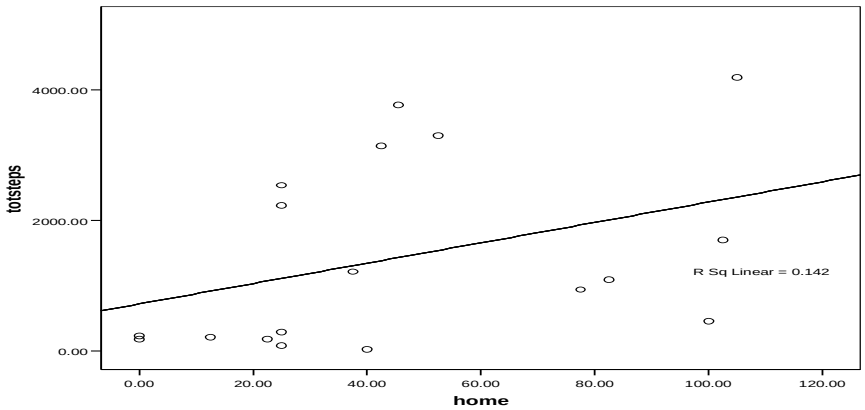


Figure 9

Figures 7, 8 and 9: n=18. Spearman's correlation coefficients, 7 r=0.569; 8 r=0.428; 9 r=0.565

Scatterplots of PASE scores are presented in Figures 7, 8 and 9. The total PASE score (r=0.569, p=0.05) and the home (r=0.565, p=0.05) subscale were significantly correlated with the mean seven-day step counts from the step activity monitor. The correlation coefficients between the mean seven-day step counts and the leisure subscale scores (r=0.428) and the work subscale (r= 0.26) were low. The work subscale was not presented graphically as 16 individuals did not engage in any work related activity.

6.4 Discussion

This chapter has shown that this sample of individuals with multiple sclerosis were less mobile than elderly and healthy populations, as have been previously reported in the literature (Pearson et al., 2004a). This was demonstrated by the results of the PASE questionnaire. In this study the mean ±sd of the total PASE score was reported to be 69.6 ±50.11. This score is substantially lower than previous studies have reported. Chad et al (2005) investigated physical activity levels in a sample of community-dwelling older adults. They found the mean ±sd PASE total score in males aged 50-64 to be 154.3 ±80.4 and 137.9 ±76.7 in females in the same age group. These scores are substantially lower than those reported in the study in this chapter, this may be attributed to the effect of MS on these individuals. These findings indicate that this sample of individuals with MS are inactive.

Individuals with MS took significantly fewer steps per day, as measured by the SAM, and their mean weekly step count was less than past literature suggests (Busse et al., 2004; Busse et al., 2006). Findings from the PASE questionnaire suggest that individuals were more active in their home environment compared with during their social or work time (as described by the social and work domain of the PASE questionnaire). This has several implications; this finding may be used to further direct the future exercise interventions, and showing the importance of considering a specific domain to target in an intervention.

Additionally, this study has investigated the frequency, intensity and duration

of physical activity that these individuals effectively participated in. It has become increasingly clear that the amount of physical activity that individuals participate in is not the only factor that contribute to increased wellbeing and health, intensity of physical activity is important and if individuals are not participating in physical activity at a high enough intensity then the health benefits will be minimal.

It can be seen from the results in Table 11 that over the period of seven days individuals did not walk for a continuous minute at their SSWS. They walked for 30 seconds at their SSWS a mean ±sd 9.5 ±19 times and walked for 15 seconds at their SSWS a mean ±sd 177.5 ±283 times. This indicates that sustaining their SSWS is difficult for longer than 15-second bursts. This has important implications for future training interventions and could perhaps help to determine the amount of time that individuals could effectively train. For example if it is found, as it has been in this study, that individuals can only maintain effective training for periods of 15 seconds then it would be of interest to develop a training protocol or intervention that takes this into consideration. No previous study has investigated physical activity using this method.

In a community-based cross-sectional pilot study, Cavanaugh et al (2007) reported surprising findings in 30 healthy younger adults, 28 healthy older adults, and 12 older adults reporting functional limitations and chronic illness. It was found that healthy older adults on average engaged in fewer daily activity bouts – the number of one-minute intervals where the step count is greater than 0 – (p=0.03) and displayed less-variable minute-to-minute activity

(p=0.02) than healthy younger adults. No significant differences were reported between healthy younger and healthy older adults for the number of daily steps (11074 ±534 and 9981 ±552 respectively), or minutes of activity (399 ±17.4 and 355 ±18.1 respectively). Older adults reporting functional limitations accumulated fewer daily steps, 7681 ±884 steps, (p=0.003), fewer daily minutes of activity 298 ±27.6 minutes, (p=0.008), fewer bouts of activity (p=0.009), and less-variable activity (p<0.001) than healthy younger adults. Their sample of older adults reporting functional limitations displayed no significant differences from healthy older adults for any ambulatory activity parameter. It should be noted that the sample of individuals used were spread over three different states of the USA, the study took place over the space of three years and the data was collected from three separate investigations of ambulatory activity. However, the authors did not discuss any issues of inter-rater reliability and the standardisation of the testing methods and protocol used. These results are interesting when considered in relation with the results presented within this study and those presented by Busse et al (2004), as the results found in this chapter are substantially lower than those of Busse et al (2004).

Busse et al (2004) assessed the use of activity monitoring in both 30 healthy individuals (age, mean ±sd; 51.3 ±17.9) and 30 individuals with neurological conditions. These conditions included 10 subjects with multiple sclerosis, 10 Parkinson's disease and 10 primary muscle disease sufferers (age, mean ±sd: 52.4 ±15.7), reporting the mean step count for seven days to be 2985, 3818, and 3003 respectively. The study presented in this chapter found that

the mean seven-day step count for individuals with MS was 1435 steps, which is substantially lower than both healthy subjects and individuals with MS in previous studies. This indicates that individuals with MS are less active than had previously been reported.

The SAM software reports peak and sustained activity indices. These allow for objective assessment for the pattern and intensity of activity in all subjects, with a valuable potential for assessment of outcome following intervention. Busse et al (2004) found that individuals with neurological conditions had more variable and lower mean peak activity measures (36 ±11 steps/min). This was consistent with the reported findings in this chapter (14.2 ±11.3 steps/min), but the mean peak activity index in the study presented in this chapter does appear to be substantially lower than that of Busse et al. Busse et al (2004) investigated the sustained activity for individuals with MS by looking at the 20-, 30- and 60-minute sustained activity counts and reported them to be 26 ±10, 22 ±9 and 17 ±8 respectively. These values are higher than those observed in this study reported in Table 10, which were observed to be 8.2 ±7, 6.8 ±6 and 5 ±4 respectively. (see 6.2.5 for description of sustained activity measure) This difference in result may be attributed to the sample used in this study being less mobile. However, this study further demonstrates that individuals with MS are less mobile than healthy individuals.

This chapter reported the mean ± sd RMI to be 9.8 ±4 in this sample, which is slightly higher than previous studies have reported (Busse et al., 2004)

Previous studies have reported that individuals with MS suffer from fatigue (Chaudhuri and Behan, 2004; Dittner et al., 2004; Krupp, 2003). This combined with the lack of mobility observed in these individuals may indicate that it is unlikely that these individuals walk continuously for 20 to 60 minutes very often. It therefore seemed apt to investigate lesser time periods of sustained activity. The SAM provides information on one minute of sustained activity. In the presented study, the one-minute sustained activity count was observed to be 23.7 ±14.7. As many of the individuals included in this study were immobile, it was of interest to further investigate this by looking at how often individuals walked at their self-selected walking speed for shorter time periods (i.e. 30 seconds, 15 seconds). It is important to note that the one-minute sustained activity count that is provided through the SAM software is a count of how many minutes individuals are walking for one-minute periods continuously, irrespective of how many steps were taken. In Table 11 activity counts for one minute, 30 seconds and 15 seconds are presented. These counts were determined using a different method to that employed by the SAM software (a description of this analysis method is given in section 6.2.5).

The mean ± sd sustained activity count for 30 seconds was observed to be 9.5 ±19 minutes and the mean ± sd 15-second activity count was 177.5 ±282.9

This means that (mean) 9.5 times over the course of a week individuals walked at their self-selected walking speed pace for 30 second time periods, and (mean) 177.5 times individuals walked at their SSWS for a period of 15 seconds. This gives us the frequency and duration of these individuals'

walking bouts, however, at no time during the week did any of the participants walk for a full minute at their self-selected walking speed. This indicates that the duration of effective walking is something that could be improved in future interventions. These findings indicate that these individuals perhaps find walking for a minute at their SSWS too strenuous and 15-second intervals seem easier to maintain. This is an exceptional finding - it demonstrates that these individuals are extremely sedentary in terms of the intensity of their walking / physical activity. These findings indicate that these individuals are not really walking at an intensity that will elicit any kind of aerobic training effect, this is concerning and has huge implications regarding health and wellbeing. The Department of Health recommend that individuals should participate in 30 minutes of exercise at least 5 times a week at a "moderate" intensity, that being an intensity that would result in one being slightly out of breath (Department of Health, 2004).

This is an important finding as this may have implications for future interventions.

Fatigue and related impairments may limit neurological patients by restricting the actual number of steps that they are able to maintain for an extended period of time. Whilst it can been seen that activity levels are lower in patients than among healthy individuals, in both the presented study and that of Busse et al (2004) the overall consistency of sustained activity levels might indicate a reduced ability to vary activity level owing to a wide range of neurological and physical impairments.

Within this study the PASE questionnaire was used in conjunction with the SAM to further investigate community mobility, by examining the different domains into which daily activity falls. Findings from the PASE questionnaire suggest that individuals are more active in their home environment as opposed to their social time period. The relationship between the number of steps taken daily and the PASE questionnaire is an interesting one, with individuals who take more steps daily having an increased PASE score.

The increased physical activity demonstrated in the workplace is likely to be due to the lack of individuals that reported engaging in work activity (only seven individuals reported working). The total PASE score is the score that is reported to represent the physical activity of individuals with MS.

The validity of the PASE questionnaire has previously been reported by Dinger et al (2004b) who found the mean PASE total score to be 115.7 ±59.9, which was observed in a population of 56 healthy participants with a mean age of 75 years. These results are not comparable with the results presented in this study, in which the mean PASE score was reported to be 69.6 ±50.11 where the mean age was 55.2 years. This score is substantially lower than that of the healthy individuals, demonstrating the difference in physical activity levels between those individuals with MS and those who are healthy. Healthy individuals appear to be more active than individuals with MS.

When using the PASE to assess the physical activity of individuals with MS, the leisure, home and work subscale PASE scores are summed to obtain the total PASE score. Investigating these separate domains of the PASE enables

further insight into where individuals are more active and provides a focus when designing a future intervention for targeting the areas within their daily lives that could benefit from increased physical activity.

Mean PASE scores within the different domains have been previously reported in only a few studies (Washburn and Ficker, 1999). Although Busse et al (2004) demonstrate clearly that ambulatory monitoring provides a reliable and valid measure of physical activity levels in daily life, the study reported in this chapter further investigates the domains in which individuals are more active using the PASE. Determining in which domain of daily life individuals are more active is an important tool, which could influence the direction of future interventions.

From findings presented in this chapter we can see that both men and women are more active in the home environment, with a mean score of 42.3. This is almost double the mean score of 22.06 achieved in the social domain. Scores achieved in the work domain are exceptionally low, which could be attributed to the fact that only seven of all participants included in the study were still working.

The physical activities required for the maintenance of one's home, such as housework, home repairs, and lawn care, would contribute to a higher PASE score, which was observed in this group. Lower physical activity levels have previously been observed in those who utilise domestic services such as housecleaning and meal preparation. This further supports the hypothesis that household tasks contribute significantly to increased physical activity levels in

older adults, regardless of age. Previous studies have shown that a significant proportion of physical activities undertaken by older adults are in the form of household-related activities (Washburn et al., 1999).

Although the PASE scores provide an assessment of physical activity levels in older adults, it is important to recognize the nature of activities contributing to the PASE scores (i.e., providing care for someone else, housework, and home repairs). Although the ability to perform activities of daily living is an important component for maintaining functional independence, these types of day-to-day activities may be insufficient to achieve health benefits as suggested by Health Canada (Health Canada, 1998) and the U.S. Surgeon General (Centre for Disease Control., 1999).

There was a statistically significant association between the seven-day mean step count and total PASE score (r=0.569) and the home subscale score (r=0.565) (Table 13). Although these correlation coefficients are modest, they are similar to those previously reported in the literature. Previous studies have reported correlation coefficients that range from 0.13 to 0.43 between total PASE scores and various indirect measures of physical activity, such as walk tests and knee strength (Martin et al., 1999; Washburn, 2002; Washburn et al., 1999). Studies that have used direct measures of physical activity, such as accelerometers, to assess the validity of the PASE have reported slightly higher significant correlation coefficients (0.43 - 0.58), (Schuit et al., 1997; Washburn and Ficker, 1999). Dinger et al (2004b) investigated the relationship between the Actigraph step monitor and the PASE questionnaire in 56 adults (age ±sd; 75.7 ±7.9) living independently in a rural setting. This

study found a statistically significant correlation of 0.43 ($p<0.01$) between Actigraph mean counts.minute^{-1} and total PASE scores. Although these are interesting findings, the Actigraph was not worn for 24 hours a day during the seven-day period, which may have affected the findings as many individuals are active throughout the night-time period. Interestingly Dinger et al (2004b) investigated the relationship between the questionnaire domains and the Actigraph counts.minute^{-1} and found the home subscale accounted for 65% of the total PASE score. Furthermore, they found the majority of their subjects participated in little, if any, leisure or occupational activity, which further supports the further development of an intervention based in the community.

Individuals appear to be more active in their home environment. This has previously been reported by Ficker and Washburn (1999), who reported PASE home scores of 78.8 $\pm$ 41.5 in individuals <70 years of age (n=9), and 73.6 $\pm$ 45.6 in individuals >70 years of age (n=11). Ficker and Washburn (1999) used an experimental design to examine the correlational-mean activity level over a three-day period to determine whether it was correlated with PASE scores. Physical activity was monitored over three days during normal daily activity in twenty healthy adult volunteers, 67-80 years of age. Physical activity from 09:00 to 21:00 hours was assessed over three consecutive weekdays (Wednesday-Friday) using a Computer Science and Applications Inc. (CSA) portable accelerometer. Following completion of the three-day monitoring period, physical activity was assessed with the PASE. PASE scores were significantly correlated with average three-day CSA readings ($r=0.49$, $p<0.05$) in the total sample and in those aged over 70 years

(r=0.64, p<0.5). However, a recent study conducted by Hale et al (2008) has found that monitoring activity for a three-day period with an accelerometer does not provide an adequate amount of data to give a true reflection of an average day's activity and results indicated that collecting data for three days was not reflective of data collected over seven days (Hale et al., 2008).

Within this study the convergent validity of the PASE questionnaire was assessed in relation to the SAM step counts, and also monitoring how the two measures of mobility related to one another.

The PASE results indicate that individuals appear to be most active within the household. Housework, gardening and daily home life routines are activities that usually follow a regular weekly schedule, while leisure time activity may be a little more random in nature.

The purpose of this chapter was to investigate actual physical activity levels in individuals with MS. However, the problem of increasing physical activity is complex and requires a multi-factorial solution.

6.4.1 Limitations

There are important findings in this study that must be considered alongside its limitations. The participants in this study were volunteers; therefore the findings should be interpreted cautiously, as the sample may not be representative of all individuals with MS. This study was limited by the relatively small sample size and owing to the nature of the disease, the sample was female-biased.

Although there was no inclusion criteria specifying how mobile individuals needed to be to participate, the sample within this study tended to be ambulatory. This may be due to recruitment bias, as it is less likely that more sedentary individuals would have been inclined to participate. Participant filtering by the recruiting neurologists is also a potential limitation of this study. Although the sample of individuals included in this study was relatively mobile the issue of wheelchair use and its relationship to overall mobility in more disabled individuals is clearly an area that requires further study. Within this study there were few wheelchair-dependent individuals. It should be noted that as there were few wheelchair-bound participants. This may have affected the results, as it may not be reflective of a true sample of MS.

The measurement of walking activity within this study directly assessed the 'real life' behaviour of individuals in the community. By measuring this we take into consideration the disease-related reasons that may alter an individual's physical activity in the community. But we must also consider external factors such as weather and the suitability of the external environment for walking, as these too may influence the walking activity of individuals (Brownson et al., 2004; Owen et al., 2004).

A common symptom of MS is fatigue, and this was taken into consideration when planning the assessments. Time was taken to ensure the research assessments were as short as possible, minimising the discomfort involved.

A limitation that should be considered for the PASE questionnaire is the 'work' domain. Sixteen participants in this study did not participate in work-related

activity owing to reasons relating to their condition. It must be anticipated that this may have affected the total PASE scores.

Although the PASE questionnaire has been previously established as a reliable tool, the separate domains that make up the questionnaire (social, home and work) have not been individually validated. Previous studies have documented problems with self-report measures such as questionnaires that involve memory recall. However observation of individuals' activity levels over a seven-day period is both impractical and unethical (Welk, 2002).

There are many methodological issues related to using ambulatory monitoring. The compliance of the subject being monitored (for example removing and remembering to put the monitor on) and the possibility of measurement reactivity are both relevant to data interpretation. There is potential for missed step counts or excessive step counts, although the device sensitivity settings mean different styles of gait can be accommodated for. There might also be problems with stair climbing and small steps covering little distance, although preliminary studies have found 96.2% accuracy during stair ascent and descent (Coleman et al., 1999).

In this chapter, the two-minute step count is used as a measure of self-selected walk speed. The step count was taken using a manual tally counter during the two-minute walk conducted as part of the baseline assessment. This has been considered an unreliable method of counting steps in previous studies. However, to eliminate inter-rater reliability only one researcher was responsible for manually counting the steps taken during the two-minute walk.

