Physical Activity Engagement in People with Multiple Sclerosis

Nicola M. Kayes

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Primary supervisor: Professor Kathryn McPherson

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ABBREVIATIONS

6MWD	Six Minute Walk Distance
6MWT	Six Minute Walk Test
7DRQ	Seven Day Recall Questionnaire
%HRR	Percentage heart rate reserve
ADL	Activities of daily living
ANOVA	Analysis of variance
BHADP	Barriers to Health Promoting Activities for Disabled Persons
CBSQ	Cognitive and Behavioural Responses to Symptoms Questionnaire
CBT	Cognitive Behavioural Therapy
CFQ	Chalder Fatigue Questionnaire
CFS	Chronic Fatigue Syndrome
CHD	Coronary Heart Disease
CI	Confidence intervals
CIS	Checklist Individual Strength
COPD	Chronic Obstructive Pulmonary Disorder
DLW	Doubly labeled water
EDSS	Expanded Disability Status Scale
EMG	Electromyography
FAB	Facilitating Activity for well-Being
FIM	Functional Independence Measure
GAS	Goal Attainment Scaling
GEE	Generalised estimating equations
GLTEQ	Godin Leisure-Time Exercise Questionnaire
GNDS	Guys Neurological Disability Scale
HADS	Hospital Anxiety and Depression Scale
HAP	Human Activity Profile
HDL-C	High density lipoprotein cholesterol
HPLP	Health Promoting Lifestyle Profile
HR	Heart Rate
ICC	Intraclass correlation coefficient
IPAQ	International Physical Activity Questionnaire
IQR	Interquartile range
LTPA	Leisure-time physical activity

MET	Metabolic equivalent
M-F	Monday to Friday
MRC	Medical Research Council
MS	Multiple Sclerosis
MSFC	Multiple Sclerosis Functional Composite
MSIS	Multiple Sclerosis Impact Scale
MSSS	Multiple Sclerosis Self-efficacy Scale
MVC	Maximum voluntary contraction
NHIS	National Health Interview Survey
NZ	New Zealand
PADS	Physical Activity Disability Survey
PADS-R	Physical Activity Disability Survey-Revised
PARS	Physical Activity Rating Scale
PAR-Q	Physical Activity Readiness Questionnaire
PASIPD	Physical Activity Survey for Individuals with Physical Disabilities
PCA	Principal Components Analysis
PGAP	Progressive Goal Attainment Programme
POMS	Profile of Mood States
PPMS	Primary progressive Multiple Sclerosis
RCT	Randomised controlled trial
RMI	Rivermead Mobility Index
RPE	Rating of perceived exertion
RRMS	Relapsing-remitting Multiple Sclerosis
SD	Standard deviation
SE	Self-efficacy
SEM	Standard error of measurement
SF-36	Short Form 36
SIP	Sickness Impact Profile
SPMS	Secondary progressive Multiple Sclerosis
TG	Triglyceride
VIF	Variance inflation factor
VO^2	Oxygen consumption

ATTESTATION OF AUTHORSHIP

I hereby declare that this submission is my own work and that, to the best of my knowledge and belief, it contains no material previously published or written by another person (except where explicitly defined in the acknowledgements), nor material which to a substantial extent has been submitted for the award of any other degree or diploma of a university or other institution of higher learning.

The work carried out for this doctoral degree has resulted in a number of publications and conference presentations. These are listed here:

JOURNAL ARTICLES

Directly relevant

Published

Kayes, N. M., McPherson, K. M., Taylor, D., Schluter, P. J., & Kolt, G. S. (2010). Facilitators and barriers to engagement in physical activity for people with Multiple Sclerosis: A qualitative investigation. *Disability and Rehabilitation, Early online,* 1-18.

Kayes, N. M., McPherson, K. M., Schluter, P. J., Taylor, D., Leete, M. & Kolt, G. S. (2010). Exploring the Facilitators and Barriers to Engagement in Physical Activity for People with Multiple Sclerosis. *Disability and Rehabilitation, Early online,* 1-11.

Kayes, N. M., Schluter, P. J., McPherson, K. M., Taylor, D., & Kolt, G. S. (2009). The Physical Activity and Disability Survey – Revised (PADS-R): An evaluation of a measure of physical activity in people with chronic neurological conditions. *Clinical Rehabilitation, 23*(6), 534-543.

Kayes, N. M., Schluter, P. J., McPherson, K. M., Leete, M., Mawston, G., & Taylor, D. (2009). Exploring Actical accelerometers as an objective measure of physical activity in people with Multiple Sclerosis (MS). *Archives of Physical Medicine and Rehabilitation, 90*(4), 594-601.

Kayes, N. M., McPherson, K. M., Taylor, D., Schluter, P. J., Wilson, B. K., & G., K. (2007). The Physical Activity and Disability Survey (PADS): reliability, validity and acceptability in people with multiple sclerosis. *Clinical Rehabilitation, 21*(7), 628-639.

Associated

Kayes, N. M. & McPherson, K. M. (2010). Measuring what matters: does ‘objectivity’ mean good science? *Disability and Rehabilitation*, 32(12), 1011-1019

McNaughton, H., Kayes, N., & McPherson, K. (2006). Interferon beta, PHARMAC, and political directives: in the best interests of people with multiple sclerosis? *The New Zealand Medical Journal, 119*(1232), U1939.

CONFERENCE PRESENTATIONS

Oral presentations

Kayes, N. M., McPherson, K. M., Taylor, D., & Schluter, P. J. (2009). The Facilitating Activity for well-Being (FAB) Programme: A pilot study of a new approach to engaging people with Multiple Sclerosis (MS) in goal-directed physical activity. Paper presented at the AFRM/NIRR/NZRA Rehabilitation Conference, Queenstown, New Zealand.

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Leete, M., **Kayes, N. M.,** Mawston, G., Schluter, P. J., McPherson, K. M., & Taylor, D. (2008). Exploring Actical accelerometers as an objective measure of physical activity in people with stroke and Multiple Sclerosis (MS). Paper presented at the 10th International Congress of Behavioural Medicine, Tokyo, Japan.

Kayes, N. M., McPherson, K. M., Taylor, D., Schluter, P. J., & Kolt, G. S. (2007, 16-18 February). The Physical Activity Disability Survey (PADS): reliability, validity and utility in people with Multiple Sclerosis. Paper presented at the Innovation in Rehabilitation: Applying theory to practice conference, Rotorua, New Zealand.

Wilson, B. J., Kayes, N. M., McPherson, K. M., Taylor, D., & Kolt, G. (2006, 20-21 May). The physical activity and disability survey (PADS): A reliability and validity study in people with Multiple Sclerosis. Paper presented at the Life! With Physiotherapy: New Zealand Society of Physiotherapy conference, Auckland, New Zealand.

Poster presentations

Kayes, N.M., McPherson, K.M., Taylor, D., & Schluter, P.J. (2009). *Facilitating activity for well-being in people with multiple sclerosis: A pilot study.* Paper presented at the Australasian Society for Behavioural Health and Medicine Conference, Auckland, New Zealand.

Kayes, N. M., McPherson, K. M., Taylor, D., Schluter, P. J., Leete, M., & Kolt, G. S. (2008). *Facilitating Activity for well-Being in people with Multiple Sclerosis: A pilot study.* Paper presented at the 10th International Congress of Behavioural Medicine, Tokyo, Japan.

Kayes, N. M., McPherson, K. M., Taylor, D., & Schluter, P. J. (2008). *Exploring the barriers and facilitators to physical activity in people with Multiple Sclerosis.* Paper presented at the 10th International Congress of Behavioural Medicine, Tokyo, Japan.

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ABSTRACT

There is a growing body of evidence confirming the benefits of physical activity and exercise in people with Multiple Sclerosis (MS). However, most engage in low levels of physical activity when compared to the general population and other chronic illness groups. Despite this, there is a paucity of research aiming to better understand physical activity behaviour and exploring factors potentially influencing physical activity engagement in this population.

The key aims of this research were therefore to gain a more in-depth understanding of the barriers and facilitators to physical activity from the perspective of people with MS, and use this information to inform the development of a novel approach to activity engagement for people with MS: The Facilitating Activity for well-Being (FAB) Programme. However, it became clear early on that prior to undertaking this work it would be necessary to carry out some preliminary research exploring physical activity measurement for this population. As a result, three phases make up this doctoral work, in which six research projects were carried out.

Phase I of this PhD focused on physical activity measurement in people with MS and included three studies exploring both self-report and objective measurement. Phase II focused on exploring the barriers and facilitators to physical activity engagement for people with MS and incorporated two studies: a questionnaire study and a qualitative inquiry. Phase III was the final phase of this work and involved developing The FAB Programme, informed by existing literature and findings from earlier phases of this research. This phase also included the final study conducted as a part of this doctorate where the FAB Programme was piloted in people with MS and revised in response to feedback from participants and their clinicians.

Several findings from this work challenge and/or augment existing knowledge in this field. In Phase I, a key contribution was the development of a conceptually sound self-report measure of physical activity for people with MS (the PADS-R). In contrast, despite their intuitive appeal, Actical accelerometers did not appear to be a valid and reliable objective measure of physical activity in people with MS; challenging assumptions about the accuracy of these devices in populations with chronic disabling conditions. A number of novel findings were determined in Phase II, including: a) that beliefs and perceptions about physical activity appear to play an important role in the

decision to engage in physical activity for people with MS; b) the decision to engage in physical activity is complex, fluid and individual; challenging the notion of intention-behaviour continuity (a basic assumption of many existing theories of behaviour change; and c) that health professionals appear to play an important role in shaping physical activity behaviour in people with MS. A key contribution of Phase III to the field was the development of a theoretically driven, evidence based approach to activity engagement for people with MS – The FAB Programme. This programme was found to be acceptable to both people with MS and their clinicians and perceived benefits reported by participants indicated it has the potential to effectively facilitate physical activity engagement in this comparatively sedentary population. Findings also indicated that engagement of clinicians in a new way of working is challenging and something to be grappled with due to the paradigm shift required and perceived threats to their scope of practice.

The body of work presented here has contributed significantly to the field of physical activity engagement for people with MS in terms of conceptual clarity, measure development, improved understanding of the complexity regarding physical activity engagement and through the development of a novel approach to activity engagement for people with MS. The development of an intervention, such as the FAB Programme, which facilitates people with MS to engage in physical activity should result in considerable health gains, and is likely to enhance the positive effects achievable in more traditional exercise programmes due to the expectation that adherence will improve.

CHAPTER 1

INTRODUCTION AND CHAPTER STRUCTURE

1.1 AIMS AND OBJECTIVES OF THIS DOCTORAL RESEARCH

MS is a chronic neurological condition affecting up to 190 per 100,000 people in some regions of the world.(1) The almost limitless number of possible demyelination patterns which can occur, results in an unpredictable illness trajectory for which there is no known cure (2) leaving people living with the condition subject to a lifetime of uncertainty. In the absence of a cure, treatment of MS is largely centred on symptom management and reducing the impact of the condition on a person's day-to-day living.(3,4) As a result, increasing attention is being directed towards exploring the potential for engagement in health promoting behaviours, such as physical activity, to reduce the physical limitation experienced by people with MS and improve their overall health and well-being.(5) A recent review synthesised evidence from existing randomised controlled trials exploring the effectiveness of exercise in MS. This review found strong evidence in favour of exercise therapy compared to no exercise therapy and no evidence of damaging effects of exercise therapy.(6)

Despite the growing body of evidence confirming the benefits of physical activity and exercise for people with MS, most engage in low levels of physical activity when compared to the general population and other chronic illness groups,(7) making them vulnerable to a range of secondary conditions linked with inactivity. Furthermore, high drop-out rates from exercise programmes (8,9) and low maintenance of activity at follow-up (10,11) have been reported in this population, suggesting that conventional programmes may be failing to meet the needs of people with MS. A greater understanding of the variables associated with engagement in physical activity could aid the development of interventions focusing on adherence, which should arguably generate more pronounced long-term intervention effects than is currently seen in traditional exercise interventions.(7)

Until recently, little research had explored the barriers and facilitators to activity faced by people with MS. Some of the earliest research in this area investigated factors predictive of engagement in positive health behaviours in people with MS, (12-15) some of which was based on a conceptual understanding developed in an earlier qualitative study.(16) However, this series of work focused on a variety of health promoting behaviours, rather than specifically on physical activity, and aimed to explore issues in a range of chronic disabling conditions, not just MS. While findings from these studies can contribute knowledge to this field, the broader focus with regard to multiple health behaviours and mixed populations may have resulted in failure to elicit key issues specific to engagement in physical activity for people with MS. More recently, a group of investigators has explored physical activity in people with MS from a Social Cognitive Theory perspective using a cross-sectional descriptive design and found self-efficacy, enjoyment and number of symptoms to be linked to physical activity levels.(17-20) MS is one of the most common neurological conditions affecting young adults, with onset typically between 20 and 40 years of age; leaving those affected by the condition living with MS-related disability for much of their lifetime.(21) Given this, and the unpredictable and/or degenerative illness trajectory associated with MS, people with MS may face barriers to engagement in physical activities which remain unexplored.

The key aims and objectives of this doctoral research were to:

(1) Gain a more in-depth understanding of the barriers and facilitators to physical activity from the perspective of people with MS;

(2) Use findings from this doctoral research and from previous research to inform the development of a theoretically driven, evidence based programme to facilitate activity engagement for people with MS; and

(3) Explore the acceptability and feasibility of the programme in people with MS and their clinicians.

In the process of developing a research proposal to address these aims, it became evident that a major limitation of research in this field to date was the lack of a valid and reliable measure of physical activity relevant to people with MS.(22,23) It became clear that before conducting research aiming to better understand the barriers and facilitators to physical activity in people with MS, one first needed to consider how to effectively measure physical activity in this population. Therefore, a fourth aim was included and addressed first:

(4) To explore physical activity measurement in people with MS and identify an appropriate measure of physical activity to utilise in subsequent phases of this doctoral research.

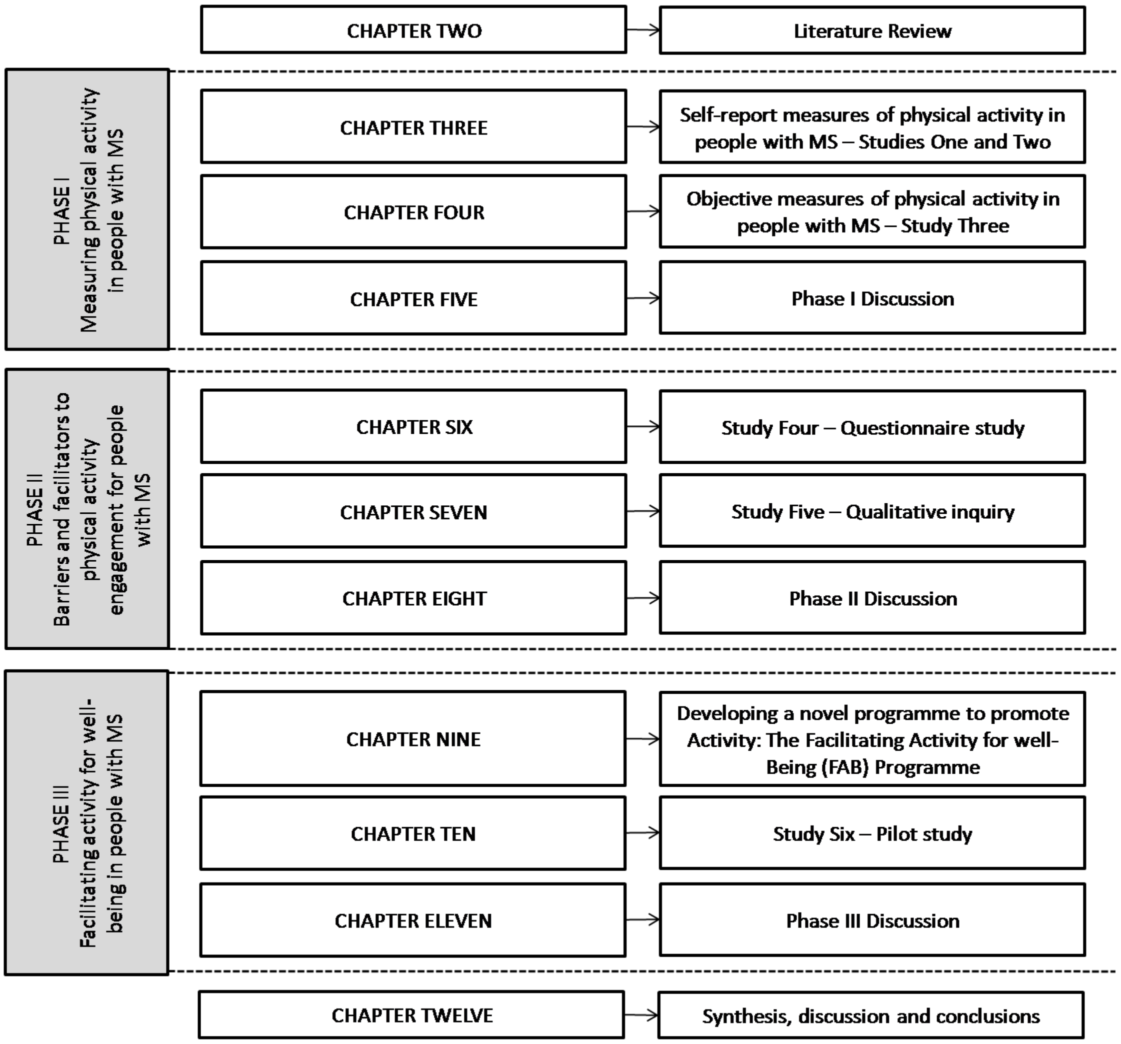
In order to achieve these four aims, three related phases of work were undertaken:

Phase I	Measuring physical activity in people with MS (aim 4)
Phase II	Barriers and facilitators to physical activity engagement for people with MS (aim 1)
Phase III	Facilitating activity for well-being in people with MS (aims 2 and 3)

1.2 CHAPTER STRUCTURE

Figure 1.1 presents an overview of the chapters contained within this thesis, and indicates which chapters are associated with each of the three phases identified above.

Figure 1.1: Overview of chapter structure



Chapter Two presents an overview of the literature relevant to this doctoral research. In particular, three literature review questions are addressed:

1. What are the benefits of engagement in physical activity for people with MS?
2. What level of physical activity do people with MS currently engage in?
3. What are the barriers and facilitators to engaging in physical activity for people with MS?

This review is limited to papers published up to and including 2006, this being the literature that informed development of subsequent studies carried out for this doctorate (enrolled in September 2005). Findings from the original research making up this doctorate are discussed in the context of more recent publications in the relevant discussion chapters.

Phase I, focusing on physical activity measurement in people with MS, is reported in Chapters Three, Four and Five. Chapter Three includes a review of self-report measures of physical activity previously used in people with MS, and reports on the first two original pieces of research carried out (Studies One and Two). Chapter Four includes a review of objective measurement of physical activity, and reports on the third original piece of research (Study Three). Chapter Five discusses the findings from this first phase of research. For the same reasons described above, the review components contained within Chapters Three and Four only includes publications up to 2006 with later publications discussed in Chapter Five where relevant.

Phase II, exploring barriers and facilitators to physical activity engagement in people with MS, is reported in Chapters Six, Seven and Eight. Chapter Six reports on Study Four, a questionnaire study investigating a range of possible associates of physical activity in people with MS. Chapter Seven reports on Study Five, an in-depth qualitative inquiry exploring activity engagement from the perspectives of those living with the condition. Chapter Eight discusses the findings of each of these studies.

Phase III, facilitating physical activity engagement for people with MS, is reported in Chapters Nine, Ten and Eleven. Chapter Nine reports on the development of a novel intervention, the Facilitating Activity for well-Being (FAB) Programme. Chapter Ten reports on Study Six, a pilot study aiming to explore the acceptability and feasibility of the FAB Programme. Chapter Eleven discusses the findings of this phase.

As shown in Figure 1.1, a discussion chapter has been included at the end of each phase. This structure was used because the findings of each phase informed subsequent phases of the research. Each phase discussion chapter includes a discussion of key findings of the phase in the context of existing literature, limitations of the research and concluding remarks. Clinical implications and recommendations for future research are not discussed in detail in these chapters. Rather, these are included in Chapter Twelve where broader implications resulting from this doctoral research are discussed.

Chapter Twelve presents a synthesis of the findings of each phase to identify the key novel findings from this doctoral research and discuss how the work carried out augments and/or challenges current knowledge in this field.

CHAPTER 2

LITERATURE REVIEW

2.1 MULTIPLE SCLEROSIS

MS is a chronic disabling illness of the central nervous system characterised by scars in the myelin sheath, a fatty membrane that acts to protect the nerves and facilitates conduction of nerve impulses.(2) The characteristics are conveyed in the name of the condition – ‘multiple’ because scattered areas of the central nervous system are affected, and ‘sclerosis’, referring to the hardening of tissue, or the scarring or plaques that are found in affected areas. MS results in a diverse range of neurological sequelae due to the virtually infinite combination of places where demyelination can occur.(24) This invariably results in each person’s experience of MS being unique, leading to an unpredictable illness trajectory and a lifetime of uncertainty. There are, however, some symptoms common to MS including, but not limited to, loss of balance and coordination, fatigue, blurred or double vision, numbness, speech distortion and bladder and bowel problems.(24)

Approximately 4000 people are affected by MS in New Zealand (NZ),(25) with approximately 2 million affected worldwide.(21) It is the most common disabling neurological condition in young adults,(21) with onset most common in mid-adulthood (26) resulting in a significant and long-term impact on those affected by the condition and their families.

There are four types of MS commonly referred to in the literature. A consensus definition of each type was established via an international survey in 1996, and this is presented in Table 2.1.(27)

Table 2.1: Consensus definition of each type of MS taken from Lublin et al.(27)

Type of MS	Consensus definition
Relapsing-remitting MS (RRMS)	Clearly defined disease relapses with full recovery, or with sequelae and residual deficit upon recovery; periods between disease relapse characterised by a lack of disease progressive.
Primary progressive MS (PPMS)	Disease progression from onset with occasional plateaus and temporary minor improvements allowed.
Secondary progressive MS (SPMS)	Initial relapsing-remitting disease course followed by progression with or without occasional relapses, minor remissions, and plateaus.
Benign MS	Disease in which the patient remains fully functional in all neurologic systems 15 years after disease onset.

In 1989, Weinshenker et al. investigated the natural history of MS.(26) They found that at the time of onset, the majority of people are diagnosed as having RRMS (approximately 66%), 19% with PPMS and 15% with SPMS. However, within 5 years of onset, 12% of those originally diagnosed as having RRMS develop SPMS, 41% within 10 years and 66% within 25 years.(26) Of those with disease duration longer than 25 years, almost 90% had developed SPMS. In this study, authors proposed that approximately 10% of people did not display symptoms of significant neurological disability after 22 years and so these people were believed to have benign MS.

It should be acknowledged that despite consensus regarding the characteristics most commonly associated with each of these disease subtypes, there is a distinct absence of studies validating them. It has been argued that given there are no biological markers which distinguish the various clinical courses, that defining them according to their common clinical characteristics and by consensus among experts in the field is defensible.(27) Due to the fact that these subtypes are frequently used to define subgroups of people with MS in the literature, therefore providing a common language, and because they offer some information regarding the anticipated trajectory of MS in an otherwise unpredictable illness; data concerning these subtypes was collected where possible in studies associated with this PhD.

2.2 LITERATURE REVIEW QUESTIONS

Having introduced the nature and epidemiology of MS, key questions addressed in this literature review included:

1. What are the benefits of engagement in physical activity for people with MS?
2. What level of physical activity do people with MS currently engage in?
3. What are the barriers and facilitators to engaging in physical activity for people with MS?

2.3 BENEFITS OF PHYSICAL ACTIVITY ENGAGEMENT FOR PEOPLE WITH MS

The benefits of physical activity have been well established in the general population, leading to the publication of physical activity recommendations,(28) and increasing emphasis being placed upon the development of population-based interventions aimed at increasing physical activity worldwide. However, such interventions are invariably targeted at the general population. It has been noted that people experiencing chronic disabling conditions are a subset of the population of particular interest. This is due to the likelihood the impairment they experience may lead to a cycle of deconditioning, making them particularly vulnerable to a range of secondary conditions associated with inactivity.(29) This assertion has been supported by data collected annually since 1998 by the United States (US) Department of Health and Human Services, which has found disparities between disabled people and non-disabled people regarding physical activity behaviour. For example, in 2006, 53% of disabled people reported no leisure-time physical activity compared with 36% of their non-disabled counterparts, and only 19% of disabled people regularly engaged in moderate or vigorous activity compared with 33% of non-disabled people.(30)

Traditionally, people with MS have been advised to rest and avoid physical activity because of uncertainty concerning whether activity would lead to further exacerbations of the illness, or worsening of symptoms such as fatigue.(31) However, inactivity in MS has been shown to lead to physical deconditioning and increased risk of secondary conditions such as coronary heart disease.(32-34) In addition, it has been proposed that the increase in physical limitation resulting from inactivity may be a factor in the social isolation and diminished general well-being reported in MS.(31) Given the conflicting advice regarding physical activity engagement in people with MS a review of the literature, utilising the principles of systematic review, was carried out to explore available evidence regarding the impact of physical activity engagement for people with MS.

2.3.1 SEARCH STRATEGY AND SCOPE

2.3.1.1 Definition of terms

2.3.1.1.1 Physical activity

The definition of physical activity used for this review, and throughout this doctoral research, was that provided by Caspersen et al. who defined it as "any bodily movement produced by skeletal muscles that results in energy expenditure".(35, p.126) Often the terms *exercise* and *physical activity* are used interchangeably, and so an important point of note regarding the definition posed by Caspersen et al. is that it distinguishes between these two terms. This definition refers to *exercise* as just one subset of physical activity, which relates to "planned, structured, and repetitive bodily movement done to improve or maintain one or more components of physical fitness".(35, p.126) This definition suggests *physical activity* is broader in scope than the term *exercise* alone implies, and may include activities such as leisure-time physical activity, occupation-related physical activity, activities of daily living and so on. This distinction is important in a population like MS where a large proportion experience disability as a consequence of their MS, likely making engagement in exercise activities difficult. Therefore, exploring the impact of *physical activity* in its broadest sense, rather than *exercise* alone, seemed appropriate.

2.3.1.1.2 Health outcome

The search was not limited to exploration of any specific health outcomes to allow exploration of *any* potential health benefits of physical activity.

2.3.1.2 Publication date

This review was limited to evidence published from 1990 and up to and including 2006. The reason for excluding research prior to 1990 was that early scoping of the literature indicated research exploring physical activity in people with MS prior to 1990 was sparse. This may be partly due to the fact that people with MS were historically advised against physical activity, and it was only in the 1990s that research began to challenge this approach. The majority of work in the field was stimulated by a randomised controlled trial (RCT) of aerobic training in people with MS published by Petajan et al. in 1996.(36) Research published after 2006 did not inform the rationale for the research questions examined throughout this doctoral research, and so although not included in the review, was considered when discussing the findings of the research.

2.3.1.3 Study design

This review primarily targeted systematic reviews of RCTs and single RCTs (see search terms in Table 2.2) due to the nature of the specific review question which aimed to explore the effectiveness of physical activity interventions in people with MS. RCTs are considered the best evidence available for answering this type of question.(37) Scoping of the literature indicated there were enough RCTs available to be able to explore the review question adequately without needing to explore other types of evidence. However, non-RCT studies captured in the search were retained if they a) elucidated any conflicting findings; b) provided further contextual information; and/or c) provided evidence in the absence of a RCT in a given area.

2.3.1.4 Database Search

Databases were searched via OVID and included Ovid MEDLINE(R), PsycINFO, Cumulative Index to Nursing and Allied Health Literature, Allied and Complementary Medicine Database, and all Evidence Based Medicine Reviews databases. The keywords used for the database searches are outlined in Table 2.2.

Table 2.2: Summary of search terms for review of benefits of physical activity in people with MS

	Keywords	
Population	multiple sclerosis	
AND		
Intervention	physiotherapy physical activit$ leisure exercise activit$ of daily living walking exercise therapy rehabilitation	OR
AND		
Study design	randomised controlled trial randomized controlled trial clinical trial RCT comparison study random$ comparative study	OR

$=truncation

2.3.1.5 Screening for relevance

All search results were imported into an Endnote XI database where all references were screened for relevance based on their title and/or keywords and were either coded as possibly relevant or left uncoded (if they did not meet the criteria for relevance to the review question). The abstracts for all papers identified as being possibly relevant were then screened. If abstracts confirmed the paper's relevance, the full text of the article was obtained.

2.3.1.6 Quality evaluation

RCTs identified in this review were critically appraised using the PEDro scale.(38) The PEDro scale is used to rate the quality of RCTs on the Physiotherapy Evidence Database (www.pedro.org.au) and is based on a list of RCT criteria proposed by Verhagen et al. who carried out a Delphi study to obtain consensus on a core set of quality criteria.(39) It was used in this review due to the focus on RCTs and given that the majority of papers captured using the above mentioned search strategy were likely to be physiotherapy-based evidence due to the focus on physical activity. For the purpose of establishing levels of evidence, articles were considered high quality if they obtained a score ≥6/10, a commonly used cutoff.(38)

2.3.1.7 Data extraction and synthesis

Details of interventions groups, methodology (recruitment methods, inclusion/exclusion criteria, participant numbers and key characteristics, outcome measures used, withdrawals) and key findings were extracted and are presented in table format (see Table 2.3). Findings of each study were synthesised by outcome and are discussed alongside their associated level of evidence, determined using the criteria proposed by van Tulder (40):

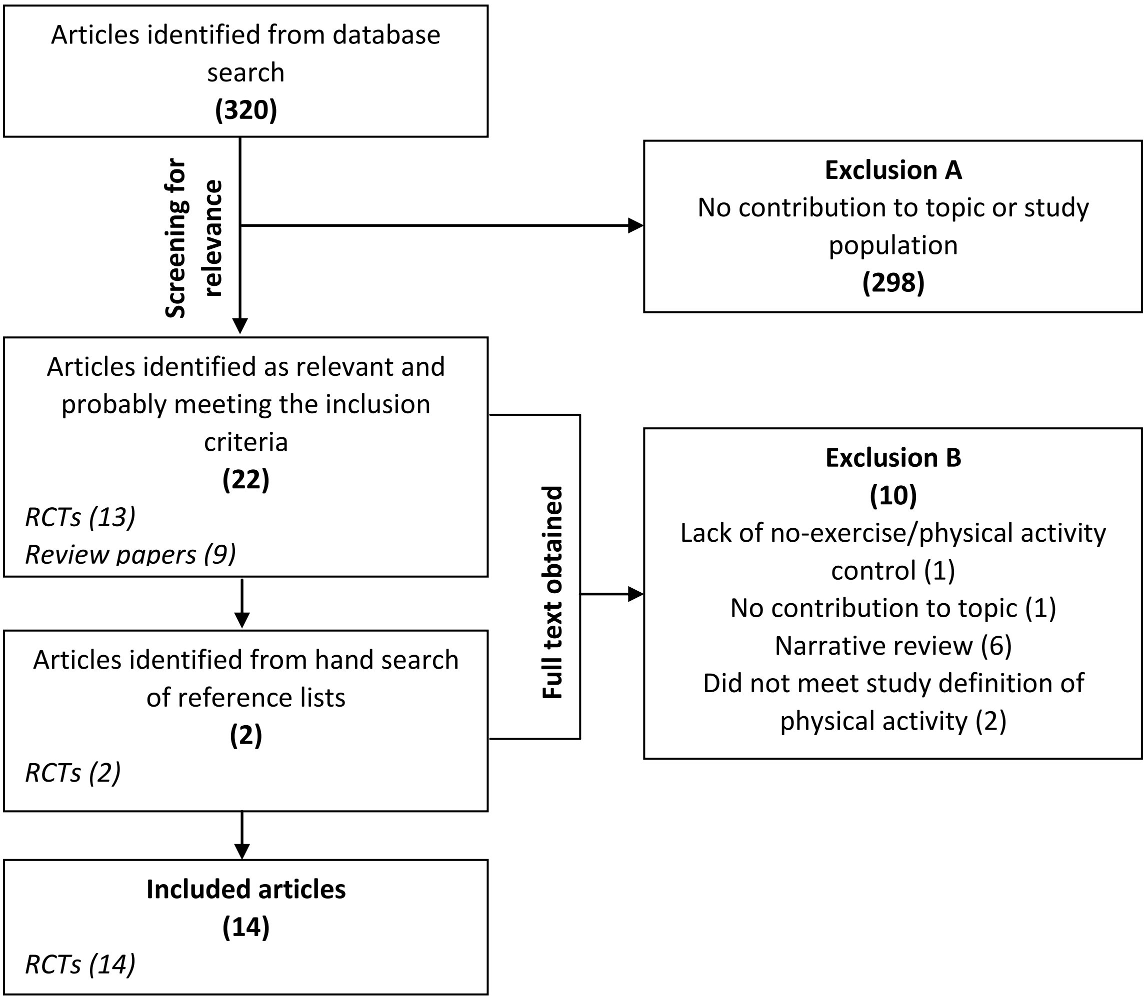
1. Strong: Consistent finding among multiple high quality RCTs
2. Moderate: Consistent finding among multiple low quality RCTs and/or Case-control trials or one high quality RCT
3. Limited: One low quality RCT or Case-control trial
4. Conflicting: Inconsistent finding among multiple trials (RCTs or Case-control trials)
5. No evidence from trials: No evidence from RCTs or Case-control trials

2.3.2 SUMMARY OF SEARCH RESULTS

Figure 2.1 presents a summary of search results. The database search yielded 320 papers after duplicates had been removed. Screening of abstracts identified nine review papers (6,31,41-47) and 13 RCTs (36,48-59) relevant to this review. One review paper exploring occupational therapy interventions in people with MS was excluded upon obtaining the full paper,(45) as it only included three studies, none of which were relevant to this review (two studies evaluating energy conservation courses and one evaluating a counseling intervention). Only two of the remaining reviews were systematic reviews.(6,42) One of these was a review of exercise therapy in people with MS, rather than physical activity in its broadest sense.(6) The reference list of this review was screened to check for any individual studies not yet included in the review, and a further two RCTs were identified for inclusion.(60,61) The other systematic review reviewed a range of non-pharmacological interventions in a range of conditions.(42) The reference list of this review was also checked for any relevant papers not already captured, but no new papers were identified. As these reviews did not specifically focus on activity interventions, their synthesised findings are not discussed here. Rather, relevant individual RCTs identified are reported separately. The remaining six reviews were all narrative reviews, four discussing exercise (31,43,44,47) and two focusing on rehabilitation (41,46) in people with MS. Due to the narrative nature of these reviews, their synthesised findings are not discussed as evidence, but rather are included in discussions to add further contextual information to the review.

Twelve of the 13 RCTs originally identified were included upon reviewing the full papers. One was excluded due to it not including a no-exercise/physical activity control group.(50) The two RCTs identified through the Rietberg et al. systematic review (6) were also included, resulting in a total of 14 RCTs. Of these 14 trials, participant overlap was identified in five papers.(53-56,58) Out of these five papers, two sets of participants were evident. Where this participant overlap existed, findings are reported together.

Figure 2.1: Literature review screening results



2.3.3 METHODOLOGICAL QUALITY OF INCLUDED STUDIES

Table 2.3 presents a summary of all included RCTs along with their PEDro scores. Overall, the methodological quality of the trials included was high, with the majority (10/14) scoring ≥6/10 on the PEDro scale. As is the case with the majority of rehabilitation interventions, it is difficult to blind participants and therapists for the types of interventions tested in the included studies. This issue alone resulted in all studies failing to meet two of the criteria essentially only allowing for the possibility of a maximum score of 8/10. After this, the most common reasons for reduced scores was failure to give sufficient information about the randomisation process to assess if allocation was concealed (36,48,49,51,55-58,60), assessors either not blinded to treatment allocation or lack of clarity on this criterion (48,49,51,55,56,58,60,61) and no indication that intention-to-treat analyses were carried out.(36,48,49,51,52,61)

Table 2.3: Summary of randomised controlled trials exploring the benefits of physical activity in people with MS presented alphabetically

Study	Intervention	Recruitment and Eligibility	Participant characteristics	Withdrawals	Measures	Key findings	PEDro score
Craig et al., 2003 (60)	Multidisciplinary rehabilitation (n=20) v standard ward routine (n=20) Treatment Team assessment. Treatment depended on goals identified during assessment and included health promotion advice, passive stretching exercises and/or bladder management techniques. Physiotherapy was the most common intervention (1.25-5 hours) followed by occupational therapy (0.25-4 hours). Control Standard ward routine and referral if necessary as per standard care	Recruited through neurology or MS clinics Inclusion criteria Confirmed diagnosis of MS; relapse requiring admission (day or inpatient) for steroid treatment Exclusion criteria None specified	Treatment Age: 26-59 yrs Female: 55% Time since diagnosis: 0-19 yrs Expanded Disability Status Scale (EDSS): 0.0-3.5 (30%); 4.0-6.5 (50%); 7.0-10.0 (20%) Control Age: 22-67 yrs Female: 80% Time since diagnosis: 0-24 yrs EDSS: 0.0-3.5 (25%); 4.0-6.5 (55%); 7.0-10.0 (20%)	N=1 withdrew after baseline, but before allocation.	Guys neurological disability scale (GNDS – *neurological disability*) Amended Motor Club Assessment (*motor*) Human Activity Profile (HAP – *physical activity*) Short Form-36 (SF-36 - *health-related quality of life*) Revised Barthel Index (*disability*)	Significant between group differences in favour of multidisciplinary rehabilitation on all measures with the exception of the SF-36.	6/10

Study	**Intervention**	**Recruitment and Eligibility**	**Participant characteristics**	**Withdrawals**	**Measures**	**Key findings**	**PEDro score**
DeBolt et al., 2004 (48)	Home-based resistance exercise programme (n=19) v control (n=18) <u>Treatment</u> Resistance training 3 x per week including chair raises, forward lunges, step-ups, heel-toe raises and leg curls. <u>Control</u> No information regarding usual care	Recruited through support groups run by local chapters of National MS Society <u>Inclusion criteria</u> Ability to walk at least 20m without rest (with or without assistive devices) <u>Exclusion criteria</u> None specified	<u>Treatment</u> Age: 40-67 yrs Female: 74% Time since diagnosis: 1-40 yrs Type of MS: Benign (n=1); RRMS (n=9); SPMS (n=2); PPMS (n=7) EDSS: 1.0-6.5 <u>Control</u> Age: 25-69 yrs Female: 78% Time since diagnosis: 1-35 yrs Type of MS: Benign (n=1); RRMS (n=8); SPMS (n=1); PPMS (n=8) EDSS: 1.5-6.0	N=1 withdrew from control due to exacerbation leaving n=18 in treatment group and n=17 in control group for statistical analyses	Leg Extensor Power Rig (*leg extensor power*) Up and Go test (*mobility*) AccuSway^{PLUS} force platform (*balance*)	Significant between-group difference for *leg extensor power.* No between-group effects were found for exercise therapy on *mobility* and *balance*.	5/10
Freeman et al., 1997 (49)	Multidisciplinary inpatient rehabilitation (n=34) v Waitlist control (n=36) <u>Treatment</u> Based on a model of comprehensive care including: 1) multidisciplinary; 2) tailored intervention; and 3) patient-centred functional goal setting. Specific information regarding content not included. Average length of stay 25 days <u>Control</u> No information regarding usual care	People with progressive MS recruited from a clinic at the National Hospital for Neurology and Neurosurgery <u>Inclusion criteria</u> Diagnosis of clinically and laboratory supported definite MS; progressive phase of disease as established by a neurologist; and considered appropriate for inpatient rehabilitation (not further defined) <u>Exclusion criteria</u> Relapse or steroid treatment within one month of baseline; required urgent admission; other conditions which may influence outcome; and/or cognitively impaired so as unable to give consent	<u>Treatment</u> Age: 25-73 yrs Female: 66% Time since diagnosis: 1.5-28 yrs Type of MS: SPMS (94%); PPMS (6%) EDSS: 0.0-4.5 (0%); 5.0-6.5 (53%); 7.0-9.5 (47%) <u>Control</u> Age: 25-61 yrs Female: 62% Time since diagnosis: 2-23 yrs Type of MS: SPMS (88%); PPMS (12%) EDSS: 0.0-4.5 (0%); 5.0-6.5 (56%); 7.0-9.5 (44%)	N=2 withdrew from each group due to assessments either being too burdensome or too distressing leaving n=32 in treatment group and n=34 in control group for statistical analyses	Kurtze's Functional Systems scales and Kurtze's EDSS (*neurological impairment*) Motor domain of the Functional Independence Measure (FIM - *disability*) London Handicap Scale (*handicap*)	No change in neurological impairment. Significant between-group differences in *disability* with significant differences in all aspects of FIM motor domain with the exception of locomotion. For locomotion, there was a significant between-group difference for wheelchair users, but not for walkers. Significant between-group differences in overall *handicap*.	5/10

Study	Intervention	Recruitment and Eligibility	Participant characteristics	Withdrawals	Measures	Key findings	PEDro score
Jones et al., 1999 (61)	Exercise to strengthen quadriceps (n-7) v general mobility exercises prescribed by a physiotherapist (n-7) v no exercise control (n=5) Weighted leg exercise Five sets of ten leg extensions on both legs, twice a day (with ankle weights designated to carry out task without discomfort, but sufficient weight to involve effort) Mobility exercises Individualised daily exercise programme including stretching, general balance and mobility exercises, swimming and sessions on an exercise bike No exercise control All participants (including exercise groups) were telephoned fortnightly.	Recruited via advertisements in local neurological clinics and an MS information centre Inclusion criteria Relapsing-remitting MS; ambulant with or without the use of walking aids; not undergoing a relapse of their MS; relapse-free for the previous six months Exclusion criteria None specified	Weighted leg exercise Age: 40-48 yrs Female: 83% Time since diagnosis: 1.5-8 yrs Mobility exercises Age: 41-59 yrs Female: 83% Time since diagnosis: 1-15 yrs No exercise control Age: 36-54 yrs Female: 80% Time since diagnosis: 2.5-20 yrs	N=1 withdrew due to transport difficulties prior to study start N=1 withdrew from the weighted leg exercise group due to back pain after four weeks N=1 withdrew from mobility exercises group due to relapse leaving n=17 for analyses (n=6 in both exercise groups and n=5 in control)	Pulse rate (*exercise capacity*) Timed walk (*walking speed*) Electromyography (EMG) and maximum voluntary contraction (MVC) of quadriceps (*leg strength*) Timed transfer (*transfer speed*) Activity diary (*usual daily activity*)	Adherence to exercise programmes was 69%. Trend for improvement in exercise groups, but no significant between-group differences on EMG, MVC and timed walk. Mobility exercise group improved on both 10m and 50m walk speeds, while the weighted leg exercise group's mean resting pulse rate after walking 50m decreased by an average of 16.4% despite little improvement in walking speed	5/10

Study	Intervention	Recruitment and Eligibility	Participant characteristics	Withdrawals	Measures	Key findings	PEDro score
Mostert et al., 2002 (51)	Aerobic exercise training group (n=19) v non-training group (n=18). <u>Aerobic training group</u> Five 30-minute sessions per week of bicycle exercise with individualised intensity for four weeks. <u>Non-training group</u> Normal physical therapy included in the rehabilitation programme. Participants in this group agreed not to increase their physical activity	Participants already taking part in an inpatient rehabilitation programme were screened for inclusion. <u>Inclusion criteria</u> Confirmed diagnosis of clinically definite MS; able to pedal on a free-standing bicycle ergometer; no history of medical conditions precluding participation <u>Exclusion criteria</u> Acute exacerbation in previous two months	<u>Aerobic training group</u> Mean age: 45 yrs Gender (Female:Male): 10:3 Disease duration: 2-27 yrs Type of MS: RRMS (31%); SPMS (46%); PPMS (23%) EDSS: 2.5-6.5 <u>Non-training group</u> Mean age: 44 yrs Gender (Female:Male): 11:2 Disease duration: 2-25 yrs Type of MS: RRMS (39%); SPMS (23%); PPMS (31%) EDSS: 1.0-6.5	N=11 withdrew due to change in the exercise ECG (2), allocation to exercise group (3), and elevated spasticity (2). Of the non-training group 3 lacked motivation and 2 had exacerbations. N=13 per gp remained for analyses.	Incremental graded exercise test on a leg cycle ergometer (*max aerobic capacity*) Cosmed K4 b spirometry function (*static and dynamic lung function*) Computerised V-slope method of the gas exchange data (*aerobic threshold*) Polar®system (*heart rate*) BAECKE Activity Questionnaire (*physical activity*) SF-36 (*health-related quality of life*) Fatigue Severity Scale (*fatigue*)	Training group demonstrated a significant improvement in aerobic threshold, health related quality of life and an increase in activity level. No between group-analyses.	4/10

Study	Intervention	Recruitment and Eligibility	Participant characteristics	Withdrawals	Measures	Key findings	PEDro score
Oken et al., 2004 (52)	Yoga v aerobic exercise class v waiting list control Intervention groups ran for 6 months Yoga 90 minutes in duration once per week + a booklet for home practice Aerobic exercise Once per week including 5 minutes of stretching, cycling at light to moderate intensity (self-managed using Borg rating of perceived exertion), option of swiss ball exercises periodically. Participants continued cycling until ready to stop due to fatigue, symptom onset or reaching personal goal (one hour for several). Given a home bicycle for use in between sessions. Control No information regarding usual care	Recruited through local newspaper, Oregon Health and Science University (OHSU) newsletter website and MS Center and newsletter of local MS Society Inclusion criteria EDSS of 6.0 or less (e.g. able to walk 100m with at most unilateral support); presence of medical conditions precluding participation and/or medical illness that may impair cognition; Colour vision intact to colour dot perception on the Stroop with 100% accuracy; and English as a primary language. Exclusion criteria Those with insulin-dependent diabetes, uncontrolled hypertension, liver or kidney failure, symptomatic lung disease, alcoholism/drug abuse, symptoms, signs of congestive heart failure, ischemic heart disease, or symptomatic valvular disease or corrected visual acuity work than 20/50 binocularly; if they had performed yoga or tai-chi in the last six months or were regularly performing aerobic exercise (more than 30 minutes per day).	Yoga Mean age: 49.8 yrs Female: 91% Mean EDSS: 3.2 Aerobic exercise Mean age: 48.8 yrs Female: 87% Mean EDSS: 2.9 Control Mean age: 48.4 yrs Female: 100% Mean EDSS: 3.1	N=12 withdrew (4 from yoga, 6 from aerobic exercise and 2 from control) leaving n=57 for statistical analyses	A battery of cognitive measures (*aspects of attention*) Physiologic measures of *alertness* Profile of Moods States (*mood and depression*) State-Trait Anxiety Inventory (*stress*) Multi-Dimensional Fatigue Inventory (*fatigue*) SF-36 (*health-related quality of life*)	Both yoga and aerobic exercise groups showed significant improvements in fatigue.	6/10

Study	Intervention	Recruitment and Eligibility	Participant characteristics	Withdrawals	Measures	Key findings	PEDro score
Patti et al., 2002 and 2003 (53,54)	Comprehensive outpatient rehabilitation (treatment – n=58) v self exercise-treatment at home (control – n=53) Treatment 6 weeks of outpatient rehab programme, 6 days a week, 50-60 minutes/day including: physiotherapy (5 days/wk), occupational therapy (2 days/wk), speech therapy (if necessary), neurologist (1/wk), psychologist (1/wk), and other complementary alternatives (video, etc) + 6 weeks at home (doing an exercise program they had been instructed in). Control 12 weeks home exercise doing a self-executed exercise programme they had been instructed in.	All patients diagnosed with primary or secondary progressive MS admitted to the Centro Sclerosi Multipla of the Policlinico of the University of Catania between January 1998 and December 1998 were screened for inclusion. Inclusion criteria Clinically definite or laboratory supported MS; EDSS between 4.0 and 8.0; aged between 18 and 65 years. Exclusion criteria One of more exacerbations in preceding three months; cognitive impairment likely to interfere with adherence to the study (determined by the Mini-Mental State Examination-MMSE score of ≤24); history of cardiovascular, respiratory, orthopaedic, psychiatric or other medical condition precluding participation; pregnancy; treatment with immunosuppressives, interferons, copolymer, 4-amminopyridine, or experimental drugs in the six months before enrolment, rehabilitation therapy in the three months before admission, non-Italian speaking.	Treatment Age: 25-60 yrs Female: 58.6% Disease duration: 5-30 yrs EDSS: 4.0-8.0 Control Age: 30-57 yrs Female: 56.6% Disease duration: 9-26 yrs EDSS: 4.0-8.0	N=5 withdrew (4 from treatment group and 1 from control group). All these patients were included in the statistical analyses	SF-36 (*health-related quality of life*) Beck Depression Inventory (*depression)* Fatigue Impact Scale (*fatigue*) Kurtze's Functional Systems scales and Kurtze's Expanded Disability Status Scale (EDSS - *neurological impairment*) Social experience Check-list of Tempelaar (*social functioning*) Motor and cognitive domains of the FIM (*disability*)	Significant improvements found on all SF-36 subscales for the treatment group at week 6 which were sustained at week 12. The difference between treatment and control was significant at week 6 and week 12. At week 12 the treatment group reported significantly reduced fatigability, improved social functioning and reduced depression. No significant change in neurological impairment. FIM motor domain scores differed significantly between groups particularly in locomotion, self-care and transfers. No significant change on FIM cognitive domain.	8/10

Study	Intervention	Recruitment and Eligibility	Participant characteristics	Withdrawals	Measures	Key findings	PEDro score
Petajan et al., 1996 (36)	15 week aerobic training program v no treatment control <u>Treatment</u> 3 supervised sessions per week for 15 weeks including 5 minute warm up at 30% VO_2max, 30 minutes at 60% VO_2max, and a 5 minute cool down and 5-10 minutes of stretching. <u>Control</u> No information regarding usual care	MS Society and physician referrals <u>Inclusion criteria</u> Confirmed diagnosis of clinically definite MS; EDSS or 6.0 or less; no history of cardiovascular, respiratory, orthopaedic, metabolic or other medical condition precluding participation. <u>Exclusion criteria</u> Regular physical activity in the 6 months prior to the study.	<u>Treatment</u> Mean age: 41.1 yrs Female: 71% Mean time since diagnosis: 9.3 yrs Mean EDSS: 3.8 <u>Control</u> Mean age: 39.0 yrs Female: 64% Mean time since diagnosis: 6.2 yrs Mean EDSS: 2.9	Of 54 originally recruited, 6 were excluded for reasons unrelated to the project or MS and 2 were excluded secondary to an MS exacerbation, leaving n=46 remaining for statistical analyses (n=21 exercise group; n=25 control).	Kurtze's Functional Systems scales and Kurtze's EDSS (*neurological impairment*) Graded exercise test (*aerobic capacity*) Maximum voluntary isometric contractions of give upper and five lower extremity muscle groups (*strength*) Profile of Moods States (POMS - *mood*) Sickness Impact Profile (SIP - *health status*) Fatigue Severity Scale (*fatigue*)	No significant change in neurological impairment. Group x time effects were significant for VO_2max, physical work capacity, and upper and lower extremity strength measures. Exercise group had significantly lower scores on depression and anger subscales of POMS at weeks 5 and 10, though these differences were no longer significant at week 15. Fatigue was significantly lower than baseline at week 10 also. Group x time interaction found on the physical dimension of the SIP. Exercise group showed significant improvements in social interaction and emotional behaviour on the SIP at week 10.	6/10

Study	Intervention	Recruitment and Eligibility	Participant characteristics	Withdrawals	Measures	Key findings	PEDro score
Romberg et al., 2004 and 2005 and Surakka et al., 2004 (55,56,58)	Progressive 6 months exercise program (n=56) v no intervention control (n=58) Treatment 3 weeks inpatient rehabilitation following by 23 weeks at home. Inpatient rehab included 5 supervised strength training and 5 aerobic sessions. Trained physiotherapists instructed participants individually about a home exercise program. Weeks 4 to 20 included 3 x strength sessions and 1 x aerobic session. A further strength session was added for weeks 21 to 26. Control Contacted three times by phone and asked to avoid any great change in their physical activity habits during the 6-month intervention period.	Screened from a waiting list for inpatient rehabilitation at the Masku Neurologic Rehabilitation Centre between 1999 and 2001. Inclusion criteria Diagnosis of clinically or laboratory supported MS; EDSS score of 1.0 to 5.5; aged between 30 and 55 years old. Exclusion criteria Relapse within one month of baseline, a medical condition precluding participation in the prescribed exercise programme, had engaged in regular exercise five or more times a week for at least 30 minutes a time in the 3 months preceding baseline.	Treatment Mean age: 43.8 yrs Female: 64% Time since diagnosis: 0-23 yrs Median EDSS: 2.0 Control Mean age: 43.9 yrs Female: 65% Time since diagnosis: 0-28 yrs Median EDSS: 2.5	For treatment group – n=7 withdrew before baseline, n=2 were excluded at baseline, n=2 dropped out after baseline. For control group – n=8 withdrew before baseline, n=2 were excluded at baseline, n=2 dropped out after baseline. N=95 were included in analyses (including those who dropped out of the intervention after baseline) – n=47 (treatment); n=48 (control).	Kurtze's Functional Systems scales and Kurtze's EDSS (*neurological impairment*) Multiple Sclerosis Functional Composite (MSFC – *impairment*) 25 foot walk test and 500m walk test (*walking speed and ambulatory fatigue index*) Dynamometer (*Maximal isometric torque of knee and flexor muscles and motor fatigue*) Multiple Sclerosis Quality of Life-54 Questionnaire (*quality of life*) *Note:* This trial was reported in three different papers with each paper focusing on different outcome measures – 1. Walking speed, 2. Functional impairment and quality of life, and 3. Motor fatigue in men and women. Only measures relevant to these primary outcomes of interest are listed here.	Significant group x time effect on the 25 foot walk test and the 500m walk test.22% of exercisers improved versus only 2% (n=1) in the control group. Significant group x time interaction on the MSFC. No significant differences found on quality of life. Ambulatory fatigue index significantly reduced for both treatment and control. Motor fatigue was reduced in knee flexion and extension among female exercisers, but not males.	6/10

Study	Intervention	Recruitment and Eligibility	Participant characteristics	Withdrawals	Measures	Key findings	PEDro score
Solari et al. 2003 (57)	Inpatient rehabilitation program (n=27) v waitlist control (n=23) <u>Treatment</u> Last three weeks and included twice-daily exercise (45 minutes long). Patient instructed in a self-executed exercise program to perform at home <u>Control</u> Home exercise program only	All consecutive, hospitalised patients and outpatients were recruited from local neurology institute. <u>Inclusion criteria</u> Clinically or laboratory-supported MS; EDSS score between 3.0 and 6.5; aged between 18 and 65 years. <u>Exclusion criteria</u> One or more exacerbations in preceding 3 months; cognitive impairment likely to interfere with adherence to the study (determined by Mini-Mental State Examination score of ≤23.8); history of other medical conditions precluding participation; and rehabilitation therapy in the 3 month before admission.	<u>Treatment</u> Mean age: 44.6 yrs Female: 63% Type of MS: RRMS (22%); SPMS (63%); PPMS (15%) EDSS: 3.0-6.5 <u>Control</u> Mean age: 44.9 yrs Female: 48% Type of MS: RRMS (22%); SPMS (61%); PPMS (17%) EDSS: 3.5-7.0	N=5 withdrew (n=3 from treatment and n-2 from control) N=1 control failed to present for final examination, n=1 treatment had an exacerbation, n=3 (one control, two treatment) deteriorated clinically and were given steroids.	Kurtze's EDSS (*neurological impairment*) Hauser's Ambulation Index (*mobility*) FIM (*disability*) Hamilton Rating Scale for Depression (*depression*) SF-36 (*health-related quality of life*)	Significant between-group differences at weeks 3 and 9 on all scale scores of the FIM motor domain and on locomotion and self-care at week 15. Treatment group improved in all in all but bodily pain on the SF-36. Significant between-group differences were observed in favour of the treatment group on the general health and mental health subscales at all time points, the vitality subscale at weeks 3 and 15, and on the role limitation (emotional) and social functional subscales at week 9.	7/10

Study	Intervention	Recruitment and Eligibility	Participant characteristics	Withdrawals	Measures	Key findings	PEDro score
Wiles et al. 2000 (59)	Cross-over design so each participant (n=42) received three 8 week periods of treatment consisting of 1) home physiotherapy, 2) hospital outpatient physiotherapy, and 3) no physiotherapy. Treatment periods were separated by 8 weeks. Physiotherapy groups Two sessions of 45 minutes each week for eight weeks either at home (for the home group) or at the physiotherapy department (for the outpatient group). No physiotherapy control No information regarding usual care	People with definite or probable chronic MS reporting difficulties with walking were recruited from neurology clinics at the University Hospital or Wales. Inclusion criteria At least 18 years of age, able to walk 5 metres with or without a mechanical aid, not currently having an MS relapse, free from any major general medical or surgical disorders or pregnancy. Exclusion criteria None specified	Age: 28.2-68.8 yrs Female: 64% Mean disease duration: 12.3 yrs EDSS: 4.0 (n=2); 4.5 (n=2); 5.0 (n=1); 5.5 (n=2); 6.0 (n=17); 6.5 (n=17)	N=2 withdrew (1 withdrew after recruitment, but before treatment and 1 declined further assessment after one treatment period). In total n=40 were included in analyses with n=39 undergoing all assessments.	Rivermead Mobility Index (RMI) as primary outcome measure *Note:* A large number of secondary outcome measures were also included to measure disability, balance, walking and upper limb function, cognitive and affective states and visual analogue scales. All measures are not listed here due to the large number of measures.	No significant differences were found between the two exercise groups (home v outpatient-based) on the RMI or any of the secondary outcome measures. Significant differences between physiotherapy versus no physiotherapy on the RMI and secondary mobility measures (balance time, timed walk, and others). Statistically significant effects in favour of physiotherapy were also found for anxiety and depression.	7/10

2.3.4 SYNTHESIS OF FINDINGS

The studies presented in Table 2.3 report a range of benefits of engagement in physical activity for people with MS. The interventions reporting benefits included progressive resistance exercise, aerobic training, inpatient and outpatient multidisciplinary rehabilitation, physiotherapy and yoga. The findings as they relate to different aspects of health outcome are discussed below.

2.3.4.1 Strength and Balance

There is moderate evidence to suggest that physical activity can improve strength in people with MS, with one high quality RCT (36) reporting improvements in upper and lower extremity strength as a result of aerobic training, and one low quality RCT reporting improvements in leg extensor power through progressive resistance training.(48) This finding was confirmed in a non-controlled pretest-posttest study, also exploring the benefits of a progressive resistance exercise programme in people with MS, which reported improvements in arm strength and leg endurance.(62) Regarding balance; while no RCT's included in this review explore the impact of physical activity on balance, an RCT exploring the effectiveness of both facilitation and task-oriented physiotherapeutic approaches reported improvements in balance.(50) Likewise, a single group experimental study piloting Tai Chi in people with MS has also reported improvements in balance measures.(63)

2.3.4.2 Functional limitation

There is strong evidence in favour of physical activity reducing functional limitations with five high quality RCTs (53,56,57,59,60) and one low quality RCT (49) reporting improvements in a range of functional measures including 25 foot walk test,(56) 500m walk test,(56) FIM motor domain,(49,53,57) Rivermead mobility index,(59) and the Amended Motor Club Assessment.(60) A range of non-controlled studies have reported similar improvements on functional measures.(62,64,65) More recently, a longitudinal study explored the trajectory of functional limitations, exercise and quality of life over a 5-year period in people with MS.(66) It was found that ongoing participation in exercise corresponded with decreased rates of change in functional limitations, and that greater reported exercise behaviour at baseline was associated with less accumulation of functional limitations over the 5-year period. This longitudinal study is one of the first studies to suggest that a relationship exists between exercise behaviour and progression in functional limitation for people with MS.

2.3.4.3 Exercise capacity

There was moderate evidence for the potential of physical activity to improve exercise capacity, with one high quality RCT reporting improvements in physical work capacity,(36) one low quality RCT reporting significant improvements in aerobic threshold,(51) and one low quality RCT reporting improvements in resting pulse rate on completion of a 50m timed walk.(61) The first two studies reported here tested aerobic training programmes, while the third tested weighted leg exercises and so this finding is only relevant to similar programmes. Supporting this finding, all three narrative reviews on exercise and MS discussed the potential for improvements in cardio respiratory fitness through aerobic training in view of available evidence.(31,44,47) However, all cautioned that findings regarding the physiological response to physical activity for people with MS may be influenced by level of impairment, and suggest exercise prescription should be individualised.

2.3.4.4 Fatigue

There was strong evidence in favour of physical activity for improving fatigue, with four high quality RCTs reporting improvements in at least one aspect of fatigue.(36,52,54,58) These trials reported on a range of different intervention types including outpatient rehabilitation,(54) yoga,(52) progressive resistance exercise,(58) and aerobic training.(36) The fatigue measures used varied, including an objective measure of motor fatigue (58) and a range of self-report measures.(36,52,54) These findings have been supported by a number of other studies including one quasi-experimental study exploring a comprehensive outpatient rehabilitation programme,(67) a non-controlled study of lower resistance training,(64) and a pilot study of an aquatic exercise programme.(9)

2.3.4.5 Health-related quality of life and self-reported health status

There was strong evidence to suggest engagement in physical activity has beneficial effects on health-related quality of life or self-reported health status with three high quality RCTs (36,54,57) and one low quality RCT (51) supporting this finding. Improvements were reported on the physical, social interaction and emotional behaviour domains of the Sickness Impact Profile (36) and on the vitality and social interaction domains of the SF-36 (51) as a result of aerobic training. Both an inpatient and an outpatient rehabilitation programme resulted in improvements on all SF-36 subscales.(54,57) Similarly, one quasi-experimental study also reported improvements on a range of SF-36 domains as a result of outpatient rehabilitation.(68) A number of cross-sectional studies also support this finding, reporting activity to be associated with better scores on social functioning, physical functioning and general health subscales of the SF-36,(9,10) and greater participation in health-promoting behaviours to have a direct effect on quality of life, regardless of illness-related disability.(15)

2.3.4.6 Psychological well-being

There was strong evidence in favour of physical activity with regard to psychological well-being, with three high quality RCTs reporting improvements in anxiety or depression or both.(36,54,59) Outpatient rehabilitation resulted in reductions in depression measured by the Beck Depression Inventory,(54) aerobic training resulted in decreased anger and depression on the Profile of Moods States,(36) and home-based and outpatient physiotherapy resulted in significant decreases in anxiety and depression measured by the Hospital Anxiety Depression Scale.(59)

2.3.4.7 Deleterious effects of physical activity

None of the RCTs reported any damaging effects of physical activity. One RCT reported a small percentage of temporary symptom change as a result of graded exercise testing (10%) and during aerobic training (6%).(51) This finding was supported by one study which set out to explore the impact that a single exercise session has on function, fatigue and sensory symptoms in people with MS.(69) This study found no changes in fatigue or function immediately post-exercise and 24 hours post-exercise, but temporary changes in intensity and number of sensory symptoms were reported. Symptoms returned to baseline levels within 30 minutes to three hours post-exercise for all except one participant who returned to baseline within 24 hours. These findings are not dissimilar to concerns reported in relevant narrative reviews regarding the risk that increases in core body temperature may result in exacerbation of symptoms.(31,44) However, both reviews argue that the apparent benefits of physical activity far outweigh any suspected risk, given the transient nature of symptoms post-exercise.

All of the studies that measured neurological impairment reported no change in impairment throughout the course of physical activity participation. This highlights two important points: 1) that contrary to historical beliefs about the potential for physical activity to negatively impact on neurological impairment, physical activity appears to be safe and indeed beneficial for people with MS; and 2) that there are a number of important health outcomes which are seemingly unrelated to neurological impairment and potentially modifiable through engagement in physical activity. This suggests that engagement in physical activity may play a crucial role in living well with the condition.

2.3.4.8 Physical activity versus exercise

It is important to acknowledge that all the interventions referred to in the RCT studies, apart from the multidisciplinary rehabilitation approaches,(49,53,54,57,60) report on the benefits of ‘exercise’, rather than ‘physical activity’ as defined earlier. However, a number of studies reporting on the potential benefits of physical activity, albeit at a lower level of evidence, do discuss physical activity in its broader sense. Of particular note is the work conducted by Stuifbergen and colleagues (10,12,14,15,66,70) which links physical activity behaviour to a range of health benefits. In addition, published physical activity recommendations make it clear that vigorous, continuous exercise is not the only way of obtaining health benefit.(28) Rather, recommendations suggest that 30 minutes or more of moderate intensity activities on most, if not all, days of the week is enough to result in health benefits, and that intermittent activity can also result in health benefit. That is, several smaller bouts of activity can be accumulated to make up the recommended 30 minutes a day.(28) Examples of activity meeting the moderate activity guidelines include climbing the stairs, walking short distances, gardening, housework and playing actively with children, making it clear that engagement in physical activity is a good alternative when engagement in a planned, structured exercise regime is difficult.

2.3.5 SUMMARY

A number of symptoms considered inherent to MS, such as muscle weakness, lack of balance, and fatigue, are areas of important health outcome which evidence suggests can be improved through engagement in physical activity. These symptoms may, at least in part, be a product of deconditioning, which may come about as a result of prolonged inactivity. While the search strategy used for this review was not exhaustive, in that a wider range of search terms or databases may have yielded further papers; it is clear from the synthesis of findings that engagement in physical activity has the potential to result in a number of positive health outcomes for people with MS. Furthermore, other than the potential for temporary symptom change believed to occur as a result of increases in core body temperature while exercising, no deleterious effects of physical activity were evident.