Previous studies have discussed a possible limitation of the two-minute walk as being the pressure participants feel to walk at an un-natural speed (Nederhof, 2006), perhaps mistaking the intention of the test or believing the researcher is looking for a different result. This is termed ‘social desirability bias’. It was addressed in this study by discussing the purpose of the test with participants and making it clear that walking ‘at a comfortable, natural walking speed for two minutes’ was all that was required. This enabled the use of the two-minute step count as the self-selected walk speed.

6.5 Conclusion

This chapter aimed to further explore actual physical activity levels and community mobility in individuals with multiple sclerosis using a step activity monitor and the physical activity scale for the elderly questionnaire.

Within this chapter it was observed that individuals with MS are less active than healthy individuals and elderly individuals. By using the PASE to observe the domains in which individuals are active within their daily lives, it is of interest to note that individuals with MS are more active in their home environments than in their social and leisure time. This chapter has demonstrated that when these individuals are active at a high enough intensity to elicit an aerobic effect, by walking for a continuous period at their self-selected walking speed, it tends to be in bursts of 15 seconds. Therefore, it is important to ensure there is an aerobic and anaerobic element to any future intervention or fitness programme.

Although this chapter has investigated physical activity levels, what remains unclear is the reasons as to why individuals may not be as active as they would like to be, and their thoughts and opinions regarding their physical activity levels. This topic is further investigated in the next chapter.

7 Perceived barriers and facilitators to physical activity in individuals with progressive neurological conditions (PNCs): a focus group and questionnaire study

7.1 Introduction

Therapeutic exercises, such as treadmill walking (Pohl et al., 2002a), muscle strengthening (Weiss et al., 2000b) and functional exercises (Duncan et al., 1998) have been shown to improve mobility in individuals with neurological conditions and can be delivered effectively in the home or the community with positive results (Ada et al., 2003b). In spite of the growing evidence that regular exercise may provide health and social benefits for people with neurological (Allen et al., 2004; Brennan Ramirez et al., 2006; Crizzle and Newhouse, 2006; Santiago and Coyle, 2004; Singh, 2002a) and neuromuscular disease (Singh, 2002a; van der Kooi et al., 2005b), few people participate. It is apparent that there are significant barriers to participation.

Literature review

Evidence from individuals with disabilities or long-term conditions suggests several factors that influence the perceptions of the individuals towards physical activity. Six barriers are most easily identified: 1) access to community leisure facilities is limited (Kersten et al., 2002; Rimmer et al., 2005); 2) there is a lack of disability awareness among fitness professionals;

3) poor knowledge among health professionals and disabled people of the benefits of exercise; 4) decreased self-efficacy and negative attitudes to exercise amongst patients; 5) symptoms of the health condition itself; and 6) a general lack of energy (Kosma et al., 2004; Rimmer et al., 2005).

The most significant barriers to exercise among healthy older adults were summed by Lees et al (2005a) to include fear of falling, inertia, negative affect and time constraints.

The findings presented here may not be applied to the UK setting for two main reasons, 1) the location of these studies are all based in the USA. 2) the studies presented have not considered long term neurological conditions. Two studies considered patients with physical disabilities, two studies used healthy older adults and only one study considered individuals with a diagnosis of MS. This makes it difficult to apply these barriers to UK settings and to individuals with long term neurological conditions.

Five studies (Finlayson and van Denend, 2003; Lees et al., 2005b; Putnam et al., 2003; Rimmer et al., 2004b; Rimmer, Rubin, and Braddock., 2000) used qualitative methods to thoroughly investigate physical activity and mobility in various populations.

Lees et al (2005b) considered barriers to exercise behaviour among healthy older adults. Sixty-six individuals took part in six focus groups at various community sites across Rhode Island, USA. Results identified 13 barriers to exercise behaviour, the most significant being fear of falling, inertia, negative affect, physical ailments and time constraints. They established that the

results would be useful in the development of exercise interventions for older adults. This study investigated the needs and barriers to healthy elderly adults and although the barriers for individuals with disabilities may be different there do appear to be many shared barriers.

The remaining four papers are perhaps a little more comparable to the study presented within this thesis, as they consider barriers and facilitators to physical activity in individuals with physical disabilities.

Rimmer et al (2000) investigated barriers to exercise in African American women with physical disabilities. Fifty individuals with severe disabilities were contacted and asked a series of questions via telephone interview. It was found the four major barriers to participation were: cost of attending an exercise programme, lack of energy, not knowing where to exercise and transportation. Interestingly it was reported in this study that barriers commonly reported in non-disabled individuals were not observed in this sample.

Rimmer et al (2004b), conducted another study using four focus group discussions to investigate the barriers and facilitators associated with participation in fitness and recreation programmes among individuals with physical disabilities. Analysis of the results revealed a number of barriers and facilitators, which were categorised into 10 themes, these were: 1) barriers and facilitators related to the built and natural environment; 2) economic issues; 3) emotional and psychological barriers; 4) equipment barriers; 5) barriers related to use and interpretation of guidelines; 6) information related

barriers; 7) professional knowledge, education and training issues; 8) perceptions and attitudes of persons who are not disabled, including professionals; 9) policies and procedures both at the facility and community level; and 10) availability of resources. This paper documents several important barriers. Interestingly of the four focus groups conducted, only one was conducted with individuals with disabilities, the others were conducted with individuals such as city planners and architects to discuss their thoughts on barriers to participation.

Finlayson and van Denend (2003) investigate the perspectives of older adults with MS. The article focuses on the loss of their mobility. Three factors were found to contribute to the participants' experience of mobility as a person with MS. These included: the reality of having MS, mobility needs and contextual factors such as the physical environment, the use of equipment, the availability of social supports and some personal factors. The findings from this study provide insight into the experience of mobility loss among older adults with MS, although this study does not specifically investigate the loss or amount of physical activity participation. The loss of mobility is a key factor that can in turn determine the amount of physical activity undertaken by these individuals.

In summary, qualitative methods, including the use of observation, field notes, interviews and focus groups, offer the best opportunity to gain an in-depth understanding of intra and inter-individual health needs. Whilst qualitative cohort data provides a description of health practices, detail regarding physical activity is not available. None of the studies above discussed actual

physical activity, only barriers or facilitators to participation. The nature of the research conducted does not allow for exploration of the issues discussed by the participants. Interestingly, in all of these studies there were four key barriers that were identified within all of the populations being investigated, these were: transportation issues, cost, not knowing where to go to receive supported exercise and perceived physical constraints.

Initial qualitative research highlights the details of the level, frequency and type of physical activity but it does not consider these details for individuals with neurological diseases.

In order to develop a physical activity support system for people living in the community with progressive neurological diseases, specifically MS, this study sets out to further investigate views and opinions on exercise, possible barriers to and specific facilitators for enabling participation in physical activity within community facilities such as leisure centres.

7.1.1 Rationale for study

Research surrounding barriers and facilitators to physical activity participation in individuals with PNCs is limited. The research that has been conducted considers individuals with a wide range of physical disabilities and does not take into account the added problems having a PNC may present.

Existing studies on neurological conditions and mobility issues have tended to use quantitative research approaches to describe the nature of mobility loss, and therapies and strategies for compensating for mobility loss (Lord et al.,

2002; Rodgers et al., 1999). While the broader literature encompassing disability studies provides some insights into the impact of mobility loss on people with chronic disabling conditions, there are no reports to-date that explore the experience of mobility loss and attitudes to physical activities in individuals with these conditions.

There are several methods of qualitative data collection that could have been employed, such as structured interviews, focus groups and questionnaires. In this study we chose to use focus groups and a questionnaire. Focus groups were used due to the ease of being able to gather a lot of detailed information in a relatively short period of time, then using a questionnaire enabled a larger cohort of individuals to be sampled.

Focus groups are a form of unstructured group interview between research participants and a group leader. They are a quick and convenient way to generate data, ideas and gain insight from several people simultaneously in order to pursue a topic in greater depth (Kitzinger, 1995). The uniqueness of a focus group is its ability to generate data based on the synergy of the group interaction (Rabiee, 2004). The members of the group should, therefore, feel comfortable with each other and engage in discussion. Krueger & Casey (2000) point out that for some individual's self-disclosure is natural and comfortable, while for others it requires trust and effort. It is for this reason that they recommend investing time and effort in selecting members of the group (Rabiee, 2004).

The use of focus groups rather than other more conventional data collection

techniques, such as one-to-one interviews, has several potential advantages. It can encourage contribution from those who feel they have nothing to say or feel intimidated by the formality of interviews, thus engaging these otherwise unresponsive participants in the discussion generated by other group members (Kitzinger, 1995; Rabiee, 2004). Such group dynamics may encourage the articulation of group norms at the expense of silencing individual voices and in this way it may be difficult to ascertain if a consensus is genuine (Kitzinger, 1995; Krueger., 2000). The ideal size of a focus group typically falls between 6 and 9 participants. Focus groups with more than 12 participants are not recommended for most situations as they can limit each person's opportunity to share insights and observations (Krueger, 2000; Stewart, 2007) indeed, much of the success of a focus group is dependent on the skills of the moderators. However, generally focus groups are an efficient, time-effective way of obtaining a vast amount of information in a relatively short amount of time.

Focus groups are used to initially document aspects of physical activity including the use, current behaviour, feasibility of change and barriers to participation in individuals with PNCs. The research presented reports on direct evidence from the individuals participating, although in some cases carers and family members were present but their comments are not presented here. A questionnaire was subsequently developed using guidelines published by the European Commission (Brancato, 2003) from the focus group findings to investigate barriers in a larger number of individuals with PNC (Medical Research Council, 2004) .

7.1.2 Purpose of the study

The purpose of this study was to seek the opinions of individuals with four neurological conditions (Multiple sclerosis, parkinson's disease, motor neurone disease and muscular dystrophy) on factors facilitating their physical activity participation. To do this we used a focus group and cross-sectional survey by questionnaire designed for use in the Oxfordshire community.

7.2 Methods

Design: Focus group and cross sectional survey by questionnaire

7.2.1 Focus groups

After ethical approval was obtained from the Local Research Committee, twenty-four individuals (mean age ±sd: 54 ±25 years) with various neurological conditions were invited to take part in the research. Support groups for people with progressive neurological conditions in Oxfordshire, were contacted by post and phone and asked to invite their members to contribute in one focus group to discuss physical activity. After giving formal consent to take part in the research individuals were asked to attend various focus group discussions within the Oxfordshire community setting. All participants had partners who acted as carers and 22 individuals brought them to the focus group. The four focus groups included adults with muscular dystrophy (n=5), multiple sclerosis (n=7) motor neurone disease (n=6) and parkinson's disease (n=6).

Table 14: Demographic data for focus group participants

	MS	MD	PD	MND	TOTAL
No attending FG	7	5	6	6	24
Age (years) mean ±sd	58 ±6	37 ±15	66 ±10	56 ±15	54 ±25
M:F	3:4	2:3	6:0	4:2	15:9

- MS - multiple sclerosis
- MD - muscular dystrophy
- PD - Parkinson's disease
- MND - motor neurone disease
- M:F - male:female ratio

7.2.2 Procedure

Various support groups for individuals with progressive neurological conditions in Oxfordshire were contacted by post and phone. They were asked to invite their members to contribute to a focus group session to discuss barriers and facilitators to physical activity and exercise in the community. There was no upper age limit and people with any level of functional ability were invited. Following ethical approval from the Oxford Brookes University Research Ethics Committee, individuals were recruited to participate in each of the four focus groups, which took place between November 2004 and April 2005. Individuals taking part in the focus groups represented a maximum variation sample (in both physical and psychological well-being) (Miles, 1994). Participants were fully informed of the nature and likely duration of the focus groups and were not recruited unless they were able to provide written consent.

Focus groups took place between April 2005 and April 2006. All participants were given an information sheet (Appendix 8) regarding the study and a signed consent form before their involvement. Twenty-four individuals participated in one of four focus group discussions (Appendix 9), focusing on perceived barriers and facilitators to participation in physical activity and exercise within a community setting. Three members of the research group (CE, HD and AD) facilitated the focus groups, attending each focus group discussion and explaining at the beginning of each session that the purpose of the study was to discuss two main topics, these were issues relating to perceived barriers and facilitators to taking part in physical activity, and

secondly, individuals experiences when exercising in a community setting. These areas were chosen as they represented important aspects found in previous studies (Rimmer, 2005; Rimmer, Riley and Wang, 2004a) that required further investigation in relation to individuals with neurological conditions.

The following quantitative data was also collected to accompany the focus groups and assist description and analysis: demographics - age, date of birth, time since diagnosis**.**

Following the analysis of the focus groups, a questionnaire was developed using the themes that emerged. This questionnaire was developed solely from the findings of the focus group, which determined what questions were to be asked within it. The questionnaire was to be self-completed and consisted of eight questions (Appendix 7). The questions covered topics such as: necessary support, barriers to participation and average time spent participating in physical activity. Patient support groups were contacted, informed of the purpose of the study and asked to identify volunteers. Once the respondents granted permission, the researcher scheduled times to visit the local support group meetings or local clinics to either distribute questionnaires to individuals or to post questionnaires to them. Individuals completed the questionnaire by themselves or with the help of a carer. The questions are shown in Table 17.

7.2.3 Questionnaire

The questionnaire used in the presented study is a novel questionnaire developed as a result of the focus group findings presented, (Appendix 7). The focus groups were not conducted specifically as a tool to develop the questionnaire; however it was thought that having investigated key barriers and facilitators to physical activity participation within the focus groups, developing a questionnaire as a result of these findings would be a method of further investigating these issues in a wider cohort of individuals.

The findings from the focus groups suggested that a single questionnaire could be utilised across all PNC groups.

After ethical approval was obtained from the Local Ethics Committee, 106 questionnaires were distributed through local user groups, of which 74 (70%) were completed. The optimal size for a focus group discussion has been previously reported to be between 8 and 10 participants. It was decided that 8 participants would be the maximum number of participants that would be accepted into each group.

Table 15: Demographic data for questionnaire participants

	Number of responses	Mean age in years ±sd	Male:female ratio
Multiple sclerosis	27 (36%)	55 ±8	6:21
Muscular dystrophy	30 (41%)	46 ±12	10:20
Parkinson's disease	13 (18%)	68 ±11	10:3
Motor neurone disease	4 (5%)	56 ±15	3:1
Total	74 (100%)	55 ±13	29:4

7.2.4 Analysis

Notes taken by the three researchers during focus group sessions were analysed using a note-based methodological approach according to Kruger (1998), this involves each researcher preparing a written description of the focus group discussion based on summary contents and notes taken throughout the discussion. A note based approach relies on the inclusion of five different types of information: notable quotes, key (major) points and themes from each question, follow up questions that could be asked, ideas and thoughts of the recorder, and other contributing factors that might aid analysis. Notes were taken throughout the focus group discussions; important points were taken down by all researchers and key quotes were transcribed verbatim.

Data trustworthiness was ensured through credibility, where investigators attempted to demonstrate that a true picture of the topic being investigated was presented, dependability, where researchers should strive to enable a future investigator to repeat the study, conformability, where researchers must ensure to take steps to demonstrate that the presented findings emerge from their data and not their own predispositions and finally transferability of data and methods (Guba, 1981; Shenton, 2004; Kidd, 2000).

Independent note analysis by the researchers (HD and CE) provided an identification of major themes, which were then reviewed and refined to three themes by consensus, these were: 1) Perception, barriers and enjoyment of physical activity, 2) Disease specific considerations and 3) Confidence in

health professionals and fitness centre staff, whilst conducting the focus group discussions these were areas that were identified by the researchers as being the most important.

The questionnaire responses were analysed using descriptive statistics.

7.3 Results

7.3.1 Focus group results

Three themes emerged from the focus group results. These included: perception, barriers and enjoyment of physical activity; disease-specific consideration; and confidence in health professionals. Each theme is discussed below:

Perception, barriers and enjoyment of physical activity

Of the 24 individuals that participated, all agreed that physical activity was a positive experience that had the potential to make them 'feel better'. Physical activities identified as being most beneficial and enjoyable were swimming, stretching and walking, which were consistent across all conditions. The reasons for participating in physical activity were varied, but in all four focus groups it was mentioned that day-to-day physical function deteriorated as the level of physical activity reduced. Individuals felt that exercise was an effective way of preventing physical deterioration. For example, an individual with multiple sclerosis stated that "*exercise helps us to focus on the positive aspects of our mobility.*" This opinion was reiterated in all the focus groups and appeared to be an important incentive to participation.

Feelings of inertia and a lack of motivation were expressed by 19 of the 24 participants and were major reasons for their reluctance to exercise.

The facilities and environment were consistently identified as a barrier to physical activity. Individuals within all four groups expressed the view that the natural environment is inherently inaccessible. Reasons for this included: access routes, doorways being too narrow for wheelchairs to pass through, and a lack of lifts. Individuals highlighted several safety issues such as wet floors in changing rooms, poorly maintained equipment and unsuitable hoists in pool areas. Finally, costs that arose due to membership and travel were discussed. Individuals felt that the costs of membership fees and transport needed to be addressed, particularly for those who do not work. This appeared to be a universal barrier to exercise throughout all condition groups.

Having to attend a new scheme or environment caused anxiety and individuals recognised the limited intervention available through primary health care services and the NHS. For example, an individual with muscular dystrophy stated that "*I enjoy swimming, but I am concerned about the rationale, I only get 6 to 8 weeks hydro and that's it, then we're out.*"

Individuals noted that a continuous scheme would be welcome as a regular part of their lives. All individuals agreed that the social aspect was important and that attending exercise sessions with others enhanced the feeling of 'normality'. The idea of a group for people in similar situations was generally perceived as positive.

Individuals were able to recall bad experiences associated with fitness centres

in the past. These memories would act to prevent their attendance, as one individual stated "*I would have fear of doing something if I had not done it for a while… As I would not be sure if [I] would judge it right… Like when I went swimming... I was so self-conscious in the changing room and this was scary and really affected my confidence*."