2.4 LEVELS OF PHYSICAL ACTIVITY ENGAGEMENT IN PEOPLE WITH MS

Despite increasing evidence highlighting the benefits of physical activity in people with MS, people living with the condition continue to engage in low levels of physical activity. In 2005, a meta-analysis synthesised the results of 13 studies including 1360 MS participants, reporting physical activity levels in MS in comparison with other diseased and non-diseased groups.(7) Overall, they reported a mean effect size of -0.60 indicating that individuals with MS were significantly less active than the overall comparison group. Secondary analyses found larger effects (greater disparity in physical activity behaviour was evident) for non-diseased populations than diseased populations; for objective versus self-report measures of activity (see Phase I of this doctoral research for a more in-depth review and analysis of physical activity measurement in this population); and for primary progressive MS versus relapsing-remitting MS. To give some context to these findings, details of 11 of the 13 studies reported in this meta-analysis are reported in Table 2.4. Data for two of the studies reported (32,71) could not be extracted directly from the published paper and therefore are not included here. Authors of these papers could have been contacted for further details of these two studies, however given that a) these studies had already been previously synthesised by Motl et al. (7) and b) the purpose of reporting details of the studies included in the meta-analysis was to add context; this was not deemed necessary.

Table 2.4: Studies included in Motl et al.'s (7) meta-analysis regarding levels of physical activity engagement in people with MS presented alphabetically

Study	**MS Participants**	**Activity measure**	**Comparison group(s)**	**Findings**	
Busse et al., 2004 (72)	N=10 Women only Type of MS not reported	Stepwatch™ activity monitor *Objective*	N=10 matched healthy adults N=10 Parkinson's N=10 Primary muscle disorder	*7 day step count – Mean (range)* MS patients: Matched healthy adults: Parkinson's: Muscle Disorder:	 2985 (689-5340) 6929 (4347-10002) 3818 (1611-5391) 3003 (716-5302)
Mostert and Kesselring, 2002 (51)	N=25 Included all types of MS	BAECKE Activity Questionnaire *Self-report*	N=25 healthy, sedentary adults	*Baseline Mean (Standard Deviation) for MS1/MS2 v healthy1/healthy2* *Note: activity scores are reported as two groups for each as participants had been randomised into groups for purpose of RCT* Sport-related activity Work-related activity Leisure activity MS groups were 13% lower than healthy controls for sport-related activity (reaching significance for MS1 v healthy1) Healthy controls reported 13-19% higher leisure activity than MS participants, but this did not reach significance.	 1.7 (0.7)/1.8 (0.4) v 2.4 (0.8)/2.4 (0.9) 2.7 (0.7)/2.5 (0.9) v 2.8 (0.6)/ 2.8 (0.6) 2.4 (0.6)/2.3 (0.7) v 2.8 (0.7)/ 2.8 (0.7)
Ng and Kent-Braun, 1997 (73)	N=18 Relapsing-remitting (RR) and primary progressive (PP) MS	TriTrac-R3D Accelerometer *Objective* Seven day recall questionnaire (7dRQ) *Self-report*	N=18 healthy, sedentary controls (no more than one formal exercise session of 20 minutes or more per week)	*Mean (Standard Deviation) for MS v sedentary controls* TriTrac-R3D 7dRQ	 121,027 (59,336) v 185,892 (60,566) 35.9 (3.0) v 36.2 (4.1)
Paul and Weinert, 1999 (74)	N=227 Women only Type of MS not reported	Two questions regarding the *amount* and *type* of activity in the last month *Self-report*	Two national samples: National cohort of midlife women (75) National cohort with chronic illness (76)	*% No activity v % Irregular activity v % Moderate/Vigorous* MS: Midlife women: Chronic Illness:	 44 v 41 v 15 28.4 v 42.7 v 28.9 38.5 v 33.1 v 28.4
Pearson et al., 2003 (77) (Abstract only)	N=20 Ambulant Type of MS not reported	Stepwatch™ activity monitor *Objective*	N=20 healthy volunteers	*Mean (range) step count/24 hours over 7 days* MS group: Healthy volunteers:	 3085 (285-5537) 5443 (2810-7933)

Study	**MS Participants**	**Activity measure**	**Comparison group(s)**	**Findings**
Pearson et al., 2003 (78) (Abstract only)	N=12 Type of MS not reported	Stepwatch™ activity monitor *Objective*	N=14 healthy volunteers	*7 day average (range) stride count in 24 hours* MS group: 3015 (285-5450) Healthy volunteers: 5431 (2810-7933)
Slawta et al., 2003 (34)	N=123 Women only Type of MS not reported	Yale Physical Activity Scale *Self-report*	National Health Interview Survey (NHIS) (79)	*% of women participating in listed activities (MS v NHIS)* Gardening 65 v 25 Leisure walking 61 v not reported Brisk walking 24 v not reported Leisure + brisk walking 67 v 48 Stretching/yoga 36 v 24 All water activity 22 v 15 Bicycle/exercycle 16 v 15 Strength training 14 v 9 Jogging 2 v 6 Stair climbing 2 v 12 Golf 1 v 2 Aerobics 2 v 11 Frequency of leisure, strengthening, swimming exercises greater in MS, but frequency of more vigorous activities greater in NHIS group.
Stuifbergen, 1997 (10)	N=37 Type of MS not reported	Human Activity Profile Maximum activity score and Adjusted activity score *Self-report*	N=477 healthy adults N=102 older adults N=83 chronic pain N=30 chronic obstructive pulmonary disorder (COPD) N=39 dialysis (80)	*Adjusted activity score – Mean (Standard Deviation)* MS: 43.4 (21.5) Healthy adults: 83.2 (7.8) Older adults: 71.6 (7.1) Chronic pain: 51.6 (16.2) COPD: 48.7 (14.2) Dialysis: 43.6 (19.1) People with MS also reported the greatest difference between their maximum activity score and their adjusted activity score suggesting that their average or usual activity was much less than their maximum capacity

Study	MS Participants	Activity measure	Comparison group(s)	Findings
Stuifbergen and Becker, 2001 (14)	N=347 Women only RRMS and PPMS	Physical activity subscale of the Health-promoting lifestyle profile-II (HPLP-II) *Self-report*	Sub-group comparison N=194 RRMS N=143 PPMS	*% of women who 'routinely' or 'often' practiced each health behaviour listed (RRMS v PPMS)* Follow planned exercise 31 v 31 Exercise vigorously 3 times a week 29 v 15 Stretching exercises 3 times a week 36 v 42 Physical activity through regular daily activities 44 v 22 Engage in light to moderate exercise 29 v 17 Take part in leisure-time physical activity 22 v 12 PPMS group reported significantly lower levels of physical activity over time.
Stuifbergen and Roberts, 1997 (15)	N=629 Women only Included all types of MS	Physical activity subscale of the Health-promoting lifestyle profile-II *Self-report*	N=712 healthy adults (81)	*Physical activity subscale – Mean item score (Standard Deviation)* Women with MS: 1.88 (0.66) Healthy adults: 2.34 (0.71) Effect size -0.67 *% of the women with MS 'routinely' or 'often' practiced each health behaviour:* Stretching exercises 3 times a week 37 Physical activity through regular daily activities 35 Engage in light to moderate exercise 22 Take part in leisure-time physical activity 19 Benign and Relapsing-remitting women with MS were more likely to engage in physical activity than those with progressive forms of MS

Study	MS Participants	Activity measure	Comparison group(s)	Findings
Vercoulen et al., 1997 (82)	N=50 Type of MS not reported	Actometer *Objective* Level of physical activity rated daily on a 7-point likert scale (Mean score for a two-week period was used for analyses – Daily Observed Activity Score) Activity subscale of the Checklist Individual Strength (CIS) Physical Activity Rating scale (PARS) Self-perceived activity *Self-report*	N=51 chronic fatigue syndrome (CFS) N=53 health adults	*Mean (Standard Deviation) for MS v CFS v healthy* Actometer 26.1 (13.6) v 23.3 (10.7) v 35.5 (10.8) Daily Observed Activity 4.3 (1.1.) v 3.8 (1.3) v 5.4 (1.0) CIS-Activity 3.4 (1.7) v 3.2 (1.7) v 5.8 (1.0) PARS 2.3 (0.4) v 2.1 (0.4) v 2.7 (0.5) Self-perceived activity 3.1 (1.1) v 2.9 (1.1) v 3.9 (0.8) No significant differences between MS and CFS groups, but both MS and CFS had significantly lower scores on all measures than the healthy adult group.

The evidence presented in Table 2.4 indicates that people with MS engage in significantly lower levels of physical activity than their non-diseased counterparts, with activity levels considerably lower even when compared with groups of sedentary non-diseased adults.(51,73) Of the studies presented in Table 2.4 only one reports people with MS to be more active on some activities (light and moderate activities) when compared with non-diseased populations.(34) However, the sample in this study was relatively active when compared with reported activity levels in other studies. For example, only 19% of the sample were classified as inactive (34), compared with 44% in an earlier study.(74) This table also highlights that while secondary analyses in the meta-analysis revealed a smaller effect size when people with MS were compared with other diseased populations,(7) people with MS do trend towards lower levels of activity than those living with other chronic illnesses such as chronic pain, COPD, dialysis patients,(10) Parkinson's disease,(72) and other chronic illness groups.(74) It should be noted that the majority of the studies reported were women-only samples. Secondary analyses conducted in the meta-analysis reported effect sizes to be larger for combined samples of men and women than for women only samples,(7) suggesting that males with MS may be even more physically inactive than their female counterparts. While MS is rarer in male populations, the disparity between the number of males and females afflicted with the disease is less in those with a primary progressive form of illness.(83) This indicates males may be prone to having a progressive form of illness, which may account for the finding that they are more inactive than their female counterparts. Studies published since this meta-analysis have confirmed the disparities in physical activity engagement between MS and their non-diseased counterparts, suggesting that physical activity levels remain low in people with MS.(19,20) Given the onset of MS is typically between 20 and 40 years of age,(26) people living with the condition face a lifetime of uncertainty, disability and, as the evidence presented here suggests, prolonged inactivity.

The detrimental effects of inactivity are well researched in the general population, leading to physical inactivity being identified as a major health risk by the World Health Organisation.(84) The low levels of physical activity reported here, coupled with the multiple disabling symptoms already experienced by people with MS, make people living with this condition particularly vulnerable to a range of secondary conditions and negative consequences associated with physical inactivity. This has been confirmed in studies exploring the risk of coronary heart disease (CHD) and other secondary conditions in women with MS.(32,33) Physical inactivity is believed to increase CHD risk due to the fact that inactivity is associated with a) higher levels of triglyceride (TG) and lower levels of high density lipoprotein cholesterol (HDL-C), both of which have been associated with CHD in women (85); b) reduced insulin sensitivity which causes increased glucose levels and has been associated with high levels of TG and low levels of HDL-C (86); and c) increased levels of abdominal fat, thought to be responsible for reduced insulin sensitivity.(86) One study exploring these risk factors in women with MS found that, after adjusting for a range of covariates, those women who were inactive had significantly greater mean waist circumference and higher mean levels of TG and mean glucose levels than those who participated in low to moderate levels of leisure-time physical activity.(33) A second study using the same sample suggested that women with MS were at no greater risk of CHD than the general population.(34) However, this study was the same as that referred to earlier where the study sample was unusually active, with the majority of participants meeting recommended physical activity guidelines, in contrast to the evidence presented in Table 2.4. Furthermore, despite being a particularly active sample, these studies highlight the link between physical inactivity and risk factors for CHD, providing evidence for the detrimental effects of the physical inactivity reported in this population. Finally, a study exploring the relationship between leisure-time physical activity and secondary conditions in women with physical disabilities, of which a large proportion were women with MS, found leisure-time physical activity to be inversely related to functional status, physical deconditioning and isolation.(32) This supports the assertion in one narrative review that the physical inactivity reported in people with MS may play a role in the social isolation and diminished general well-being which has been reported in this group.(31)

2.4.1 SUMMARY

Despite increasing evidence regarding the benefits of physical activity for people with MS, they continue to engage in low levels of physical activity when compared with the general population and a range of other chronic illness groups. This physical inactivity has been linked with a heightened risk of secondary conditions and other associated negative consequences. While it appears that people with progressive forms of MS may be at greatest risk, with even lower levels of physical activity than those living with relapsing-remitting MS, the levels of physical activity for all types of MS are low. In response to the findings of the meta-analysis reported here, the authors called for research aiming to better understand the reasons why people with MS do or do not choose to participate in physical activity,(7) to inform the development of more effective interventions aimed at enhancing adherence to physical activity. Given that the benefits of physical activity for people with MS have been well established, it seems appropriate that research in this field shifts its focus to exploration of the barriers and facilitators to engagement in physical activity in this population. One could argue that knowledge of the wide-ranging benefits of physical activity is of little value if one cannot facilitate engagement in physical activity. The authors of the meta-analysis go so far as to suggest that interventions that focus on addressing issues of adherence may result in more pronounced intervention effects than currently seen in traditional exercise trials.

2.5 BARRIERS AND FACILITATORS TO PHYSICAL ACTIVITY ENGAGEMENT FOR PEOPLE WITH MS

In order to explore current knowledge regarding the barriers and facilitators to physical activity for people with MS, a second review of the literature was undertaken. Due to the diversity in design and methodology adopted for research in this field, this review was pragmatic in methodology with regards to quality evaluation and synthesis of findings.

2.5.1 SEARCH STRATEGY AND SCOPE

The same search strategy described in Section 2.3.1 was used with regard to the definition of physical activity, publication date and databases searched. However, rather than utilising search terms to limit the study design, a range of search terms were selected to identify literature aimed at exploring the barriers and facilitators to physical activity. A summary of the keywords used for the database searches are outlined in Table 2.5.

Table 2.5: Summary of search terms for review of barriers and facilitators to physical activity for people with MS

	Keywords	
Population	multiple sclerosis	
AND		
Intervention	physiotherapy physical activit$ leisure exercise activit$ of daily living walking exercise therapy rehabilitation	OR
AND		
Study aims	barrier$ facilitat$ correlate predict$	OR

$=truncation

2.5.2 SUMMARY OF SEARCH RESULTS

In total, nine studies were identified which conducted some level of exploration into the barriers and facilitators of physical activity for people with MS. Seven of these studies were carried out by two research groups, both based in the United States.(12,13,16,19,20,70,87) The remaining two were specifically focused on exploring the barriers and facilitators to engagement in particular exercise programmes including a progressive resistance programme (88) and an aquatic exercise programme.(9) Details of the nine studies, along with their strengths and weaknesses regarding their ability to advance knowledge about physical activity engagement in people with MS, are presented in Table 2.6. If studies had multiple aims, the aims and associated findings presented in Table 2.6 are those that were specific to engagement in physical activity for people with MS.

Table 2.6: Studies exploring the barriers and facilitators to physical activity in people with MS

Study	**Design**	**Aims/Objectives relevant to participation in physical activity**	**Participants**	**Key findings**	**Strengths**	**Weaknesses**
Becker and Stuifbergen, 2004 (87)	Longitudinal study	To identify factors associated with barriers to health promotion in people with MS	N=557 Recruited through two local chapters of the National MS Society. Mean age: 52 yrs Female: 84%	The top five reported barriers to health promoting behaviours were: Fatigue, impairment, lack of time, interferes with other responsibilities and what I do doesn't help.	• Good sample size.	• Focus on health promoting behaviours rather than physical activity alone. • Barriers scale is a pre-defined list of barriers, and so may not be an exhaustive list of potential barriers experienced by people with MS. • Convenience sample through MS Society.
Dodd et al., 2006 (88)	Qualitative study using in-depth semi-structured interviews	To identify factors that might facilitate or create barriers to participation in and completion of a 10-week progressive resistance exercise programme	N=9 All those who participated in the 10-week programme were invited to take part. Age: 27-61 yrs Female: 78% Time since diagnosis: 1-13 yrs Specific types of MS not specified, but had to be able to walk 200m without assistance to be included in the programme	A number of factors important for programme completion were identified by participants: *Extrinsic* included: Leadership (by physiotherapists and fitness trainers), leaders' knowledge, diversity in leaders' expertise, the support of the group, low cost, convenient location, start time of programme. *Intrinsic* included: Determination to complete, positive attitude to exercise, seeing signs of progress, programme novelty, enjoyment.	• Qualitative so coming from the perspective of people with MS.	• Focus on engagement in a specific programme rather than physical activity generally. • Primary aim of study was regarding acceptability of the programme rather than barriers to participation. • Sample had consented to take part in a physical activity intervention, which may imply they already have an interest in physical activity.

Study	Design	Aims/Objectives relevant to participation in physical activity	Participants	Key findings	Strengths	Weaknesses
Motl, Snook, McAuley and Gliottoni, 2006 (19)	Cross-sectional	Drawing on Social Cognitive Theory. To examine associations among symptoms, self-efficacy and physical activity.	N=196 Recruited through three local chapters of the National MS Society. Mean age: 46 yrs Female: 88% Mean time since diagnosis: 9 yrs Type of MS: RRMS (89%); SPMS (9.5%); PPMS (1.5%)	↑ number of symptoms during past 30 days was associated with lower level of physical activity. Inverse relationship was partially accounted for by self-efficacy. Alternative model also found physical activity to have a direct effect on symptoms suggested *reciprocal determinism* (i.e. that person's behaviour both influences and is influenced by personal factors and the social environment).	• Theoretically based focus. • Variables explored are potentially modifiable through intervention.	• Cross-sectional. • Only counted number of symptoms, not frequency, intensity or type. • Focusing on a specific theoretical underpinning may limit capacity for knowledge in this area given how little is known about barriers and facilitators to activity from the perspective of people with MS. • Convenience sample through MS Society. • Majority of sample have RRMS.
Motl, Snook, McAuley, Scott and Douglas, 2006 (20)	Cross-sectional	Drawing on Social Cognitive Theory. To examine self-efficacy, enjoyment, social support, and disability as correlates of physical activity.	Same sample as above study.	Enjoyment, social support and disability had a direct significant relationship with self-efficacy. Enjoyment and self-efficacy had a direct significant relationship with physical activity. Model accounted for 31% of variance in physical activity.	• Theoretically based focus. • Variables explored are potentially modifiable through intervention.	• Cross-sectional. • Focusing on a specific theoretical underpinning may limit capacity for knowledge in this area given how little is known about barriers and facilitators to activity from the perspective of people with MS. • Convenience sample through MS Society. • Majority of sample have RRMS.

Study	Design	Aims/Objectives relevant to participation in physical activity	Participants	Key findings	Strengths	Weaknesses
Roehrs and Karst, 2004 (9)	Pilot study	Explore the effects of an aquatic exercise program and identify common barriers to participation.	N=31 (only n=19 completed the programme) Recruited through MS clinic in local medical centre. Demographics for n=19 only: Age: 39-71 yrs (Female); 40-65 yrs (Male) Female: 63% Type of MS: SPMS and PPMS only	N=12 withdrew N=6 before start (exacerbation (2), systemic infection (1), perception that programme would impair ability to complete daily tasks (3)) N=6 after start (exacerbation (2), dissatisfaction with class (1), no caregiver support (1), attendance impaired ability to complete daily tasks (2)) Only 8/31 completed at least 75% of classes; 6/31 between 50-74% of classes; 5/31 between 25-49% of classes. Reasons cited included: physical and psychological symptoms, employment-related reasons, transportation difficulties, significant other not available, social conflict, and fatigue. 169 sessions missed in total.	• Actively seeking information around barriers to participation.	• Focus on engagement in a specific programme rather than physical activity generally. • Primary aim of study was regarding effect of the programme rather than barriers to participation. • While reasons for withdrawal or missed sessions are cited, they are not explored in-depth with participants. • Included only progressive forms of MS. • Sample had consented to take part in a physical activity intervention, which may imply they already have an interest in physical activity.
Stuifbergen, 1995 (12)	Cross-sectional descriptive	To test a preliminary model of health promoting behaviours. *More specifically:* To explore the relationship between antecedents identified from a synthesis of literature and health promoting behaviours	N=77 Recruited through mail out to local chapter of National MS Society Age: 20-76 yrs Female: 77% Mean time since diagnosis: 8.5 yrs Specific types of MS not specified	↑age, social support, reciprocity, specific self-efficacy, general self-efficacy; and ↓barriers, conflict: were associated with greater participation in health promoting behaviours Physical activity was the health promoting behaviour participants felt least able to complete (low efficacy for physical activity)	• Preliminary model tested was based on a synthesis of findings from the literature.	• Focus on health promoting behaviours with a specific focus on quality of life rather than physical activity per se. • Barriers scale is a pre-defined list of barriers, and so may not be an exhaustive list of potential barriers experienced by people with MS. • Cross-sectional. • Convenience sample through MS Society.

Study	**Design**	**Aims/Objectives relevant to participation in physical activity**	**Participants**	**Key findings**	**Strengths**	**Weaknesses**
Stuifbergen and Rogers, 1997 (16)	Qualitative study using in-depth semi-structured interviews Phase II of a 10 yr multi-phase study	To explore factors which serve to influence the selection and use of health promoting behaviours in order to clarify which factors should be included in an explanatory model of health-promoting behaviours.	N=20 Theoretical non-probability sampling through rehabilitation nurses, neurologists, rehabilitation workers, MS Society Age: 32-65 yrs Female: 75% Mean time since diagnosis: 5.8 yrs Type of MS: Benign (n=1); RRMS (n=7); SPMS (n=2); PPMS (n=3); Not specified (n= 7)	Antecedents to health promoting behaviours identified included: *Barriers* (fatigue, demands related to illness, time, other responsibilities, safety concerns, lack of accessible facilities, embarrassment, lack of money, lack of motivation procrastination, effects of the disease, lack of transportation, heat) *Resources* (major category of support which different aspects of support including *type, source*, and *perceived result* of support). *Perceived demands of illness* (relating to physical, familial, and social demands) *Acceptance* of changes in life *Perceived benefits of health promoting behaviours.*	• First qualitative study developed to explore the barriers/facilitators to health promotion practices in people with MS.	• Focus on health promoting behaviours with a specific focus on quality of life rather than physical activity per se. • Researchers had already developed an explanatory model based on previous quantitative work, which may have influenced analysis. • Only short excerpts of raw data to back up findings.
Stuifbergen, 1999 (13)	Descriptive comparative study Part of a larger 10 yr multi-phase study	To compare the barriers and health promotion behaviours of rural and urban persons with MS	N=807 (n=603 urban; n=204 rural) Recruited from two local chapters of the National MS Society Mean age: 48 yrs (urban); 49 yrs (rural) Female: 79% (urban); 82% (rural) Mean time since diagnosis: 10.6 yrs (urban); 11.8 yrs (rural) Specific types of MS not specified	Significant between group differences on 9 of the 18 barrier items with the rural sample reporting a higher mean score on all plus overall score on barriers scale significantly higher for rural group. Top five barriers *urban* were: Too tired, impairment, lack of time, interferes with other responsibilities and lack of money. Top five barriers *rural* were: Too tired, impairment, lack of money, lack of convenient facilities and safety concerns. Urban group reported greater levels of participation in physical activity than rural group. Reported barriers accounted for a greater proportion of variance in physical activity for urban participants than rural ones, though this was significant for both groups ($P<0.01$).	• Good sample size.	• Focus on health promoting behaviours with a specific focus on quality of life rather than physical activity per se. • Barriers scale is a pre-defined list of barriers, and so may not be an exhaustive list of potential barriers experienced by people with MS. • Convenience sample through MS Society.

Study	Design	Aims/Objectives relevant to participation in physical activity	Participants	Key findings	Strengths	Weaknesses
Stuifbergen, Seraphine, and Roberts, 2000 (70)	Cross-sectional questionnaire Phase II of a 10 yr multi-phase study.	To test if the theoretical model (developed in response to 1995 and 1997 studies) represents an adequate fit to the data from a sample of people with MS using structural equation modeling.	N=834 Recruited through mailing lists from National MS Society Chapters. Age: 18-70 yrs Female: 80% Mean time since diagnosis: 10.6 yrs Type of MS: Benign (14%); RRMS (45%); SPMS (6%); PPMS (35%)	While chi square was found to be significant (therefore a discrepancy between sample and fitted model), other goodness of fit indices suggest an adequate fit. All pathways in the proposed model bar one were significant and in the hypothesised direction. Key target variables for future interventions include social support, perceived barriers, and specific self-efficacy.	• Model tested is based on previous phases of work. • Good sample size.	• Focus on health promoting behaviours with a specific focus on quality of life rather than physical activity per se. • Cross-sectional. • Barriers scale is a pre-defined list of barriers, and so may not be an exhaustive list of potential barriers experienced by people with MS. • Convenience sample through MS Society.

2.5.3 SYNTHESIS OF FINDINGS

Overall, research exploring the barriers and facilitators to physical activity is sparse, with two research groups identified as carrying out work in this area. Given the alternate approaches taken by each of these research groups, the findings from each group are discussed separately, followed by additional considerations identified by the remaining two studies not associated with these research groups.

2.5.3.1 Stuifbergen and colleagues

Stuifbergen and colleagues conducted some of the earliest work in this area during the development of their explanatory model of health promotion and quality of life in chronic disabling conditions. For the most part, Stuifbergen and her team were interested in the wider population of chronic disabling conditions, but believed that MS provided a useful model for research in this field due to the unpredictability and often progressive and disabling nature of the illness.(16) As a result, much of their work is conducted in samples of people with MS. Some of the variables reported to play a role in engagement in physical activity common across the studies by this group include social support, specific self-efficacy, number of perceived barriers to health promoting behaviours and acceptance of changes in life resulting from one's condition. The explanatory model tested in their 2000 study incorporates these components.(70)

There are a number of strengths of the work carried out by this research group, including a) that the explanatory model tested was informed by a synthesis of findings in the literature (12) and by a series of their own research conducted in this area (12,13,16,70) and b) they carried out some qualitative work to explore the perspective of people living with MS.(16) However, there are a number of limitations to this work when specifically considering engagement in physical activity for people with MS.

a) Health promoting behaviours v physical activity

The work focused on a broader model of health promotion and so includes exploration of a range of health promoting behaviours as well as physical activity, such as health responsibility, nutritional behaviours and stress management. However, it is possible that symptoms inherent to MS such as fatigue, lack of balance and coordination, impaired mobility, spasticity, thermosensitivity and the unpredictable nature of illness trajectory may make engagement in physical activity particularly difficult in comparison to other health promoting behaviours where the physical limitation of the illness may pose less of a threat. Stuifbergen and colleagues suggested physical activity to be the health behaviour people with MS felt least able to complete, with particularly low efficacy for physical activity reported by people with MS in one of their studies.(12) It is possible then, that focusing on a broader range of health promoting behaviours may have lead to a failure to identify factors unique to physical activity engagement for people with MS.

b) *Limitations of their qualitative exploration*

Surprisingly, given how little is known about physical activity engagement for people with MS, the qualitative work carried out by Stuifbergen and colleagues was the only fully qualitative study found in this review of the literature. This is a major strength of the work conducted by this research group. However, prior to carrying out this study, Stuifbergen and colleagues had already developed a preliminary model of health promotion and quality of life and the stated purpose of their qualitative study was to clarify factors relevant to this model.(16) This raises the possibility that their findings were interpreted in light of their explanatory model, potentially biasing their interpretation and limiting the capacity for knowledge that this qualitative work may have otherwise yielded.(89) Furthermore, given that Stuifbergen was also interested in the interaction between health promoting behaviours and quality of life, a key aim of this qualitative work was to also explore conceptualisations of quality of life held by people with MS. This tangential focus, coupled with the fact that the focus of their work went beyond physical activity behaviour alone, may limit what one can conclude from their findings when considering physical activity engagement specifically.

c) *Pre-defined barriers*

Much of the work exploring perceived barriers to health promoting behaviours conducted by Stuifbergen and colleagues rests on The Barriers to Health Promoting Activities for Disabled Persons Scale (BHADP) they developed in 1991.(90) This scale contains a list of 18 pre-defined barriers and respondents are asked to indicate how often the listed barriers keep them from engaging in health promoting behaviours by rating each of the barriers on a scale of 1 (never) to 4 (routinely). While the exploration of barriers using this scale has led to some key findings in this field, which should not be undermined; using this scale alone to identify barriers assumes the list provided is an exhaustive one. This may lead to key barriers being left untapped.

d) *Convenience sample*

All of Stuifbergen and colleagues' work, with the exception of the qualitative study, relies on a convenience sample recruited through local chapters of the National MS Society. It is possible that those people who access MS Society services hold different views from those who do not, potentially limiting the generalisability of findings.(91)

Stuifbergen and colleagues' work led to a randomised controlled trial of a wellness intervention for people with MS.(71) The findings indicated initial support for the intervention with the intervention group reporting improved self-efficacy and increased engagement in health behaviours. However, as with their previous work, this trial is limited in terms of their focus on a wide range of health-promoting behaviours and convenience sampling which restricts what can be drawn from it when specifically considering physical activity engagement in people with MS.

2.5.3.2 Motl and colleagues

More recently, Motl and colleagues have published a series of studies in this field. Unlike Stuifbergen and colleagues' research, Motl and his group were specifically interested in *physical activity engagement* for *people with MS*. The two papers presented in Table 2.6 discuss findings from a series of work carried out in the same sample.(19,20) Social cognitive theory underpins the work carried out by this group. This is a major strength of their work given that social cognitive theory has been well-researched, has a strong theoretical background and is regarded as a key theory for explaining physical activity behaviour in other populations.(92,93) It also lends itself to the identification of predictor variables which are potentially modifiable via intervention. However, focusing on such a tight theoretical underpinning may also be considered to be a weakness of this work. This and other limitations are discussed below.

a) Limited by a focus on theoretical underpinning

Given that so little is known about physical activity engagement for people with MS, there is little theoretical justification for focusing solely on one theoretical framework, and doing so may have limited the findings of this work. It is possible that supplementing the findings with a qualitative exploration may have allowed for identification of further barriers, not accounted for by the theory, allowing for further advancement of knowledge in this field.

b) Sample predominantly relapsing-remitting MS

The majority of the sample in the research carried out by Motl and colleagues lived with a relapsing-remitting form of MS (89%). Given that their own meta-analysis identified those with progressive forms of MS to engage in particularly low levels of physical activity, further exploration into the barriers and facilitators for this more physically impaired group is needed.

c) Convenience sample

As with Stuifbergen and colleagues' work, the sample recruited for Motl et al.'s studies were a convenience sample recruited through local chapters of the National MS Society, potentially limiting the generalisability of their findings.

2.5.3.3 Other research

Outside of these two research groups, only two other studies were identified that explored physical activity engagement in people with MS and both of these studies were specifically interested in adherence issues in relation to specific exercise programmes.(9,88) While these studies are limited with regard to the knowledge they provide regarding physical activity engagement in people with MS in general, they do offer some insight into important aspects to consider when developing a programme for people with MS, such as the importance of the credibility of programme leaders and of key considerations such as cost, location and timing.(88) In addition, they highlight other potential influencing factors such as the importance of mind-set and being able to see signs of progress.(88)

2.5.4 THE NEED FOR FUTURE RESEARCH

The work of the Stuifbergen and Motl teams offer an important contribution towards a better understanding of physical activity behaviour in people with MS. However, further research is warranted to overcome a number of the limitations highlighted above and, to explore the applicability of alternative theoretical frameworks. One possible framework for consideration is a cognitive-behavioural perspective which suggests that cognitions, behaviour and emotions all interlink and that it is possible to modify cognitive processes to achieve different ways of feeling and behaving.(94-96)

Research in people with pain-related disability has determined the role that cognitive-behavioural factors, such as fear-avoidance beliefs, play in the maintenance of maladaptive illness behaviours such as physical inactivity. For example, in pain patients, the fear that movement will result in re-injury or exacerbate pain results in the formation of fear-avoidance beliefs, leading to inactivity.(97) Interventions targeting such psychosocial correlates of maladaptive illness behaviours have been shown to markedly improve outcomes in the chronic pain patient group.(97,98) Research investigating the nature and impact of psychosocial factors in MS is not new, with factors such as self-esteem, depression and social support all being linked to adjustment in MS.(99-102) Recent work also suggests that illness beliefs may play a role for people with MS, with cognitive illness representations found to be the most significant predictors of social dysfunction, fatigue, anxiety, depression and self esteem in people with MS.(103) Another study found that those with distorted cognitive interpretations of symptoms and maladaptive behavioural responses to their symptoms were more likely to be fatigued and socially disabled.(104) This work supports the view that people with MS may form illness cognitions that are similar to those with chronic pain which may be just as debilitating, such as the fear that participation in activity may result in increased fatigue.

2.6 CONCLUSION

The review of evidence presented in this chapter indicates that despite clear evidence that exercise and physical activity is beneficial for people with MS, actual participation in activity remains low. This inactivity contributes to the onset of secondary conditions, reduced physical functioning, worsening mental health and social isolation. Whilst we know that exercise and physical activity are beneficial; this knowledge is irrelevant if we are unable to support people with MS to engage in physical activity. A better understanding of the barriers and facilitators to physical activity is crucial to the development of effective strategies aimed at facilitating engagement.

To date, little research has explored factors influencing the decision to engage in physical activity in this population; and that which has is subject to a range of limitations as described earlier. The key aim of this doctorate was to further develop research in this area and to overcome some of the limitations of existing research by a) focusing specifically on physical activity behaviour in people with MS; b) exploring an alternative theoretical framework; c) supplementing quantitative data with an in-depth qualitative inquiry; and d) sampling via a range of recruitment sources. The theoretical framework underpinning the investigation in this doctoral research is cognitive-behavioural theory; however, variables already identified as important in previous research will also be explored.

More specifically the key aims and objectives of this doctoral research were to:

(1) Gain a more in-depth understanding of the barriers and facilitators to physical activity from the perspective of people with MS;

(2) Use findings from this doctoral research and from previous research to inform the development of a theoretically driven, evidence based programme to facilitate activity engagement for people with MS; and

(3) Explore the acceptability and feasibility of the programme in people with MS and their clinicians.

In addition to this, as highlighted on page 22, it became clear early in this research that before conducting research aiming to better understand the barriers and facilitators to physical activity in people with MS, one first needed to consider how to effectively measure physical activity in this population. Therefore, a fourth aim was included and addressed first:

(4) To explore physical activity measurement in people with MS and identify an appropriate measure of physical activity to utilise in subsequent phases of this doctoral research.

PHASE I: MEASURING PHYSICAL ACTIVITY IN PEOPLE WITH MULTIPLE SCLEROSIS

OVERVIEW

Chapter Two highlighted the benefits of physical activity for people with MS are wide ranging, with a growing body of research linking physical activity to improvements in a number of aspects of health and well-being. Despite this, people with MS engage in low levels of physical activity when compared to the general population and other chronic illness groups. A clearer understanding of the factors associated with physical activity and its relationship to health and well-being in people with MS is paramount for the development of effective interventions aimed at enhancing engagement in physical activity. However, research investigating such factors in people with MS (and other illness and disability groups) is limited by the lack of valid and reliable measures of physical activity available for use in this population.(22,23) To conduct research aiming to better understand the barriers and facilitators to physical activity in people with MS, one first needs to consider how best to measure physical activity in this population. Therefore, Phase I of this research aimed to explore physical activity measurement in people with MS and identify an appropriate measure of physical activity to utilise in subsequent phases.

Chapter Three focuses on self-report measures of physical activity in people with MS, and reports on the first two original pieces of research conducted as a part of this doctorate. Chapter Four considers objective measurement of physical activity in people with MS and reports on the third research project carried out. Chapter Five discusses the key findings of each of these studies in the context of recent research.

CHAPTER 3

SELF-REPORT MEASUREMENT OF PHYSICAL ACTIVITY IN PEOPLE WITH MULTIPLE SCLEROSIS

3.1 INTRODUCTION

A review of the literature exploring physical activity in people with MS revealed that a range of self-report measures have been used previously in this population. However, just because these measures have been used in people with MS, it does not necessarily follow that they have been evaluated and found to be suitable for use as a measure of physical activity. The first aim of this doctoral research, and the focus of this chapter, was to identify a self-report measure of physical activity available for use in people with MS. To assist with measure selection, Fitzpatrick and colleagues propose eight criteria to assess measures against, including appropriateness, reliability, validity, responsiveness, precision, interpretability, acceptability and feasibility.(105) Table 3.1 outlines the questions Fitzpatrick and colleagues suggest need to be asked when applying these criteria to a measure.(105)

Table 3.1: Criteria for selecting an outcome measure proposed by Fitzpatrick et al.(105)

Criteria	**Key question**
Appropriateness	Is the content of the instrument appropriate to the questions which the research is intended to address?
Reliability	Does the instrument produce results that are reproducible and internally consistent?
Validity	Does the instrument measure what it claims to measure?
Responsiveness	Does the instrument detect changes over time that matter to patients?
Precision	How precise are the scores of the instrument?
Interpretability	How interpretable are the scores of an instrument?
Acceptability	Is the instrument acceptable to patients?
Feasibility	Is the instrument easy to administer and process?

3.1.1 EVALUATING MEASURES OF PHYSICAL ACTIVITY FOR USE IN PEOPLE WITH MULTIPLE SCLEROSIS

Table 3.2 displays a summary of self-report measures previously used in studies exploring physical activity in people with MS, along with details of how well they meet the criteria outlined in Table 3.1. A number of measures identified in this review were excluded from this evaluation for the following reasons:

- As discussed in Chapter One, this review only includes papers published up to 2006 due to this being the literature that informed development of subsequent studies carried out for this doctorate. However, findings from this phase will be discussed in the context of more recent publications.
- While a number of researchers used existing measures of physical activity, others developed measures specifically for use in their study either by: developing a completely new measure (74,82); compiling individual items sourced from a range of existing scales (106); or, modifying an existing scale. (32-34,107) While developing a new scale or modifying an existing one may mean it matches the needs of the study, rigour may be compromised if its measurement properties are not tested. As such, measures were excluded from this discussion if no evidence that they had undergone psychometric testing was found.

Measures were reviewed whether or not testing had been undertaken in people with MS specifically. When assessing these measures against the eight criteria outlined in Table 3.1, specific focus has been given to their potential for use in people with MS and in subsequent phases of this doctoral research.

Table 3.2: Self-report measures of physical activity previously used in people with MS

Measure	Studies measure used	Appropriateness	Reliability	Validity	Responsiveness	Precision	Interpretability	Acceptability	Feasibility
Health Promoting Lifestyle Profile II (HPLP-II) (108,109)	(13-15,66,71)	A 52 item scale assessing engagement in a range of health promoting behaviours; not just physical activity Focus on structured exercise rather than physical activity in a broader sense Development and original testing carried out with healthy individuals No information is collected about the *type* of activities people take part in	Exercise subscale has good internal consistency (α = 0.84) in people with MS (66)	Not published for people with MS Only reported for the original HPLP in general adult samples (108,110,111)	Not published for people with MS or for any population	Response categories include: never, sometimes, often and routinely Appears to be able to detect variability in frequency of health-promoting behaviours in people with MS; uses full range of potential scores (70)	Higher score equals greater participation in health-promoting behaviours	Not formally explored in people with MS	Self-administered Administration time not reported Appears easy to administer, but this has not been formally explored in people with MS
Seven Day Recall Questionnaire (7dRQ) (112,113)	(73,114)	A semi-structured interview that estimates an individual's time spent in physical activity for the 7 days prior to the interview. Interviewer-administered to probe for specific activities more completely and to improve recall by helping participants estimate the intensity of various activities more accurately Development and original testing carried out with healthy individuals	Not published for people with MS Only reported in general adult samples (113,115-117) and college students (118,119)	Good convergent validity (r=0.75 – 0.84) in people with MS when measured against alternative self-report and objective measures of physical activity (114)	Not published for people with MS or for any population	Relies on the ability of the interviewer to prompt effectively Ambiguity in how the activities are classified into different intensities	Metabolic equivalent (MET) value is assigned to each activity to derive the total score	Not formally explored in people with MS	Purported to be easy to administer, but this has not been formally explored in people with MS Costly to have an interviewer in large epidemiological studies

Measure	Studies measure used	Appropriateness	Reliability	Validity	Responsiveness	Precision	Interpretability	Acceptability	Feasibility
Human Activity Profile (HAP) (80)	(10)	A 94-item self-report measure of energy expenditure or physical fitness. The 94-items are a list of activities ranging from very easy to very strenuous. The respondent is asked to indicate whether they are 'still doing this activity', 'stopped doing this activity', or 'never did this activity' Considers activities at the low end of the physical activity spectrum, such as getting in and out of chairs or bed Measures one's *ability* to engage in activity, rather than actual *participation* in physical activity	Not published for people with MS Only reported in adults enrolled in a smoking cessation programme, adults with chronic pain, arthritis and an osteoarthritic knee (120)	Distinguishes between exercisers and non-exercises in people with MS (known groups validity)(10)	Large effect sizes reported for both maximum activity score (0.77) and adjusted activity score (0.95) in people with MS (120)	Response categories do not account for seasonal or illness-related changes in activity (e.g. if one has stopped doing an activity temporarily due to an exacerbation)	Activities ranked according to the energy expenditure required to perform the task based on MET values for those activities	Not formally explored in people with MS	Self-administered Administration time not reported Appears easy to administer, but this has not been formally explored in people with MS
Baecke Activity Questionnaire (121)	(51)	A 16-item questionnaire designed to measure habitual physical activity, measuring three dimensions, including: (1) work-related, (2) sport-related, and (3) leisure-time related Does not consider activities at the low end of the activity spectrum such as household activities Development and original testing carried out with healthy individuals	Not published for people with MS Only reported for adult women with hip disorders (122), older adults (123,124) and adult males (125)	Sport-related subscale distinguishes between people with MS and healthy controls (known groups validity)(51)	Not published for people with MS or for any population	Response categories differ depending on the item, but are scored on a scale of 1 to 5	Intensity rating of sports activities appears to be determined by the scorer and seems subjective	Not formally explored in people with MS	Self-administered A short questionnaire with simple items, making it appear easy to administer, but this has not been formally explored in people with MS

Measure	Studies measure used	Appropriateness	Reliability	Validity	Responsiveness	Precision	Interpretability	Acceptability	Feasibility
Godin Leisure-Time Exercise Questionnaire (GLTEQ) (126)	(114)	A self-administered two item measure of usual physical activity. The first question has three open ended items that measure frequency of strenuous, moderate and mild exercise for periods of more than 15 minutes in a typical week. The second measures the frequency of engaging in any regular activity long enough to work up a sweat Only considers structured activity time and activities conducted for a minimum of 15 minutes at a time Development and original testing carried out with healthy individuals No information is collected about the *type* of activities people take part in	Not published for people with MS Only reported for healthy adults (126) and school children (127)	Moderate convergent validity (r=0.54 – 0.67) in people with MS when measured against alternative self-report and objective measures of physical activity (114)	Not published for people with MS or for any population	Appears to be able to detect variability in frequency of exercise and leisure-time activities in people with MS; uses wide range of potential scores (114)	Scored by multiplying activities by MET values	Not formally explored in people with MS	Self-administered Appears easy to administer, but this has not been formally explored in people with MS

Information contained in Table 3.2 highlights there are a number of key limitations common to the measures previously used in people with MS which shed doubt on their suitability as a measure of physical activity in their current form. Each limitation is discussed in more detail below.

a) *Developed and originally tested in healthy individuals*

All measures, with the exception of the Human Activity Profile, were originally developed and tested for use in healthy individuals.(108,109,112,113,121,126) As a result, conceptually, the measures were not developed with the types of physical activity someone experiencing disability may engage in. For example, therapy-related activities or wheelchair use are activities which may be common in people with MS and which need to be accounted for when measuring their physical activity.

b) *Psychometric properties not explored in people with Multiple Sclerosis*

While many of these measures have been used in clinical populations since their original development, including people with MS, there has been little exploration of the measures' psychometric properties in those populations. Although one or two single properties, such as internal consistency of a subscale (66) or convergent validity,(114) have been reported in people with MS for a couple of the measures (HPLP-II and GLTEQ), full psychometric testing is rarely reported. Furthermore, acceptability of these measures to people with MS has not been explored, nor has their feasibility for use in this population been taken into consideration.

c) *Ignoring physical activity at the low end of the physical activity spectrum*

The majority of the scales listed in Table 3.2 tend to focus on structured exercise activities,(108,109) moderate to vigorous intensity activities,(121,126) or activities that last for a minimum period of time (15 minutes),(126) and so may miss activities considered more characteristic of someone with MS; such as short spurts of activity, incidental activities (e.g. household chores) or illness-related activities (e.g. wheelchair use, therapy-related activities). Measures which fail to take into account such activities, many of which fall at the low end of the activity spectrum, may suffer from floor effects and fail to discriminate small inter- or intra-individual differences in activity when used in people experiencing chronic illness or disability.

d) Scored using metabolic equivalent (MET) values

A Compendium of Physical Activities was developed by Ainsworth and colleagues (128) to aid physical activity researchers by coding the type and intensity of an activity so that comparisons can be made across studies and populations. All activities in the Compendium are assigned an intensity unit based on their rate of energy expenditure expressed in METs. One MET is equivalent to the energy expenditure required for an average adult to sit quietly. A number of the items in the measures listed in Table 3.2 are scored using the MET value of the activities reported.(80,112,113,126) While MET values may be considered a useful method of comparison in average, healthy adult populations, the developers of the Compendium (128,129) and others since (130) have cautioned that they do not take into account individual differences in energy expenditure and are not intended for use in adults with conditions "that would significantly alter their mechanical or metabolic efficiency".(128, p.73) Given that published MET values have not yet been validated for subgroups, such as people with MS, the appropriateness of using them to calculate physical activity scores in this population might be questioned. Furthermore, it could be argued that energy expenditure is at best a proxy measure of physical activity engagement. This however is discussed further in Chapter Four in relation to objective measures of physical activity (see page 121).

3.1.1.1 Physical activity measures designed specifically for disabled people

Due to the limitations identified in the measures previously used in people with MS, a search was conducted to identify any existing measures of physical activity developed specifically for people experiencing illness or disability. Two measures were identified: The Physical Activity Survey for Individuals with Physical Disabilities (PASIPD) (23) and Physical Activity Disability Survey (PADS).(131) While neither measure had been used in people with MS, both appeared to have good face and content validity in terms of the types of activities they cover. For example, both measures consider incidental activities (e.g. household chores) and both take into account illness-related activities (e.g. wheelchair use, therapy-related activities). However, like several of the measures described in Table 3.2, scores on the PASIPD are calculated using MET values derived in healthy populations, the limitations of which have already been discussed.

The most promising scale identified was the PADS which displayed good psychometric properties in a previous validation study (test-retest reliability: ICC ranged from 0.83 to 0.95).(131) However, since this original validation study, modifications to the subscales and scoring had been made but not validated. Furthermore, the PADS had not been used or psychometrically evaluated in people with MS. In the absence of an existing valid and reliable self-report measure of physical activity available for use in people with MS, a series of studies were carried out exploring the psychometric properties of the PADS and modifying and developing the measure for use in this population. Details of this work are described below.

STUDY ONE

THE PHYSICAL ACTIVITY AND DISABILITY SURVEY (PADS): RELIABILITY, VALIDITY AND ACCEPTABILITY IN PEOPLE WITH MULTIPLE SCLEROSIS[1]

3.2 AIMS

Study One was developed to:

(1) Evaluate the psychometric properties of the PADS in people with MS, specifically test-retest reliability and construct validity; and
(2) Assess its acceptability to people with MS.

3.3 METHODS

Ethical approval for this study was obtained from the Northern Y Health and Disability Ethics Committee in NZ (see Appendix A).

3.3.1 DESIGN

This study used a repeated measures design where participants completed the PADS twice with seven days between repeated measures, while also wearing an Actical accelerometer to assess test-retest reliability and construct validity. In addition, semi-structured interview questions were used to explore the acceptability of the PADS.

3.3.2 PARTICIPANTS

Participants for this study were recruited from the Multiple Sclerosis Society of Auckland, New Zealand. An information pack about the study was sent to a random selection of 120 members on the society's database (every 6th person on the database). This was based on the aim of recruiting at least 30 participants into the study and an anticipated response rate of at least 25%. The target sample size of 30 was determined, as a) this sample size is considered to be adequate for this study type

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[1] Study One resulted in the first publication directly linked to this doctoral research (132):
Kayes, N. M., McPherson, K. M., Taylor, D., Schluter, P. J., Wilson, B. K., & Kolt, G. (2007). The Physical Activity and Disability Survey (PADS): reliability, validity and acceptability in people with multiple sclerosis. *Clinical Rehabilitation, 21*(7), 628-639.

(133); b) it is comparable to other studies carried out in these populations (114,132,134); c) it was considered that this target would capture a diverse sample, a critical issue for this study type (135); and d) it was thought that this sample size would be logistically possible to recruit. Regarding the anticipated response rate, previous research carried out utilising the same database reported a 50% response rate.(136) However, it was anticipated this study would yield a lower response rate than this for two reasons. First, this study required a greater commitment from participants than this previous cited work, which was a cross-sectional questionnaire study. Second, a major MS prevalence study was being carried out at the same time as this research which was believed to have the potential to impact on response rates due to the possibility that some potential participants would feel over-burdened by research at that time.

The information pack posted to potential participants included a cover letter written by the MS Society on behalf of the research team (see Appendix B), an information sheet (see Appendix C), consent form (see Appendix D) and a self-addressed stamped envelope. People were eligible to participate if they had been given a definite diagnosis of MS by a neurologist and were able to communicate with the researchers. Those who were interested in taking part completed the consent form and returned it to the research team in the envelope provided.

3.3.3 MEASURES

3.3.3.1 Demographic and illness-related variables

A range of demographic and illness-related variables were collected at the first assessment point, including gender, age, employment status, receipt of disability compensation, confirmation of definite diagnosis of MS, time since diagnosis, type of MS and remission status. For type of MS, due to the possibility that participants would not be familiar with the actual terminology used to refer to each type (e.g. primary progressive), a description of each type was developed based on the predominant characteristics of that type and participants were asked to select which pattern best described their course of MS. In addition, a range of questions were asked to help make sense of the physical activity data collected. These included questions around the participants' sleeping and bathing patterns, their use of assistive aids and use of their arms and legs.

3.3.3.2 Physical Activity Disability Survey (PADS)

Physical activity was measured using the PADS. The original version of the PADS consisted of four empirically derived subscales: *Exercise, Leisure-Time Physical Activity, Household Activity* and *Time Indoors* and was validated in people with a primary disability of stroke and type 2 diabetes.(131) However, the authors have since developed the PADS further so that it now consists of six subscales: *Exercise, Leisure-time Physical Activity, General Activity, Therapy, Employment/School*, and *Wheelchair Use*. (Dr James Rimmer, personal communication, 05 October, 2005) This version of the PADS has primarily been used within the National Center of Physical Activity and Disability in the United States, where it was developed. The PADS was originally developed as a semi-structured interview, but has also been used as a questionnaire.(131) The score is calculated based on the time respondents spend doing activities multiplied by an intensity rating of that activity. Higher scores indicate higher levels of activity and negative scores can be obtained for sedentary behaviour, such as long periods of sleeping, sitting or lying. Appendix E contains sample copy of the PADS form, along with scoring methodology obtained from the authors.

3.3.3.3 Criterion measure of physical activity

Choosing a 'gold standard' measure of physical activity is problematic, as each method has its limitations. For example:

- *Direct observation* of activity is useful if activity is being measured under set conditions, but not in free-living conditions
- *Physical activity logs* are criticised for their reliance on subjective recall;
- *Pedometers* are limited to use in ambulatory populations and fail to measure slow walking speeds accurately (137-139);
- *Accelerometers* do not discriminate between different types of activities and waist mounted devices do not detect arm movements.(140)

See Chapter Four for a more detailed discussion of the strengths and weaknesses of available objective measures of physical activity (see page 118).

The choice of 'gold standard' is largely dependent on the specific research needs. For this study, an Actical accelerometer (Mini Mitter, Bend, OR) (141) was used as the criterion measure. Accelerometers are increasingly used in research and as a criterion measure in validation studies,(142) because they are sensitive to lower levels of activity, they can measure movement in multiple planes and they have been used successfully in people with disability, including people with MS.(73) Following Trost, McIver and Pate's (143) guidelines on choosing an accelerometer, Actical accelerometers were selected as the criterion measure in this study because they: (1) contain an omnidirectional motion sensor and therefore likely to pick up a range of free-living activities; (2) are compact and easy to wear and should generate little participant burden; (3) are tamper free and so participants cannot interfere with data collection; and (4) are waterproof and so can be worn in the shower and during water-based activities. Actical accelerometers detect low frequency (0.5-3.2Hz) gravitational-forces (0.05-2.0g) common to human movement and generate a signal, proportional to the magnitude and duration of the sensed acceleration, which is digitised and summed over a user-specified time-interval (epoch).(144) The digitised value is known as an activity count. The accelerometer was set to record data at 15-second epochs, the minimum epoch length, in order to capture short bouts of physical activity and the total activity counts were collected over a seven-day period. At the end of the seven-day period a range of questions were asked about the participants' experiences of wearing the activity monitor in order to ascertain how compliant participants were with wearing the accelerometer. A sample of these questions is provided in Appendix F.

3.3.3.4 Acceptability of the PADS

A series of semi-structured questions were developed to obtain feedback from participants on the acceptability of the PADS questionnaire to people with MS. These included "How did you find completing the activity questionnaire?"; "Do you feel the questions in the activity questionnaire enabled you to give an accurate picture of the activities you participate in?"; "Were there any activities that you currently participate in that you were not asked about in the questionnaire?"; and "Is there anything else you would like to tell us about the activity questionnaire?". A list of all the semi-structured questions asked is provided in Appendix F. Appendix F also contains a series of additional questions regarding the participant's perceived barriers and facilitators to engaging in physical activity and their experiences regarding the impact of physical activity. However, the focus here is only on those questions relating the acceptability of the questionnaire as that is most relevant to the current study. In addition to feedback from participants, observations by the research team throughout the interview and data interpretation phases were noted.

3.3.4 PROCEDURES

After receiving the signed consent forms, participants were contacted and an appointment arranged to complete the PADS questionnaire with an interviewer who also fitted their accelerometer. For ambulatory participants, the accelerometer was mounted onto a waistband and fitted around the participants' waist so that the device rested on the iliac crest of the left hip. Wheelchair users wore two accelerometers: one on the left hip as described above and another on their non-dominant wrist, worn like a wristwatch. Participants were asked to wear the accelerometers 24 hours a day for seven days and they were encouraged to wear the accelerometers while sleeping and bathing. Participants were given an instruction sheet which included guidelines about the accelerometer use (see Appendix G).

At the end of the seven-day period the accelerometers were collected and the PADS questionnaire was completed a second time (with demographic and illness-related questions removed). A seven-day period was chosen between repeated measures as no change in deficit from MS would normally be expected over this short period. At this second time point, the participants also completed the semi-structured interview questions to give their feedback on the acceptability of the questionnaire. Data from the accelerometers were downloaded using Actical software version 2.0.(141)

3.3.5 ANALYSES

All statistical analyses were performed using SPSS version 14.0 (145) or Stata version 8.0 (Stata Corp, College Station, TX, USA).(146)

3.3.5.1 Test-retest reliability

Raw PADS scores (possible range: -95.0, 384.2) were standardised (possible range: 0.0, 100.0) and summary statistics determined. The intraclass correlation coefficient (ICC) and Bland-Altman method were used to assess agreement between participants' repeated standardised PADS score measurements. A one-way random effects model (1,1) was used to calculate the ICC, which has been recommended and employed for this type of experiment, as the participants represented the only systematic source of variation.(147,148) The Bland-Altman approach (149) calculates and tests (using a one-sample t-test) the mean difference between standardised PADS scores measured on the first occasion (Time 1) and seven days later (Time 2). It then determines the 95% limits of agreement, after the distributional assumptions have been fulfilled. Distributional checks included ensuring that no pattern was evident in the scatter plot of the standardised PADS score differences against average standardised PADS scores and that the histogram of the measurement differences was approximately normal. The 95% limits of agreement provide an interval within which 95% of the differences between standardised PADS score measurements made at Time 1 and Time 2 are expected to lie.

3.3.5.2 Validity

Accelerometer activity counts were regressed against the standardised PADS scores from Time 2 and 95% upper and lower prediction intervals determined using linear regression. Time 2 standardised PADS scores were used because the period of PADS elicitation mapped over the period the accelerometers were worn. Diagnostic analyses were carried out prior to regression analyses to identify any influential data points and to assess normality. This included plotting studentised residuals against total activity counts on the accelerometer with a lowess curve superimposed in order to identify patterns in the data and any potentially influential data points. Residuals are effectively the differences between the model and the observed values. So, for example, if the model fits the data well, the residuals will be small. However, because the residuals are in the same units of measurement as the outcome variable, it is sometimes difficult to ascertain what might be considered a small or a large residual.

Therefore the residuals are standardised by dividing them by their standard deviation. *Studentised* residuals are a variation of the *standardised* residuals which vary point by point.(150) Therefore, plotting studentised residuals against total activity counts as described above enables visual identification of any large residuals which may represent an outlier. In order to assess normality, a histogram of studentised residuals was examined and subjected to the Shapiro Wilks test. The Shapiro Wilks test assesses if the distribution of the studentised residuals are significantly different from normal. A non-significant test indicates that the distribution is not significantly different from normal which is consistent with regression assumptions.

Upon viewing the accelerometer data, it was decided that the accelerometer data from wheelchair users would not be included in these analyses because wheelchair users wore two accelerometers which should have been generally detecting different activities – one on the wrist for activities such as pushing the wheelchair and one on the hip for activities the participant engaged in while out of their wheelchair. Therefore, neither accelerometer could be used in isolation in the analyses. It would be inappropriate to add the activity counts obtained from each accelerometer as both accelerometers may have inadvertently picked up the same activity on occasion. More investigation into accelerometer data obtained from this sub-population is needed prior to amalgamating their data with ambulatory participants.

3.3.5.3 Acceptability of the PADS

Initially answers to semi-structured questions were reviewed and categorised as positive or negative, after which content analysis was conducted. Given the brevity of responses, further in-depth analysis did not seem justified. Observations of the research team were also subjected to content analysis.(151)

3.4 RESULTS

From the 120 people invited to participate, 34 (28%) returned signed consent forms indicating their willingness to participate in the study. Of these, two participants did not provide their full contact details and so could not be followed up, one participant was not available for data collection at both time-points and a further participant was admitted to hospital in between the data collection time-points (for reasons unrelated to this study) and so was withdrawn from the study. This left 30 participants in the study.

3.4.1 PARTICIPANT CHARACTERISTICS

Table 3.3 provides a summary of participant characteristics. The sample is reasonably characteristic of what one would expect to see in an MS sample with the majority of participants being female and of European descent. Previous epidemiological studies have reported female:male ratios of up to 3.4:1 in Europe and 4.4:1 in New Zealand (152-154) which is not dissimilar to the ratio of 3.3:1 in this sample. Likewise, previous reports suggest MS to be disproportionately high in populations of European descent (1) and a low prevalence of diagnosed MS in New Zealand Maori, the native people of New Zealand,(152,153) which is reflected in the current study where the majority of participants are of European descent. The sample included a wide range in age and time since diagnosis and all the types of MS were represented. One participant did not feel their experience of MS fitted with any of the MS types described. The majority of participants were ambulatory (n=26; 87%). Four participants (13%) reported using a wheelchair to get from place to place indoors and outdoors, though only two of these participants were completely wheelchair dependent.

Table 3.3: Participant characteristics for Study One

Gender	Female	23 (77%)
	Male	7 (23%)
Age	54 years (median)	27 to 76 years (range)
Ethnicity	European	26 (87%)
	NZ Maori	1 (3%)
	Other	3 (10%)
Type of MS	Benign	3 (10%)
	Relapsing-remitting	11 (37%)
	Secondary progressive	10 (33%)
	Primary progressive	5 (17%)
	Other	1 (3%)
Time since diagnosis	12 years (median)	1 to 54 years (range)

3.4.2 SUMMARY STATISTICS

Summary statistics of the standardised PADS score at each time point are shown in Table 3.4. These summary statistics show a wide range of PADS scores, suggesting the PADS is able to detect physical activity at a range of levels of participation.

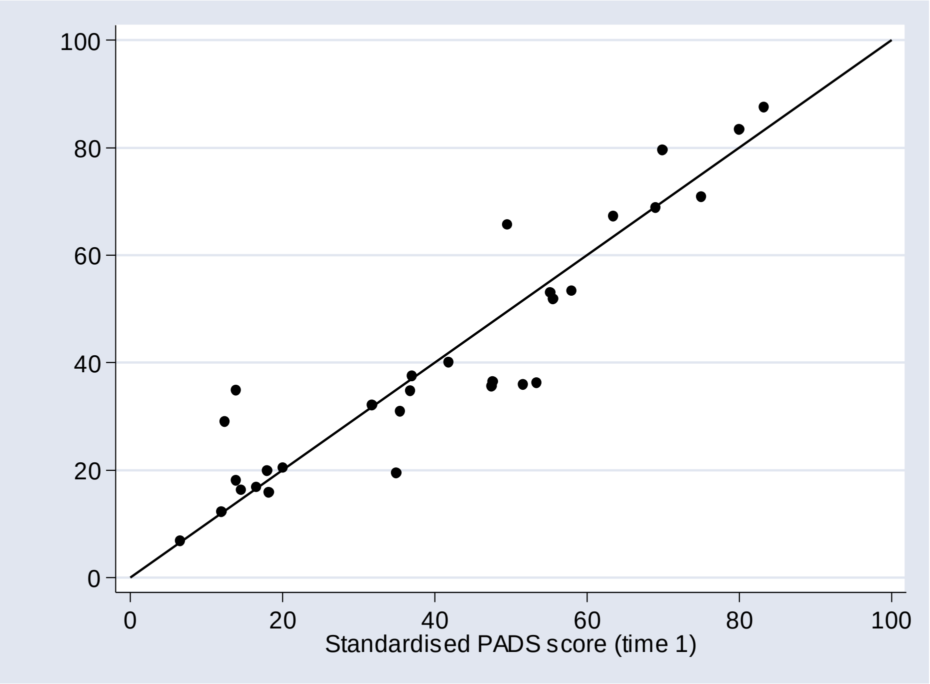
Table 3.4: Summary statistics of standardised PADS scores for Time 1 and Time 2

	Standardised PADS Score *Possible score: 0.0 to 100.0*	
	Time 1 (n=30)	**Time 2 (n=30)**
Median	39.6	35.6
Interquartile range	18.1 to 55.6	19.7 to 53.2
Range	6.7 to 83.3	6.7 to 87.4

3.4.3 TEST-RETEST RELIABILITY

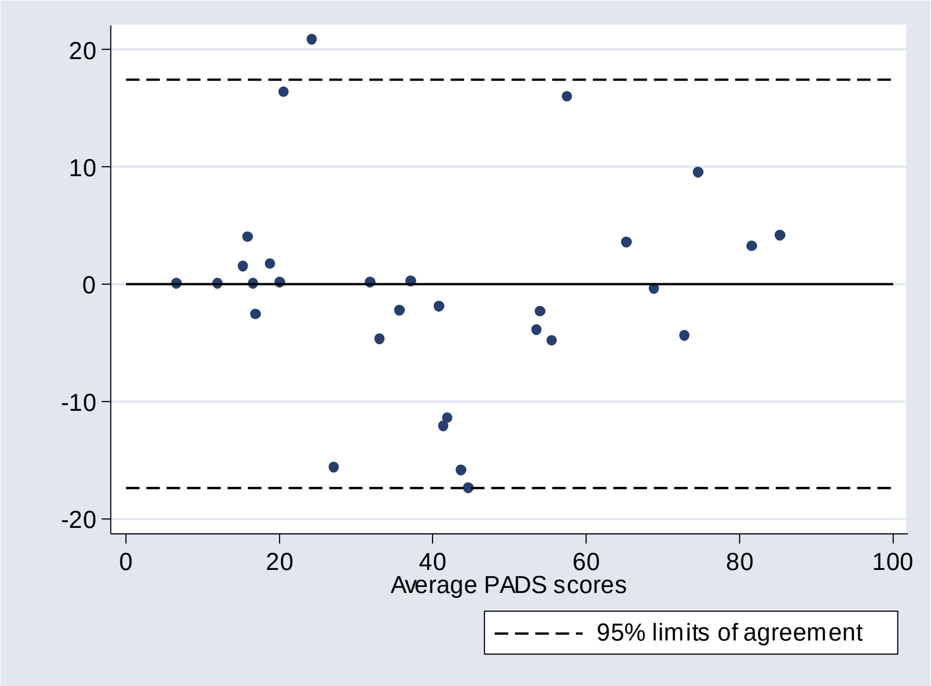
Figure 3.1 shows a scatter plot with the standardised PADS score at each of the two time points plotted against each other, along with the line of equivalence. Calculations yielded an ICC of 0.92 (95%CI: 0.88, 0.98).

Figure 3.1: Scatter plot of participants' standardised PADS scores at Time 1 and Time 2



The mean difference between standardised PADS scores at Time 1 and Time 2 was -0.7, with standard deviation 8.9, and was not significantly different from 0 (*P*=0.69) suggesting that there was no systematic bias or instrument 'learning'. The scatter plot of the standardised PADS score differences against average standardised PADS scores in Figure 3.2 indicated no obvious pattern. The histogram of the measurement differences (not shown) was consistent with the normal assumption (Shapiro Wilks test, *P*=0.06) and so Bland-Altman assumptions appear fulfilled. The 95% limits of agreement were calculated to be ±17.4 and have been superimposed upon Figure 3.2.