Fear and worry was associated with adapting to a new environment. The unknown location and surroundings, the new equipment and different people contributed to this. Individuals needed reassurance that their needs would be met and that staff would be sensitive to and knowledgeable about their condition. This need was especially highlighted in those users who had had a bad experience previously. One individual identified a specific incident: "*I really enjoyed the treadmill, but when I fell over on it, there was no-one there to help me*"

Some participants also expressed a fear of not performing the exercise correctly and that it would be embarrassing for them. The memory of falls and lack of confidence in their ability also was mentioned as a worry. Individuals requested a supported environment that could aid these aspects and be addressed by aspects of self-efficacy.

Disease-specific considerations

The disease progression and feelings of hope in exercise and recovery was important and influenced a participant's motivation and feeling towards physical activity. It was felt across conditions that by participating in regular physical activity the rate of disease progression may be slowed. Participants

identified a specific need to consider two aspects associated with their disease first, the physical problems associated with each disease and second, the nature of the disease and its responsiveness to change influenced some participants faith in exercise. This was illustrated by one individual who said "*I'm fed up with continuously having to explain everything to them [the instructors] and then they don't understand how fatigue is part of my condition.*"

Table 16 details some of the disease-specific considerations that may be addressed when working with specific conditions.

Table 16: Disease-specific considerations

Disease	Barrier
Motor neurone disease	Walking is hard, legs need to be conditioned Fatigue Incontinence Fear of falling Progression of disease - exercise becomes less safe Can easily overdo it, resulting in aches and physical and mental fatigue Cramps occur regardless of activity levels. Unpredictable nature of the disease.
Multiple sclerosis	Warmer environments cause over-heating Over-stretching Easy access to the loo
Parkinson's disease	Difficulty moving about in swimming pool and public spaces Medication effects timing and need to consider when it is taken Swimming pool is too cold, can't move fast enough to get warm Losing balance is a big problem

Some individuals with Parkinson's disease preferred medication as they felt that '*exercise can't cure me'*. Also, one individual with motor neurone disease indicated that exercise is not proven to be helpful therefore it may be "*pointless in influencing our health state*".

Confidence in health professionals and fitness centre staff

All of the focus group participants agreed that staff in fitness facilities would benefit from some training to help them understand the specific neurological conditions and which exercises would be of benefit to them. Informational support was essential and the instructor needed to be aware of exactly what can be obtained. Many individuals felt that they had a lack of confidence in the fitness staff with regards to their condition and what exercises were appropriate for them. An individual with motor neurone disease suggested that the rarity of the disease meant that people don't always understand it, including GPs. One individual said "*I want a trainer to be familiar with [my] condition and confident to deal with me*."

Individuals with multiple sclerosis suggested that support from a specialist neuro-physiotherapist would help the exercise sessions and make them feel more confident. The majority of participants stated that they would only feel comfortable with some form of physiotherapist support. This was due to several reasons, including previous bad experiences with non-medical staff being unfamiliar with their specific condition. Additionally, it was indicated that support from professionals such as physiotherapists and occupational therapists to assist with the transition from rehabilitation settings, such as hospitals, to community settings, such as leisure centres, would help and would reduce the reluctance to participate.

The participants reported wanting a choice of activities that they enjoy participating in, including activities such as ballroom dancing. The gym

instructor also needed to know other aspects regarding the conditions (e.g. any issues regarding lifting and handling issues in rare conditions). Individuals with MS reported that they feel they have ample knowledge and experience in managing their own conditions. This is evident and individuals also discussed the need for fitness professionals to increase their knowledge of the specific conditions they are dealing with and utilise this when working within these groups. It would appear that individuals are less unaware of the problems associated with conditions that are less common, such as motor neurone disease and parkinson's disease. But lack of knowledge also appears to be an issue even when considering MS, where therapeutic exercise delivered by physiotherapists has a longer history and bigger profile as part of current management.

An individual with muscular dystrophy said that having to ask for help was unpleasant: "*At first I had no confidence in the new machines. I want the instructor to be familiar with my condition and confident to deal with me*."

Ideally participants often requested having someone there they already knew. Another individual stated "*I like to have a point of contact, [I] feel safer if I know someone there and I would be scared to turn up cold*."

Individuals with MS said they like to find exercise through the MS society because they trust it.

7.3.2 Questionnaire results

All responders provided estimates of the time spent exercising during a typical week. Participants exercised within the range of 32 to 140 minutes a week, taking those who did report exercising, the mean ±sd 108 ±76 minutes a week, 14 (19%) individuals reported not participating in any physical activity at all. Age of responders in years ranged from 42 to 68, mean ±sd 55 ±13, 45 (61%) were women, 27 (36%) people had multiple sclerosis, 30 (41%) subjects had muscular dystrophy, 13 (18%) had parkinson's disease and 4 (5%) had motor neurone disease.

Table 17: Questionnaire results.

1. How often do you participate in exercise on average in a typical week?	Not at all 6 (20%)		1-3 times 37 (46%)		More than 4 times 29 (36%)		
2. On the occasions that you do exercise, how long on average would you say each session lasts?	15-30 (minutes) 40		45 (minutes) 12		60+ (minutes) 22		
3. To what extent do you enjoy exercising?	A lot 17		Quite a lot 33		Not a lot 13	Not at all 11	
4. Who would you most like to support you while you were exercising?	Specially trained fitness professional 7		Trained physiotherapist 40		Specially trained fitness professional with physio support 23	Specially trained carer 4	
5. Which activities do you enjoy?	Walking 31	Stretching 31	Swimming 36	Specific exercises 6	Group classes 19	Circuits 8	Other 26
6. If you were to have exercises provided for you in the community, where would you like to exercise? *	Leisure centre 44	Home 42	Community centre 26	Gym 38	Other 8		
7. If you were to exercise in a gym, would you like to exercise…? *	On your own but know help was available 29	In a group for those with mobility problems 31	In a group with the same condition as yourself 37	In a group with no disabilities. 6	Any of these 16		
8. What factors prevent you from participating in physical activity within an exercise environment such as a leisure centre? *							
Cost 22	Travel 22	Facilities 26	Lack of time 19	Concerns regarding help available in the gym 27	Embarrassment 29	Staff's lack of knowledge regarding your condition 38	Staff's lack of knowledge regarding suitable exercises 35	Other 11

* Individuals were able to circle more than one response.

Table 17 details the responses to the questionnaire. In this sample 50 individuals reported enjoying exercise either a lot or quite a lot. When questioned as to their preferred support during exercise, 40 individuals suggested they would prefer to exercise with a physiotherapist with 23 requesting a physiotherapist to be in support of a fitness professional. The most popular exercise was swimming followed by stretching and walking. The least popular exercises were 'specific exercises'. Individuals suggested a range of preferred community exercise venues. Six individuals said they would prefer to exercise with able-bodied individuals. In the sample, 38 individuals reported a lack of knowledge of their condition and 35 reported a lack of knowledge of suitable exercises by staff as a barrier to participation.

Table 18: Condition-specific responses to activity.

	Multiple sclerosis	Muscular dystrophy	Parkinson's disease	Motor neurone disease	All conditions
Number of completed questionnaires	27	30	13	10	80
Average ±sd time exercising per week (minutes)	106 ±80	60.5 ±62	121 ±93	105 ±17	87.6 ±78
Number of individuals reporting no exercise	2	9	1	4	16
Favourite 3 activities	Swimming Group ex. class Stretching	Swimming Walking Stretching	Walking Stretching Swimming	Walking Stretching Swimming	Walking Swimming Stretching

Table 18 details condition-specific responses to activities. People with multiple sclerosis and Parkinson's disease reported themselves to be most active, with more people with muscular dystrophy responding that they did not exercise at all. Swimming, walking and stretching were popular for all conditions although people with MS also reported enjoying group exercise.

7.4 Discussion

Individuals in our sample were relatively inactive compared to healthy populations, with mean weekly activity levels of 108 minutes compared with 300 minutes for healthy middle-aged women (Guthrie, 2002). Levels were more comparable with those of older people whose activity levels have been reported to be between 119 and 161 minutes a week (Davis and Fox, 2006a). It should be noted that the discussed activity levels in this study were reported by the participants and not actually measured. Also the participants in this study may be a biased sample, as individuals chose whether to attend the focus group discussions and may already have an interest in physical activity. It would seem unlikely that individuals would have attended if they had little interest in physical activity. The wide range of activities in which individuals with PNCs would like to participate indicates that a degree of flexibility is required in supporting physical activity participation. This finding has not been reported before and certainly may be difficult to implement in practice. This has been observed in a recent study by McAuley et al (2007) who conducted a small RCT to look at exercise adherence after implementing an efficacy enhancement exercise intervention. Individuals in this study were asked to attend exercise classes and their attendance was monitored. The authors state the difficulty they encountered in recruiting for this study. The results were interesting and those individuals who participated in the exercise efficacy intervention group showed no significant change in their attendance of the exercise classes. The lack of attendance could be due to the physical activity offered as part of the study. The authors suggest that a next step would be to

investigate the type of physical activity in which individuals with MS want to participate, using focus group discussions. The presented study investigates these topics and determined that a variety of activity needs to be provided if increased attendance and adherence is to be achieved. Certainly when considering long-term adherence to programmes, enjoyment is key and a wide choice of supported activities has been associated with better adherence to physical activity in healthy elderly individuals and elderly individuals with arthritis (Der Ananian et al., 2006). Unpublished observations from a focus group with IFI fitness trainers commented that they were reluctant to support activities such as swimming as they demanded too many resources. This is really important in terms of conflict in delivering sustainable exercise programmes that individuals want. We observed the previously described barriers to exercise such as high costs, poor access, inappropriate facilities and equipment in both focus group discussions and questionnaire responses (Rimmer et al., 2004c; Rimmer et al., 2000). Inadequate transport, cited as a major problem in a North American study of individuals with physical disabilities (Rimmer et al., 2004c), did not appear to be problematic in the present study.

These individuals with progressive neurological conditions indicated that they enjoyed participating in a range of activities from walking and swimming to group exercises and that they would like to access these activities in a number of different community settings, such as sport centres, community centres and local gyms. The majority of these individuals indicated that they would prefer to exercise in these environments. However, this is contradictory

to the previous findings of Ashworth et al (2005), who conducted a study comparing a home vs. centre-based activity programme and found that home-based activity programmes had better long-term adherence than centre-based activity programs, and were more enjoyable. This may be true for that particular group but in the presented study it was found that many of the activities that were desirable to these populations necessitated centre-based facilities, and the 'centre' used in Ashworth's study was actually a hospital-based physiotherapy gym, not a community-based centre. When considering the delivery of exercise, the majority of individuals indicated that they would prefer to exercise in a group of people with the same or other disabilities, with few indicating they would like to exercise alone. The MS Society is unique in the provision of services they offer their members. They run exercise support in the form of organised fitness classes that are led by physiotherapists and tend to be in local community spaces such as fitness centres and community centres. The downside to this system of exercise provision is the very specific times at which it is conducted, which may not always be convenient.

The majority of individuals indicated they would prefer to exercise with the support of health and fitness professionals with expertise relevant to their condition. The Gary Jelen Report in 1998 (Gary Jelen Foundation, 1999) reported that disabled people would like to have the opportunity to exercise in an environment available to able-bodied individuals. This was contradictory to the presented findings in which six individuals reported wanting to exercise with able-bodied individuals and the vast majority reported the desire to exercise with others with mobility problems or the same condition as

themselves. It has been noted that those who exercise within their own condition-specific support group have performed slightly better than those individuals who chose to exercise in mixed condition groups (McAuley et al., 2007). It was also observed that most individuals wished to exercise alongside others with disabilities in community environments such as gyms and leisure centres, and these findings have not been reported before. Although Rimmer et al (2000) investigated how African American women with physical disabilities would like to exercise he found that 39% of these individuals did not mind whether they exercised alone or in a group, 28% wanted to exercise in a group only and 23% wanted to exercise alone. But he did not discuss who they wanted to exercise with – for example, others with disabilities or able-bodied individuals – nor did they discuss who they would like supporting them in the exercise environment. These are key points that needed to be addressed. It would appear that people with certain conditions have specific requirements and therefore, our findings are an important consideration in implementing community exercise and support the need to examine opinions in a range of conditions.

The largest perceived barriers relating to personal issues, reported in the focus groups findings, included embarrassment and support issues such as a perceived lack of knowledge of conditions or suitable exercise by staff. These are similar findings to those of Rimmer et al (2004a). However, no previous studies have investigated the type of physical support and assistance that would facilitate increased physical activity participation. This was investigated within this study and it was found that individuals preferred physiotherapy

support or the less costly option of a fitness professional supported by a physiotherapist. Support in emotional, physical and informational domains can be addressed within prescription to enable participation in exercise environments and would appear to be an important facilitator. Becoming or remaining active for individuals with disabilities can be a daunting step, and their anxiety about being able to participate or use equipment at a 'regular' fitness centre (Steadward, 1998) was evident in this study. Many people with a disability lack the confidence, both in themselves and in fitness professionals, (Steadward, 1998) to participate in physical activities. Our findings show that most individuals felt more comfortable in the presence of a physiotherapist when they participated in exercise, this could be due the fact that when exercising on previous occasions, these individuals had spent more time with medical personnel such as physiotherapists. They feel secure with physiotherapists, as they are confident when dealing with disabled individuals and they are familiar with their specific condition. This is demonstrated by the MS Society (www.mssociety.org.uk/), which chose physiotherapists to conduct its exercise classes. Fitness instructors tend to be less medically informed and less aware of specific neurological conditions and this proved to be a concern for the participants in this study.

A perceived lack of knowledge of neurological disorders and of suitable exercises for these conditions was highlighted within our findings. Participants highlighted disease-specific considerations, stating their fear of going to exercise in an unfamiliar environment where staff would not be aware of specific symptoms such as continence and fatigue issues. Knowledgeable

support has previously been highlighted as an important determinant of physical activity participation in people with arthritis (Der Ananian et al., 2006). Developing new fitness opportunities, provided by informed instructors may serve to encourage and support increased participation. The value of the patients' knowledge for managing their own conditions was clearly evident in the current study and has been previously identified in government publications (Department of Health, 2001). The patient's knowledge could be utilised by fitness staff and documented in a way that can be recalled. This would enable staff to be aware of specific conditions and exercise responses before meeting patients, which could give them confidence in prescription and aid trust within the relationship. This would be supported by a client-centred approach that is based on a partnership and allows autonomy and patient choice (Sumsion, 1997). This approach would clearly be beneficial for the current population group.

There are several limitations to this study, primarily related to the small size and selectivity of the groups involved in both the focus groups and questionnaire survey. Post hoc sample size calculations suggest that for the questionnaire to produce significant results approximately 400 individuals are needed in each condition group. It is possible that individuals only attended the focus groups or responded to the questionnaire if they were already interested in the topic of exercise and physical activity, which may have presented a bias in the results. Geographical and socio-economic factors also need to be considered when making generalisations. It is important to note that barriers identified by individuals in this study were perceived, not

objectively measured. With any self-administered questionnaire there are issues of an individual's comprehension of the content of the questions. However, the questionnaire was thoroughly piloted prior to its use with questions clarified in response to comments made by the pilot audience. The questionnaire was piloted on all participants who attended the focus group discussions. This was to ensure that the questions within the questionnaire were representative of the opinions and views they expressed in the focus group discussions. . Perhaps future investigations should consider looking at reasons why individuals want to be provided with medical expertise, such as physiotherapists instead of fitness instructors. This wasn't investigated within this study, as the questionnaire was developed to be short and gain primarily, as we found from the focus groups, to be the most essential information. Further studies should examine the gap between perception of barriers and attitudes, and their actual presence for the individual.

The focus groups discussions were transcribed by three researchers but no tape recordings were made of the sessions. This may be a limitation of the study but there is no current literature that states the benefits of having this type of data taped. The note-based approach employed within this study has been shown by Krueger et al (1998) to be no less accurate than audio-taped or video-taped data, and when using three transcribers or more it is common that all the key themes and discussions are noted.

7.5 Conclusion

Participants in this study indicated that they were not as active as they felt they would like to be. It is heartening that individuals considered exercising in a range of community settings given that previous findings suggest that exercise may be more effective when delivered in a community setting than in a medical setting (Ansved, 2003a; Logan et al., 2004). The pursuit of exercise provision through a range of activities within the available facilities in the community is an attractive option. This pilot work highlights barriers that, if addressed by simple practical solutions, such as improving the surrounding environment by making it more accessible and increasing training given to fitness instructors to encompass knowledge of neurological conditions, could enhance exercise delivery within current community facilities. It is interesting to note that although the barriers and facilitators for individuals with PNCs are similar it's clear that knowledge of symptoms and exercise prescription needs to be more condition-specific.

Further work will evaluate if the implementation of such changes can increase participation and make available health benefits that are regularly accessible for the general population.

The previous chapter discussed the current trends in exercise participation and provision within this population. This chapter explored the barriers and facilitators to physical activity and exercise participation in individuals with progressive neurological conditions within a community setting, and examined their opinions on factors facilitating their physical activity participation. The

study was undertaken by conducting focus groups and a cross-sectional survey by questionnaire. The findings from this study were used to develop the intervention to be trialled in Chapter 8.

8. A Phase II randomised controlled trial of a Long-term Individual Fitness Enablement (LIFE) intervention for people with multiple sclerosis

8.1 Introduction

The findings from the physical activity scale for the elderly (PASE) questionnaire (Chapter 6) demonstrated that individuals with multiple sclerosis (MS) reported being less active in the social domain than the home domain and in Chapter 7 individuals with MS stated that barriers to activity outside the home were common, barriers such as feelings of inertia and lack of motivation, the inaccessibility of the natural environment, and cost were all discussed.