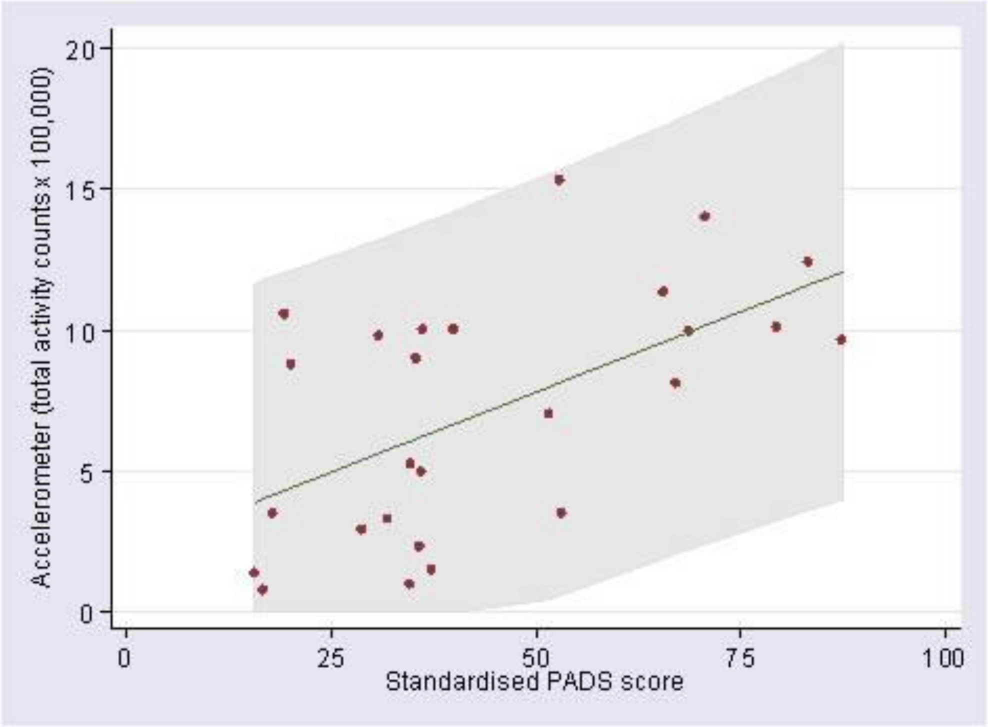
Figure 3.2: Bland-Altman plot with 95% limits of agreement



3.4.4 VALIDITY

The majority of participants (n=20; 67%) reported that they wore the accelerometers for the entire seven days. Nine participants (30%) wore the accelerometer at all times except while they were showering to avoid getting the waistband wet. One participant (3%) did not wear the accelerometer in the shower or while sleeping. Figure 3.3 shows the linear prediction for the standardised PADS score at Time 2 plotted against the total activity counts on the accelerometer, along with the 95% prediction intervals.

Figure 3.3: Linear regression and 95% prediction intervals of the standardised PADS scores measured at Time 2 plotted against total activity counts on accelerometers



Diagnostic tests on the studentised residuals provided no evidence of patterns or influential data points, and normality tests confirmed the residuals were not significantly different from normal (Shapiro Wilks test, *P*=0.20). As can be seen in Figure 3.3, the 95% prediction interval shows variability which increases as the total activity count increases. This variability is further exposed when interpreting the width of the prediction interval shown in Figure 3.3 numerically. For example, at a standardised PADS score of 50, one would expect the mean accelerometer count to be 7,820,000, but that any observed accelerometer count would fall within a wide interval (290,000, 15,350,000) 95% of the time.

3.4.5 ACCEPTABILITY OF THE PADS

Overall, feedback from participants on the acceptability of the PADS was positive (n=23; 77%) with participants finding it easy to understand and complete over a reasonably short administration time (approximately 20 minutes).

A breeze — easiest questionnaire I have ever done. (Female, Age 31)

A small number of participants (n=7; 23%) responded with negative comments for two reasons. Firstly, some had difficulty trying to calculate the time they spend doing specific activities as: (a) it was difficult to consider *all* activities one takes part in over the course of a year; and (b) it is difficult to calculate the time spent doing incidental activities which are not necessarily structured into the day or done consciously. Even some of the participants who responded positively overall, did so with this caveat in mind.

> *Would've been easier to have prepared for questions, like how long spent doing things like sitting. (Female, Age 48)*

> *Difficult to put into hours how long you spend doing things. (Female, Age 56)*

Secondly, some participants found it difficult to complete due to the variable nature of the activities they take part in from day to day or week to week.

> *As the day is always changing it is hard to give precise answers. (Male, Age 58)*

> *It was difficult with specific questions as my activities are quite variable. (Female, Age 67)*

The majority of participants (n=24; 80%) felt the questionnaire enabled them to give an accurate picture of the activities they engaged in. The key activities highlighted as missing by other participants included those activities associated with childcare, use of stairs in the home, sexual activity and volunteer work. There were also some anomalies identified with regard to two of the subscales. Firstly, those who indicated most of their housework was done by someone else in the *General Activity* subscale, did not have the opportunity to list *any* indoor household activities that they may engage in. Similarly in the *Wheelchair Use* subscale, those who indicated that their wheelchair was ‘usually’ pushed by someone else did not have the opportunity to indicate small amounts of time they may spend pushing themselves.

In addition to feedback from participants, the research team identified some areas of concern during the interviews and data interpretation. First, there was some crossover in reporting between subscales, suggesting a lack of clarity in which subscales certain activities should be reported. For example, some people reported physiotherapy in both the *Exercise* and *Therapy* subscales. Second, people appeared to have difficulty giving a global assessment of exercise intensity if they took part in more than one exercise activity. Instead, many resorted to giving an intensity rating for each individual activity. Third, there were some scoring anomalies identified:

a) Coding sedentary activity as a negative score resulted in some overall subscale scores seeming intuitively wrong when comparing between participants. For example, on the employment subscale; a person who is unemployed (score=-5) could score more than someone who is employed, but spends most of their day sitting and does not engage in any physical activity getting to and from work (score=-7).
b) Some items seemed to influence the overall score disproportionately to the overall importance of the item. For example, on the global assessment of intensity a participant scored 5, 10 or 20 for low, moderate or vigorous activity respectively. In some cases, this weighting contributed to a high proportion of the overall score – sometimes more than the actual activities themselves.

3.5 SUMMARY

Study One was the first study to be carried out as a part of Phase I of this doctoral research. This study aimed to evaluate the psychometric properties of the PADS in people with MS and assess its acceptability to people with MS. While the response rate would be considered too low to make inferences about the nature of physical activity in this population, the wide range of scores on the PADS suggests it was sufficient for the purposes of assessing the reliability of this measure. The wide range of scores also showed the PADS appeared to discriminate well between different levels of activity within this population, which is particularly sedentary when compared to the general population.(10,15,107) This is a particular strength of the PADS, given that a problem common to tools developed to measure activity is their inability to detect differences in sedentary populations.(22,23,131) With regard to test-retest reliability of the PADS, the high ICC shows that a strong relationship existed between the repeated measures. However, the 95% limits of agreement calculated using the Bland-Altman method, were wide (-17.4, 17.4) indicating high variability in the measure and suggesting agreement between repeated measures to be only moderate. Likewise, the validity of the PADS was poor when using total activity counts on the accelerometer as a criterion measure, as can be seen by the wide 95% prediction intervals generated (Figure 3.3). Despite these discrepancies the acceptability of the PADS to people with MS was excellent in terms of its ease of administration and relevance to people with MS, evidenced by the positive feedback from participants.

3.6 POSSIBLE EXPLANATIONS FOR FINDINGS

The PADS was found to be acceptable to people with MS (indicating good face validity) and appeared to discriminate well between different levels of activity in this population. Given this, it seemed important to consider why the psychometric properties explored were poor, and identify aspects of the measure which could be modified to improve these psychometric properties. Some possible explanations for the findings are discussed further below.

a) *Test-retest reliability*

Figure 3.2 indicates a small number of participants were clustered around the critical values of the 95% limits of agreement. A closer look at the actual responses and feedback from these participants helped to explain some of the variability from the mean score difference. For example, some of these participants reported finding it difficult to think of the time they spent doing some activities at the first time point, but found it easier at the second time point as they had time to think about it and so were more prepared.

While recall of activities is a limitation of all self-report measures of activity, it was thought that a revision of some PADS items could reduce this problem. For example, there is some literature to suggest that the longer the time interval between exposure to the event and recall, the less accurate the response.(155) Therefore, a reduction in the response period from the past year to a more recent period may improve the test-retest reliability. Research has also found that vigorous activities are more easily recalled than lower intensity activities.(113,156,157) This is consistent with participant feedback on this study suggesting participants had difficulty calculating time spent on incidental activities, but less difficulty calculating time spent doing structured activities, such as a daily exercise programme. To overcome this problem, Durante and Ainsworth propose the use of a cognitive model approach to asking questions.(158) For example, they suggest that respondents follow four basic stages of cognitive processing when answering survey questions: (1) comprehension, (2) retrieval, (3) decision making, and (4) response generation. During the retrieval stage they propose that respondents use the information in the question to generate retrieval cues, and that if the information in the question is insufficient then they resort to inefficient retrieval strategies, such as estimation, to generate a response. If their theory is correct then it is possible that further clarifying instructions and giving examples of the kinds of activities that one might report in specific subscales may improve recall and test-retest reliability.

b) Validity

There are a number of possible explanations for the discrepancy between the accelerometer counts and PADS scores including the following:

- Participants identified some activities missing from the PADS, such as childcare activities and use of stairs in the home, which were in all likelihood picked up by the accelerometer.
- The PADS asks participants to list activities in terms of days/week, minutes/day, and months/year rather than asking them about their ‘current’ level of activity, while accelerometer counts are a measure of total counts generated over the seven-day period it is worn.
- As described earlier, some scoring anomalies were identified during data interpretation on the *Employment* and *Wheelchair Use* subscales where those who displayed sedentary behaviour could score higher on the subscale overall than those who scored low on the activities described in these subscales.
- While accelerometers have been commended for their ability to discriminate between lower levels of activity,(73,140) some research has reported them to underestimate lower levels of activity and overestimate more vigorous activities.(159) It is possible that this has influenced the validity analyses in the current study and highlights the possibility that the poor validity we observe may not only be a reflection of the PADS limitations, but also a result of limitations in accelerometer measurement. This has been further explored in Study Three (Chapter Four).

It is possible that many of the discrepancies highlighted regarding the psychometric properties of the PADS could potentially be avoided by making some simple revisions to the questionnaire and its scoring protocol. Such revisions should arguably improve the test-retest reliability and validity. As such, the second study associated with Phase I of this doctorate (Study Two) was designed to develop and pilot a revised version of the PADS in response to the findings of this study.

STUDY TWO

DEVELOPMENT AND EVALUATION OF THE PHYSICAL ACTIVITY AND DISABILITY SURVEY-REVISED (PADS-R)[2]

3.7 AIMS

Study Two aimed to develop a revised version of the PADS, the Physical Activity Disability Survey-Revised (PADS-R). The specific objectives of this study were to:

(1) Modify the contents of the PADS in response to feedback from Study One;
(2) Re-develop the scoring protocol; and
(3) Explore the acceptability and test-retest reliability of the revised measure, the PADS-R.

3.8 METHODS

Ethical approval for this study was obtained from the Northern Y Health and Disability Ethics Committee in New Zealand as an extension to the previous study (see Appendix H [for PADS-R questionnaire development] and Appendix I [for PADS-R acceptability and reliability assessment]).

3.8.1 DESIGN

Study Two was comprised of three phases: (1) PADS-R questionnaire development; (2) PADS-R scoring development; and (3) PADS-R acceptability and reliability assessment. The method for each of these phases is discussed in detail below.

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[2] Study Two resulted in the second publication directly linked to this doctoral research (160):
Kayes, N. M., Schluter, P. J., McPherson, K. M., Taylor, D., & Kolt, G. S. (2009). The Physical Activity and Disability Survey – Revised (PADS-R): An evaluation of a measure of physical activity in people with chronic neurological conditions. *Clinical Rehabilitation, 23*(6), 534-543.

3.8.2 PARTICIPANTS AND PROCEDURES

3.8.2.1 PADS-R questionnaire development

Development of the PADS-R took place over three stages: modification, field testing and refinement.

3.8.2.1.1 Modification

Initial modifications to the original PADS were carried out in response to findings from Study One.

3.8.2.1.2 Field testing

As with Study One, a random selection of 120 members from the local MS Society (every 5th person on the database) were sent an information pack about the study (including the same cover letter, information sheet and consent from used in Study One – see Appendix B, C and D respectively for sample copies of these documents). The rationale for inviting 120 people with MS to take part was the same as that described in Study One (see page 83). Those people who had participated in the previous study were removed from the potential sample pool prior to random selection taking place. People were eligible to take part if they had been given a definite diagnosis of MS by a neurologist and were able to communicate with the researchers. Members indicated their interest by returning a signed informed consent form. The first thirty consenting members were contacted and an appointment arranged to complete the modified PADS questionnaire. Upon completion, participants were asked to respond to the same series of semi-structured questions regarding the acceptability of the questionnaire as those used in Study One. Feedback from participants was subjected to content analysis and themes derived.

3.8.2.1.3 Refinement

Themes which were either commonly referred to or strongly reported by participants resulted in further refinements and modifications to the PADS measure, yielding the PADS-R.

3.8.2.2 PADS-R scoring development

The final version of the PADS-R questionnaire was used in two separate, but related and concurrent studies, exploring the correlates of physical activity in people with neurological conditions. The first consisted of 264 people with MS (the first 264 respondents in Study Four of this doctoral research which is described in more detail in Chapter Six). The second included 83 people post-stroke. In an effort to maximise sample numbers for increased statistical estimate precision, PADS-R data from these respondents were utilised to develop the scoring protocol for the revised measure. Additionally, PADS-R data collected for the reliability assessment (described below) were also utilised in the development of the scoring protocol.

3.8.2.3 PADS-R acceptability and reliability assessment

All participants who took part in Study One (n=30) and those who took part in the earlier field testing during the PADS-R questionnaire development (n=30) were invited to participate in the PADS-R reliability assessment phase of this study. All of these previous participants were sent a dissemination leaflet which included a summary of findings from Study One and from the field testing phase of this study (see Appendix J). Included with this dissemination leaflet was an invitation to take part in the reliability assessment phase of this study (see Appendix K), an information sheet (see Appendix L), a consent form (see Appendix M) and a self-addressed stamped envelope. Those participants who were interested in taking part indicated this by either returning a signed consent form in the envelope provided or by phoning the research team. After receiving signed informed consent forms, participants were contacted and an appointment arranged to complete the PADS-R over the telephone with an interviewer. Participants were re-contacted three days later and the PADS-R re-administered over the telephone. Testing was carried out via telephone interviews in this stage due to there being limited resources available to cover researcher travel costs to carry out the testing in person. Note also that the interval between repeated measures in this study is three days which is different to the design used in Study One where the interval between repeated measures was seven days. The reason for the reduced interval is that this final phase of PADS-R testing was carried out concurrent to

Phase II of this doctoral research. Given that physical activity was the key outcome of interest in Phase II, it was crucial that this study be completed and reliability of the PADS-R confirmed. The three-day interval was therefore chosen to balance the competing demands of time constraints, the effects of questionnaire item recall and change in the participant's condition. After the second PADS-R completion, participants were asked the same series of semi-structured acceptability questions used in the previous field testing phase.

3.8.3 STATISTICAL ANALYSES

All statistical analyses were performed using Stata version 9.0 (Stata Corp, College Station, TX, USA).(161)

3.8.3.1 PADS-R scoring development

Figure 3.4 presents the process for the derivation of the total PADS-R score. Scoring development took place over two stages: (1) generating scoring coefficients for subscale scores using principal components analysis (PCA) whereby each domain with multiple item scores were combined to create a single subscore (PCA_1 – PCA_3; Stage One), and (2) combining subscores and scores from domains with single items using PCA to create the total PADS-R score (PCA_4; Stage Two). All principal components were calculated using correlation matrices. To give an example, details of PCA_3 (employment subscale) are given below to demonstrate how PCA was used to derive scoring coeffients for each item and then how these were aggregated to obtain a subscale score.

Step 1: After scoring each item in the employment subscale, a PCA was carried out. Component 1 was found to explain the majority of variance at **0.4674**.

Step 2: The eigenvectors obtained for each item (Empmove, Empstairs, Emptransport) in component 1 were adopted as scoring coefficients:

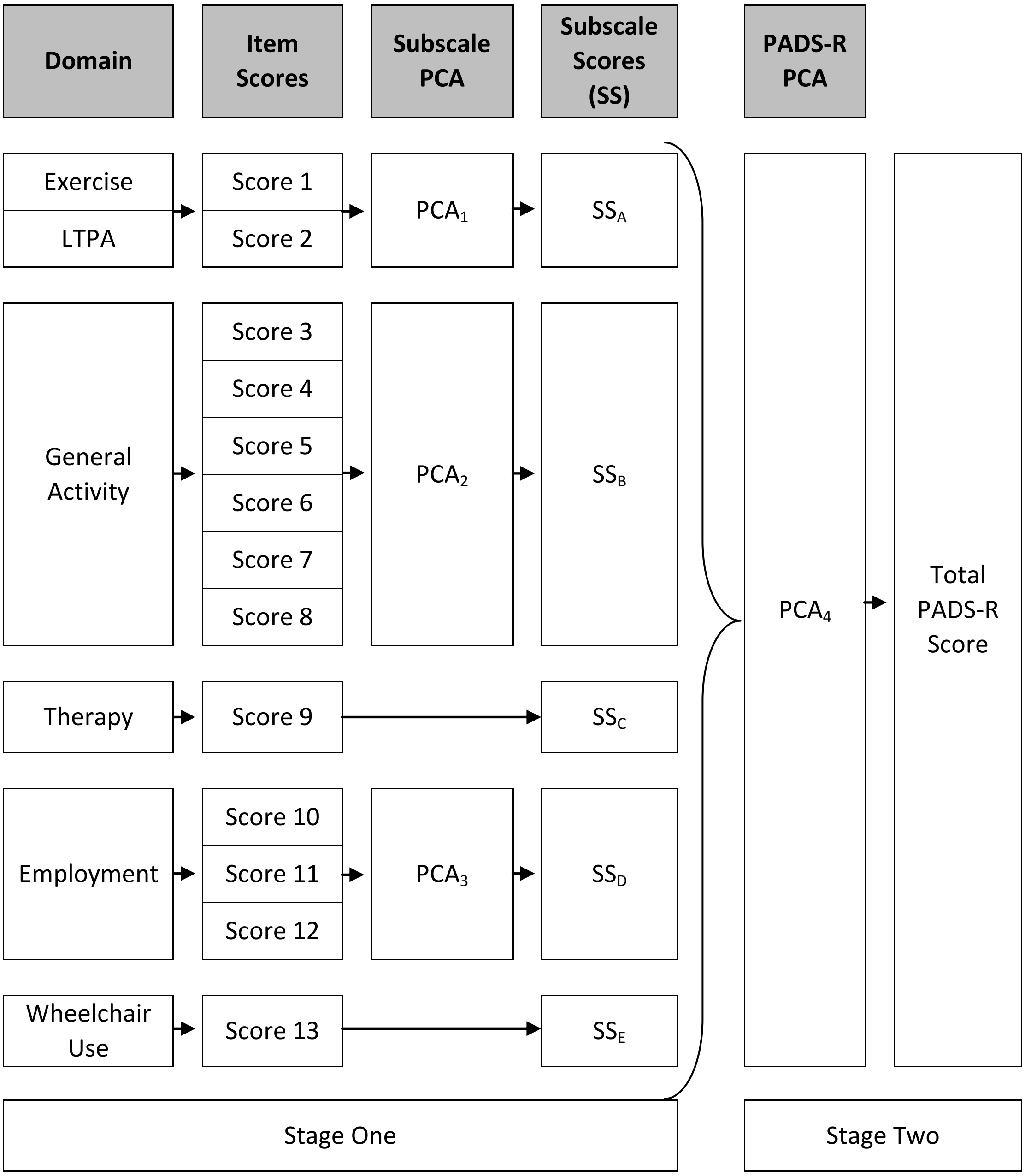
Empmove (W_1) = 0.60211; Empstairs (W_2) = 0.62898; Emptransport (W_3) = 0.49178

Step 3: The subscale score for each observation is then obtained using the following formula:

$$W_1 \times ((X_1 - \text{mean}_1)/SD_1)) + W_2 \times ((X_2 - \text{mean}_2)/SD_2)) + W_3 \times ((X_3 - \text{mean}_3)/SD_3))$$

(Where X is the item score)

Figure 3.4: Process for principal components analysis (PCA) and generating scoring coefficients.



LTPA=Leisure-time Physical Activity

3.8.3.2 PADS-R acceptability and reliability assessment

Acceptability and reliability was assessed using the same methods as those described in Study One.

3.9 RESULTS

3.9.1 PARTICIPANT CHARACTERISTICS

Participant characteristics for all phases of Study Two are presented in Table 3.5. Note that response rates for each stage are detailed below as the findings of each stage are presented.

Table 3.5: Participant characteristics at each individual phase of Study Two

Questionnaire Development: Field Testing (n=30)		
Condition	Multiple Sclerosis	30 (100%)
Gender	Female	25 (83%)
	Male	5 (17%)
Age	53 years (median)	24 to 81 years (range)
Ethnicity	European	30 (100%)
Scoring Development (n=376)		
Condition	MS	293 (78%)
	Stroke	83 (22%)
Gender	Female	265 (70%)
	Male	110 (29%)
	Not identified	1 (0%)
Age	56 years (median)	23 to 93 years (range)
Ethnicity	European	345 (92%)
	NZ Maori	6 (2%)
	Indian	3 (1%)
	Pacifika	2 (1%)
	Malaysian Chinese	1 (0%)
	Not identified	19 (5%)
Reliability Testing (n=29)		
Condition	MS	29 (100%)
Gender	Female	24 (83%)
	Male	5 (17%)
Age	55 years (median)	34 to 81 years (range)
Ethnicity	European	28 (97%)
	NZ Maori	1 (3%)

3.9.2 PADS-R QUESTIONNAIRE DEVELOPMENT

3.9.2.1 Modification

Table 3.6 details all modifications made to the original PADS in response to the findings from Study One.

Table 3.6: Modifications made to the original PADS in response to Study One

Study One findings	Modification
Participants indicated that it was difficult to calculate the time they spent doing activities, and in particular, to recall all the activities they take part in over a year.	Reduced the response period of the questionnaire from one year to 'an average week'.
Participants identified a number of physical activities they took part in but were not asked to report on in the questionnaire in its original format.	Incorporated new items into the questionnaire, including: activities related to childcare roles, use of stairs at home, sexual activity and engagement in volunteer work.
Participants identified some subscales where the question pathway meant that if someone else took on some of their activities (e.g. household activities or pushing their wheelchair) then they were not able to report on any small amounts they might engage in.	Modified these items to give participants the opportunity to report on all the activities they do, even if only small amounts.
There was some crossover in reporting of activities between sections due to a lack of clarity about which activities participants should list in which sections.	Made some clarifications to instructions for item completion and included more detail about the nature of the response required within each section.
The original PADS elicited a global assessment of intensity for all activities and participants found it difficult to give an overall intensity if they engaged in a range of different activities at different intensity levels.	Removed the questions asking participants to describe the 'average intensity' of the activities they take part in and instead asked participants to indicate the intensity of each individual activity they listed.
Using the original PADS scoring protocol, sedentary behaviour obtained a negative score which sometimes resulted in a scoring anomaly.	Scoring was changed to follow two key rules: 1. Any sedentary behavior is scored as zero; and 2. As participation in physical activity increases, so does the item score.

<table>
<tr><th>Study One findings</th><th>Modification</th></tr>
<tr><td>For the <i>Exercise</i> and <i>Leisure-time Physical Activity</i> subscales, the original scoring protocol did not account for the changes made in the revised version to include an intensity rating for each activity (see above) and so a new scoring protocol for these items needed to be developed. In addition, the activity intensity weightings seemed to influence the overall score disproportionately when compared to the overall importance of the item.</td>
<td>An activity matrix was developed to score activities listed on the <i>Exercise</i> and <i>Leisure-time Physical Activity</i> subscales. In the modified version of the PADS, participants report an activity type <i>and</i> intensity rating for each separate activity. Using the same weights and ratios adopted in the original PADS (transformed to an integer scale), activity matrices were derived by multiplying the activity type weight by the intensity rating weight for each activity level. The derived activity matrices are shown below. Activity scores are then estimated by multiplying the time spent doing an activity by the associated value in the activity matrix.
<table>
<tr><th rowspan="2"></th><th rowspan="2">Activity Type
(original PADS weight)</th><th colspan="3">Activity Intensity (original PADS weight)</th></tr>
<tr><th>Light (5)</th><th>Moderate (10)</th><th>Vigorous (20)</th></tr>
<tr><td rowspan="3">Exercise</td><td>Flexibility (0.1)</td><td>1</td><td>2</td><td>4</td></tr>
<tr><td>Strength (0.2)</td><td>2</td><td>4</td><td>8</td></tr>
<tr><td>Aerobic (0.3)</td><td>3</td><td>6</td><td>12</td></tr>
<tr><td rowspan="2">LTPA</td><td>Non-endurance (0.15)</td><td>1</td><td>2</td><td>4</td></tr>
<tr><td>Endurance (0.3)</td><td>2</td><td>4</td><td>8</td></tr>
</table>
LTPA=Leisure-time Physical Activity</td></tr>
</table>

3.9.2.2 Field testing

Of the 120 people invited, 34 (28%) returned signed consent forms and as noted in the methods, 30 were recruited (the first thirty indicating interest) (see Table 3.5 for participant characteristics). All but one participant (n=29; 97%) reported the modified version of the PADS to be easy to understand and complete. All participants reported that it enabled them to give an accurate picture of the kinds of activities they take part in over an 'average' week. However, even though the response period had been modified so that participants reported on physical activity they had taken part in over an 'average week', like the original version, a number of participants (n=8; 27%) found it difficult to calculate or estimate the time they actually spent doing different activities over this 'average' week, as articulated by one participant:

> *Easy to understand, but hard to remember how many hours you spend doing things so some things are a bit of a guesstimate. (Female, Age 34)*

Reporting on an 'average' week was problematic for some participants due to the cyclical nature of their MS, or because their schedule varied widely from week to week:

> *It was difficult to come up with an average time for each activity because I do not follow a regular pattern. Every day is different in terms of what I do so it is difficult to describe an 'average' typical day's activity. (Female, Age 44)*

Participants generally liked having examples provided in the questions as it gave them an idea of the activities to report on. More examples throughout was suggested:

> *Should definitely include more examples in the text. (Female, Age 34)*

3.9.2.3 Refinement

In response to the field testing feedback, the questionnaire was further refined (see Table 3.7 for details of modifications made in response to field testing), yielding the PADS-R instrument. See Appendix N for a sample copy of the final version of the PADS-R questionnaire.

Table 3.7: Modifications made in response to field testing

<table>
<tr><th>Field testing findings</th><th>Modification</th></tr>
<tr><td>Participants found reporting on an ‘average week’ difficult. Existing literature supports this finding suggesting that people have difficulty calculating averages as they require a level of mental computation on the part of the respondent which is prone to error.(158)</td><td>Modified the response period to ask people what they did in the ‘<i>last week</i>’ rather than on an ‘<i>average week</i>’</td></tr>
<tr><td>Participants reported that examples provided were useful in prompting thinking and reminding them of the activities they did in the last week. They were particularly helpful in the <i>General Activity</i> subscale as the kinds of activities people recorded here were often miscellaneous activities which people tend to do unconsciously and so are easy to forget.</td><td>Clarified instructions for item completion further and provided more examples of the kinds of activities they could list in response to different questions</td></tr>
<tr><td>In addition to participant feedback, the research team identified some items which had wide response categories and were concerned about the potential responsiveness of such questions to small changes in physical activity. For people with chronic disabling conditions, it may be important for an instrument to detect such small changes. One example was an item on the <i>General Activity</i> subscale which asks respondents to indicate how many waking hours they spend inside their home. For this item, respondents selected the category which best described their situation. The response categories were as follows:
<table>
<tr><th></th><th>Score</th></tr>
<tr><td>Less than 6 hours a day</td><td>+2</td></tr>
<tr><td>6 to 10 hours a day</td><td>0</td></tr>
<tr><td>More than 10 hours a day</td><td>-2</td></tr>
</table></td><td>In an attempt to make the PADS-R more responsive to small changes in chronic disabling conditions such as MS, such items were modified. For instance, the example item was modified to the following categories:
<table>
<tr><th></th><th>Score</th></tr>
<tr><td>Less than 6 hours a day</td><td>4</td></tr>
<tr><td>6 to 8 hours a day</td><td>3</td></tr>
<tr><td>9 to 10 hours a day</td><td>2</td></tr>
<tr><td>11 to 12 hours a day</td><td>1</td></tr>
<tr><td>More than 12 hours a day</td><td>0</td></tr>
</table>
Note: the changes to scoring seen here also reflect the changes to scoring described earlier in Table 3.6 (i.e. that all sedentary behavior is scored as zero and that as activity increases, so does the score)</td></tr>
</table>

3.9.3 PADS-R SCORING DEVELOPMENT

As described in the methodology, existing PADS-R data were available from 264 people with MS and 83 people with stroke for scoring development. Furthermore, 29 (48%) of the 60 people with MS invited to participate in the reliability testing phases of this study consented to take part and their data were also utilised for scoring development. Therefore, in total, observations from 376 people with MS and Stroke were utilised (see Table 3.5 for the participant characteristics of this group). As the 29 participants who took part in the reliability testing phase completed the PADS-R twice (for the purposes of test-retest reliability assessment), a total of 405 PADS-R instrument completions were available for the scoring development.

Distributional checks revealed that data on the *Exercise* and *Leisure-time Physical Activity* subscale were highly skewed, with the majority of participant scores clustered at the low end of the activity spectrum. Further investigations revealed that the skewness could be removed using the natural logarithm and so this transformation was applied. Initial exploratory analyses also showed that when the *Exercise* and *Leisure-Time Physical Activity* subscales were treated as separate scores, small changes in activity influenced the total PADS-R score disproportionately. Combining these subscales reduced this impact.

The two-stage PCA analysis then commenced (see Figure 3.4). Each item score and resultant weights in determining the total PADS-R score is included in the final version of the questionnaire (see Appendix N). In addition to the final version of the questionnaire, a scoring worksheet has also been developed. This tool has been made available as a supplementary file at:

http://cre.sagepub.com/content/23/6/534/suppl/DC1

in association with the related publication.(160) Using the new scoring protocol, the PADS-R score for this group of observations was approximately normal in distribution and had median 0.01, interquartile range (IQR): -0.76, 0.82, and range: -2.75, 3.37.

3.9.4 PADS-R ACCEPTABILITY AND RELIABILITY ASSESSMENT

As noted above, 29 (48%) of the 60 people with MS who had participated in previous phases of this work (Study One and the field testing phase of this study) consented to participate in the acceptability and reliability assessment phase of this study. Participant characteristics of these participants are provided in Table 3.5.

3.9.4.1 Acceptability

The PADS-R took approximately 20 minutes to administer. Most (n=25; 86%) participants reported the PADS-R to be easy to understand and complete. The following comments are examples which are representative of this feedback:

> *Good. No problem. (Female, Age 76)*
>
> *Definitely was easy to understand and complete. (Female, Age 68)*
>
> *Couple of questions I needed to think about, but generally it was easy.*
> *(Male, Age 54)*

Five (17%) participants reported that they had some difficulty remembering the amount of time they spent doing some activities but, nonetheless, found recall over the previous week easier than previous versions (which used 'average' weeks or years). One participant highlighted that their activity was more erratic than usual, as data collection took place over the Christmas holiday period.

> *This week is not normal due to Xmas. (Female, Age 67)*

Despite these concerns, all participants felt that the items on the PADS-R enabled them to give an accurate picture of the physical activities they had engaged in and none could identify any physical activities which they had taken part in that the PADS-R had excluded.

3.9.4.2 Reliability

Summary statistics of the PADS-R score at each time point are shown in Table 3.8. As with the original PADS, these summary statistics show a wide range of PADS-R scores.

Table 3.8: Summary statistics of PADS-R scores for Time 1 and Time 2

	PADS-R Score	
	Time 1 (n=29)	**Time 2 (n=29)**
Median	-0.03	0.21
Interquartile range	-0.99 to 0.52	-0.66 to 0.55
Range	-2.48 to 2.57	-2.48 to 1.88

Figure 3.5 shows a scatter plot of individuals' PADS-R scores at each of the two time points plotted against each other. Calculations yielded an ICC of 0.87 (95%CI: 0.78, 0.96). The mean difference between PADS-R scores at Time 1 and Time 2 was not significantly different from 0 (Student's paired t-test, *P*=0.47; 95%CI: -0.14, 0.29) suggesting that there was no systematic bias or instrument 'learning'. The Bland-Altman plot with the 95% limits of agreement (±1.13) superimposed is shown in Figure 3.6. Visual inspection of the Bland-Altman scatter-plots revealed no distinct patterns or funneling that would indicate important heteroscedasticity. No other important violation in the Bland-Altman assumptions was noted. Despite the ICC being high, the 95% limits of agreement appear wide once again indicating variability in the measure.