8.1.1 Background

Exercise is recognised as an important component within the management of MS (Rietberg et al., 2005). Despite this, people with MS engage in significantly lower levels of physical activity than healthy populations (Motl et al., 2005b), a factor directly associated with the worsening of symptoms in a longitudinal study over a five-year period of 51 MS sufferers (Motl, 2008).

Evidence for exercise within MS has increased considerably over the last decade. A 2004 Cochrane review of nine randomised controlled trials including 260 participants (Rietberg et al., 2005) and a systematic review of resistance and endurance training (Dalgas, 2008) both concluded physical

activity can improve muscle strength, aerobic capacity, mobility-related activities of daily living and mood. Whilst the reviewed evidence was acknowledged as moderately high in methodological quality (Rietberg et al., 2005), clear areas of improvement regarding concealed allocation, control groups, intention-to-treat analysis and adequate description of drop-outs were highlighted, resulting in the need for further high quality studies.

Studies of exercise in MS have often occurred within hospital or structured rehabilitation settings, resulting in difficulties translating findings to the community environment. Community-based evidence is limited, and studies have usually taken place within the home environment (DeBolt and McCubbin, 2004). Community-based rehabilitation is of the utmost importance within the management of long-term neurological conditions, offering the continuing care and self-direction people with MS require (Hopcutt, 2008). However, rehabilitation in the home environment can lead to issues with compliance, particularly if unsupervised (Dalgas, 2008; DeBolt and McCubbin, 2004), and lacks the social interaction and support that may enhance exercise interventions. In particular, support provided by professionals with disease-specific knowledge is recognised as a key facilitator of exercise among people with disabilities (Rimmer et al., 2004a).

This study aimed to assess the feasibility of a physical activity programme within community leisure centres, offering exercise within a non-NHS setting. To improve activity and social integration outside the home a long-term individual fitness enablement intervention was devised (described in section

8.2.8) and implemented within the study described in this chapter.

This chapter describes a phase II randomised controlled trial (RCT), designed to provide preliminary evaluation of the intervention in terms of its effects on physical activity participation and community mobility. The RCT was the choice of design as it is considered to be a good method of eliminating bias and comparing groups whilst ensuring the internal validity of clinical trials (Black, 1996; McPherson, 1994; Abel and Koch, 1999). It has been considered the gold standard for evaluating the effectiveness of health care interventions.

8.1.2 Purpose of the trial

The purpose of this trial was to

1. Assess the feasibility of the intervention, the suitability of the measures of outcome and to provide data to inform the sample size calculation for a larger study.

2. Provide preliminary data on the effectiveness and feasibility of a personalised physical activity provision support system (PAPSS) for people with MS living in the community. The benefit of receiving exercise provision with PAPSS will be assessed in terms of activity levels, community mobility and physiological and psychological health.

This chapter set out to evaluate the exercise intervention and physical activity provision support system developed from the findings from the focus groups and the questionnaire study carried out in Chapter 7. This study investigated

the feasibility of delivery of exercise and physical activity, and assessed whether it can be effectively delivered in a community setting (Inclusive Fitness Initiative (IFI) centres) by fitness professionals employed and trained by the IFI scheme, working within a physical activity provision support system that includes physiotherapy support.

8.1.3 Research questions

Does a personalised targeted progressive exercise programme with PAPSS (in comparison to a waiting list control) in a group of community-dwelling people with MS…

1. Increase activity and participation in physical activities as measured by the PASE questionnaire?

2. Increase community mobility as measured by the step activity monitor (SAM)?

In addition, pooled before/after data from the intervention groups (both immediate and delayed) will assess the efficacy of the intervention.

8.2 Methods

8.2.1 Study design

A single blind randomised controlled trial with independent assessment. The trial design incorporated the recommendations of the CONSORT statement and followed guidelines set out by the Medical Research Council (Altman et al., 2001; Begg et al., 1996; Medical Research Council, 2004). A randomised controlled design was chosen, as it is the most effective way to eliminate bias.

There were two groups in the study: an immediate exercise intervention group and a waiting list control group that received the exercise intervention after a wait of three months. Thus, all participating individuals with MS received the exercise intervention for three months.

8.2.2 Setting

All research assessments took place in a physiotherapy gym at the Oxford Centre for Enablement (OCE) at the Nuffield Orthopaedic Centre in Oxford. The fitness sessions were conducted at the White Horse Leisure Centre, Blackbird Leys, Oxfordshire.

8.2.3 Participants and recruitment

Adults with MS from the Oxfordshire community were eligible to participate and were recruited through Oxfordshire neurologists (D.T.W and U.K). Eligible participants were recruited from January 2006 to September 2006. Inclusion Criteria included all individuals:

- With a diagnosis of multiple sclerosis, there was no need for individuals to be at a specific stage of MS or have a more specific diagnosis other than Multiple Sclerosis.
- Aged eighteen years and over.
- With no cognitive, sensory or psychological impairments precluding full engagement with training and experimental paradigm, assessed by the referring neurologist.
- Able to participate for the study period.

Exclusion criteria included individuals who:

- Were unable to meet the inclusion criteria.
- Were unwilling or unable to undertake the programme.
- Had any contraindications to exercise, i.e. cardiac complaints.
- Had suffered a relapse of their MS symptoms within the last 6 weeks.

8.2.4 Sample Size

As this was a pilot study, no formal power calculation was performed: the sample size was pragmatically determined by the resources available for the PhD. Referring neurologists estimated that over the nine-month recruitment period the likely referral rate into the study would be 25 eligible participants.

8.2.5 Intervention: exercise and physical activity provision support system (PAPSS) intervention

Development of the intervention

The intervention detailed below was developed as a result of findings from previous studies, available literature and expert guidance. Chapter 7 reports a study in which a questionnaire was developed from the findings of various focus groups that were held to investigate the opinions of individuals with neurological conditions regarding facilitators and barriers to physical activity participation. The resulting questionnaire enabled a larger sample of individuals to be sampled, and enabled us to determine and prioritise the most important barriers to participation that needed to be addressed. Acknowledging the recommendations of Dalgas et al (2008), this study aimed to provide individualised and progressive exercise, driven by participant-led goals to maximise self-efficacy.

There were five main aspects of support provided which made up the PAPSS.

Physical activity provision support system

The PAPSS includes information, practical advice and physical support from a physiotherapist for both people with neurological conditions and health and fitness professionals involved in activity provision.

The participant

It was imperative that the participants understood that it was thought that they were the experts in their condition and the study was devised to help them exercise. Participants were encouraged to guide and advise the fitness professional in matters relating to their condition as and when they thought necessary.

The Inclusive Fitness Initiative (IFI) instructors and gym.

Therapeutic exercises were to be delivered by fitness professionals, utilising Inclusive Fitness Initiative (IFI)[1] gyms with local authority support under the mentorship of a specialist physiotherapist.

The IFI is an initiative aimed at increasing participation under the auspices of the English Federation of Disability Sport. In 2001 the IFI received a grant of £1million from the Sport England Lottery Fund towards a total project cost of £1.3million. Local authority partners contributed further funding of £0.3million. IFI facilities offer a wide range of benefits to disabled customers, including:

[1] Further details of the Inclusive Fitness Initiative can be found at http://www.inclusivefitness.org/

“Facilities that have undertaken both physical and communication access improvements, staff that have a high level of training, an opportunity to exercise in a truly inclusive environment and access to healthy lifestyle choices.”

Every IFI site has to ensure that their facilities effectively meet the needs of disabled people. They have done this by assessing and improving various barriers such as:

- Access - there is always good physical access to the gym and fitness area, and there are changing rooms and toilet facilities that have been made accessible for everyone.

- Fitness equipment - the fitness equipment has been designed, tested and used by people with neurological conditions

- Staff training - All fitness instructors hold the highest IFI level 3 qualification which ensures that they have the knowledge required to deliver safe and effective exercise sessions. These instructors are all experienced in working with individuals with neurological conditions.

Physiotherapy advisor

A physiotherapist advisor was provided to support the participant and the IFI fitness instructor with clinically relevant, specialist knowledge on neurological conditions so that therapeutic exercises of the person's choice could be safely and effectively delivered in the community setting.

The physiotherapist attended up to the first six exercise sessions, in line with current physiotherapy session provision. This is the approximate number of physiotherapy sessions individuals would expect to receive through NHS referral.

Free exercise sessions for three months

The study funded all exercises sessions that individuals attended within the three-month time period. It was made clear that after the study period was over we would encourage individuals to continue exercising, however, it would not be possible for the funding to continue.

Free transport

For the duration of the study individuals were supported in any way necessary for all their transport needs. This included fuel and a pick-up service for those unable to drive.

Individuals were supported by a physiotherapist and an IFI accredited fitness professional for their initial sessions and from then on by an IFI fitness trainer under the support of the therapist as required. In order to make the service comparable to current hospital physiotherapy provision in neurological populations, a physiotherapist attended when needed for up to five sessions and then provided the fitness trainer and patient with phone/web-based support as required.

Exercise Sessions

As part of the intervention, individuals were assessed by the fitness professional for a suitable programme and a profile created taking into consideration each individual's family and social background, their hopes and health and fitness needs. The programme was devised with expert physiotherapy support as required, which aimed to improve the individuals' ability to perform physical activities. Individuals were closely monitored in their exercise progression by the exercise professional, who themselves was supported by a physiotherapist as required.

The exercise intervention was created to address individual requirements. Interventions typically included components of endurance, muscle strength, flexibility and cardiovascular fitness. Exercise sessions typically lasted up to one hour and components were programmed at an appropriate intensity, duration, frequency and progression according to exercise prescription principals (American College of Sports Medicine, 1995).

After each session participants were asked to complete a session progress sheet (Appendix 5) in which he or she had to detail the date and time of the session, they were also asked to complete a four-item questionnaire on the progress sheet.

8.2.6 Outcome measures

Assessments were carried out in the OCE at the Nuffield Orthopaedic Centre in order to ensure patient comfort and safety by a researcher blinded to the exercise intervention. Assessments were carried out 0, 3 and 6 months from consent.

The primary outcome measure was the physical activity scale for the elderly (Washburn et al., 1993b), the PASE is divided into three domains: leisure, home and work. Each of these domains is scored individually and the total PASE score is the sum of the three domain scores. Scores on PASE can range from 0 to 400 with a higher score indicating a greater level of physical activity. (See Chapter 3 for a detailed description of the PASE.)

Home mobility step counts and community activity levels were measured with a long-term ambulatory activity monitor that was worn on the leg for eight days (Full 168 hour week and not removed for sleeping or bathing). This method of ambulatory monitoring provides essential information relating to the actual level of activity (and hence a good measure of functional ability) as measured by step counts and time spent sitting or lying compared to walking (Busse et al., 2006) (further described in Chapter 3).

Secondary measures included:

Fatigue: The fatigue severity scale (FSS). Subjects read nine statements on the questionnaire and choose a number from 1 to 7 that best described their feelings towards each statement (1=strongly disagree and 7=strongly agree). The FSS score is obtained by computing the average rating (range 1-7) (LaRocca et al., 1989).

Mobility: two-minute walk (Wade, 1992b). The two-minute walk is a time-based test. Individuals were asked to walk at their self-selected walking speed for two minutes round a pre-determined 10-metre track, and the distance they reached was recorded.

Other measures collected included:

- Age (years),
- Height (cms),
- Medication,
- Barthel Index (Wade, 1992b),

Physical activity participation as measured by attendance to the IFI leisure centre, the number of sessions attended determined by diaries of attendance kept by the trainer and the participating individuals.

8.2.7 Analysis

The primary analysis was the between group change in PASE score at 3 months. Between group differences in change scores were analysed between the waiting list control and the PAPSS. Descriptive statistics are reported for attendance at sessions.

SPSS version 14 was used to do the exploratory analysis on demographic data, the primary outcome measure (PASE) and on secondary outcome measures (mobility test, fatigue severity scale and SAMs data). Summary statistics are presented to summarise the exploratory data. All data was tested for normality and was of equal variance.

Before-treatment for the immediate group will be baseline data and after-treatment will be three-month data. Before-treatment for the delayed group will be three-month data and after treatment will be six-month data. A before and after treatment analysis was done on the pooled data for each outcome variable using the paired t-test to compare the data.

The primary analysis was intention-to-treat (ITT) and involved all patients who were randomly assigned.

Statistical support was provided by Dr Hooshang Izadi, Oxford Brookes University and Dr Smitaa Patel, University of Birmingham.

8.2.8 Assessment Procedures

On attendance to the first assessment it was explained to participants that this is a study investigating the provision of support for individuals who wish to participate in physical activity in the community within fitness centres with Inclusive Fitness Initiative status.

The research assessment session took place at the OCE and lasted approximately an hour and 30 minutes. Individuals would be asked to refrain from tobacco, food, drink and exercise or physical activities for at least two hours before attending assessment sessions at the OCE. Individuals would then complete the baseline clinical measures. Following the assessment, individuals were provided with refreshments.

Individuals in both groups were assessed at 0, 3 and 6 months. The waiting list group acted as a control group during the first part of the study. Comparisons of treatment and waiting list control during the first three months helped determine whether or not the intervention was effective. The six-month assessment will be used to investigate any persistence of treatment effect in the initial exercise group.

8.2.9 Randomisation and allocation concealment

The Movement Science Group, Oxford Brookes University, provided independent randomisation. Randomisation was computer generated in randomly ordered block sizes of 2 and 4 and maintained in sealed opaque envelopes. Envelopes were prepared prior to recruitment by persons not

involved in this study.

Following the first research assessment individuals were randomised. Opaque envelopes revealing treatment assignment were opened by another researcher once baseline assessments were completed, whereby individuals were then informed of their group allocation.

Individuals allocated to the immediate PAPSS with the physiotherapist support group had an initial induction at the IFI leisure centre organised with an IFI fitness professional. Individuals allocated to the delayed intervention group had an appointment organised for another assessment at three months. The delayed intervention group entered the exercise phase after their second assessment.

8.2.10 Research governance and ethics

Approval for this research project was obtained from The Mid & Buckinghamshire Local Research Ethics Committee (Reference: 06/Q1607/13). Sponsorship for this study was provided by the University of Birmingham and Oxford Brookes University provided indemnity.

All ethical standards were adhered to according to the guidelines set out in the Research Governance Framework for Health and Social Care (Department of Health, 2005c)

CONSORT Statement

This chapter adheres to guidelines set out in the CONSORT statement (Altman et al., 2001). The CONSORT statement is an evidence-based, minimum set of recommendations developed to improve the standards of reporting trials (Appendix 10).

Guidance for trials of complex interventions (such as behavioural interventions) has been developed and supported by the Medical Research Council. A framework for development and evaluation of RCTs for complex interventions to improve health.

Obtaining consent

Individuals were referred to the researchers by Oxfordshire consultants, Professor Derick Wade and Professor Udo Kichka. Potential subjects were then sent an invitation letter and information sheet (Appendix 11). Individuals who wished to take part were asked to return the reply consent slip at the

bottom of the letter in the stamped addressed envelope provided. Potential participants were encouraged to talk to relatives and friends regarding the study and to contact the research team with any questions.

Individuals were contacted by phone at a previously arranged time and given an appointment to attend the Oxford Centre for Enablement for their first assessment session. At this session there was a further opportunity to ask questions. At this assessment session consent was recorded by a signature on two copies of the study consent form, one original was retained by the patient and one was held on file in a locked cabinet in the research office at the Oxford Centre for Enablement at the Nuffield Orthopaedic Centre.

It was emphasized that this was a research project and as such the aim was to examine provision of support systems for physical activity and health in people with neurological conditions. It was explained that whilst of course their well-being was of paramount concern to the researchers involved, and it is hoped that they would experience some benefit from the training they receive, the scientific work to which the researchers are committed must be completed, thus limiting our ability to respond to what may be perceived as their specific therapeutic needs.

Safety

Individuals were recruited to the study following referral from a neurological consultant. All assessments were carried out at the Oxford Centre for Enablement to ensure the safety and comfort of participants. All training programmes were prescribed and delivered in IFI centres with IFI trained

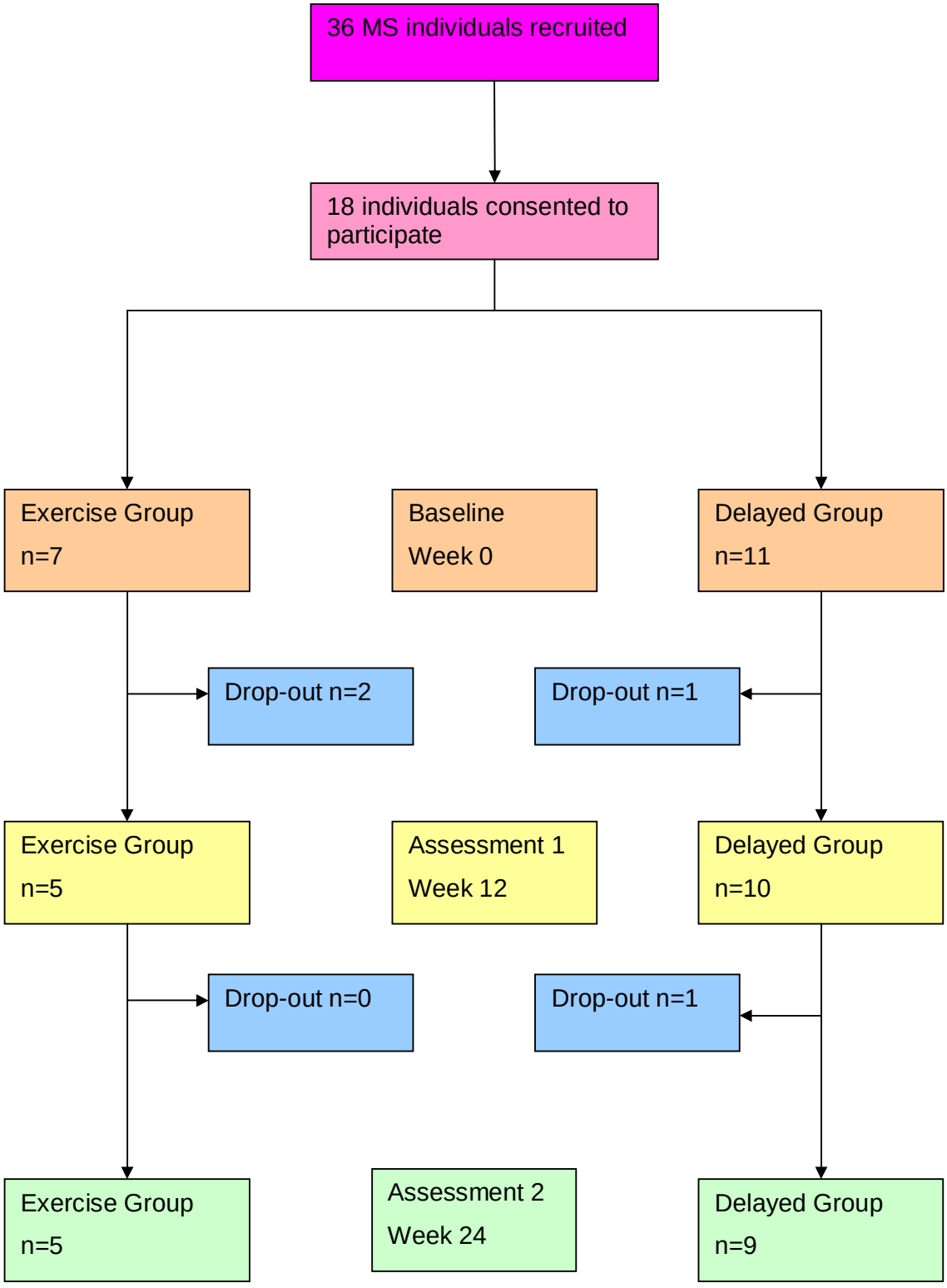
fitness professionals. At all times the fitness trainers individually assessed, prescribed programmes and acted within their scope of practice with additional support from a specialist physiotherapist. The fitness instructors who participated in this study all hold qualifications recognised by the American College of Sports Medicine (ACSM) and all have the recognised IFI qualifications,

Any immediate/emergency issues would have been dealt with by the fitness professional according to standard practice. During exercise, individuals were monitored for possible adverse events (such as the development of ischemic cardiac pain or musculoskeletal injury) according to ACSM guidelines for exercise in clinical groups (American College of Sports Medicine, 1995). In the event of an adverse event or suspicion of harm to the patient on the part of the study researcher, the subject would have been immediately withdrawn from the study and further management discussed with the patients general practitioner/usual consultant. No participants were withdrawn from the study as a result of this.

8.2.11 Study Management

For the duration of the study procedures were implemented to ensure efficient management of the trial. At monthly intervals steering groups were held to update and inform the group of the study progress. Weekly meetings were held with all members of the research group, including PhD supervisors.

8.3 Participant flow diagram



There were four dropouts. Two individuals from the exercise group and one from the delayed group dropped out. These three individuals stated that they could not continue due to personal time constraints, making attending and organising exercise sessions difficult. One individual dropped out in the delayed group, suffering a relapse and was subsequently admitted to hospital before commencing the intervention.

8.4 Results

8.4.1 Baseline data

Individuals were randomised between the exercise group and the delayed group (further described in 8.2.9). At baseline there was no significant difference between groups on the baseline characteristics. No stratification occurred within the randomisation process.

Table 19: Baseline characteristics of each group.

	Exercise Group (n=7)	Delayed Group (n=11)
Age (yrs)		
Mean ±sd	52 ±10.42	56 ±5.59
Range	33 – 62	46 – 64
Height (m)		
Mean ±sd	1.69 ±0.11	1.67 ±0.09
Range	1.57 – 1.87	1.52 – 1.80
Weight (kg)		
Mean ±sd	69 ±12.52	74 ±10.53
Range	52 – 86	54 – 90
BMI (kg/m^2)		
Mean ±sd	24 ±3.91	26 ±3.13
Range	19 – 29	22 – 31

Table 20 shows the clinical measures used to assess mobility, activities of daily living and cognitive state at baseline. No significant difference is present between groups in any of the measures.

Table 20: Baseline clinical characteristics of each group.

	Exercise Group (n=7)	Delayed Group (n=11)
Rivermead Mobility Index		
Mean ±sd	10.9 ±3.39	9.5 ±3.96
Range	5 – 13	3 – 14
Median	13	11
IQR	7 – 13	6 – 13
Barthel Activity of Daily Living Index		
Mean ±sd	17.9 ±2.73	16.8 ±3.06
Range	13 – 20	11 – 20
Median	19	18
IQR	15 – 20	14 – 19
Repeatable Battery for the Assessment of Neuropsychological Status (%)		
Mean ±sd	25.3 ±20.57	20.1 ±20.14
Range	7 – 59	1 – 58
Median	18	18
IQR	9 – 50	2 – 30

8.4.2 Outcomes

Table 21 demonstrates a slight increase in PASE score in the exercise group between baseline and assessment one at three months. However, this difference is not significant (p=0.05). Individuals in the delayed group demonstrated no difference in PASE score between assessment one and assessment two. Change scores within the exercise group demonstrate a mean increase of 4.29, compared to 0.5 in the non-exercise group. The exercise group has a smaller standard deviation of 19.6 compared to that of the delayed group at 39.5. Table 21: PASE results.

	Exercise group (n=7)	Delayed group (n=11)
Baseline		
Mean ±sd	77 ±54.54	65 ±47.01
Range	32.8 – 188.1	5 – 135
Median	53	55
IQR	33.6 – 97.9	11.2 – 105.7
Assessment 1		
Mean ±sd	82 ±71.44	65 ±51.57
Range	27.4 - 237.6	9 – 170.7
Median	59	69
IQR	41.7 – 91.6	15.6 – 97.1
Change Scores		
Mean ±sd	4.29 ±19.6	0.5 ±39.5
IQR	-6.21 - 7.31	

The numbers of attendances were recorded by participants on their session progress sheets and by the fitness instructors, who kept a record of each

participant's attendance.

These results demonstrate the similarity between groups - with the mean number of gym session attendances being 10.4 and 10.1 for the exercise group and delayed group respectively. Although the standard deviation of 6.15 for the delayed group demonstrated slightly more variance around the mean.

Table 22: Summary of gym attendance results for each group.

		Number of attendances at gym	Enjoyment score *	Staff helpfulness *	Problems encountered with equipment *	Happiness with life? *
Exercise	Mean ±sd	10.4 ±3.5	1.22 ±0.74	1.04 ±0.2	1. 08 ±0.34	3.18 ±1.5
n=5	Median	11	1	1	1	3
Delayed	Mean ±sd	10.1 ±6.15	1.73 ±1.03	1.52 ±0.9	1.33 ±0.8	1.76 ±0.97
n=9	Median	9	1	1	1	1

* Scores range from 1 to 6, on a 6-point Likert scale

Table 23 shows the mean ±sd total seven-day step count in the delayed and exercise group. There is no significant difference between groups at baseline (p=0.78) or at assessment one (p=0.77).

Table 23: Total mean step activity monitor counts.

	Non-exercise	**Exercise**
	Mean ±sd	
Baseline	1522.1 ±1524.55	1326.12 ±-1355.76
Assessment one	969.56 ±-1030.63	1197 ±-1563.97
Change Scores	-230.2 ±-672	-274.7 ±434.2

Table 24: Indicates number of times during the week individuals were active for a specific time period (1 minute, 30 seconds, 15 seconds).

Mean ±sd		Two-minute step count	One-minute step count	Number of times during the week spent walking for the below time periods. 1 minute	30 seconds	15 seconds
Exercise Group	Baseline	136	68	0	17	77.42
		±57	±28	±0	±27.61	±82.12
	3 Months	136	68	0	16.4	38.6
		±57	±28	±0	(36.67)	±80.8
Delayed	Baseline	153	72	0	3.2	298.42
Group		±53	±25	±0	±4.1	±403
	3 Months	153	72	1.33	7	151.7
		±53	±25	±2.8	±10.6	±196

Table 25 shows two-minute walk data that was reported for those individuals participating in the study that were still walking. There is no significant difference between groups at either baseline, p=0.9, or at assessment one, p=0.5.

Table 25: Two-minute walk data over the course of the intervention.

Two-minute walk distance	Exercise Group (n=7)	Delayed Group (n=11)
Baseline		
N	6	8
Mean ±sd	66 ±66.62	62 ±33.87
Range	15.8 – 192	19.8 – 129
Median	36.9	60.7
IQR	27 – 89.2	38.3 – 75.3
Assessment one: 3 months		
N	5	7
Mean ±sd	40 ±19.96	49 ±25.02
Range	20.5 – 71	13 – 93.5
Median	42	50.5
IQR	24.5 – 43	35 – 57
Change Data		
Mean ±sd	-0.94 ±12.6	-3.9 ±6
Median	1.7	-4.4
IQR	-7.9 – 4.7	-5.7 – -2.5

Table 26 shows the baseline and data taken for the fatigue severity scale at assessment one. There was no significant difference between the group.

Table 26: FSS shown at baseline and assessment one at three months.

	Exercise Group (n=7)	Delayed Group (n=11)
Baseline		
n	7	11
Mean ±sd	4 ±1.54	4 ±1.04
Range	2.3 – 6	2.1 – 6
Median	3.5	4.3
IQR	2.5 – 5.8	3.9 – 4.9
3 Months		
n	7	11
Mean ±sd	4 ±1.36	4 ±1.12
Range	1.8 – 5.5	1.5 – 5.8
Median	4.3	4.3
IQR	2.5 – 5.1	3.4 – 4.6
Change Data		
Mean ±sd	0.13 ±1	-0.33
Median	0.12	-0.25
IQR	-0.5 - 1	-0.62 - 0

8.4.3 Pooled before and after intervention data

The results in Table 27 demonstrate the seven-day step counts from the step activity monitor and the mean change score between assessment one at baseline and assessment three at six months.

Table 27: Mean Step Activity monitor results

N=11 Mean ±sd	Before	After	P*
Total step Counts	1435 ±1413	1907 ±1503	0.4
Change score.	-58 ±458.3		

*** Significance is shown at the 0.05 level (2 tailed)**

Table 28 demonstrates the number of time periods that individuals were walking at their self-selected walking speed, therefore working at an aerobic threshold of 40% of VO_2 max.

The amount of times spent walking at their Self-Selected Walking Speed for 30 seconds increased to 28 from 10, however the amount of time spent walking for just 15 seconds decreased from 188 to 120.

Table 28: Step activity monitor counts revealing activity levels in 1-minute, 30-second and 15-second time periods.

			Number of times spent during the week walking for the below time period at self-selected walking speed.		
	Two-min. step count	One min. step count	1 minute	30 seconds	15 seconds
Before n=11	145	70.2	0	10	188
	53	26	0	20.2	302
After n=11	145	70.2	0	28	120
	53	26	0	57	157

Table 29 shows no significant difference is reported after the intervention in the PASE, FSS or two-minute walk.

Table 29: Pooled Before and after data physical activity scale for the elderly, fatigue severity scale and 2 minute walk.

	Before		After		Difference (After – Before)		P-value*
	n	Mean ±sd	n	Mean ±sd	n	Mean ±sd	
PASE	16	77.08 ±49.70	16	96.17 ±58.60	16	19.09 ±40.23	0.3
FSS	16	3.87 ±1.30	16	3.74 ±1.36	16	-0.14 ±0.83	0.8
Two-minute Walk	12	45.56 ±25.50	12	62.29 ±32.61	12	16.73 ±27.27	0.2

* Significant to 0.05, paired t-test.

8.5 Discussion

This study confirms the feasibility of the exercise programme combined with the PAPSS within the community environment for people with MS and thereby successfully fulfilling one of the main aims of this Phase II exploratory trial. Furthermore, the intervention was adhered to, as illustrated by the high level of gym attendance within both the intervention and control group throughout their periods of exercise intervention (mean attendance n=10, see Table 22).

8.5.1 Results interpretation

The primary outcome measure, the physical activity scale for the elderly, was successfully completed. Scores improved following the exercise intervention in both the immediate exercise group (between baseline and three months) and the control (delayed exercise) group (between three and six months). This was contrasted by a lack of improvement between baseline and three months for the control group. Combined, these findings suggest that the supported exercise intervention may improve physical activity levels within MS. Whilst the PASE has not been previously utilised as an outcome measure following exercise within MS; similar positive results have been reported using another self-report physical activity measure. Mostert and Kesselring (2002) noted an improvement in self-reported physical activity through utilisation of the Baecke Activity Questionnaire following five weeks of aerobic exercise (Mostert and Kesselring, 2002). However, the results of the PASE are not supported by the improvements in mean step count reported by the SAM; individuals appeared to take an average of 300 steps less after the intervention. This was a

surprising finding and may be due to increased fatigue after the intervention or a reduction in steps taken at home due to the increased activity in a fitness centre.

After every gym session each individual was required to complete a session progress sheet (Appendix 5). There were several reasons for this: it served as an effective way of monitoring numbers of attendances, and as this was a pilot study, the ratings and comments provided could be used as a guide for future studies.

8.5.2 Efficacy

The pooled before-after intervention scores for the fatigue severity scale indicated a slight improvement in fatigue following completion of the exercise programme. Previous studies investigating various exercise programmes, including both a stand-alone aerobic intervention (Mostert and Kesselring, 2002) and a 24-week combination of yoga and aerobic exercise (Oken et al., 2004), have also led to improvements in fatigue in MS patients. However, these studies utilised multidimensional fatigue measures, such as the Multidimensional Fatigue Inventory (Oken et al., 2004) rather than the FSS. The FSS is a widely used measure, but its sensitivity in capturing possible improvements in the complex phenomenon of fatigue within MS has been questioned following a recent systematic review (Dalgas, 2008). No studies reported within the review that had utilised the FSS could demonstrate an effect of exercise on fatigue. From this perspective, these results differ slightly from previous findings. However, it could be hypothesised that a greater effect

would have been seen within this study if a multidimensional fatigue measure had been used instead of the FSS.

The pooled results for the two-minute walk test showed an improvement in endurance following the exercise intervention. This is in agreement with a previous study by Taylor et al (2006), who reported similar changes in the two-minute walk test following a four-week resistance training intervention in nine people with MS. Whilst evidence for this particular outcome measure is limited in this clinical population, other studies have noted similar improvements in endurance following exercise in MS. This is exemplified by improved six-minute walk test results in 19 people with MS following an eight-week aerobic training programme (Rampello, 2007). However, the six-minute walk was deemed unsuitable for this study due to the time constraints, the study assessment was relatively long and therefore asking individuals to walk for the 6 minute walk was too long a period. . Therefore, there appears to be some consensus from this study and the previous literature that exercise improves physical endurance in MS.

The results presented in this study are in line with the findings of McAuley et al (2007), who conducted a three-month randomised controlled trial (n=26) aiming to influence self efficacy in MS patients, in an effort to increase physical activity participation. The trial, contrasted the effects of an efficacy enhancement condition and a control exercise condition on exercise adherence, well-being and affective responses to exercise. Analyses indicated that individuals in the efficacy enhancement condition attended more exercise sessions and reported greater levels of well-being. However, although

promising, the overall multivariate effect for the intervention condition on adherence was non-significant, which is unsurprising considering the small sample size.

Participants within this study were informed that observations from previous studies (McAuley et al., 2007) have indicated that it is expected that people who have been through a similar type of training regime will experience an improvement but that some may not.

8.5.3 Intention-To-Treat analysis (ITT)

This study conducted ITT analysis, intention-to-treat gives a pragmatic estimate of the benefit of a change in treatment policy rather than of potential benefit in patients who receive treatment exactly as planned (Hollis and Campbell, 1999) and is a strategy for the analysis of randomised controlled trials that compares patients in the groups to which they were originally randomly assigned. This is generally interpreted as including all patients, regardless of the treatment they actually received, and subsequent withdrawal or deviation from the protocol. However there is a debate about the validity of excluding specific cases within each of these categories from an intention-to-treat analysis (Fisher, 1990). Clinical effectiveness may be overestimated if an intention-to-treat analysis is not done (Bollini et al., 1999).

8.5.4 Limitations

This study does have some limitations. It was a feasibility study and for future larger trials, a total sample size of 180 would allow the detection, with 90% power, of a moderate to large treatment effect of 2/3 of a standard deviation this was calculated using the physical activity scale for the elderly outcome measure.

Six of the 18 participants could not complete the two-minute walk test, and step activity monitor data was unavailable for six participants at three months and 11 participants at six months. This was due to four participants dropping out from the study. Four individuals forgot to wear the SAM at all, and three individuals did not complete the full seven-day period. This resulted in a reduction in sample size, decreasing the power of the SAM results.

Gym attendance was self-reported and all data was cross-confirmed with data from the gym instructor. Whilst the positive PASE result suggested this community-based, supported exercise programme may have a positive effect on physical activity levels, the self-report nature of the session progress sheet (Appendix 5) and its reliance on retrospective recall of activity leaves this outcome measure open to recall bias.

The sample of participants within this study may have been subject to recruitment bias, as Oxfordshire-based neurologists were responsible for referring appropriate individuals into the study. Hence their decision not to refer certain individuals may reflect recruitment bias. The sample may have been representative of a self-selected group, it must be considered that those

who consented to take part in the study already had an interest in physical activity, and so would not be considered a true representation of a non-bias group of individuals with MS. Although this study aimed to be as inclusive as possible, there are certainly individuals who were not included, such as those with severe cognitive impairment or those who are bed bound.

This study was conducted as part of a PhD, so funding and time were also limitations, and resources were limited throughout this study.

Blinding was an issue within this study. Approximately 1/4 of participants accidentally revealed their group allocation to the researcher conducting the assessments, which was unfortunately unavoidable.

A limitation of the PAPSS was the initiation of exercise sessions. It is possible that attendance would have been higher if more assistance had been provided, and some individuals expressed difficulty in 'getting started' with their exercise sessions.