Figure 3.5: Scatter plot of participants' PADS-R scores at Time 1 and Time 2

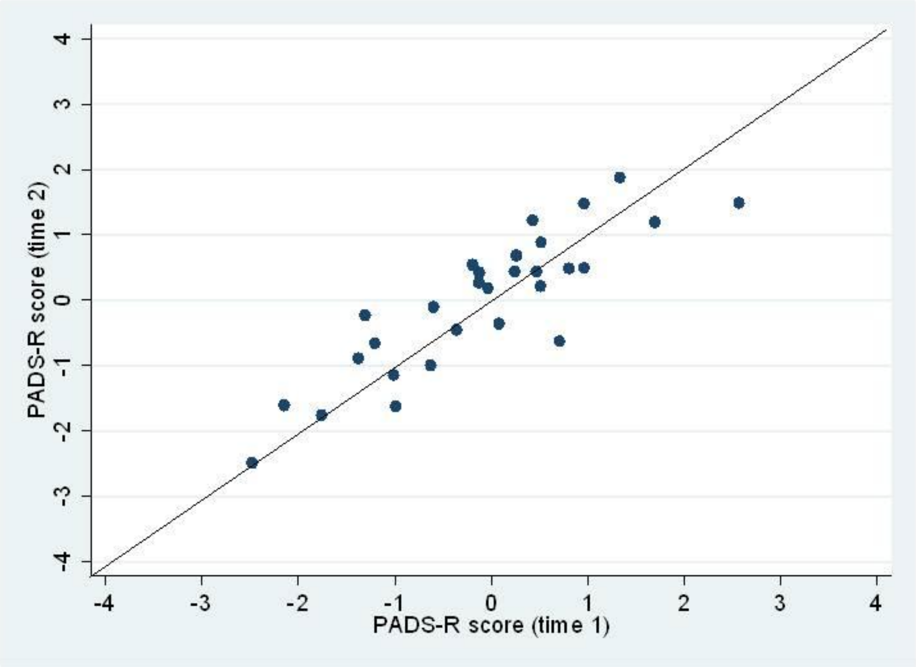
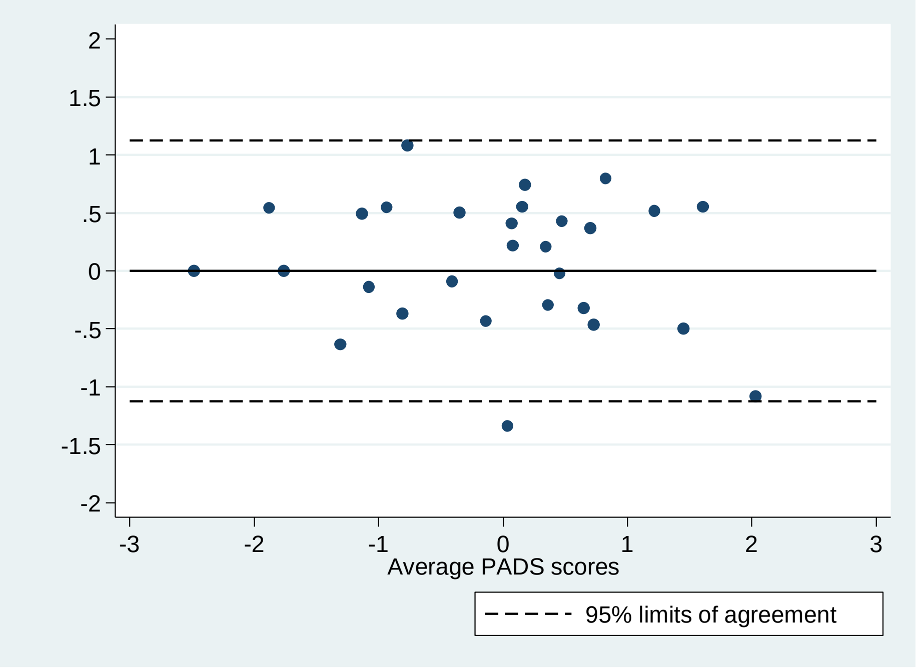


Figure 3.6: Bland-Altman plot with 95% limits of agreement



To explore this further, the raw scores of individuals where the difference in PADS-R scores between Time 1 and Time 2 exceeded '1' were identified and checked. Visual inspection of the score distributions indicated that a score difference of this size might represent meaningful changes in activity. A change of one unit over a six unit range (the range of PADS-R scores in the PADS-R scoring development stage was -2.75 to 3.37, approximately six units) indicates at least a 17% change in PADS-R score between time points which in most standardised measures would represent meaningful change. For example, Perera et al. explored meaningful change in common physical performance measures and found changes of only 8 and 9% in gait speed and six minute walk distance respectively reflect small meaningful change in stroke survivors, and changes of 15 and 22% reflect substantial individual change on the same measures.(162) Three participants were identified with scores exceeding '1'. For the first (score difference=1.34) the main score difference occurred on the *General Activity* subscale where they reported over five hours indoor activity and 90 minutes outdoor activity at Time 1 versus only two and a half hours indoor activity and 30 minutes outdoor activity at Time 2. The second participant (score difference=1.08) obtained their highest score difference on the *Exercise/Leisure-Time Physical Activity* subscale where they reported no Leisure-Time Physical Activity at Time 1, but three hours a day of Leisure-Time Physical Activity at Time 2. The third participant (also a score difference of 1.08) obtained their main score difference on both the *Exercise/Leisure-Time Physical Activity* subscales and the *Employment* subscale. This participant reported that they had walked for 60 minutes on three days in the previous week at Time 1, but took part in no exercise at Time 2. Furthermore, they reportedly moved around all day and climbed seven flights of stairs, eight times a day while at work at Time 1; while at Time 2 they spent most of the day standing and only climbed three flights of stairs, five times a day.

The change in activity level observed in these three participants could be a result of either: (1) the participant not understanding the format of the questionnaire and so reporting their activity incorrectly; or (2) an actual change in behaviour between the two assessment points (maybe as a result of the holiday period as one participant suggested in their feedback earlier) – a feature the PADS-R should ideally detect. As the majority of participants reportedly found the questionnaire easy to understand and believed that it captured an accurate picture of their physical activity, change observed between the repeated measurements is likely to be attributable to actual changes in their level of activity.

An underlying assumption of test-retest reliability analysis is that no important change takes place between repeated measures, so analyses were repeated excluding these three participants. With these observations removed, the ICC was estimated at 0.91 (95%CI: 0.85, 0.98), the Bland-Altman 95% limits of agreement were ±0.89 and the highest PADS-R score difference obtained was 0.80. To provide insight as to what this difference represents, the raw score of the participant with this score difference was reviewed. The main score difference for this participant was obtained on the *Employment* subscale where they reported that they sat most of the day while they were at work at Time 1 but moving around most of the day at Time 2. Unlike the three participants reviewed previously, this kind of change or variation in activity would be considered normal or expected even in a stable population, depending on their work role.

3.10 SUMMARY

Study Two was the second study to be carried out as a part of Phase I of this doctoral research. This study aimed to modify the contents of the PADS in response to feedback from Study One; re-develop the scoring protocol; and explore the acceptability and test-retest reliability of the revised measure in people with MS. The test-retest reliability of the revised measure was good, with a high ICC showing that a strong relationship exists between repeated measures. It should be noted, however, that this high ICC could be a result of large variability in the range of PADS-R scores obtained, and be interpreted with caution. Bland-Atman 95% limits of agreement were initially wide (±1.13), but when we removed observations for the three individuals who appeared likely to have made a meaningful change in their activity level between the two time points, then the limits of agreement narrowed considerably (±0.89). Given that the next highest score difference observed (0.80) appeared to be a result of normal variations in activity rather than reflective of meaningful change, then the threshold to denote clinically important change in the PADS-R score (in repeated measures or longitudinal studies) might be somewhere around 0.90. Further work is needed to confirm this threshold. As was the case with the original PADS (132), the PADS-R appears to discriminate well between different levels of activity in a relatively sedentary population, evidenced by the wide range of scores obtained on the PADS-R in the final phase of this study. The ongoing consultation which took place with participants throughout the revision process has ensured that the PADS-R covers a wide range of activities relevant to people experiencing disability, resulting in people with MS reporting it to be highly acceptable and relevant to the kinds of activities they participate in. In addition, the PADS-R was reported to be easy to administer and easy to understand.

The findings of Study One and Two are discussed in detail within the context of existing research in Chapter Five. Prior to this however, the following chapter addresses objective measurement of physical activity for people with MS by a) reviewing what objective measures are currently available and b) testing one measure in particular for use in people with MS, the Actical accelerometer.

CHAPTER 4

OBJECTIVE MEASUREMENT OF PHYSICAL ACTIVITY IN PEOPLE WITH MULTIPLE SCLEROSIS

4.1 INTRODUCTION

While a valid and reliable self-report measure of physical activity has certain strengths, such as being less expensive and easily administered, which make it a practical solution for large epidemiological studies where resources are often limited, the nature of self-report also has limitations. Such limitations have been debated extensively in the physical activity measurement literature (22,140,159,163,164) and include the following:

a) *Social desirability bias*

Social desirability bias occurs when a respondent is concerned about the social acceptability of their response, and so moderates their response either by overestimating desirable behaviours or underestimating undesirable behaviours.(165) Warnecke and colleagues explored this trait in an ethnically diverse sample and found that social desirability bias can lead to over-reporting of physical activity.(165) Conversely, Motl and colleagues recently found there to be no significant correlation between measures of social desirability and self-reported physical activity.(166)

b) *Inaccurate recall*

Moderate correlations between self-report questionnaires and objective measures have been found, with questionnaires accounting for only a portion of the variance found in these measures.(167) It is thought that this is at least partly due to people’s inability to accurately recall the details of their past physical activity.(158) Factors which influence recall can include the time interval between taking part in physical activity and being asked to report on it (the response period), the nature of activities being asked to report on, questionnaire administration techniques, personal characteristics of the respondent and, as described above, the social desirability of the responses.(155,158) *c) Intra-individual variation in physical activity*

Seasonal and intra-individual variation in physical activity has been reported, resulting in some tension between how best to capture this variation while also maintaining accurate recall of physical activity.(168) For example, Blair and colleagues proposed that recalling physical activity over seven days is more accurate than asking people to report on their 'usual' activity.(169) Conversely, Levin and colleagues propose that while this may result in an accurate representation of the activity conducted over the previous seven days, that it may not be an accurate representation of 'usual' activity. To capture 'usual' activity they argue that one would need to consider activity over a much longer period of time in order to account for intra-individual variations in physical activity.(168)

d) Differing interpretations of physical activity and its components

While consensus on the definition of physical activity has been established within the scientific community,(35) people continue to have contrasting perceptions of what physical activity and the different types of physical activity are.(170) Furthermore there is discrepancy even amongst experts about how best to classify different activities into specific *intensity* levels, hence the development of the Compendium of Physical Activities to aid consistency in how different activities are classified.(129) However, as discussed earlier, the MET levels allocated to activities in this Compendium should be interpreted with caution as they do not account for inter- and intra-individual differences in the energy cost associated with different activities.

As a result of these limitations, many researchers and funding bodies advocate supplementing or replacing self-report measures of physical activity with an objective measure where resources allow. There are a range of objective measures available for use and there is much debate over which objective measure is the most appropriate, and in which circumstance.(163,171-173) Table 4.1 lists a range of existing objective measures of physical activity most commonly discussed in measurement reviews in this field,(171,172,174,175) along with their strengths and weaknesses regarding their potential use in people with MS.

Table 4.1: Objective measures of physical activity

Measurement Method	Measurement Output	Background	Description	Strengths	Limitations
Heart Rate	Activity intensity	Heart rate is a physiological marker of physical activity. Close relationships have been found to exist between heart rate and energy expenditure and so energy expenditure can be estimated using measures of heart rate.(163)	Heart rate is measured using heart rate monitors where a transmitter is strapped to the participants' chest and a receiver watch is worn where data is recorded and downloaded to a personal computer.	Non-invasive Inexpensive Easy to administer	A measure of activity intensity, not physical activity People with MS may have different physiological responses which may affect heart rate Autonomic nervous system abnormalities evident in people with MS may limit accuracy of HR measures in this population Heart rate can be affected by a range of variables other than physical activity (e.g. emotional stress, fitness, body weight, medication)
Calorimetry	Energy expenditure	Developed by Lavoisier and Seguin through their investigations of respiration.(176) Energy expenditure is determined by measuring heat loss from the body (direct) or expired gases (indirect) to determine oxygen consumption (VO^2).	Direct – participant is placed in a self-contained chamber, and the heat they dissipate is recorded. Indirect – A portable measurement system is used including a face mask and portable gas analyser.	Useful for measuring energy expenditure for short bouts of activity in controlled conditions	A measure of energy expenditure, not physical activity Requires specialist equipment and trained personnel Chambers designed to measure VO^2 using direct methods are not able to reproduce human activity in free-living conditions Portable measurement systems inhibit normal movement

Measurement Method	Measurement Output	Background	Description	Strengths	Limitations
Doubly Labeled Water (DLW)	Energy expenditure	The DLW method was originally developed in the 1950s in laboratory mice.(177) The first validation study using DLW in humans was published in 1982.(178) It was developed in human subjects as a measure of energy expenditure in free-living physical activity in response to recognition of the inadequacy of traditional calorimetry.	Administering an oral dose of water containing a known amount of isotopes of both hydrogen and oxygen. The isotopes, ^{2}H (deuterium) and ^{18}O, mix with the normal hydrogen and oxygen in the body water within a few hours and the rate of loss of these isotopes over time reflects the rate of CO^2 production which is then used to estimate energy expenditure.	Measures energy expenditure in free-living conditions Considered to be the gold standard measure of energy expenditure	A measure of energy expenditure, not physical activity Expensive to administer due to the high cost of the isotopes as a result of limited supply Requires specialist equipment and trained personnel Formulas used to convert CO^2 to energy expenditure use population based averages which may not be appropriate when calculating energy expenditure in people with MS where metabolic processes may be different It is necessary to collect complete urine samples which may limit its usefulness in MS where difficulties in bladder control is a common symptom Not validated in the MS population
Direct Observation	Physical activity		Direct observation is a method whereby observers watch and record physical activity of the participants.	Measures actual participation in physical activity A useful measure of physical activity for small scale studies	Time and personnel intensive, making it an expensive measurement option in larger studies and impractical for measuring free-living physical activity Observation may alter the behavior of those being observed

Measurement Method	**Measurement Output**	**Background**	**Description**	**Strengths**	**Limitations**
Pedometer	Cumulative step counts	A number of researchers in the physical activity field consider walking to be a proxy indicator to the amount of physical activity undertaken by a person.(140) The pedometer is a motion sensor designed to measure locomotion by counting the number of steps taken.	A waist-mounted or ankle-mounted monitor is fitted to the participant.	Non-invasive Inexpensive Easy to administer	A measure of steps taken, not physical activity in general. Limited to use in ambulatory participants only due to the focus on walking behaviour Accuracy of the device deteriorates with slow walking speeds and in those with abnormal gait (138-140)
Accelerometer	Physical activity (via activity counts) and energy expenditure	A more complex motion sensor than the pedometer which is designed to measure acceleration and motion in a limb or trunk (depending on where the monitor is attached). Triaxial and omnidirectional accelerometers measure movement in multiple planes, while uniaxial measure movement in one plane only.	A monitor is fitted to the participant (in most cases on the ankle, hip, or wrist) and motion and acceleration of the body generates a signal which is digitized. This digitised value is known as an activity count.	Non-invasive Easy to administer Can measure movement in multiple planes (179) Have been found to detect changes in physical activity at the low end of the activity spectrum in people with MS (73) Some devices are waterproof and so can be used to measure land and water-based activities (141)	Despite being used in MS previously, reliability and validity has not been tested previously in people with MS and the results of the study described in Chapter Three of this thesis indicate that the accuracy of accelerometers may be questionable in people with MS There is a general lack of understanding about what an *activity count* actually is and what it represents clinically

From Table 4.1 it can be seen that while there are a range of objective measures of physical activity available for use, few of them appear to be appropriate for use in people with MS. Some of the key weaknesses common to a number of the methods identified here are discussed in more detail below.

a) Using energy expenditure as an indicator of participation in physical activity

While energy expenditure is a good indicator of physical activity, it is a distinct construct and is affected by a range of variables including: inter-individual differences in mechanical efficiency; basal metabolic rate and food intake; not just participation in physical activity. Important information about different aspects of physical activity (such as activity type and intensity) is not identified using measures of energy expenditure. A further concern is that formulae used to convert different measures into energy expenditure include values derived from population based studies and have not been validated in people with MS.

b) Prohibitive cost

A number of the measures identified in Table 4.1 are prohibitively expensive for use in larger scale studies (e.g. the DLW method can cost around $800 per assessment) and require specialist equipment and trained personnel making them a difficult measure to administer.

c) Symptoms and physiological changes inherent in MS may challenge validity

The majority of the measures identified in Table 4.1 were originally developed for use in the general population where the symptoms and physiological changes that are often inherent in a chronic disabling condition such as MS are not accounted for. As a result, the validity of these measures may be affected when using them in people with MS and other chronic disabling conditions. For example, the impact that difficulties in bladder control has on urine collection using the DLW method is unknown. Research has already indicated that the accuracy of pedometers deteriorates with slow walking speeds and abnormal gait (137-139); both of which are characteristic of people with MS.(138,139) *d) Inappropriate for measuring free-living physical activity*

A number of measures are impractical for measuring free-living physical activity either due to the need for controlled conditions (e.g. calorimetry) or because they are too time or personnel-intensive to enable prolonged assessment of free-living activity (e.g. direct observation).

Of the measures identified in Table 4.1, the one that appears to have the most potential for people with MS are accelerometers. Recently, accelerometers have been growing in popularity as an objective measure of physical activity, particularly in the general, healthy population.(143,179,180) As described in Table 4.1, compared to pedometers, accelerometry-based devices may offer important advantages as they have been shown to be sensitive in detecting varying levels of activity at the lower end of the physical activity spectrum (73); detect movement in multiple planes (179); and some are compact, waterproof, and can be worn in a variety of land based and aquatic activities.(141) A range of accelerometers have been used previously in people with disability, including people with MS.(73,114,132,181,182) However, despite their wide use, the ability of accelerometers to reliably detect amount and intensity of activity in the MS population has not been established. The accuracy of these devices in disabled people requires consideration due to the complexity of measuring physical activity in such populations. For example, many people with MS engage in low levels of physical activity; have gait and ambulatory difficulties; rely on a range of assistive devices; have limitations in fine motor control and lack balance and coordination: all of which could impact on the precision of accelerometers. In addition, other important outcome measure criteria, such as feasibility and acceptability, are yet to be explored. See Table 3.1 for details of these criteria as described by Fitzpatrick et al. (105) Ideally, both criteria should be satisfied. As such, the third study associated with Phase I of this doctorate (Study Three) was designed to further explore the potential of accelerometry as an objective measure of physical activity in people with MS.

Due to the large number of accelerometers available for use in research and practice, two research groups have offered 'best practice' guidelines for choosing an accelerometer.(143,180) Both sets of guidelines suggest that no accelerometer is necessarily preferred over another (though some may have more psychometric data available) and so selection is dependent on the intended use of the accelerometer. Trost and colleagues (143) suggest that in the first instance important factors to take into consideration include: cost of the accelerometer, accessories and software; monitor size and sturdiness; and availability of technical support. Ward and colleagues (180) add that one also needs to consider the storage capacity if aiming to measure free-living physical activities over a period of time. They also emphasise the need to consider the potential for the accelerometer to be acceptable to the participant, which highlights the importance of taking into account the characteristics of the population being studied when selecting an accelerometer.

When taking these guidelines into account, Actical accelerometers (Mini Mitter, Bend, OR) (141) appeared to be a potentially appropriate accelerometer for use in people with MS. Figure 4.1 shows a picture of the Actical accelerometer, which is 28 x 27 x 10 mm in size, weighing 17.5g.

Figure 4.1: Actical accelerometer

Reasons why Actical accelerometers were perceived to have potential as an objective measure of physical activity in people with MS included:

(1) They contain an omnidirectional motion sensor and so should capture a range of free-living activities
(2) They are compact, easy to wear and tamper free, making them practical for use in research.
(3) They are waterproof, an important consideration for people with MS who often engage in water-based activities;
(4) They have the ability to store activities for up to 45 days (using a one minute epoch length); and

(5) A number of Actical accelerometers were available for use at AUT University as they have been used previously by researchers at the institution, an important consideration given the cost of similar devices.

STUDY THREE

EXPLORING ACTICAL ACCELEROMETERS AS AN OBJECTIVE MEASURE OF PHYSICAL ACTIVITY IN PEOPLE WITH MULTIPLE SCLEROSIS[3]

4.2 AIMS

The specific objectives of Study Three were to:

(1) Assess the feasibility and acceptability of the Actical accelerometer in people with MS; and

(2) Explore the test-retest reliability and validity of the Actical accelerometer in people with MS.

4.3 METHODS

Ethical approval for Study Three was obtained from the Northern X regional Health and Disability Ethics Committee in NZ (see Appendix O). This study was incorporated as a sub-study of the larger questionnaire study which makes up Study four (Phase II) of this doctoral research. While these two studies were carried out concurrently, Study Three is reported here due to its direct relevance to the aims and objectives of Phase I of this doctoral research.

4.3.1 DESIGN

This study used a repeated measures design where participants carried out a series of activities twice, with seven days between repeated measures, while wearing an Actical accelerometer and a Polar heart rate monitor. In addition, feedback was obtained from both participants and members of the research team to explore the feasibility and acceptability of the Actical accelerometer regarding their potential for use in people with MS.

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[3] Study Three resulted in the third publication directly linked to this doctoral research (183): Kayes, N. M., Schluter, P. J., McPherson, K. M., Leete, M., Mawston, G., & Taylor, D. (2009). Exploring Actical accelerometers as an objective measure of physical activity in people with Multiple Sclerosis (MS). *Archives of Physical Medicine and Rehabilitation, 90*(4), 594-601.

4.3.2 PARTICIPANTS

Participants were recruited for this study through the local MS Societies and one of the District Health Boards in Auckland. A more detailed description of the recruitment procedures appears in Chapter Six. All those who agreed to participate in the larger questionnaire study (Study Four) were asked to indicate on their consent form if they would also be willing to participate in this accelerometer testing study. Potential participants were eligible to take part if they had received a definite diagnosis of MS by a neurologist, were able to communicate with the researchers, and were independently mobile (with or without the use of an assistive device). Potential participants were excluded if they had any medical condition that precluded them from participation in any physical activity component of the study. Of those who gave consent, the aim was to recruit 30 participants, a sample size commonly used in this population and studies of this type,(114,132,134) where capturing a diverse sample is fundamental to making appropriate assessments of instrument reliability and acceptability.(135) Participants were purposefully selected aiming for diversity in level of reported disability, age, gender and type of MS. To do this, consenting participants were initially stratified into low, medium and high disability groups, based on a combination of self-reported disability items collected as a part of the larger study, such as the number of assistive devices and use of arms and legs (full, partial or no use). From each of these strata, participants were then purposefully selected aiming for diversity in the other criteria listed above. Selected participants were then contacted via the telephone and screened for eligibility using a modified version of the Physical Activity Readiness Questionnaire (PAR-Q).(184) If participants answered ‘yes’ to any of the questions on the PAR-Q, then medical clearance was obtained from their general practitioner before taking part in the testing.

4.3.3 MEASURES

4.3.3.1 Feasibility and Acceptability

Feasibility was assessed drawing on the experiences of the research team throughout the accelerometer testing period. Consideration was given to ease of use, staff training, processing time pre and post testing, fitting of the accelerometer and data preparation. Acceptability was explored with participants via two methods: (1) On completion of the testing session participants were asked to rate how comfortable they felt the accelerometer was to wear on a 5-point Likert scale (with 1 being ‘not comfortable at all’ and 5 being ‘very comfortable’); and (2) they were asked to report any feedback they had regarding the acceptability of the accelerometer.

4.3.3.2 Test-retest Reliability and Validity

4.3.3.2.1 Actical accelerometers (141)

Actical accelerometers (Mini Mitter, Bend, OR) detect low frequency (0.5-3.2Hz) gravitational-forces (0.05-2.0g) common to human movement, and generate a signal proportional to the magnitude and duration of the sensed acceleration, which is digitised and summed over a user-specified time-interval (epoch) length of 15, 30 or 60 seconds.(185) This digitised value is known as an activity count. Data can be displayed in activity counts or Actical software can convert these counts to energy expenditure (kcal and METS). In the current study, 15-second epochs were selected and investigated because of the interest in testing the reliability and validity of the accelerometer in measuring short bouts of activity likely to be common in people with MS. Raw activity count data were used rather than energy expenditure data as there are currently no existing algorithms for predicting energy expenditure in people experiencing disability.(129) Furthermore, energy expenditure equations used by Actical have been found to underestimate time spent in vigorous activities and overestimate walking and sedentary activities.(186)

4.3.3.2.2 Criterion Measures

In the absence of a gold standard measure of physical activity in people with MS, a range of proxy criterion measures were used to assess validity including both physiologic (heart rate) and self-reported (rating of perceived exertion) activity intensity and actual observed physical activity on two standardised measures; the six-minute walk test (6MWT) (187) and the 30 second chair stand test.(188)

Heart rate (HR): Heart rate R-R interval data were recorded simultaneously with accelerometer data via Polar S810i and RS800sd heart rate monitors (Polar Electro Oy, Finland). The 'R' in R-R interval refers to the first positive (upward) deflection of the QRS complex in an electrocardiogram and the R-R interval is the time elapsing between two consecutive Rs.(189) R-R interval heart rate data were converted to average HR (in beats per minute). Raw R-R interval data were filtered using the Polar Precision Performance Software, version 4.10.029 (Polar Electro Oy, 2004). Filtered data were then exported to excel and converted to percentage heart rate reserve (%HRR) using the Karvonen formula (190):

$$\%HRR = [(HR_{activity} - HR_{resting})/(HR_{max} - HR_{resting})]*100,$$

where $HR_{activity}$ is equal to the average beats per minute during activity completion, and HR_{max} is equal to 220 minus the person's age. The Karvonen method has the advantage over predicted percentage HR maximum as it takes into account resting heart rate, which has been reported to be significantly lower in MS groups when compared to age-matched healthy people.(191)

Perceived exertion: The Borg Rating of Perceived Exertion (Borg RPE) (192) was used to measure self-reported activity intensity. The Borg RPE is a measure of subjective feeling of exertion during physical activity where the person undertaking the activity rates their activity intensity on a scale ranging from 6 (no exertion at all) to 20 (maximal exertion).

Six minute walk test: The six minute walk test (6MWT) (187) is a measure of functional exercise capacity where a person is asked to walk as far as they can for six minutes. In the current study the 6MWT was performed indoors in a 30-metre stretch of hallway on a hardened and flat surface. The six minute walk distance was used as the criterion measure. This is the total distance (m) covered by the participant during the six minute time period. The protocol for administering this test and instructing participants followed that outlined by the American Thoracic Society.(187)

30 second chair stand test: The 30 second chair stand test (188) involves counting the number of times a person can stand fully upright from a seated position over a 30-second period without pushing off with their arms. The number of chair stands the participant completed over the 30-second time period was used as the criterion measure. The protocol for administering this test followed that outlined by Rikli and Jones.(188)

4.3.4 PROCEDURES

All eligible participants were scheduled to attend two testing sessions, seven days apart, at the Health and Rehabilitation Research Institute at AUT University. Research staff administrating the testing process followed a structured testing protocol (see Appendix P). As described in the testing protocol, on arrival at each testing session participants were fitted with an Actical accelerometer and a Polar heart rate monitor. Accelerometers were mounted onto waistbands and fitted around the participant's waist over the iliac crest of the left hip, in accordance with the manufacturer's recommendations. The Polar heart rate transmitter was moistened and strapped to the chest. Participants were then instructed on the use of the Borg RPE and their resting heart rate was recorded.

During testing sessions, participants completed a series of six activities ranging in intensity from sedentary to vigorous (see Table 4.2), while wearing the Actical accelerometer and Polar heart rate monitor. Activities were conducted in random order for each participant at each testing session, with the exception of the 6MWT which was always conducted last in order to eliminate the possibility that it would impact on the participant's ability to complete subsequent activities. A set of standardised instructions was read to each participant before completing each activity (see Appendix Q).

At the commencement and completion of each activity, the marker button on the accelerometer and the start/finish button on the heart rate monitor were pressed simultaneously to enable comparison of data. On completion of each activity participants were asked to rate the activity intensity using the Borg RPE. Between activities, participants rested until their heart rate had returned to resting rate before commencing the next activity. A record of each individual accelerometer testing session was kept using a standardised format (see Appendix R).

Table 4.2: Activities completed by participants during the accelerometer testing sessions

Activity	**Description**
Newspaper Reading	The object of this activity was for the participant to read the newspaper while seated for five minutes.
Washing	The object of this activity was for the participant to first hang each item in the washing basket on the washing line one by one and then take each item off and fold it one by one.
Vacuuming	The object of this activity was for the participant to vacuum a marked area of the floor for five minutes. Participants were permitted to stop, and to rest as necessary. They were instructed to lean against the wall while resting, but to resume vacuuming as soon as they were able.
Stair Climb	The object of this activity was for the participant to walk up and down a flight of stairs for 30 seconds. Participants were permitted to stop, and to rest as necessary. They were instructed to lean against the wall while resting, but to resume climbing the stairs as soon as they were able.
30 Second Chair Stand	The protocol for administering this test followed that previously outlined by Rikli and Jones.(188)
6MWT	The protocol for administering this test and instructing participants followed that previously outlined by the American Thoracic Society.(187)

Raw data from the accelerometer and heart rate monitor were downloaded using the Actical manufacturer's software (141) and Polar Pro Trainer 5 software (Polar Electro Oy, Finland) respectively. Raw 15-second epoch activity data were then imported into Microsoft Excel and total activity count for each individual activity obtained. For the majority of analyses, the total activity count was then converted into average activity counts per minute using the following equation:

$$(\text{Total Activity Count} / \text{Length of Activity (seconds)}) * 60$$

The purpose of this was to make it comparable with the primary criterion measure, %HRR, which was calculated using average HR (beats per minute) as described earlier.

It was necessary to use this method rather than simply collect activity data using 60-second epochs for three reasons. Firstly, some of the activities were less than one minute in length (e.g. 30 second chair stand). Secondly, there was no way of ensuring that an activity started at the beginning of an epoch, resulting in the likelihood that many of the activities would start and finish midway through a 60-second epoch period. While this is also possible with 15-second epochs, there is less risk of the accelerometer picking up movement unrelated to the activity within that same epoch period with the shorter epoch. Lastly, because some activities resulted in partial epochs (e.g. if an activity was 1 minute 7 seconds in length it resulted in four full epochs and one partial epoch) then averaging total activity count over the number of epochs would have been misleading. In all of these instances, averaging total activity count across the total length of the activity and then converting this into average activity counts per minute allowed for higher accuracy.

4.3.5 ANALYSES

4.3.5.1 Feasibility and Acceptability

Observations relevant to feasibility were collated into the pre-identified categories listed above e.g. ease of use, training, processing time pre and post testing, fitting of the accelerometer and data preparation. Acceptability was assessed by calculating percentages of participant responses on the Likert scale and collating participant feedback.

4.3.5.2 Test-retest Reliability and Validity

Using the methods described above, raw accelerometer data were converted to average activity counts per minute for the majority of analyses, with the exception of the validity analyses using actual observed activity as a criterion measure (6MWT and 30 second chair stand), where total activity count was used. Recognising the likelihood for highly skewed empirical distributions, medians, interquartile ranges (IQR) and ranges were employed to report estimates of central location and spread. Test-retest reliability was assessed using the one-way analysis of variance (ANOVA) ICC and Bland-Altman’s 95% limits of agreement method.(193) Graphical checks advocated by Bland and Altman (135,193) were undertaken to detect whether important distributional violations existed. Due to the repeated nature of the data, validity was assessed using generalised estimating equations (GEE) models. Initially, scatterplots and lowess curves (a nonparametric mean estimator function) were drawn to graphically depict relationships between accelerometer counts and chosen criterion measures (principally, %HRR and the Borg RPE). GEE models were then fitted to estimate parameters and relationships between variables for each of the six activities. Unstructured within-person correlation matrices were specified and robust (Huber-White) sandwich estimators of variance employed to calculate standard errors and confidence intervals. Diagnostic and residual checks of these analyses followed that recommended by Dupont.(194) All analyses were performed using SAS version 8.2 and Stata version 8.0.

4.4 RESULTS

The sample for this study were recruited from 282 people involved in a larger questionnaire study (Study Four, see page 152). In total, 128 (45%) consented to take part in the accelerometer testing. Initially, 30 of these were purposefully selected as per the criteria outlined in the methods (see page 125) and all were deemed eligible to take part. Two potential participants failed to attend the testing sessions so a further three participants were selected to account for those and the potential for future drop outs. However, there were no further drop outs, leaving a total of 31 participants.