This study was a phase II randomised controlled trial. Although RCTs are currently recognised as the gold standard methodology for enabling assessment and quantification of treatment/intervention effectiveness (McPherson, 1994), some of the limitations of RCTs must be considered. These limitations are discussed below.

Depending on their size, follow-up times and number of personnel required, RCTs are expensive research methodologies (Koes, 1998). And although RCTs are attractive to funders, a prohibitively expensive trial may prevent a

trial from ever being launched. This was certainly a factor that limited the trial size in this study.

A further issue that needs to be considered is contamination. Black (1996) describes the possibility of contamination if clinicians involved in a trial have to provide more than one intervention arm. Since the way in which the arms are delivered to patients may be influenced by this, this was of concern in this study as several of the participants were members of the same MS society branch and attended regular meetings together, where it would have been possible to discuss their involvement in this study.

One final limitation of randomised trials is excessive bias, which can render a trial inadequate. Randomisation may give rise to bias. However, depriving patients of choice can also affect therapeutic outcome and thus may lead to a biased measure of effectiveness (McPherson, 1994). As discussed above, bias may have occurred from several sources within this study.

In order to confirm the effectiveness of this intervention, a phase III trial of adequate power is required.

8.6 Conclusion

This study suggests that an exercise intervention, carried out within community leisure centres with physiotherapeutic and fitness instructor support, is feasible, well received by people with multiple sclerosis and appears to improve physical activity levels, physical endurance and fatigue.

9 Discussion

9.1 Summary of study findings.

The aim of this thesis was to present a detailed investigation into various aspects of physical activity among individuals who have multiple sclerosis (MS). There were 5 studies that endeavoured to do this. This chapter will summarise the main findings from these studies. For each of these five component pieces of research the main implications of the research and the priorities for future research will also be summarised. Finally the conclusions of this thesis will be presented.

9.1.1 Pedometer step counts in individuals with neurological disease

The main purpose of this study was to investigate pedometer accuracy in individuals with neurological disease. The results showed that pedometers were relatively accurate in healthy individuals (mean pedometer step count: 229 $\pm$ 13) however they appear to under-count when utilised by people with neurological conditions (138 $\pm$ 85).

Implications of research

Pedometers are a useful motivational tool, however in a clinical setting the use of pedometers should be limited and the suitability of pedometer use for exercise monitoring should be individually determined.

Future research suggestions

Further study of pedometers using larger sample sizes is warranted to highlight characteristics for use of such a tool in all settings and to explore the possibility of predicting gait characteristics that relate to the level of inaccuracy.

9.1.2 The test – retest reliability of the Physical Activity Scale for the Elderly (PASE)

This study investigated the test-retest reliability of the PASE questionnaire, as this was to be used throughout the thesis as a primary outcome measure. The PASE questionnaire was deemed to be reliable and sensitive to this population and with a test - retest reliability coefficient for the total PASE score of 0.934 (95% CI=0.62-0.97), the PASE, appeared to be robust enough to use throughout the thesis.

Implications of research

This study is the first one to assess the PASE questionnaire in individuals with multiple sclerosis, it was well tolerated and shown to be reliable when used within this population. This indicates the potential use of the PASE In clinical environments when a short assessment of physical activity is required. Previously the PASE has only been used in the elderly and physically disabled.

Future research suggestions

This study was underpowered due to recruitment time restraints so a clear suggestion for future research would be to further investigate the reliability of the PASE using a larger sample size. Also of interest would be to assess the reliability of the PASE in other neurological diseases. This would provide useful information as to the usefulness of the PASE as an outcome measure when studying physical activity in these clinical populations.

9.1.3 Mobility and physical activity levels in the community in individuals with multiple sclerosis.

This study aimed to inform researchers how active individuals with multiple sclerosis actually are in a community environment. Actual physical activity levels were measured in 23 individuals with MS using a step activity monitor, combined with the PASE questionnaire. The PASE can be broken down into three domains of physical activity, home, work and social. It was clear in this study that individuals were more active in their home environment and were least active in their social domain.

This study contributed new knowledge to the area of physical activity research by determining the proportion of physical activity in which individuals with MS participate, that was intense enough to elicit an aerobic effect. The findings from this were used to determine the frequency, intensity and duration of the physical activity in which individuals with MS participated. Although individuals with MS are physically active to a certain degree, it was found in this study that they only are active enough to illicit an aerobic effect for a very limited

amount of time.

Implications of research

This study contributes information with regards to where individuals with multiple sclerosis are most active in their everyday lives. It was interesting that they were more active in their home environment, and least active in their social domain, this should be taken into account by health care professionals such as physiotherapists when prescribing exercise.

In this study the step activity monitors (SAMs) were used to assess weekly physical activity, specifically using step counts. Interestingly, this study provided information regarding the frequency, intensity and duration of their walking activity. This was observed by looking at how many occasions during a week individuals walked at their self-selected walking speed (SSWS) continuously for periods of 1 minute, 30 seconds and 15 seconds. Despite the SAM recording activity during the week it fails to record or detect how meaningful the proportion of steps taken are. The data recorded showed that individuals spend very little time in a week walking continuously at their SSWS, and are therefore not spending enough time walking at an aerobically efficient threshold (40% of VO_2 max).

Future research suggestions

Following on from the PASE findings, further investigation would be warranted to determine actual reasons as to why individuals are more active in certain environments. Also targeted exercise programs that aim to increase physical

activity in an aerobic zone may be developed by using the physical activity intensity findings, this may be helpful when guiding individuals exercise prescription.

9.1.4 Perceived barriers and facilitators to physical activity in individuals with progressive neurological conditions (PNCs): a focus group and questionnaire study

This study investigated the barriers and facilitators to physical activity and exercise participation in individuals with progressive neurological conditions. The study revealed interesting findings and it was clear that individuals are not as active as they would like to be. Barriers to physical activity included travel problems, cost, and lack of confidence in fitness professionals and feelings of embarrassment when exercising in the same environment as healthy individuals. This study also investigated where individuals would prefer to exercise and with whom. The findings were contradictory to previous studies, with the majority of individuals stating that they would prefer to exercise within a community environment, under the supervision of fitness staff with experience of neurological conditions. It was interesting to note that the majority of individuals discussed how they would prefer to exercise in an environment or group with others who have the same condition, or at the very least, a physical disability.

This study discussed many findings that contribute to previous barriers to physical activity participation. However, the novel findings from this study include the investigation of location and personnel with whom participants feel

confident to exercise.

Implications of research

This study is one of the few available that looks into barriers and facilitators to physical activity in individuals with neurological diseases, and so has contributed new knowledge to the limited research available. This study also contributes useful information as to where and with whom these individuals would like to participate in regular exercise; this information could be taken into consideration by health professionals when planning exercise participation.

Future research suggestions

This study reported that individuals with neurological conditions feel more comfortable when exercising under supervision of medical staff, such as physiotherapists. What was not explored within this study was the reasoning behind this. It would be of interest to further study why this is and how these feelings could be changed in the future.

Exercise experience prior to diagnosis is a topic that was not really touched on in the presented study; however, it would be an interesting topic for further investigation. Borkoles et al (2008) state that "The social implications of having MS are that the person will eventually exclude themselves form sport/exercise/physical activity. The enjoyment and adherence in turn are also affected, and again results in less (exercise/ physical activity) participation."

9.1.5 A Phase II randomised controlled trial of a Long-term Individual Fitness Enablement (LIFE) intervention for people with multiple sclerosis

This study reported findings from a phase II randomised controlled trial entitled 'The LIFE study' in which a novel physical activity provision support system (PAPSS) was developed. This study evolved from many of the findings within this thesis and aimed to eliminate the main barriers to exercise participation outlined in Chapter 7. To do this, physiotherapy support was provided to encourage confidence in the fitness instructor, costs were covered for gym admission and transport to and from the facility was organised for the duration of the intervention.

An important feature of the LIFE study was to promote confidence and encourage increased independence when exercising and participating in physical activity in individuals with MS. The study in Chapter 7 highlighted the emphasis individuals with neurological conditions place on the perceived necessity for medical (physiotherapy) presence when they are participating in physical activity.

Current NHS practice provides individuals with an average of six physiotherapy sessions after referral (Chartered Society of Physiotherapists, 2002). These physiotherapy sessions are where the majority of individuals receive their physical activity. Obviously this is not practical. Giving encouragement to these individuals and explaining that attending a gym or leisure centre is achievable would be highly beneficial to the NHS system, and would also increase independence, physical activity levels and hopefully

fitness levels. The LIFE study found that if barriers are addressed then attendance to a leisure facility/fitness session can be increased.

Implications of research

This study demonstrated the feasibility of an exercise programme combined with a PAPSS, within the community environment for people with MS.

The PAPSS was unique in its multi-factorial approach to solving issues that had been identified as barriers to participation among these individuals. No previous study had investigated the effects of a community based intervention, with fitness staff delivering the intervention.

Future research suggestions

Firstly it is believed that the current trial demonstrated the need for a future adequately powered trial to further investigate the effectiveness of the PAPSS. This Phase III trial was funded by the Department of Health's' National Service Framework for Long Term Neurological Conditions (NSF LTNC). This Phase III study was completed in 2010. It is hoped that this will provide further information on the effectiveness of the physical activity provision support system.

Secondly, further study into the type of exercise preferred by these individuals would provide useful information for health professionals regarding exercise session planning and also for researchers to gain an insight into the differing preferences between disease groups.

Thirdly, one of the interesting observations from this study, which taken into consideration when planning the Phase III trial, was the difficulty in initiating the first session. It was evident and discussed openly by participants that they found it particularly difficult to make the initial contact with the leisure facility and respective fitness instructor. This was due to lack of confidence and the Phase III trial took this into account and the physiotherapist made contact with the individual to organise their first session.

Fourthly, as a result of this study further investigation into the type of exercise individuals selected to do whilst they were exercising in a gym and the duration of their exercise sessions is warranted. This was not something that was investigated during this study, due to time restraints.

Finally, to further investigate the physiological effects of increased physical activity would be of interest. It has been demonstrated that it is feasible to increase individual's physical activity, but is this benefiting them physiologically? An important factor when investigating physical activity participation and perhaps a predictor as to how much these individuals exercise is level of exercise experience and activity prior to MS diagnosis and onset. It would be of interest to determine whether there is a correlation between pre and post diagnosis exercise levels.

9.2 Implications of Research

A clear message delivered throughout this thesis is the need for individuals with neurological conditions, specifically multiple sclerosis, to become more active and increase their participation in physical activity and exercise.

Clinicians should actively encourage physical activity participation among individuals with neurological conditions and it is important that both doctors and physiotherapists encourage this type of participation in a community-based environment to discourage dependence on medical services. One of the barriers to participation found, and discussed in Chapter 7, was lack of confidence when exercising without the supervision of medical personnel, such as physiotherapists.

Physiotherapists who specialise in neurological conditions may lack confidence when prescribing exercise for fitness and when recommending a suitable leisure facility that individuals with MS would feel comfortable attending. If they are to take an active role in promoting exercise for fitness and health, physiotherapists should have a better understanding of what facilities can provide.

If individuals with MS are to be encouraged to attend gyms, leisure facilities and community-based centres then it is also important that these facilities acknowledge and make adaptations to the barriers to participation that are expressed by these individuals. A benchmark for these facilities would be to become Inclusive Fitness Initiative (IFI) approved.

The Inclusive Fitness Initiative is a programme encouraging the fitness

industry to become more inclusive, catering for the needs of disabled and non-disabled people, and raising physical activity participation levels. The model is built around developments in four key areas: accessible facilities, inclusive fitness equipment, staff training, and inclusive marketing strategies.

None of the participants in the studies in this thesis had previously heard of a facility that was IFI approved, nor had they had the confidence to go to their local leisure centres to see whether the facilities were suitable for them to use. This lack of knowledge needs to be addressed; this may be in the form of improved marketing and advertising by the IFI in hospitals and within condition user groups, where it would target the appropriate individuals more readily.

Findings from the focus group study revealed several barriers to physical activity participation, these findings should be shared within several domains if they are to be acknowledged and resolved. Leisure facilities should be made aware of the key barriers (e.g. regarding access) and facilitate change to enable better access. Improved staff training is also another consideration that the leisure industry should consider.

The benefits of this are two-fold: individuals with neurological conditions will benefit from the increased knowledge of the fitness instructor, feeling more confident that they understand their condition, and the fitness instructor will feel more confident when prescribing exercise to these populations.

In 2006 the National Service Framework for Long Term Neurological Conditions (NSF LTNC) was allocated £2million from the Department of Health (DoH) and six research projects were commissioned. The projects look

at different aspects of implementing the NSF LTNC and aim to provide useful tools and information for commissioners and service providers.

The six original research topics are:

1) Integrated services: impact of the NSF LTNC,

2) Needs & experiences of people with progressive neurological conditions,

3) Carer support needs,

4) Palliative care needs in late stage Long-term Neurological Conditions,

5) Transition into adulthood in Duchenne MD,

6) Fitness enablement programme for Long-term Neurological Conditions.

After conducting the Phase II RCT trial detailed in Chapter 8, the Movement Science Group at Oxford Brookes University applied for and were successful in being awarded funding to conduct a Phase III trial of the LIFE study (6 - Fitness enablement programme for Long-term Neurological Conditions) in a larger cohort of individuals with a range of neurological conditions.

A further £1million funding was made available in 2007 and four more projects were commissioned in spring 2008. The overall programme ended in 2010.

9.3 Limitations

9.3.1 Sample size

The Phase II study reported in Chapter 8 was primarily a feasibility study so no formal power calculation was conducted. This study had a small sample size; this was due to a lack of resources, time and funding.

9.3.2 Outcome measures

Implications of the use of primary outcome measures

Chapter 3 established that the PASE questionnaire was demonstrated to be valid and reliable. Chapter 3 demonstrates that The step activity monitors, originally designed for use by amputees, have been demonstrated to be valid in individuals with neurological conditions (Busse et al., 2004) and are reliable (Coleman et al., 1999) and accurate (Shepherd et al., 1999).

The presence of these properties implies that the PASE questionnaire and the SAMs are sound measures that evaluate the constructs intended. No negative effect was found for any properties with the PASE or the SAMs.

Implications of use of secondary measures

The secondary outcome measures were selected to support the primary outcome measures, providing additional descriptive information. As a result their use does not have major implications regarding the primary outcomes of the trial. However, it is worth noting that the properties of the fatigue severity scale (FSS) have been questioned in a recent paper (Mills et al., 2008). The

paper by Mills et al (2008) found that two items had poor discrimination across the scale, and two further items showed bias for factors such as age. A recent paper found the FSS has acceptable reliability with regard to internal consistency, test-retest reliability, and validity in persons with motor complete SCI (Anton et al., 2008). A study conducted by Flachenecker et al (2002) found the FSS to be significantly correlated with physical disability ($r=0.33$, $p<0.0001$) but not with age, disease duration, clinical activity, and treatment with interferon-beta. The FSS was used successfully as a secondary measure throughout this thesis and it was thought the evidence supporting the FSS constructs made it an appropriate outcome tool.

9.3.3 Bias in the RCT

Recruitment bias may have been a concern in Chapter 8. Individuals were recruited through Oxfordshire-based consultant neurologists (subjecting the study to recruitment bias) and the referring neurologists were potentially only referring subjects they deemed suitable to participate.

It is possible that the participants within this study were representative of a self-selected group and it is likely that the individuals that chose to participate in the RCT had a previous interest in physical exercise, so this sample may not reflect a true random sample of individuals with MS.

9.3.4 Blinding within the RCT

It would be naive to assume that all participants remained blinded to the researcher conducting the assessments. Although it had been previously stressed that individuals were not to reveal their group allocation to the researcher carrying out their assessments. Approximately 1/4 of individuals revealed their group allocation; however it is unlikely that assessor bias had any implications regarding the outcomes of the trial.

9.4 Conclusions

In conclusion, it is evident that individuals with multiple sclerosis are not as active as they say they would like to be. This thesis has investigated their physical activity levels, the reasons, and perceived and actual barriers to participation. These findings served to guide the development of a Phase II randomised controlled trial that aimed to determine the feasibility of a physical activity provision support system. Based on the findings of the RCT study described in Chapter 8, it is conceivable that if a better support system was to be put in place for these individuals then regular community-based exercise sessions could be increased. However, making moves to improve exercise support systems would necessitate a multi-disciplinary approach.

2. Appendices

Appendix 1

Rivermead Mobility Index

Instructions

The patient is asked the following 15 questions (observed for item 5). A score of 1 is given for each 'yes' answer. If the patient has communication problems, ask the carer. Please indicate if the responses are those of the carer.

Subject (please record the subject using a code to protect the patients anonymity).

Date of stroke

Date of assessment

Qu No	Question	Comment
1	*Turning over in bed* Do you turn over from your back to your side without help?	
2	*Lying to sitting* From lying in bed, do you get up to sit on the edge of the bed on your own?	
3	*Sitting balance* Do you sit on the edge of the bed without holding on for 10 seconds?	
4	*Sitting to standing* Do you stand up (from any chair) in less than 15 seconds and stand there for 15 seconds (using hands and with an aid if necessary)	
5	*Standing unsupported* Observe standing for 10 seconds without any aid?	
6	*Transfer* Do you manage to move from bed to chair without any help?	
7	*Walking inside* Do you walk 10 metres (yards) with an aid if necessary but with no standby help?	
8	*Stairs* Do you mange a flight of stairs without help?	
9	*Walking outside (even ground)* Do you walk around outside on pavements without help?	
10	*Walking inside (no aid)* Do you walk around inside with no calliper, splint, or aid and no standby help?	
11	*Picking off floor* If you drop something on the floor, do you manage to walk 5 metres, pick it up and then walk back?	
12	*Walking outside (uneven ground)* Do you walk over uneven ground (grass, gravel, dirt, snow etc) without help?	
13	*Bathing* Do you get in and out of the bath or shower unsupervised and wash yourself?	
14	*Up and down four steps* Do you mange to go up and down four steps with no rail, but using an aid if necessary?	
15	*Running* Do you run 10 metres without limping in four seconds (fast walk is acceptable)	

Appendix 2: Modified Physical Activity Scale for the elderly (PASE)

I am interested in how much time you have spent doing the following activities over the last 7 days.