4.4.1 PARTICIPANT CHARACTERISTICS

Table 4.3 provides a summary of participant characteristics for this study. As was the case in studies one and two, the sample is characteristic of what one would expect to see in an MS sample (see page 90), with the majority of participants being female and of European descent.(1,152-154) The sample was diverse in terms of illness-related variables with a wide range of time since diagnosis and all types of MS represented. Fourteen (45%) participants used an assistive device of some kind either inside or outside the home; predominantly using a cane, a walker or both interchangeably.

Table 4.3: Participant characteristics for Study Three

Gender	Female	21 (68%)
	Male	10 (32%)
Age	50 years (median)	34 to 80 years (range)
Ethnicity	European	29 (94%)
	NZ Maori	1 (3%)
	Pacifika	1 (3%)
Type of MS	Benign	3 (10%)
	Relapsing-remitting	11 (35%)
	Secondary progressive	5 (16%)
	Primary progressive	12 (39%)
Time since diagnosis	7 years (median)	1 to 40 (range)

4.4.2 SUMMARY STATISTICS

Summary statistics of the average activity counts per minute, %HRR and Borg RPE at each time point are shown in Table 4.4. Available data for analysis fluctuates between activities as: two participants did not attend their second testing session for reasons unrelated to testing (schedule clashes and feeling unwell); some participants opted not to complete all activities, either at one or both time points, as either they or the researcher conducting the testing had concerns about their ability to complete these activities safely; and on a small number of occasions, the heart rate monitor failed to detect the participant’s heart rate during testing. Average accelerometer counts were observed to have relatively large ranges compared with %HRR and the Borg RPE, particularly for the more vigorous activities such as the 6MWT (range: 1 to 6275), the 30 second chair stand (range: 34 to 6418) and the stair climb (0 to 3472).

Table 4.4: Descriptive statistics of average accelerometer counts, percentage heart rate reserve and the Borg rating of perceived exertion by activity and time point

Activity	**Participants (n)**	**Time 1**			**Time 2**		
		Median	**IQR**	**Range**	**Median**	**IQR**	**Range**
Average accelerometer counts							
Newspaper reading	29	3	(0, 6)	(0, 22)	1	(0, 4)	(0, 25)
Hanging washing	29	31	(8, 89)	(0, 291)	17	(6, 69)	(3, 283)
Vacuuming	29	61	(10, 161)	(0, 807)	32	(9, 115)	(3, 1001)
Stair Climb	29	1440	(574, 2362)	(0, 3060)	1296	(534, 2114)	(8, 3472)
30 Second Chair Stand	24	718	(312, 1070)	(34, 6418)	663	(313, 1118)	(60, 5286)
6MWT	26	2552	(1159, 3489)	(1, 4528)	2235	(1369, 3474)	(3, 6275)
Percentage heart rate reserve							
Newspaper reading	27	2.5	(0, 3.9)	(0, 8.8)	3.0	(1.9, 4.9)	(0, 12.0)
Hanging washing	28	20.9	(14.8, 23.5)	(8.3, 45.5)	19.3	(17.1, 23.4)	(5.8, 47.5)
Vacuuming	27	25.0	(18.0, 30.2)	(15.3, 46.9)	23.3	(19.6, 29.4)	(10.4, 51.2)
Stair Climb	28	29.8	(21.9, 35.9)	(15.7, 54.0)	27.8	(22.3, 32.6)	(18.0, 65.3)
30 Second Chair Stand	22	22.8	(14.8, 27.0)	(7.4, 41.6)	22.4	(14.6, 26.2)	(4.2, 38.7)
6MWT	25	32.0	(22.3, 42.9)	(14.1, 57.1)	35.4	(24.3, 39.4)	(12.5, 56.0)
Borg rating of perceived exertion							
Newspaper reading	29	6	(6, 6)	(6, 15)	6	(6, 7)	(6, 14)
Hanging washing	29	9	(7, 11)	(6, 17)	10	(7, 11)	(6, 18)
Vacuuming	29	11	(11, 12)	(6, 17)	11	(9, 13)	(6, 19)
Stair Climb	29	11	(11, 13)	(6, 19)	12	(9, 13)	(6, 18)
30 Second Chair Stand	23	11	(9, 13)	(6, 15)	11	(9, 12)	(6, 15)
6MWT	26	12	(11, 13)	(6, 17)	13	(11, 15)	(6, 20)

4.4.3 FEASIBILITY AND ACCEPTABILITY

The research team found the Actical accelerometers and the Actical software package very straightforward and easy to use. Staff training required was minimal with one 60-minute face-to-face session, after which staff worked independently, familiarizing themselves with the monitor and software and ran through a mock testing session. The time spent setting up the accelerometers for use with participants and downloading the data was minimal, taking no more than five minutes per participant pre and post testing. Fitting the accelerometer onto the participant was simple, taking no more than one minute to fit pre-testing. Furthermore, the tamper-free design of the monitors made them particularly useful and appropriate for research, eliminating the potential for participant interference during data collection. However, there were some minor technical difficulties. Firstly, the marker button did not always work on the first occasion and so the researcher had to press it twice each time to ensure it inserted a marker into the data set to indicate the start and finish time of each activity. Secondly, the 'custom interval' function of the software, which enabled computation of summary data for a user-selected time period could only be utilised when working with energy expenditure data and so could not be applied to raw activity count data. Rather, the raw data had to be imported into Microsoft Office Excel 2007 to manage it more effectively.

Acceptability of the accelerometers was very high for participants, with the majority of participants (90%) rating the accelerometer as 'very comfortable' (5/5) to wear. The remaining participants rated it as moderately comfortable to wear with two participants rating it at 4/5 and one rating it as 3/5. The majority of participants commented that they could not feel the accelerometer and hardly noticed it was there once it was fitted. The following comments are representative of this feedback:

> *Didn't notice it (Male, Age 48)*
>
> *Not even aware that it was there (Male, Age 37)*
>
> *Almost forgot it was there (Female, Age 47)*

Even the one participant who rated the device as 3/5 with regard to how comfortable it was to wear commented similarly:

Didn't know it was there (Female, Age 80)

This suggests that the small, compact design of the accelerometers generated very little participant burden.

4.4.4 TEST-RETEST RELIABILITY

Results of the average accelerometer counts test-retest reliability analyses with both the ICCs and Bland-Altman 95% limits of agreement displayed for each activity is presented in Table 4.5. ICCs ranged from 0.00 (newspaper reading) to 0.90 (6MWT) and the 95% limits of agreement were wide overall, ranging from ±16 (newspaper reading) to ±1330 (6MWT).

Table 4.5: Test-retest reliability of average accelerometer counts by activity

Activity	**N**	**ICC**	**95%CI**	**Bland-Altman**		
				Bias	***P*-value***	**95% Limits of Agreement**
Newspaper reading	29	0.00[†]	(0.00, 0.37)	0.4	0.48	(-16, 16)
Washing	29	0.38	(0.07, 0.70)	2.7	0.84	(-145, 145)
Vacuuming	29	0.75	(0.58, 0.91)	7.0	0.73	(-247, 247)
Stair Climb	29	0.85	(0.76, 0.95)	96.3	0.26	(-1065, 1065)
30 Second Chair Stand	24	0.87	(0.77, 0.96)	31.8	0.74	(-1192, 1192)
6MWT	26	0.90	(0.83, 0.97)	-139	0.33	(-1330, 1330)

*P-value from the Student's t-test comparing the estimated bias against the null value of zero.

[†] While estimated, the distribution of ICC is highly skewed and hence the reported estimates and confidence intervals may be relatively unstable.

4.4.5 VALIDITY

Scatter-plots of average accelerometer counts against %HRR and the Borg RPE for each activity are depicted in Figure 4.2 and Figure 4.3.

Figure 4.2: Scatter plot of average accelerometer counts against percentage heart rate reserve (%HRR) by each activity

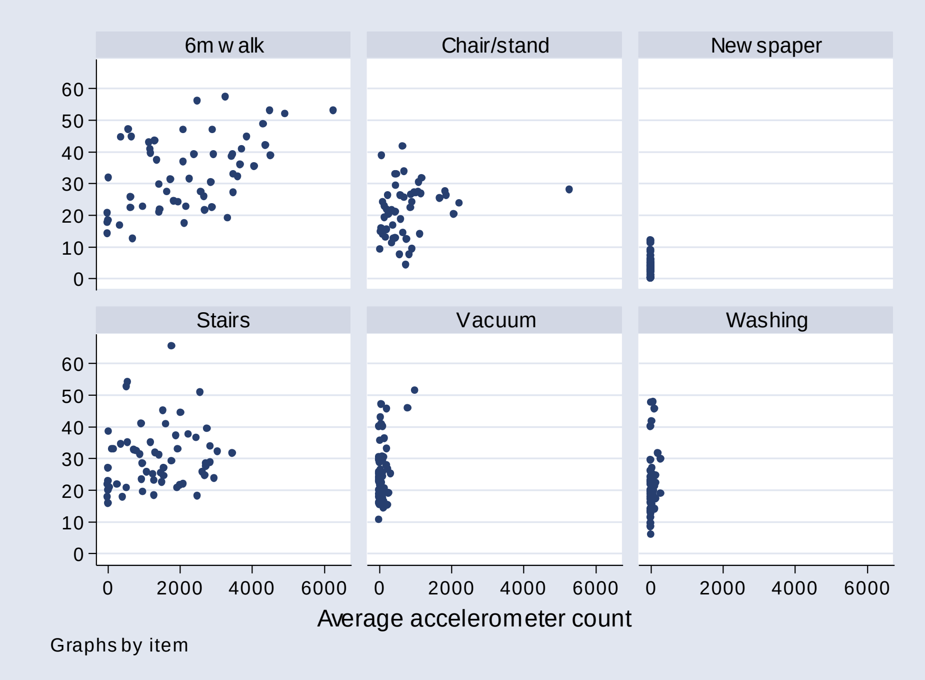
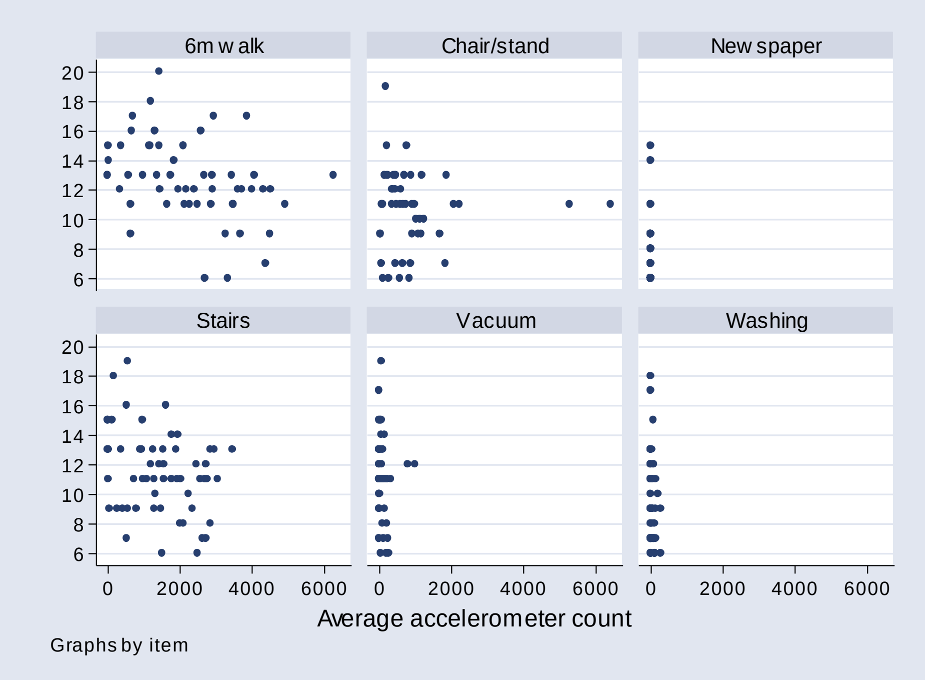


Figure 4.3: Scatter plot of average accelerometer counts against the Borg rating of perceived exertion by each activity



Examination of the scatter plots suggests that only weak relationships exist between average accelerometer counts and both %HRR and Borg RPE. In particular, sedentary (newspaper reading) and free living (washing) activities were seen to have relatively high variability in %HRR and Borg RPE measurements compared to the average accelerometer counts.

Results from the GEE analysis together with the Bland-Altman 95% prediction intervals by each activity for all the criterion measures is presented in Table 4.6. The parameter estimates indicate that a significant linear relationship exists between %HRR and the average accelerometer counts for the 6MWT, 30 second chair stand and vacuuming activities. However, for the Borg RPE, only the average accelerometer counts obtained on the 6MWT and the stair climb activities had a significant relationship. For both criterion measures, the prediction intervals show high variability ranging from ±5.7 (newspaper reading) to ±19.7 (6MWT) for %HRR and ±3.6 (newspaper reading) to ±5.3 (washing) for Borg RPE.

Significant linear relationships exist between total accelerometer counts and both the six minute walk distance and the number of chair stands on the 30 second chair stand test (Table 4.6). However, once again, the 95% prediction intervals show high variability at ±195 (six minute walk distance) and ±6.2 (number of chair stands).

Table 4.6: Parameter Estimates of Generalized Estimating Equations analysis together with the Bland-Altman 95% Prediction Intervals for all criterion measures

Activity	**n(obs)**	**Estimate**	**95%CI**	***P*-value**	**Bland-Altman 95% Prediction Intervals**
Average accelerometer counts related to percentage heart rate reserve (%HRR)					
Newspaper reading	31 (58)	-0.097	(-0.211, 0.018)	0.10	(-5.7, 5.7)
Washing	31 (59)	0.02	(-0.002, 0.042)	0.07	(-16.9, 16.9)
Vacuuming	30 (57)	0.019	(0.007, 0.030)	0.002	(-16.0, 16.0)
Stair Climb	31 (59)	0.002	(-0.001, 0.005)	0.16	(-19.3, 19.3)
30 Sec Chair Stand	28 (50)	0.005	(0.002, 0.009)	0.005	(-16.6, 16.6)
6MWT	31 (56)	0.004	(0.002, 0.006)	<0.001	(-19.7, 19.7)
Average accelerometer counts related to Borg rating of perceived exertion					
Newspaper reading	31 (60)	-0.01	(-0.067, 0.047)	0.73	(-3.6, 3.6)
Washing	31 (60)	-0.007	(-0.015, 0.00)	0.06	(-5.3, 5.3)
Vacuuming	31 (60)	0.00	(-0.003, 0.003)	0.96	(-5.2, 5.2)
Stair Climb	31 (60)	-0.001	(-0.002, 0.00)	0.04	(-5.1, 5.1)
30 Sec Chair Stand	28 (51)	0.00	(-0.001, 0.00)	0.37	(-5.2, 5.2)
6MWT	31 (57)	-0.001	(-0.001, 0.00)	0.03	(-5.0, 5.0)
Total accelerometer counts related to six minute walk distance (6MWD[m])					
6MWD	31 (57)	0.015	(0.012, 0.019)	<0.001	(-195, 195)
Total accelerometer counts related to number of chair stands on the 30 second chair stand test.					
No. of chair stands	28 (52)	0.007	(0.005, 0.008)	<0.001	(-6.2, 6.2)

4.5 SUMMARY

Study Three was the third study to be carried out as a part of Phase I of this doctoral research. This study aimed to assess the feasibility and acceptability of the Actical accelerometer in people with MS and explore its test-retest reliability and validity in this population. Feasibility and acceptability of the Actical accelerometers was good, with the research team reporting them to be easy to use and implement, experiencing only minor technical difficulties, and participants finding them to be very comfortable to wear. However, test-retest reliability analyses indicated mixed findings. Low ICCs were obtained for sedentary (newspaper reading) and free-living activities (washing), while moderate to high ICCs were obtained on the more vigorous activities (6MWT) and rhythmic activities which required an alternate change in direction or change in acceleration (30 second chair stand). Bland-Altman 95% limits of agreement were modest for all activities suggesting high variability exists in the measure. Similarly, while validity analyses indicated a significant relationship between activity intensity and accelerometer counts on the more vigorous or rhythmic activities, such as the 6MWT, no such relationship existed on sedentary and free-living activities. The only exception was the vacuuming activity, considered a free-living activity, where accelerometer counts were significantly related to %HRR. It is possible that this is because vacuuming sometimes requires a relatively rapid change in hip position and the accelerometer may be more sensitive to this type of movement. Despite this, the wide 95% prediction intervals obtained for all activities suggest that accelerometer counts do not predict either physiologic (%HRR) or self-reported (Borg RPE) activity intensity very well.

CHAPTER 5

PHASE I DISCUSSION

Research investigating physical activity in people with MS has been hampered by the lack of a conceptually and psychometrically sound measure of physical activity relevant to this population. As highlighted in Chapter Three, the majority of existing self-report measures were designed for use in healthy populations, and their psychometric properties not yet explored in people with MS. The large majority of questionnaires focus on structured exercise activities and/or leisure-time physical activity, without consideration of those activities which may fall at the low end of the activity spectrum, such as household chores and employment related activity. Further, due to their original development being informed by healthy populations, they fail to take into account other illness-related activities, such as wheelchair use and therapy-related activities. Given that a) people with MS have been found to be a relatively sedentary population when compared with other chronic illness groups and the general population and are perhaps more likely to engage in activities at the low end of the activity spectrum; and b) evidence now suggests that health benefits can be achieved through an accumulation of short bouts of physical activity and engagement in incidental activities (28); it seems important that measures be designed to capture even small changes in physical activity behaviour in this population. In this phase, both a self-report (PADS-R) and objective (Actical accelerometer) measure of physical activity were tested in people with MS in an attempt to address this gap.

5.1 KEY FINDINGS

Table 5.1 presents a summary of the measurement properties for both the PADS-R and the Actical accelerometer examined in this phase.

Table 5.1: Summary of measurement properties for the PADS-R and the Actical accelerometer

	PADS-R	Actical accelerometer
Acceptability	Consultation with people with MS throughout the revision process resulted in people reporting it to be highly acceptable and relevant to the kinds of activities they participate in (face validity).	Reported to be acceptable to both participants and research team. Participants reported them to be very comfortable to wear.
Utility/ Feasibility	Easy to administer Approximately 20 minutes to complete Easy to understand and complete	Easy to use and implement Some minor technical difficulties Some limitations to data management software
Test-retest reliability	**ICC**=0.91 **Bland-Altman 95% limits of agreement**=±0.89 *Representing 15% of the total range of PADS-R scores*	**ICC** ranged from 0.00 (newspaper reading) to 0.90 (6MWT) **Bland-Altman 95% limits of agreement** ranged from ±16 (newspaper reading) to ±1330 (6MWT) *Representing from 21% [6MWT] to 64% [newspaper reading] of the total range of accelerometer counts on those activities*
Validity	Not tested	**%HRR** 95% prediction intervals ranged from ±5.7 (newspaper reading) to ±19.7 (6MWT) *Representing from 39% [stair climb] to 48% [30 second chair stand test] of the total range of %HRR for each activity* **Borg RPE** 95% prediction intervals ranged from ±3.6 (newspaper reading) to ±5.3 (washing) *Representing from 36% [6MWT] to 58% [30 second chair stand test] of the total range of Borg RPE for each activity* **Six minute walk distance (6MWD)** 95% prediction intervals=±195 *Representing 26% of the total range of 6MWD scores* **Chair stands** 95% prediction intervals=±6.2 *Representing 24% of the total range of chair stands*

The summary in Table 5.1 suggests that, subject to further testing of validity and other psychometric properties such as responsiveness, the PADS-R appeared to be a conceptually sound, acceptable and robust measure of physical activity, relevant to people with MS. While the 95% Bland-Altman limits of agreement indicated some variability in the measure, it could be argued that this was at an acceptable level at 15% of the total range of PADS-R score. Some level of variability is expected in a self-report measure of this type where recall bias is recognised as a common flaw.(155,158) This variability would need to be considered and accounted for if using the PADS-R as an outcome measure in a clinical trial.

In comparison the Actical accelerometer appeared to be a less robust measure for use in people with MS. As a general rule, test-retest reliability fared better for more vigorous activities (such as the 6MWT) or those activities requiring more purposeful or rhythmical movements (such as the 30 second chair stand). However, even for those activities which yielded a high ICC, indicating a strong relationship between times 1 and 2 activity counts; the 95% Bland-Altman limits suggested high variability in the measure. A similar picture is evident for validity of the device, with wide 95% prediction intervals obtained for all activities. This indicates that accelerometer counts do not predict physiologic (%HRR), self-reported (Borg RPE) activity intensity or actual observed activity (Six minute walk distance and Number of chair stands) very well.

5.1.1 POSSIBLE EXPLANATIONS FOR FINDINGS

When interpreting these results, it is important to consider alternative reasons for the poor reliability and validity observed with the Actical accelerometers. Monitor placement may be one such reason. As one would expect, activity monitors are likely to measure motion most accurately when they are placed on the part of the body where motion occurs. It is possible then that for free-living activities such as washing and vacuuming that hip placement might record less activity counts than wrist placement, for example. However, wrist placement is also subject to potential error as it is more likely to pick up motion unrelated to the task, such as fidgeting and movements due to muscle spasm. Furthermore, researchers exploring the ability of Actical accelerometers placed at different locations (wrist, hip and ankle) to predict energy expenditure in healthy persons over a range of free-living activities found hip location to be the only site which accurately predicted energy expenditure at all intensity levels (light, moderate and vigorous).(185) With this in mind, it could be argued that hip placement had little impact on the outcome of the validity analyses.

Another issue to consider is the possibility that activity intensity (measured by %HRR and Borg RPE) may be limited in usefulness as a criterion measure of physical activity. Heart rate monitors and ratings of perceived exertion have faced some criticism as discussed earlier in Chapter Four.(140,172,195,196) Heart rate can be influenced by a number of factors other than participation in physical activity, such as emotional stress and physical fitness,(172) and has been found to overestimate light activity and underestimate moderate activity.(195) In addition, there are some factors to take into consideration specific to people with disability when using heart rate monitors, such as the impact that the disabling condition has on the participants' autonomic nervous system and the impact of certain medications on heart rate.(140) However, this study attempted to reduce the impact of these influences by using %HRR. Finally, Borg RPE has been reported to have high inter-individual variability (196) which could impact on its validity as a criterion measure.

Despite the concerns noted above about using heart rate or Borg RPE as criterion measures, a number of factors indicate the validity of the Actical accelerometer for use in people with MS must still be questioned. First, on free-living activities (such as washing and vacuuming) the accelerometer counts obtained seemed markedly low, and disproportionate to the nature of the activity and indeed the self-rating of the activity. Second, the 95% predictions intervals were wide for all activities, even for those activities where significant relationships between the criterion measure and activity counts were observed. Furthermore, wide 95% prediction intervals were evident even when actual observed activity (six minute walk distance and number of chair stands completed in the 30 second chair stand test) was used as a criterion measure rather than a measure of activity intensity.

5.1.2 CONSIDERING FINDINGS IN THE CONTEXT OF RECENT RESEARCH

Since carrying out this research, a number of studies have been published exploring physical activity measurement in people with MS.(181,182,197-199) All of these studies set out to specifically explore objective measures of physical activity, with the exception of two, which explored both objective and self-report measures of physical activity.(182,199) In their study, Gosney and colleagues explored the validity of the GLTEQ (described in Table 3.2), International Physical Activity Questionnaire (IPAQ), Yamax SW-200 pedometer, and the Actigraph single-axis accelerometer by examining the pattern of correlations between the multiple measurement methods. They hypothesised a large correlation between self-report methods and between objective methods and a moderate correlation between the two alternative types of measurement methods. They reported large correlations between objective measures (r=0.82) and moderate to large between the GLTEQ and objective measures (r=0.51-0.53), but only moderate correlations between self-report measures (r=0.37) and between the IPAQ and objective measures (r=0.32-0.36).(182) The authors suggested this provided support for the validity of the GLTEQ and both objective measures of physical activity. However, it could be argued that the reported pattern of correlations is simply confirmation of the fact that each of the measures appears to measure similar constructs; they are not necessarily confirmation that they measure free-living physical activity specifically. For example, the GLTEQ only considers structured activity time and activities conducted for a minimum period of 15 minutes at a time (as highlighted in Chapter Three, page 79) and pedometers are designed to measure steps taken and therefore primarily capture walking behaviour. If one considers this in light of the findings of the research carried out in Phase I of this doctorate, the moderate to large correlations between these measures and the accelerometer measure may be interpreted as an indication that all three measures measure vigorous, structured activity. This is consistent with the findings of Study Three of this doctoral research where the Actical accelerometer appeared to have difficulty measuring a broad range of free-living activities, particularly those activities at the low end of the spectrum. This also supports the view expressed in this doctoral research that a gap still exists regarding the measurement of free-living physical activity, a gap that the PADS-R measure attempts to address.

Klassen and colleagues (199) examined the known groups validity of the TriTrac RT3 accelerometer and a self-report activity diary by exploring their ability to discriminate between inactive, moderately active and active individuals with MS. Both measures were found to detect differences between inactive and active groups. However, the accelerometer was better at detecting differences between moderately active and active participants, while the activity diary was better at detecting differences between inactive and moderately active individuals. This further supports the findings from this doctoral research which suggest accelerometers may only capture activities at the high end of the activity spectrum.

The remaining studies referenced above explored reliability in a range of objective measures, including the Yamax SW-200 pedometer, Actigraph single-axis accelerometer (181) and the TriTrac RT3 Accelerometer in people with MS.(197,198) While the authors of these papers were positive about the reliability of these measures, examination of their findings revealed a number of limitations which should be considered. First, all three studies primarily considered the ICC as an indicator of agreement between repeated measures. While the two studies examining the TriTrac RT3 Accelerometer also considered the standard error of measurement (SEM) as an indicator of variability between repeated measures,(197,198) more emphasis appeared to be placed on the ICC when reporting the results, despite the fact that the SEM indicated variability ranging from 10 to 80% in one study (197) and 17 to 25% in another.(198) The ICC seems to be readily accepted by research consumers as a measure of agreement due to it yielding a single index considered to be easily interpretable (ranging from 0 to 1, with scores approaching 1 indicating higher agreement). However, they have a number of limitations. For example, the ICC ignores systematic bias, and high ICCs may hide measurement error and therefore should be interpreted with caution.(200) The findings of the research carried out in this phase is testament to this, where despite a number of high ICCs, there appeared to be disparity between the findings from the ICC and Bland-Altman methods.

Second, one study only explored test-retest reliability of the TriTrac RT3 Accelerometer in a range of selected activities, all of which could be considered vigorous (e.g. 5 minute walk test) or requiring more purposeful or rhythmical movements (e.g. a stair climbing task).(197) Given the findings of Study Three of this doctoral research, focusing only on these types of activities may have inflated the reliability results when considering measurement of free-living physical activity.

Finally, all the studies cited above excluded those people with MS who were not independently mobile (with or without an assistive device). While the reasons for this exclusion criterion were not disclosed, it is possible that it is a reflection of the complexity of utilising accelerometry devices with wheelchair users, resulting in this subset of the population being routinely excluded from research (if an objective measure is the key outcome). In Study One of this doctorate, accelerometer data collected from wheelchair users were excluded from subsequent analyses due to the complexity of amalgamating data from two accelerometers (wrist and hip placement). Having not overcome this issue, this difficulty also led to their exclusion from Study Three. In a population like people with MS, where the impact of the condition is so variable between individuals and where some people are fully mobile, while others use wheelchairs part or all of the time; excluding wheelchair users seriously limits the applicability of any research conducted. While exclusions such as this are common to all research studies and in some cases are perfectly reasonable, if the measurement choice results in exclusion of a significant portion of the population of interest when alternative, more inclusive, measures are available (such as the PADS-R), there seems to be something fundamentally wrong with the research process. Given that individuals with primary progressive MS in particular have been reported to engage in particularly low levels of physical activity (see page 51) and a large proportion of those with primary progressive MS rely on mobility devices, such as a wheelchair, it could be argued that the development of robust measures which capture physical activity in this subset of the MS population should be a research priority.

Very recently, Snook and colleagues carried out a study to examine in more detail exactly what accelerometry measures in people with MS; physical activity, walking mobility or both.(201) Interestingly, they found that accelerometer counts reflected both engagement in physical activity *and* walking mobility, raising concerns about their ability to distinguish between the two. This has implications for the construct validity of accelerometers as a measure of physical activity in their own right. Conversely, the two self-report measures they included in their exploration, the GLTEQ and IPAQ performed well and appeared to have good convergent and discriminate validity when compared against other measures of physical activity and walking mobility.

5.2 LIMITATIONS

It is important to consider the findings of the studies in Phase I in the context of their limitations. A number of limitations have already been discussed both regarding the first of the two PADS studies (see Section 3.6, page 96) and the accelerometer testing (see Section 5.1.1, page 143) in trying to make sense of the findings. However, there are also some limitations of the second PADS study (Study Two) not yet addressed and so these are discussed further here.

First, with a cyclical condition such as MS, it is important to consider the potential for changes in condition to impact on reliability scores and to balance this with the impact of item recall. This was the reason for the decision to explore test-retest reliability using three day repeated measures in this study. However, the PADS-R asks individuals to report on physical activity undertaken in the 'last' week so there would have been a four day overlap in the response period participants were reporting on between assessment points, potentially influencing repeatability analyses. It may be that using seven days between repeated measures might have eliminated this potential bias.

Second, the reliability testing phase of this study had a sample size of n=29; less than that recommended by Altman, 1991.(202) However, this sample size is comparable to other studies in these populations (114,132,134) and the more critical issue in such studies is capturing a diverse sample (135) which was achieved.

Finally, there were some limitations in the scope of this study which should be acknowledged if considering the PADS-R for wider use.

(1) The acceptability and test-retest reliability was only explored in people with MS and so these measurement properties should be explored in other populations of interest to assess if the measure is acceptable and reliable for use in people with other chronic disabling conditions.

(2) Other important psychometric properties such as validity and responsiveness were not explored in this study. The importance of these measurement properties has already been discussed in Chapter Three (see page 75). Future research on the PADS-R should prioritise assessment of these properties.

5.3 CONCLUSION

Despite the intuitive appeal of accelerometers such as the Actical accelerometer, concerns about the quality of the data they provide when used in people with MS were identified. They should be used with caution in people with MS and possibly other people with chronic disabling conditions, particularly when intending to measure sedentary or free-living activities. This study has highlighted that the accuracy and reliability of accelerometry-based devices cannot be assumed across populations, and researchers and practitioners should ensure their device of choice has been well validated and is a stable measure in their population of interest before using them in future research and practice.

In contrast, exploration of the PADS-R suggests it is a conceptually sound measure of physical activity for people with MS, with good test-retest reliability. While the PADS-R is likely to be subject to the same limitations that other self-report measures of physical activity are (e.g. recall bias), it appears to be an appropriate measure for use in people with MS. A notable strength of the PADS-R is that it is a conceptually sound measure, developed in consultation with, and specifically for, people experiencing disability. Further research should formally evaluate the validity and responsiveness of the PADS-R. Despite the need for further research, at the time of carrying out this research, the PADS-R was arguably the best measure currently available for measuring physical activity in people with MS and as such was the measure of choice for subsequent phases of this research.

PHASE II: BARRIERS AND FACILITATORS TO PHYSICAL ACTIVITY ENGAGEMENT FOR PEOPLE WITH MULTIPLE SCLEROSIS

Phase I explored physical activity measurement in people with MS to identify a measure of physical activity that could be used in subsequent phases of this doctoral research. The PAD-R was identified as the most suitable measure for this purpose currently available. The key aim of Phase II of this research was to explore the barriers and facilitators to physical activity experienced by people with MS. Two studies were carried out during this phase. First, a cross-sectional questionnaire study aiming to quantitatively explore the associates of physical activity in people with MS using the PADS-R as the primary dependent variable measure; and second, a qualitative investigation of the barriers and facilitators to physical activity engagement to enable a deeper understanding of the decision to take part in physical activity (or not) from the perspective of people living with the condition.

Chapter Six reports on the cross-sectional questionnaire study, the fourth piece of original research conducted as a part of this doctorate. Chapter Seven reports on the qualitative investigation, the fifth project carried out. Chapter Eight discusses the key findings of each of these studies, comparing and contrasting findings from both and considering them in the context of recent research.

CHAPTER 6

STUDY FOUR

EXPLORING THE BARRIERS AND FACILITATORS TO ENGAGEMENT IN PHYSICAL ACTIVITY FOR PEOPLE WITH MULTIPLE SCLEROSIS[4]

6.1 AIMS

Study Four was the first study carried out as a part of Phase II of this doctoral research. It was developed to:

(1) Explore the role that cognitive-behavioural variables, such as health beliefs and illness behaviours, have in influencing engagement in physical activity as well as a range of other variables previous research had identified as important correlates of physical activity such as perceived barriers to activity, self-efficacy and subjective fatigue (see Chapter Two); and

(2) Explore the relationship that self-reported participation in physical activity has to overall well-being in people with MS.

6.2 METHODS

Ethical approval was obtained from the Northern X Health and Disability Ethics Committee in NZ (see Appendix S).