Leisure time activity

1. Walking outside the home
How much time was spent on the activity over the last 7 days (tick as appropriate)

Never (0 days)	Seldom (1 to 2 days)	Sometimes (3 to 4 days)	Often (5 to 7 days)

How many hours per day did you spend on this activity?

Less than 1hour	1 to 2 hours	2 to 4 hours	More than 4 hours

2. Light sport/recreation
Name the activity/activities_____
How much time was spent on the activity over the last 7 days (tick as appropriate)

Never (0 days)	Seldom (1 to 2 days)	Sometimes (3 to 4 days)	Often (5 to 7 days)

How many hours per day did you spend on this activity?

Less than 1hour	1 to 2 hours	2 to 4 hours	More than 4 hours

3. Moderate sport/recreation
Name the activity_____
How much time was spent on the activity over the last 7 days (tick as appropriate)

Never (0 days)	Seldom (1 to 2 days)	Sometimes (3 to 4 days)	Often (5 to 7 days)

How many hours per day did you spend on this activity?

Less than 1hour	1 to 2 hours	2 to 4 hours	More than 4 hours

4. Strenuous sport/recreation
Name the activity_____
How much time was spent on the activity over the last 7 days (tick as appropriate)

Never (0 days)	Seldom (1 to 2 days)	Sometimes (3 to 4 days)	Often (5 to 7 days)

How many hours per day did you spend on this activity?

Less than 1hour	1 to 2 hours	2 to 4 hours	More than 4 hours

5. Muscle strength/endurance exercises
Name the activity_____
How much time was spent on the activity over the last 7 days (tick as appropriate)

Never (0 days)	Seldom (1 to 2 days)	Sometimes (3 to 4 days)	Often (5 to 7 days)

How many hours per day did you spend on this activity?

Less than 1hour	1 to 2 hours	2 to 4 hours	More than 4 hours

Household Physical Activities

Have you performed the following activities over the last 7 days (tick appropriate box)

1. Light housework

No	Yes

2. Heavy housework and chores

No	Yes

3. Home repairs

No	Yes

4. Lawn work

No	Yes

5. Outdoor gardening

No	Yes

6. Caring for another person

No	Yes

Work related physical activity

In the last 7 days how many hours paid work have you done._____

Would you describe your work as mainly: (Please tick appropriate box)

1. Sitting with slight arm movements	
2. Sitting or standing with some walking	
3. Walking with some handling of materials generally weighing less than 50 pounds	
4. Walking and heavy manual work often requiring handling of materials weighing over 50 pounds.	

Appendix 3. BARTHEL ADL

	Score
Feeding	
0 = unable	
1 = needs help cutting, spreading butter, etc, or requires modified diet	
2 = independent	
Bathing	
0 = dependent	
1 = independent (or in shower)	
Grooming	
0 = needs help with personal care	
1 = independent face/hair/teeth/shaving (implements provided)	
Dressing	
0 = dependent	
1= needs help but can do about half unaided	
2 = independent (including buttons, zips, laces, etc.)	
Bowels	
0 = incontinent (or needs to be given enemas)	
1 = occasional accident	
2 = continent	
Bladder	
0 = incontinent, or catheterised and unable to manage alone	
1 = occasional accident	
2 = continent	
Toilet use	
0 = dependent	
1 = needs some help, but can do something alone	
2 = independent (on and off, dressing, wiping)	
Transfers (bed to chair and back)	
0 = unable, no sitting balance	
1 = major help (one or two people, physical), can sit	
2 = minor help (verbal or physical)	
3 = independent	
Mobility (on level surfaces)	
0 = immobile or < 50 yards	
1 = wheelchair independent, including corners, > 50 yards	
2 = walks with help of one person (verbal or physical) > 50 yards	
3 = independent (but may use any aid; for example, stick) > 50 yards	
Stairs	
0 = unable	
1= needs help (verbal, physical, carrying aid)	
2 = independent	

Appendix 4: Fatigue Severity Scale (FSS)

My motivation is lower when I am fatigued.

---

0 1 2 3 4 5 6
Strongly disagree disagree neither agree nor disagree agree, strongly agree

Exercise brings on my fatigue.

---

0 1 2 3 4 5 6
Strongly disagree disagree neither agree nor disagree agree, strongly agree

I am easily fatigued.

---

0 1 2 3 4 5 6
Strongly disagree disagree neither agree nor disagree agree, strongly agree

Fatigue interferes with my physical functioning.

---

0 1 2 3 4 5 6
Strongly disagree disagree neither agree nor disagree agree, strongly agree

My fatigue prevents sustained physical functioning.

---

0 1 2 3 4 5 6
Strongly disagree disagree neither agree nor disagree agree, strongly agree

Fatigue interferes with carrying out certain duties and responsibilities.

---

0 1 2 3 4 5 6
Strongly disagree disagree neither agree nor disagree agree, strongly agree

Fatigue is among my three most disabling symptoms.

---

0 1 2 3 4 5 6
Strongly disagree disagree neither agree nor disagree agree, strongly agree

Fatigue interferes with my work, family, or social life.

---

0 1 2 3 4 5 6
Strongly disagree disagree neither agree nor disagree agree, strongly agree

Appendix 5: Individual Progress Sheet

Long – term Individual Fitness Enablement (LIFE) Pilot
Progress Sheet

- So we can see how you are finding attending the gym we would like you to fill in one of these forms after each time you have attended the gym.
- This shouldn't take more than a few minutes of your time and will be really useful for us to be able to see how you have enjoyed your sessions at the gym; it will also provide a good way for you to flag up any problems you may have encountered along the way.

Date of visit……..

Time of visit……..

How was today's session in relation to the areas below:

How enjoyable was you session?	Very Enjoyable 1	2	3	4	5	Not at all enjoyable 6
How helpful were the staff?	Very Helpful 1	2	3	4	5	Not at all Helpful 6
Did you encounter any problems with the equipment?	No problems at all 1	2	3	4	5	Major problems 6
How happy, satisfied or pleased are you with your personal life today?	Extremely Happy 1	Very Happy 2	Fairly happy 3	Satisfied, pleased 4	Somewhat dissatisfied 5	Very dissatisfied 6

If you have any comments you think we should know about please tell us here!

……
……
……
……

Appendix 6: Instructions for wearing a Step Activity Monitor

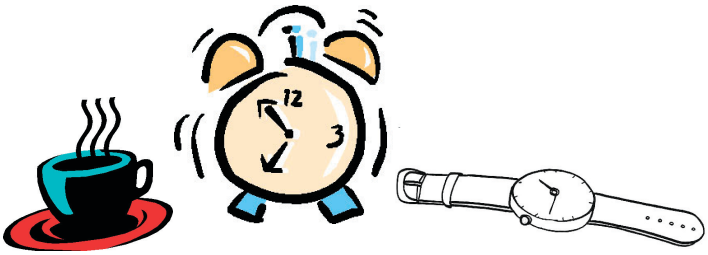
Instructions for Wearing the StepWatch

ORIENTATION: The StepWatch must to be worn with the rounded end UP. The writing on the case should appear right-side up to someone standing beside you.

PLACEMENT: The StepWatch is worn just above the ankle bone on either side of either leg. It should not be worn on the front or back of the ankle.

Adjust the velcro strap for comfort. Do not fasten it overly tightly. If you want additional padding, you can wear an extra sock. Alternatively, you may stick moleskin to the back of the monitor. Be sure the strap is in place before attaching the moleskin.

SCHEDULE: Put the StepWatch on right away when you get up in the morning, and wear it throughout the day. When you take it off at night, put it somewhere that you will remember to put it on first thing in the morning such as with your glasses, clock or watch.



CARE: Do not leave the StepWatch in hot places such as on the dashboard of a car. Please treat it with reasonable care. Do not throw it, cut into it, or remove the label. The StepWatch is waterproof. You can bathe or swim with it, but you may find the wet strap uncomfortable afterwards. If you want to wash the StepWatch, use only mild soap and water.

WEAR DAILY UNTIL the end of the day on: _____

RETURN YOUR STEPWATCH ON: _____

If you have questions, feel free to contact us at:

Appendix 7: Questionnaire developed by researcher, used in Chapter 7

Despite the vast amount of evidence that links regular exercise with improved health and well-being - it is also evident that people with disabilities are far less likely to exercise. According to the Healthy People 2010 report, more than half of all adults with disabilities do not take part in exercise. Our study sets out to investigate the factors that encourage or discourage exercise for people with disabilities.

Exercise and physical activity can take place in a variety of settings, such as a fitness centre or simply in the home. We are interested in your views, where you would like to exercise and factors that may enable you to take part.

One of the problems is that people use different terms to describe exercise, such as physical activity.

For the purposes of this questionnaire we are assuming the definition of “exercise” to be:

> “ A form of physical activity to improve well being. ”

Examples include:

Exercises in a fitness centre
Exercise classes
Swimming
Walking for pleasure
Stretching

Please bear this in mind when answering questions.

Date of Birth -……..

Sex – Male / Female

Condition - ……

1.a How often do you participate in exercise on average in a typical week? (Please circle appropriate answer)

Not at all 1 x week 2 x week 3 x week 4 x week 5 x week

b) On the occasions you do exercise, how long on average would you say each session lasted for?

15 mins 30 mins 45 mins 1 hour +

2. To what extent do you enjoy exercising? (Please circle appropriate answer)

A lot quite a lot not a lot not at all

3. What activities do you enjoy? (Please circle all those that apply)

1 Walking

2 Stretching

3 Swimming

4 Specific exercises (please describe)

5 Group exercises (i.e. exercise classes)

6 Circuit training

7 Strength work (using weights)

8 Other (please describe)

……
……

4.If you were to have exercises provided in the community where would you like to exercise? (Please circle all those that apply)

1 Leisure centre

2 Home

3 Community centre

5 Exercise facility i.e. Gym

4 Other (please state)

……
……
……

5. What factors would/do prevent you from participating in physical activity/ exercise within an exercise environment? (Please circle all those that apply)

1 Cost

2 Travel problems

3 Facilities i.e. equipment, changing rooms

4 Lack of time

5 Concerns about help available within the gym

6 Embarrassment,

7 Timing of sessions,

8 Lack of knowledge of condition by staff,

9 Lack of knowledge of suitable exercise by staff

10 Lack of knowledge about where to go

11 Other (please describe),
……
……
……
……

6 If you were able to exercise in a gym environment would you like ….(Tick as appropriate)

To exercise on your own but to know help was available if necessary	
To exercise in a group specifically for those with mobility problems	
To exercise in a group with the same condition as yourself	
To exercise in a group of individuals without physical disability (or without disabilities)	
Any of the above	

7 What factors would/do prevent you from participating in physical activity/ exercise at home? (Please circle those that apply)

1 Facilities- see above

2 Lack of time

3 Concern about help with the exercises

4 Embarrassment

5 Lack of knowledge of what exercise to do

6 Lack of knowledge as to whether you are doing the exercise correctly

7 Other (please state)

……
……
……

8 Using the numbers 1 to 4 (1 being the most important) please prioritise who you would like to support you while you were exercising.

Specially trained fitness professional

____

Trained physiotherapist

____

Specially trained fitness professional with physio support

____

Specially trained carer

____

Other (please describe)

……
……

Many thanks for taking the time to fill out this questionnaire.

Your contribution is greatly appreciated!
If you have any further queries now or in the future please don't hesitate to contact me on :

Charlotte Elsworth

[redacted]

[redacted]

Movement Science Group
School of Biological and Molecular Sciences
Oxford Brookes University
Gipsy Lane
Headington
Oxford
OX3 0BP

Appendix 8: Focus Group Ethics information sheet.

movement science

OXFORD BROOKES UNIVERSITY

Movement Science Group
Human Performance lab
School of Biological and Molecular Sciences
Oxford Brookes University
Gipsy lane, Headington
Oxford
OX3 OBP

Dear…….

Investigation of exercise participation for adults with long term neuromuscular disorders.

We would like to ask you to consider participating in a research project.

What is the purpose of the study?

The purpose of the study is to determine what individuals with neuromuscular conditions think would help them to take part in physical activities.
We will use your ideas to develop a questionnaire that we can send out to a larger number of individuals with neuromuscular conditions.
We hope that the findings of this study will inform further research into what could help individuals with MD, MS and stroke to improve their involvement in physical activities.

Why have you been chosen?

You are being invited to take part in the study as someone who has MS and can we would like you to talk about your experiences with this condition in relation to physical activity.

Do I have to take part?

There is no obligation to take part in the study. If you decide to take part you would be free to withdraw at any time and with out reason.

What would happen to me if I take part?

You would be asked to attend a focus group which would involve discussion issues about physical activity participation with other participants with neuromuscular conditions at Oxford Brookes University. The meeting will last approximately 1-½ hours. Travel expenses will be paid and a light lunch will be provided.

Are there any risks involved?

There are no specific risks associated with participating in the focus group above those involved in everyday living. The questions asked at the meeting will be in relation to what you think would enable participation in physical activities. You would be able to leave at anytime with out giving a reason.

Are there any benefits in taking part?

We do not expect any specific benefits for you in taking part, but the information obtained from the focus group would be used to develop a questionnaire that we can send out to individuals with a range of neuromuscular conditions. The information we get back from the questionnaires would be used to plan a study investigating improving exercise/physical activity participation and provision in individuals with a range of neuromuscular conditions.

Will the information I give you be kept confidential?

All information would be kept strictly confidential. Any information about you would have your name and address removed so you cannot be recognised. All information would be stored under conditions complying

with Data Protection Act; it will remain confidential and your name and other personal details will not be revealed under any circumstances.

What will happen to the results of the study?

The results of the study would be used as part of a PhD thesis and used to aid the future planning of studies involving exercise for individuals with Muscular Dystrophy. You would not be identified in any of the reports.

Who can I contact if I have any questions?

If you have any questions or queries please don't hesitate to contact:

Charlotte Elsworth 01865 484295 / 07780 690 419
or Dr Helen Dawes 01865 463293

If you have any concerns regarding the conduct of this study you should contact Professor Mary Boulton, the Chair of the Oxford Brookes University Research Ethics Committee on e[redacted] or the School Research Ethics officer, Dr Richard Craven on [redacted]

Investigation of exercise participation for adults with long term neuromuscular disorders.

Thank you for taking the time to read the information sheet. Please would you initial; the appropriate box and sign the consent form.

Name of Researcher…….

Please initial box

I have read and understand the information sheet for the above study and have had the opportunity to ask questions.

Yes **No**

I understand that my participation is voluntary and that I am free to withdraw at any time with out reason.

Yes **No**

I agree to take part in the above study.

Yes **No**

Name of participant…….

Date……

Signature……...

Name of researcher…….

Date……

Signature……...

Appendix 9: Focus Group guide questions:

The following statements will be explained and made clear to the individuals attending the meeting:

- You have been invited today because you are representative of individuals with neuromuscular conditions.
- The discussion will be taped to help us remember exactly what was said (so two requests: please speak up and please speak one person at a time).
- It is important that at this stage you understand that we are not offering any type of intervention and this study is not about evaluating what exercises are good for you.
- It is important for us to repeat that you are volunteering to be part of this group and that you can leave the meeting at any time without giving a reason
- This study is investigating exercise/physical activity participation and provision – and factors that affect participation in individuals with a range of neuromuscular conditions. Thus we are specifically asking questions that are related to potential exercise/physical activity provision and support development
- We are looking for your opinions and ideas about exercise/activity provision and participation. There are no right or wrong answers and we'd like everyone to give their views. It's unlikely everyone will think the same so, if you have a different view, please speak up.
- We are hoping to use the information to help direct a future study.
- Thank you very much

Exercise.

What do you think about exercise/physical activity?

Follow up to explore:
- exercise/phys activity in general - exercise for people with their neuromuscular condition
- their experiences of exercising/activities (positive/negative factors)
- whether they believe exercise is a good/bad idea. Why?
- what exercise/activities they have enjoyed/disliked and why
- what exercise/activities they think they would like/not like to try. Why?
- what makes exercise/activities enjoyable or not?
- where people exercise (eg, home, gym, hospital etc)

Examples of questions that might be asked are:

What do you think about exercise/physical activities in general?
Do think exercise is a good/bad idea?
What do you think about exercise/physical activities for people with (named condition)?
What exercise/physical activities do you think are good/bad for people with (named condition)?
What exercise/physical activity do you do/have you tried? How do/did you find it? (*probe for experiences and the types of exercise/activities which are enjoyed/disliked and why*)
How do you feel about exercise? Do you enjoy it or dislike? (*probe why*)
Which type of exercise/physical activity do you most enjoy / most dislike? (*probe why*)
Where do you exercise? (*probe why, probe preferences*) Where do/would you most like to participate in exercise/physical activity? (*probe for advantages/disadvantages of different settings)*

Barriers to exercise/physical activity.

Is there anything that prevents you from exercising?

Follow up to explore barriers:

- *e.g. time, when people are able to do the activity (day/evening/weekend), travel, finance, environment, lack of support in exercise environment, fatigue, lack of confidence in the exercise provider, other people's opinions, don't know what exercise/activities to do, lack of motivation, fear of falling*

Examples of questions that might be asked are:

How easy/difficult is it to find time to exercise?
Do things like (*named factor such as* travel *or* cost) affect the exercise/activities you do? (*probe to find how the factor impacts upon the amount and type of exercise/activity done*)

Support.

Have you had any support to exercise or take part in any physical activities?

Follow up to explore:
- *level of support, adequate or inadequate*
- *Support from whom? How?*
- *How the support was given*
- *Whether additional support would increase exercise/activity levels?*

Examples of questions that might be asked are:

What type of support have you had? *(Probe type and level of support, from whom)*
How did it go?
Have you met any exercise practitioners/professionals? (*Probe who, when, where, how did the experience go?*) How did it go? (Probe level of support and perceptions re: level and type of support)
Is there any kind of exercise/physical activity you would like to do if support was provided? *(Probe what exercise? What support?) OR* What kind of exercise/physical activity would you like to do if support was provided?
What type of support do you think would help you to take part (*probe to find out what type of support, how given and by whom e.g. personal trainer, exercise classes, one-on-one, physiotherapist etc*)

Exercise at home.

What do you think about exercise at home?

Follow up to explore:
- *if they do/have exercise/d at home (explore experiences and opinions, type of exercise, frequency, duration, equipment)*
- *whether they think exercise at home is good /bad, beneficial or not, positives and negatives (explore reasons for views)*
- *whether they exercise at home if they were provided with suitable exercises (explore perceptions re: what they might expect these exercises to be)*

Examples of questions that might be asked are:

What do you think of home exercises? (*Probe for experiences and opinions*)

Do you do any home exercises? (*Probe for experiences, type of ex/activity, frequency).* How do you find it? *(Probe for advantages/disadvantages)*
How do you decide/ know which exercises to do? (*Probe for reasons such as confidence, uncertainty, previously taught.…..*)
Would you exercise at home if you were provided with suitable exercises? (*Probe reasons why? Probe how best to provide exercises and what sort of exercise/s would they expect?)*

Internet/web based support scheme.

What is your opinion on an Internet / web based exercise/physical activity support scheme?

Follow up to explore:
- accessibility - ? Do they have computer/internet access?
- acceptability- Would they use it?
- Practicalities – what kind of support would be needed for the scheme to work? What kind of service would people like? Who would they trust/like to provide this type of service? How would this work? - support from whom?

Examples of questions that might be asked are:

Do you think such a scheme should be provided? (*Probe why*)
What kind of support do you think such a scheme should provide to people? (*Probe to find level and type of expected support, eg set web page of exercises, additional public question and answer page, additional private email answering service or telephone line*).
Do you think (*named factor such as email/telephone*) should be included in the service? (*probe why? And from whom)*
Who do you think should set up and run this type of service? Why? Would it worth setting up a service like this? Would you use it yourself do you think? (*probe why*)
Who do you think should finance services like a helpline?

Do you have any other ideas/thoughts that we haven't mentioned yet?

Examples of general cues/prompts which might be used to encourage talk and participation:

What do you think about?
What do other people think?
Has anyone else tried/experienced……..)? How was it?
It seems that people are saying…….does every one agree with that?
Who disagrees with that?
Who agrees?
Who has a different opinion/experience?
What other views are there?
How do you feel about?
Why do you think…….
Could you tell me a bit more about that?
That's quite a long pause – are you all thinking about what to say or shall I move on?
Do I need to rephrase the question?

Thank yous ……

Appendix 10: The CONSORT statement checklist

CONSORT Statement 2001 - Checklist

Items to include when reporting a randomized trial

PAPER SECTION **And topic**	**Item**	**Descriptor**	**Reported on Page #**
TITLE & ABSTRACT	1	How participants were allocated to interventions (*e.g.*, "random allocation", "randomized", or "randomly assigned").	
INTRODUCTION Background	2	Scientific background and explanation of rationale.	
METHODS Participants	3	Eligibility criteria for participants and the settings and locations where the data were collected.	
Interventions	4	Precise details of the interventions intended for each group and how and when they were actually administered.	
Objectives	5	Specific objectives and hypotheses.	
Outcomes	6	Clearly defined primary and secondary outcome measures and, when applicable, any methods used to enhance the quality of measurements (*e.g.*, multiple observations, training of assessors).	
Sample size	7	How sample size was determined and, when applicable, explanation of any interim analyses and stopping rules.	
Randomization -- Sequence generation	8	Method used to generate the random allocation sequence, including details of any restrictions (*e.g.*, blocking, stratification)	
Randomization -- Allocation concealment	9	Method used to implement the random allocation sequence (*e.g.*, numbered containers or central telephone), clarifying whether the sequence was concealed until interventions were assigned.	
Randomization -- Implementation	10	Who generated the allocation sequence, who enrolled participants, and who assigned participants to their groups.	
Blinding (masking)	11	Whether or not participants, those administering the interventions, and those assessing the outcomes were blinded to group assignment. If done, how the success of blinding was evaluated.	
Statistical methods	12	Statistical methods used to compare groups for primary outcome(s); Methods for additional analyses, such as subgroup analyses and adjusted analyses.	
RESULTS Participant flow	13	Flow of participants through each stage (a diagram is strongly recommended). Specifically, for each group report the numbers of participants randomly assigned, receiving intended treatment, completing the study protocol, and analyzed for the primary outcome. Describe protocol deviations from study as planned, together with reasons.	
Recruitment	14	Dates defining the periods of recruitment and follow-up.	
Baseline data	15	Baseline demographic and clinical characteristics of each group.	
Numbers analyzed	16	Number of participants (denominator) in each group included in each analysis and whether the analysis was by "intention-to-treat". State the results in absolute numbers when feasible (*e.g.*, 10/20, not 50%).	
Outcomes and estimation	17	For each primary and secondary outcome, a summary of results for each group, and the estimated effect size and its precision (*e.g.*, 95% confidence interval).	
Ancillary analyses	18	Address multiplicity by reporting any other analyses performed, including subgroup analyses and adjusted analyses, indicating those pre-specified and those exploratory.	
Adverse events	19	All important adverse events or side effects in each intervention group.	
DISCUSSION Interpretation	20	Interpretation of the results, taking into account study hypotheses, sources of potential bias or imprecision and the dangers associated with multiplicity of analyses and outcomes.	
Generalizability	21	Generalizability (external validity) of the trial findings.	
Overall evidence	22	General interpretation of the results in the context of current evidence.	

Appendix 11 - Ethics information sheet for the LIFE study

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OXFORD BROOKES UNIVERSITY

Nuffield NHS Orthopaedic Centre NHS Trust

Human Performance lab
Oxford Brookes University
Gipsy lane, Headington
Oxford
OX3 OBP

Oxford Centre for Enablement
Nuffield Orthopaedic Centre
Windmill Rd, Headington.
Oxford
OX3 7LD

Date…….

Long term Individual Fitness Enablement (LIFE).

Reference number (The Mid & Buckinghamshire LREC): 0[redacted]
Version: 2

Dear…….

We are undertaking a research project to investigate how to enable participation in physical activities for individuals with a range of neurological conditions. We are inviting you to take part. Before you decide, it is important for you to understand why the research is being done and what you would have to do. Please take the time to read the information on the following pages carefully and, if you wish, discuss it with relatives and friends. Please take your time to decide whether or not you wish to take part and feel free to ask any questions you may have.

If, when you have read the information sheet you are interested in taking part in this study, please complete the reply slip and return it in the envelope provided, giving a contact phone number. Remember that you do not have to participate in this study. Furthermore, you would be free to leave the study at any time and there would be no need for you to give a reason. Your routine medical care would not be affected in any way.

We suggest that you keep this letter so that you can show it to anyone concerned with your medical care. Please don't hesitate to contact us on one of the numbers if you have any questions.

Yours Sincerely.

What is the purpose of the study?

The study aims to determine factors that could enable individuals participate in physical activity if they so wish. We are looking at developing and testing a support package that will make getting more involved in physical activity easier to do and hopefully not such a daunting idea.
We are also interested in what factors affect individual's participation and attendance at the fitness centre.

A better understanding of these factors may inform rehabilitation and exercise provision in the future. The research will take place over two years.

Why have I been chosen?

You are being asked to participate, as we are a recruiting a group of individuals who are diagnosed with neurological conditions.
We are involving individuals with a range of conditions such as, stroke, multiple sclerosis, muscular dystrophy, motor neurone disease and Parkinsons Disease.

Dr Talbot, Dr Hilton-Jones, Professor Wade or Professor Kischka will have suggested that you might be suitable for the study. We aim to recruit 30 people with each condition for the study.

Do I have to take part?

There is no obligation to take part in the study. If you decide to take part you would be given this information sheet and ask to fill in a consent form. If you decide to take part you would be free to withdraw at any time and without reason. It is important to note that your decision would not affect your normal medical care.

What would happen to me if I take part?

If you chose to take part we would ask you to attend 3 assessment sessions, three months apart.
These sessions would last for two hours each time and you would be asked to either attend for either three or four sessions depending on whether you are in the group who receive the three months of physical activity/exercise immediately or the group who are asked to wait for three months before receiving this period of physical activity/exercise.

We would invite you to attend an assessment session at the Nuffield Orthopaedic Centre, where we would measure your height, weight and leg length and also how strong your hands, arms and legs are, we would also be interested in asking you some

questions regarding your general health, fitness levels, if you have fallen at all and how active you are.
We would then ask you to complete a measure of how well you can remember and tackle thinking problems. We would also like to measure how fast you can walk 10 metres and how far you can get in 2 minutes, and how fit you are in an exercise test specially designed for people with neurological problems. We would then ask you to take a device like a pedometer home with so you that can measure how many steps you take each day. We would ask you to wear this in the day for seven days.

After this session you would be given the opportunity to withdraw from the study.

After the first assessment you would then be randomly allocated to one of two groups. You would be allocated by using computer generated numbers and you or the researcher would have no influence on which group you go into. The difference you would experience in the two groups would be that one group would receive the intervention immediately and the other group would receive the intervention after a delay of 3 months.

When receiving the intervention each group would receive the following: advice regarding physical activity, a specifically planned activity programme designed to meet your needs, ongoing support in participating in this programme from a specially trained Fitness Instructor and free access to the leisure centre. You would also have a physiotherapist attending the initial sessions if you required this in order to support you and advise the fitness trainer. You may get additional support of how to best change and maintain an active lifestyle.

We would pay for your fitness centre attendance and provide support for the duration of this study, all we would have to do is attend the sessions and be prepared to exercise.
You would attend a leisure centre whenever suits you for three months. We would then invite you to attend for another assessment so we can determine the effect of the activity.

The second and third assessment sessions would be very similar to the first and would last no longer than an hour and 30 minutes.

What do I have to do?

Apart from your attendance at the 3 sessions and your fitness centre attendance over three months your participation in the study should not affect your normal daily routine in anyway.

What are the possible disadvantages and risks of taking part?

Attending a fitness centre and increasing activity participation is not without risk but while exercising you would be supervised by staff trained to deal with any potential problems.

If you become pregnant during the study the participation in exercise should not harm the unborn child. Some individuals may find exercising uncomfortable or unpleasant. You would be able to stop at anytime without reason.

What are the possible benefits of taking part?

We would expect you to gain general health benefits if you increase the level of exercise/physical activity you are participating in, your level of physical fitness may improve.

The information we get from this study may help us alter rehabilitation methods of future patients.

What happens when the research study stops?

After you have attended the 3 sessions your participation in the study would end, although continued participation in physical activity would be recommended.

After this time you would still be free to contact any of the researcher with any question or queries you my have regarding the study. If you are interested in the data collected during your participation we would be happy to send you a report.

What if something goes wrong?

If you are harmed by taking part in this research project, there are no special compensation arrangements. If you are harmed due to someone's negligence, then you may have grounds for a legal action but you may have to pay for it. Regardless of this, if you wish to complain, or have any concerns about any aspect of the way you have been approached or treated during the course of this study, the normal National Health Service and University complaints mechanisms should be available to you.

Would my taking part in this study be kept confidential?

We would like to reassure you that your personal and medical details would be kept strictly confidential. No-one except the named investigators would have access to these details or your medical notes, and no identifying details would appear in our published results. Any information about you which leaves the hospital or University would have your name and address removed so that you cannot be recognised from it.

If you wish we would provide you with a summary of the final results. Any information about you would have your name and address removed so you cannot be recognised.

What would happen to the results of the research study?

The results of the study may be presented at conferences and published in medical or scientific journals and used as part of PhD theses. If you would like we can inform you of where you can obtain a copy of the published result. You would not be identified in any of the reports.

Who is organising and funding the research?

The research is organised and funded by Oxford Brookes University (Movement Science Group) and University of Birmingham in association with the Nuffield Orthopaedic Centre.

Who has reviewed the study?

The study has been reviewed and ethical permission approved by the Oxfordshire Research Ethics Committee (REC) and the Oxford Brookes University School of Biological and Molecular Sciences ethical officer. The study has been reviewed by the Department of Health.

Contact for Further Information

The study is being carried by: Dr Helen Dawes (research physiotherapist), Charlotte Elsworth (PhD student), James Bateman (MSc Student) and Prof Derick Wade (consultant neurologist), If you have any questions or queries please don't hesitate to contact:

Charlotte Elsworth
Phone: [redacted]
Email: [redacted]
Or

Dr Helen Dawes
Phone: [redacted]
[redacted]

You would be given a copy of the information sheet and a signed consent form to keep.

movement science

OXFORD BROOKES UNIVERSITY

Nuffield Orthopaedic Centre NHS Trust

Centre Number:;
Study Number:
Patient Identification Number for this trial:……..

CONSENT FORM

Title of Project: Long term Individual Fitness Enablement (LIFE)

Name of Researcher: ……

Please initial box

1. I confirm that I have read and understand the information sheet dated ..... (version1) for the above study and have had the opportunity to ask questions. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected. ☐
3. I understand that sections of any of my medical notes may be looked at by responsible individuals from [company name] or from regulatory authorities where it is relevant to my taking part in research. I give permission for these individuals to have access to my records. ☐
4. I agree to take part in the above study. ☐

_____	_____	_____
Name of Patient	Date	Signature
_____	_____	_____
Name of Person taking consent (if different from researcher)	Date	Signature
_____	_____	_____
Researcher	Date	Signature

1 for patient; 1 for researcher; 1 to be kept with hospital notes

Appendix 12: Publications and Presentations relevant to this thesis

Elsworth C, Dawes H, Ramsbottom R, Collett, J, Dennis A, Sackley C, Wade D. (2007) *Accuracy of pedometers in individuals with neurological conditions (abstract).* Annual Conference of the British Association of Sport and Exercise Sciences, 2006. Journal of sport science. 25 (3), 260-262.

Collett J, Dawes H, Howells K, **Elsworth C**, Izadi H, Sackley C. (2006) *Anomalous centre of mass energy fluctuations during treadmill walking in healthy individuals*. Gait & Posture,

Elsworth C, Dawes H, Collett J, Howells K, Ramsbottom R Izadi H, Sackley C. (2006) *Oxygen cost during treadmill walking with hip and knee immobilised.* Journal of Sports Science and Medicine. 5, 640-645. Available from URL: http://www.jssm.org.

Elsworth C, Dawes H, Collett, J. Ramsbottom R, Howells K, Izadi H, Sackley C. (2005) *Oxygen cost during treadmill walking at different speeds, with hip and knee immobilised (Abstract)*. Annual Conference of the British Association of Sport and Exercise Sciences, Loughborough, September 2005. Journal of sport science. 23 (11/12), 1149-1303.

Collett J, Dawes H, **Elsworth C**, Howells K. (2005) *Energy Fluctuations During Estimated Centre of Mass Displacement in Treadmill and Ground Walking at a Range of Speeds*. 3rd International conference for Biomechanics of the Lower Limb in Health, Disease and Rehabilitation, Salford, September 5-7 (conference proceedings).

Dawes H, **Elsworth C**, Korpershoek N, Van Tintelen N, Freebody J, Wade DT, Izadi H, Hilton Jones D. *A pilot randomised controlled trial of a home based, targeted progressive exercise programme aimed at improving endurance and function in adults with neuromuscular disorders*. (2005) J Neurology Neurosurgery and Psychiatry. 2006 Aug;77(8):959-62

4th June 2005 – FSH Annual Conference, Wythall Community Centre Birmingham , Exercise and Muscular Dystrophy. (presented)

3rd September 2005 – Limb Girdle Muscular Dystrophy Information Day – Birmingham. Exercise and Muscular Dystrophy. (presented)

4th – 7th September 2005 British Association of Sports Exercise Sciences (BASES) Annual Conference, University of Loughborough, UK (presented poster)

15th March 2006 - Muscular Dystrophy Annual Conference. Presented a workshop “Exercise and MD”

5th – 7th July 2006 The Society for Research in rehabilitation (SRR) annual summer conference – Winchester, UK (Oral Presentation)

12th February 2007. North Shore Life Centre, Auckland. Muscular Dystrophy Association of New Zealand. Oral Presentation "To exercise or Not?"

15th February 2007. CCS Building, Wellington. Muscular Dystrophy Association of New Zealand. Oral Presentation "To exercise or Not?"

20th February 2007. University of Canterbury, Christchurch. Muscular Dystrophy Association of New Zealand. Oral Presentation "To exercise or Not?"

2nd July 2008 - The Society for Research in rehabilitation (SRR) annual summer conference – Preston, UK (Oral Presentation). "Long-term Individual Fitness Enablement (LIFE) Pilot". To be published in Clinical Rehabilitation.

3-6th September 2008. British Association of Sports Exercise Sciences (BASES) Annual Conference, Brunel University, UK (presented poster). " Perceived barriers to physical activity in individuals with progressive neurological conditions; a focus group and questionnaire study" To be published in Journal of Sports Sciences.

Elsworth, C, Dawes, H., Sackley, C., Soundy, A., Howells, K., Wade, D., Hilton-Jones, D., Freebody, J., Izadi, H, (2009) *Perceived facilitators to physical activity in individuals with progressive neurological conditions; a focus group and questionnaire study.* International Journal of Rehabilitation and Therapy. 16 (1): 17-24

Elsworth, C., Dawes, H., Winward, C., Howells, K., Collett,J., Dennis, A., Sackley, C., Wade, D. (2009) *Pedometer step counts in neurological conditions*. Clinical Rehabilitation. 23:171-175.

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