6.2.1 DESIGN

This study was a cross-sectional descriptive design, utilising a questionnaire incorporating both a set of standardised measures and a series of open-ended questions. Figure 6.1 presents a diagrammatic view of the relationships tested, along with the relevant standardised measures. A more detailed discussion of measures is

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[4] Study Four is related to the fourth publication directly linked to this doctoral research (203):
Kayes, N. M., McPherson, K. M., Schluter, P. J., Taylor, D., Leete, M., & Kolt, G. S. (2010). Exploring the Facilitators and Barriers to Engagement in Physical Activity for People with Multiple Sclerosis. *Disability and Rehabilitation, Early online*, 1-11.

included in Table 6.1 on page 155. The open-ended questions were included to give participants an opportunity to provide context to their answers, identify any barriers or facilitators they experience that were not explored in the standardised portion of the questionnaire, and to explore their current experiences of physical activity.

6.2.2 HYPOTHESES

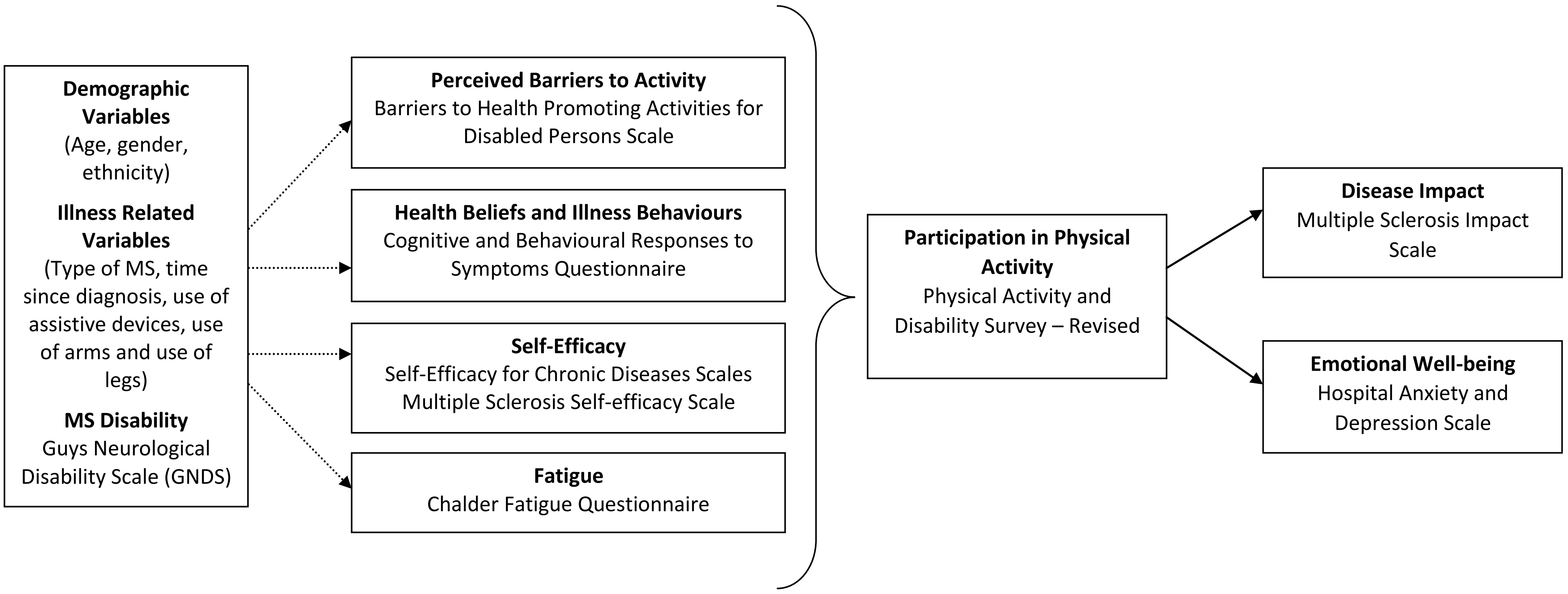
Based on the review of literature reported in Chapter Two, the hypotheses of this study were:

(1) Those who report a higher number of perceived barriers to activity, more cognitive distortions and maladaptive behaviours, lower self-efficacy, and higher subjective fatigue will participate in significantly lower levels of physical activity than their counterparts;

(2) The degree of variance in self-reported participation in physical activity accounted for by the above psychosocial variables will be significant even after controlling for important demographic and illness-related variables;

(3) Those who report lower levels of participation in physical activity will report a significantly greater perceived negative impact of MS, both physically and psychologically, and lower emotional well-being than their counterparts.

Figure 6.1: Standardised measures and the proposed relationships tested in the questionnaire analyses



6.2.3 PARTICIPANTS

All people listed on the Auckland region MS Society databases (n=450) and those identified as having MS by the MS Specialist nurse at one of the District Health Boards (DHB; n=900) in Auckland, NZ were invited to take part in the study. It was anticipated that approximately half of those participants listed on the MS Society databases would also be listed on the DHB database (approximately 225), reducing the sample frame to approximately n=1125. People with a definite diagnosis of MS by a neurologist and able to communicate with the researchers were eligible to take part.

6.2.4 MEASURES

The questionnaire included three parts: demographic and illness-related variables; standardised measures; and a series of open-ended questions.

6.2.4.1 Demographic and Illness-related variables

A range of demographic and illness-related variables were collected including age, gender, ethnicity, employment status, receipt of disability compensation, self-reported confirmation of definite diagnosis of MS, time since diagnosis, type of MS and remission status. For type of MS, due to the possibility that participants would not be familiar with the actual terminology used to refer to each type (e.g. primary progressive), a description of each type was developed based on the predominant characteristics of that type and participants were asked to select which pattern best described their course of MS.

6.2.4.2 Standardised measures

Details of all standardised measures included in the questionnaire are presented in Table 6.1.

Table 6.1: Details of standardised measures included in the questionnaire

Measure	**Description**	**Psychometric properties and rationale for choice of measure**
MS Disability		
Guys Neurological Disability Scale (GNDS) (204)	MS disability was assessed using the Guys Neurological Disability Scale (GNDS). This scale is designed to assess a range of disabilities encountered in MS, covering 12 areas of disability: memory and concentration; mood and emotion; vision; speech and communication; swallowing; use of arms and hands (lower limb function); mobility (upper limb function); bladder function; bowel function; sexual function; fatigue; and other disabilities. Each of the 12 disability areas are assessed using four to eight questions. In four of the sections (memory and concentration, mood and emotion, speech and communication, and mobility) the opinion of another person (e.g. a carer or relative) is also sought. Each disability area is scored between 0 (normal) and 5 (total loss of function). A total score is computed by summing across all disability areas, yielding a score range of 0 to 60 where higher scores depict greater disability.	GNDS was developed in response to an international call from neurologists for the development of a new scale of disability for use in people with MS. It was developed in consultation with neurologists and people with MS; resulting in a multidimensional scale without bias towards any one disability experienced in MS. It has been found to be acceptable to both people with MS and neurologists and is reliable, valid and responsive. Furthermore, it is one of the few measures of this type available that does not need to be administered by a neurologist and can be completed by postal questionnaire.(204)
Physical Activity		
Physical Activity Disability Survey-Revised (PADS-R)(160)	Details of the development and content of this questionnaire are discussed in Chapter Three of this doctoral research, along with the psychometric properties that have been tested to date. This questionnaire was developed for the purpose of carrying out this research.	

Measure	**Description**	**Psychometric properties and rationale for choice of measure**
Possible Correlates of Physical Activity		
The Cognitive and Behavioural Responses to Symptoms Questionnaire [CBSQ] (104,205)	The Cognitive and Behavioural Responses to Symptoms Questionnaire (CBSQ) was used to measure health beliefs and illness behaviours. The cognitive (health beliefs) component of the questionnaire is made up of six subscales including illness identity, symptom focusing, catastrophising, damaging beliefs, fear avoidance and embarrassment avoidance. The first subscale, illness identity, measures somatic attributions and respondents are asked to rate whether a range of symptoms are more related to their illness, to stress, or to a lack of fitness or inactivity. This subscale is scored by summing the number of symptoms attributed to their illness. The remaining five cognitive subscales are rated on a five point scale ranging from 'strongly disagree' to 'strongly agree' and measure how much respondents focus on their symptoms (symptom focusing [6 items]), their interpretations of their symptoms (catastrophising [4 items], damaging beliefs [7 items]), and their emotional response to their symptoms (fear avoidance [6 items], embarrassment avoidance [6 items]). The behavioural response (illness behaviours) component of the questionnaire is made up of two subscales including avoidance/resting behaviour (8 items) and all or nothing behaviour (5 items). On both subscales respondents are asked to rate how often they respond in a certain way which they rate on a five point scale ranging from 'never' to 'all of the time'. Higher scores represent greater number of potentially maladaptive cognitions and behavioural responses.	The CBSQ is the first measure specifically designed to measure a range of cognitive and behavioural responses to symptoms. While a number of scales have been developed to measure similar constructs such as the Tampa Scale for Kinesiophobia,(206,207) the Fear Avoidance Beliefs Questionnaire,(208) and the Pain catastrophizing Scale (209); all of these scales are specifically designed for the pain population. In contrast, the CBSQ is a more generic measure suitable for use with people with a range of conditions. Due to this scale being only newly developed at the time of carrying out this research, papers reporting on its development and measurement properties are not yet available. However, the scale has been used in the MS population previously.(104) Furthermore, internal consistencies of the subscales in this study were high, with Cronbach's alpha ranging from 0.74 (damaging beliefs) to 0.90 (symptom focusing and embarrassment avoidance).

Measure	Description	Psychometric properties and rationale for choice of measure
Possible Correlates of Physical Activity Cont'd		
Barriers to Health Promoting Activities for Disabled Persons Scale [BHADP] (90)	The Barriers to Health Promoting Activities for Disabled Persons Scale (BHADP) was used to measure perceived barriers to physical activity. This scale contains 18 items asking respondents how often the listed barriers keep them from engaging in health promoting behaviours. Items on the scale include intrapersonal, interpersonal and environmental barriers. Respondents rate each of the barriers listed on a scale of 1 (never) to 4 (routinely). With the permission of the original authors, the questionnaire instructions were altered slightly for this study to focus only on barriers to taking part in physical activity, rather than barriers to engaging in health promoting behaviours in general. So, the participants were asked to consider 'how much each of these problems keeps you from participating in *exercise or physical activity*'. Higher scores represent greater number of perceived barriers to physical activity.	The BHADP scale is the only scale designed to assess barriers to health promoting activities for disabled people. Content development was informed by existing literature, disabled people and experts working with disabled people. It has been used a number of times in people with MS previously.(12,13,71) It has been found to have good internal consistency in disabled adults (0.82) and discriminates well between a disabled and non-disabled sample (known groups validity).(90) While the change in wording to focus only on *exercise* and *physical activity* has not been tested formally, the internal consistency in this study was high with a Cronbach's alpha of 0.86.
Chalder Fatigue Questionnaire [CFQ] (210)	Subjective fatigue was measured using the Chalder Fatigue Questionnaire (CFQ). This scale is made up of 14 items: eight of which make up the physical fatigue subscale and the remaining six making up the mental fatigue subscale. Chalder et al. recommend reducing the scale to 11 items (physical [7 items] and mental [4 items] fatigue) and so the 11-item scale was used in this study. Respondents rate each item on a four-point likert scale ranging from 0 (much worse than usual) to 3 (better than usual) with low scores representing higher levels of subjective fatigue.	A number of fatigue measures are available for use in people with MS. However, the Chalder Fatigue Scale is one of the few who distinguish between mental and physical fatigue which was considered a key feature by representatives of the MS Society consulted during study development. It has been used previously in people with MS (103) and the internal consistency of the subscales were high for this study, with Cronbach's alpha of 0.85 (mental fatigue) and 0.88 (physical fatigue).

Measure	**Description**	**Psychometric properties and rationale for choice of measure**
Possible Correlates of Physical Activity Cont'd		
Self-Efficacy for Chronic Diseases Scales (211)	Specific self-efficacy was measured using a selection of the Self-Efficacy for Chronic Diseases Scales. The Self-Efficacy for Chronic Diseases Scales are a series of self-efficacy scales designed to measure self-efficacy specific to individual health behaviours which were developed for use in the Stanford Chronic Disease Self-Management Study.(211) A selection of the scales most relevant to this study were utilised including self-efficacy for exercise (3 items), managing your illness (5 items), household chores (3 items), leisure and recreation (2 items), and managing your symptoms (5 items). For each scale, respondents were asked to rate their confidence to do certain tasks on a scale of 1 (not at all confident) to 10 (totally confident). Higher scores depict higher self-efficacy.	While another self-efficacy scale has been used in previous research exploring exercise self-efficacy in people with MS (19,20) the scale's origin is not clear from these papers, except that it may be a derivation of a Physical Activity Self-Efficacy Scale developed in 1982.(212) However, a) this scale was developed in healthy undergraduate students and b) only considered *exercise* self-efficacy. The self-efficacy for chronic diseases scales have two advantages in that they were developed for use in people experiencing chronic illness and they have a series of subscales that can be select depending on the purpose of the study. This meant that scales could be selected which were representative of self-efficacy for physical activity as per the broader definition of physical activity adopted for this study (see page 29). While measurement properties have not been specifically explored in people with MS, the internal consistencies of the subscales were high in this study, with Cronbach's alpha ranging from 0.80 (exercise self-efficacy) to 0.93 (household chores self-efficacy).
Multiple Sclerosis Self-efficacy Scale [MSSS](213)	General self-efficacy was measured using the MSSS. The MSSS was specifically developed to measure self-efficacy in people with MS, or the belief in the ability to overcome challenges presented to them. It is made up of 14 items and respondents are asked to rate their agreement to the statement in each item on a six point scale ranging from 'strongly disagree' to 'strongly agree'. The higher the score, the better the self-efficacy.	This scale was developed specifically for people with MS and so is an appropriate choice of scale to measure general self-efficacy. This scale has been found to have good test-retest reliability, acceptable validity and good responsiveness in people with MS.(213) In addition, the internal consistency for this scale in the current study was high, with a Cronbach's alpha of 0.81.

Measure	Description	Psychometric properties and rationale for choice of measure
Disease Impact		
Multiple Sclerosis Impact Scale [MSIS-29] (214)	Disease impact was measured using the MSIS-29. The MSIS has 29 items, 20 of which address the physical impact of MS and nine assess the psychological impact. Participants are asked to rate how much MS has impacted on their ability to do certain tasks or how much they have been bothered by their MS on a five point scale ranging from 'not at all' to 'extremely'.	The MSIS was the first MS-specific measure developed incorporating items generated from patient interviews, expert opinion and a literature review.(214) Reliability, validity and responsiveness have all been tested in people with MS and found to be good.(214) The internal consistency of the subscales and were high for this study with Cronbach's alpha of 0.90 (psychological impact) and 0.95 (physical impact).
Emotional Well-being		
Hospital Anxiety and Depression Scale [HADS] (215)	Emotional well-being was measured using the Hospital Anxiety and Depression Scale (HADS). The HADS is a 14 item scale divided into two subscales: anxiety (7 items) and depression (7 items). Participants rate their responses on a four point scale. The response descriptor for each item is adjusted according to the item content.	The HADS is a depression and anxiety scale specifically developed for illness populations and as a result excludes items regarding symptoms of anxiety and depression which could be confused with symptoms inherent in the illness or injury to avoid over-inflated scores. This scale has been used previously in people with MS.(103) The internal consistency of the subscales for this study were high, with Cronbach's alpha of 0.78 (depression) and 0.85 (anxiety).

6.2.4.3 Open-ended questions

In addition to the above standardised measures, participants were asked a range of open-ended questions. Four of these questions asked them to identify anything that acts as a barrier or facilitator to physical activity from their perspective. These were: 'What would you say is the main thing that stops you from participating in physical activity or exercise?'; 'Please list any other barriers that you feel prevent you from participating in physical activity or exercise'; 'What would you say is the main thing that helps you to participate in physical activity or exercise?'; and 'Please list any other facilitators that help you to participate in physical activity or exercise'. The remaining two questions asked about the impact of physical activity while they were taking part in it, and then after they had finished. For example, 'In general, how does taking part in physical activity and exercise impact on you while you are actually doing it?' It was thought that responses to these questions would provide supplementary information regarding the experience of engaging in physical activity and exercise for people with MS. However, the responses to these final two questions were not subsequently analysed. This was because a) the questions were not directly relevant to the study questions; and b) it was recognised that if the experience of engaging in physical activity in itself acted as either a barrier or facilitator to engagement, then this should have already been represented in the responses to earlier open-ended questions.

6.2.5 PROCEDURES

All potential participants were invited to take part in the study via a three-staged recruitment process: (i) a letter informing potential participants of the study and its components (see Appendix T); (ii) an information pack including a cover letter (see Appendix U), an information sheet (see Appendix V), consent form (see Appendix W), questionnaire (see Appendix X), pen and a self-addressed stamped envelope; (iii) a reminder pack including a reminder letter (see Appendix Y) and replacement copies of the information sheet, consent form, questionnaire, a pen and a return-addressed stamped envelope. This method of recruitment follows advice in the literature that suggests that an introductory letter,(216) including a pen with a study logo,(217,218) and repeated mailings (219) are all low-cost methods of improving response rate.

Those who were interested in taking part completed the consent form and questionnaire and returned them to the research team in the envelope provided. If the participant preferred, or if they were unable to complete the questionnaire on their own, they could phone the study freephone number and complete the questionnaire via telephone interview. All those who agreed to participate were asked to indicate on their consent form if they would be happy to be contacted for a more in-depth interview to explore their identified barriers and facilitators in more detail (see Chapter Seven) or if they would be willing to take part in the accelerometer testing study (described in Chapter Four).

6.2.6 ANALYSES

6.2.6.1 Standardised measures

All statistical analyses were performed using SPSS version 14.0 (145) or Stata version 8.0.(146)

6.2.6.1.1 Summary statistics

Summary statistics were computed for all variables including mean, standard deviation and range. The assistive devices item (see questionnaire booklet in Appendix X) was initially scored by adding the number of ticked items. So, if a person indicated that they used all the assistive devices listed indoors and outdoors they would score 8 on this item. However, distributional checks of this item found it to be highly skewed, with a large proportion of participants reporting no use of assistive devices. In addition, in hindsight, it did not seem to make intuitive sense to simply add indoor and outdoor use together. As a result, this variable was dichotomised for the analysis as either reporting no use of an assistive device or use of an assistive device of some description. Furthermore, while it was originally intended that this variable would be considered alongside other demographic and illness-related variables as a potential covariate, previous work had indicated that use of assistive devices is not only related to impairment, but rather is influenced by a range of factors relating to the user, the device, their environment and related interventions.(220) This suggests that this variable may in fact be a modifiable one, and the underlying reasons for choosing to use or not use an assistive device may to some extent be related to the decision to take part in physical activity. As a result, it was treated as an independent variable in the analyses alongside the other standardised measures.

6.2.6.1.2 Hypotheses one and two

When testing hypotheses one and two, the aim was to test whether independent variables including perceived barriers to activity, health beliefs and illness behaviors, self-efficacy and subjective fatigue can significantly predict participation in physical activity; and if they can, whether the degree of variance accounted for by these variables are significant after controlling for important demographic and illness-related variables. Therefore, these hypotheses were tested using a multi-staged approach to regression analyses:

(1) Identification of covariates – Hypothesis two details the intention to explore the effect that the independent variables have on physical activity over and above important demographic and illness related variables. As such, this first stage of analysis aimed to identify any significant demographic or illness related variables which were then forced into all subsequent models.

(2) Identification of important predictors – In total there were five independent variable measures, a number of which contained subscales that the measure developers did not intend to be added together. For example, the CBSQ has eight subscales measuring health beliefs and illness behaviours which are distinct from one another. Therefore, adding them together to obtain a summary score would not make conceptual sense. As a result, in measures where a summary score is not calculated, the individual subscales are each considered as separate predictor variables, resulting in up to 17 possible predictor variables. The purpose of this second stage of analysis was to investigate predictor variables in thematic clusters to identify variables which were significant over and above those covariates identified in stage one of the analyses. This phase of analysis was carried out to reduce the large number of candidate variables, thereby reducing the risk of various statistical anomalies including multicollinearity, test multiplicity, and model stability.

(3) Multivariable analyses to explore the combined effect of important predictors – In this final stage of analysis, a multivariable model was determined by combining all variables found to be significant in stage two analyses.

All regression analyses were performed using the automated stepwise procedure on SPSS. This automated procedure was adopted due to the paucity of literature identifying barriers and facilitators to physical activity in people with MS, meaning there was little theoretical justification for entering predictor variables in any particular order. In the absence of a theoretically driven model, it seemed appropriate that the decision for entry of a given predictor into the model be a statistical one.

The stepwise method on SPSS utilises a forward stepwise approach, where a combination of *forward entry* and *backward removal* methods are employed. Using this method, the programme searches for the independent variable that best predicts the outcome variable (in this case physical activity) using a specified entry criteria based on the Wald statistic, which in this study was set at $P<0.05$. If this variable significantly improves the ability of the model to predict the outcome variable, it is retained in the model, after which the software searches for a second predictor, and so on. At the same time as searching for any further predictor variables, the software conducts a removal test of the least useful predictor using a specified removal criteria (in this case, $P>0.10$) and so the model is constantly being reassessed.(150)

For all regression analyses, standardised residuals were checked and Cook's distance statistic computed to identify any outliers or influential cases. Assumptions were checked using the following methods:

- Multicollinearity: Correlation matrices were checked for any correlations between independent variables >0.8, and variance inflation factor (VIF) values were checked for any values >10 to identify if any predictor variables had a strong linear relationship with other predictor variables. VIF values were also averaged to check for any average values substantially >1;
- Scatterplots of standardised residuals were checked for evidence of heteroscedasticity and non-linearity; and
- Histograms of the dependent variable (PADS-R) were checked for normality, and a Shapiro-Wilks test carried out to check for any deviation from normality prior to analysis. This process was repeated subsequent to analysis on the standardised residuals of the final regression model.

6.2.6.1.3 Hypotheses three

For hypothesis three, the aim was to test whether participation in physical activity significantly predicted disease impact and emotional well-being. It was initially thought that this hypothesis would be tested using simple linear regression; however visual inspection of histograms of the dependent variables for these analyses (disease impact and emotional well-being) revealed a uni-modal skewed distribution, indicating that they did not meet the assumption of normality. Shapiro-Wilks tests were carried out on all dependent variables to confirm that the observed deviation from normality was statistically significant, and this was confirmed for all variables ($P<0.001$). The Index of dispersion (observed variance/observed mean) was calculated and found to be >1 for all dependent variables, suggesting that a negative binomial regression may be useful to model these data. As the two MSIS variables (physical and psychological subscales) had a minimum score of 20, values were transformed by subtracting 20, so that the minimum value was 0; consistent with negative binomial assumption.

In negative binomial regression there is no statistic equivalent to R^2 which is commonly used to assess the goodness-of-fit in multiple linear regressions.(221) Therefore, a number of Pseudo R^2s have been developed.(222) They are named as such due to being on a similar scale to R^2, ranging from 0 to 1. Pseudo R^2s were reported for each of the analyses. However, given that caution is advised regarding interpretation of these,(221) they are not discussed as a % of variance accounted for as one might with R^2. Rather, it is recommended that a pseudo R^2 has more meaning when compared to another pseudo R^2 using the same data, predicting the same outcome. Therefore, the pseudo R^2 for each of the individual analyses are discussed in the context of the others presented, rather than interpreted in isolation. Higher pseudo R^2 indicate better prediction.

6.2.6.2 Open-ended questions

Answers to open-ended questions were reviewed and coded into categories using content analysis according to what was perceived to be the main message intended by the respondent. Due to the brevity of responses, further in-depth analysis did not seem justified.

6.3 RESULTS

Of the 1350 invitations sent out, 365 (27%) were returned incomplete due to misdiagnosis, inaccurate addresses, or the addressee being deceased. Accounting for this and the overlap of approximately 225 between the databases described earlier (see page 155), the actual sampling frame was approximately 760. In total, we received 278 completed questionnaires in the post, and 9 questionnaires were completed via telephone interview (287 questionnaires, 38% response rate). However, five of these reported they did not have a definite diagnosis of MS and so were excluded, reducing the sampling frame to 755 and leaving 282 completed questionnaires for analyses (37% response rate). This response rate is approximate, as the actual overlap between the MS Societies and DHB database was unknown.

6.3.1 PARTICIPANT CHARACTERISTICS

Table 6.2 provides a summary of participant characteristics for this study. As was the case with Phase I studies, the sample represented what one would expect to see in an MS sample (see page 90), with the majority of participants being female and of European descent.(1,152-154) The sample was diverse in terms of illness-related variables, with all types of MS represented and a wide range of time since diagnosis. About half the participants reported using an assistive device of some kind (54%). In addition, the majority of participants reported having full use of their arms and legs. However, a substantial proportion of people reported having only partial use of their arms or legs (22% and 38% respectively). One person reported having no use of their arms, while 21 (7%) reported having no use of their legs.

Table 6.2: Participant characteristics of Study Four

Gender	Female	222 (79%)
	Male	60 (21%)
Age	52 years (mean)	23 to 83 years (range)
Ethnicity	European	263 (93%)
	Canadian	3 (1%)
	Pacifika	2 (1%)
	NZ Maori	1 (0%)
	Not specified	13 (5%)
Type of MS	Benign	54 (19%)
	Relapsing-remitting	90 (32%)
	Secondary progressive	45 (16%)
	Primary progressive	89 (32%)
	Not specified	4 (1%)
Time since diagnosis	11.2 years (mean)	0.1 to 50 years (range)
Use of an assistive device	Yes	153 (54%)
	No	129 (46%)
Use of arms	Full use	218 (77%)
	Partial use	61 (22%)
	No use	1 (0%)
	Not specified	2 (1%)
Use of legs	Full use	155 (55%)
	Partial use	106 (38%)
	No use	21 (7%)

6.3.1.1 Guy's Neurological Disability Scale (GNDS)

Table 6.3 presents the summary statistics for the GNDS for both total score and each of the individual disability areas assessed by the GNDS. Complete data for the GNDS were available for n=200 participants. The mean (SD) of the total score was 15.9 (9.4), with a range of 0 to 42. This score is lower than the postal questionnaire mean (SD) reported by Rossier and Wade (2002) in their study evaluating the psychometric properties of the GNDS, which reported a mean (SD) of 20.3 (5.7),(223) suggesting this sample reported marginally less neurological disability than the Rossier and Wade sample. Fatigue was reported to be the most disabling symptom overall, yielding the highest mean (SD) at 2.3 (1.5). To put this into context, 70% of the sample scored 2 or more on the fatigue subscale, suggesting that fatigue is present most days for 70% of respondents. A large proportion (27%) indicated that fatigue affects their ability to perform some of their usual daily activities (a score of 3), 12% indicated it prevents them from doing all their usual daily activities (a score of 4) and a further 7% reported that it prevents them from doing all physical activities.

The frequency of reported fatigue was followed closely by difficulties with bladder function, which had a mean (SD) of 2.3 (1.8). For bladder function: 34% reported a frequent need to rush to the toilet, urinary frequency or difficulty starting to pass urine (a score of 2); 11% had *occasional* urinary incontinence (a score of 3); 6% had *frequent* (a score of 4); and 18% had *daily* urinary incontinence (a score of 5). Disability relating to mobility, sexual function and upper limb function were also highly prevalent relative to the other disability areas assessed, with a mean (SD) of 2.0 (1.7), 1.9 (2.1) and 1.6 (1.5) respectively. To help put these scores into context, a score of 2 on mobility is equivalent to using unilateral support (such as a single crutch or cane) to walk outdoors; for sexual function it equates to reduced sexual drive; and for upper limb function it indicates a problem in one or both arms which affects, but does not prevent, functioning on tasks such as doing up zips or buttons, washing and brushing hair, using a knife and fork and handling small coins.

Table 6.3: Summary statistics for GNDS subscales and total score

	N	Mean	Standard Deviation	Actual score range	Possible score range
Fatigue	267	2.3	1.5	0 to 5	0 to 5
Bladder function	269	2.3	1.8	0 to 5	0 to 5
Mobility	263	2.0	1.7	0 to 5	0 to 5
Sexual function	245	1.9	2.1	0 to 5	0 to 5
Use of arms and hands	261	1.6	1.5	0 to 5	0 to 5
Bowel function	267	1.3	1.6	0 to 5	0 to 5
Memory and concentration	267	1.2	1.2	0 to 4	0 to 5
Mood and emotion	261	0.8	1.0	0 to 4	0 to 5
Vision	271	0.8	0.7	0 to 5	0 to 5
Speech and communication	271	0.5	1.0	0 to 5	0 to 5
Swallowing	273	0.5	1.0	0 to 4	0 to 5
Other	275	1.1	1.5	0 to 5	0 to 5
Total score	200	15.9	9.4	0 to 42	0 to 60

6.3.2 SUMMARY STATISTICS

Table 6.4 displays the mean, standard deviation and range obtained on all the outcome measures.

Table 6.4: Summary statistics for all standardised measures

	N	Mean	Standard Deviation	Actual score range	Possible score range
Physical activity (PADS-R)	275	0.0	1.3	-3.7 to 3.5	No limit
Perceived barriers to physical activity (BHADP)	232	28.9	7.6	18 to 72	18 to 72
Health beliefs and illness behaviours (CBSQ)					
Illness Identity	272	8.4	5.1	0 to 26	0 to 27
Fear avoidance beliefs	261	9.4	4.6	0 to 24	0 to 24
Damaging beliefs	255	14.2	4.7	3 to 28	0 to 28
Catastrophising	258	8.2	3.6	0 to 16	0 to 16
Symptom focusing	263	11.1	5.3	0 to 24	0 to 24
Embarrassment avoidance	267	8.7	5.5	0 to 24	0 to 24
Avoidance behaviour	261	8.3	5.1	0 to 28	0 to 32
All or nothing behaviour	261	6.7	4.2	0 to 20	0 to 20
Self-efficacy (SE)					
Exercise SE	273	6.4	2.7	1 to 10	1 to 10
Illness management SE	273	7.3	2.0	1 to 10	1 to 10
Household chores SE	272	6.4	3.0	1 to 10	1 to 10
Leisure and recreation SE	272	6.7	2.6	1 to 10	1 to 10
Symptom management SE	274	6.1	2.3	1 to 10	1 to 10
MSSS	253	54.0	12.8	14 to 82	14 to 84
Fatigue (CFQ)					
Total fatigue	266	16.0	5.4	3 to 33	0 to 33
Physical fatigue	268	10.6	3.8	2 to 21	0 to 21
Mental fatigue	270	5.5	2.3	0 to 12	0 to 12
Disease Impact (MSIS)					
Physical	254	46.8	19.2	20 to 100	20 to 100
Psychological	271	40.0	16.4	20 to 100	20 to 100
Emotional well-being (HADS)					
Total HADS	269	11.3	6.6	0 to 41	0 to 42
Anxiety	271	6.3	4.1	0 to 21	0 to 21
Depression	272	4.9	3.5	0 to 20	0 to 21

6.3.2.1 Physical Activity

The mean (SD) of the total score on the PADS-R (n=275) was 0.0 (1.3), with a range of -3.7 to 3.5. To put this into context, Table 6.5 gives an overview of the raw data for three participants: the participants whose PADS-R scores yielded the lowest and highest scores and a participant whose score was equivalent to the overall mean score.

Table 6.5: Examples of raw data on the PADS-R for participants over the full range of PADS-R scores

	PADS-R Score	Exercise	LTPA	General Activity	Therapy	Employment	Wheelchair Use
1	-0.4 (low score)	No exercise	No LTPA	>13 waking hours inside (M-F) 6-8 waking hours inside (weekend) 14 hours/day sleeping 10 hours/day sitting/lying down No indoor household activity No outdoor household activity No stairs Full assistance with ADLs	3 days/week @ 30 minutes/day	Not employed	Power wheelchair
2	0.0 (equal to the mean score)	Strengthening exercises 4 days/week @ 8 minutes/session Varying intensity levels	No LTPA	9-10 waking hours inside (M-F) <6 waking hours inside (weekend) 8 hours/day sleeping 3 hours/day sitting/lying down Indoor household activity includes cleaning, washing, preparing meals and ironing No outdoor household activity No stairs No assistance required for ADLs	No therapy	Not employed	No wheelchair use
3	3.5 (high score)	Karate - 2 days/week @ 2 hours/day (vigorous intensity) Horse riding - 7 days/week @ 90 minutes/day (moderate intensity)	No LTPA	<6 waking hours inside (M-F) 9-10 waking hours inside (weekend) 7 hours/day sleeping 2 hours/day sitting/lying down Indoor household activity includes food preparation and general cleaning Outdoor household activity includes walking the dog Climbs one flight of stairs, 10 times a day at home No assistance required for ADLs	No therapy	Employed Moves around most of the day at work Climbs two flights of stairs, 6 times a day at work No transportation activity	No wheelchair use

Abbreviations: LTPA – leisure-time physical activity; M-F – Monday to Friday; ADLs – activities of daily living

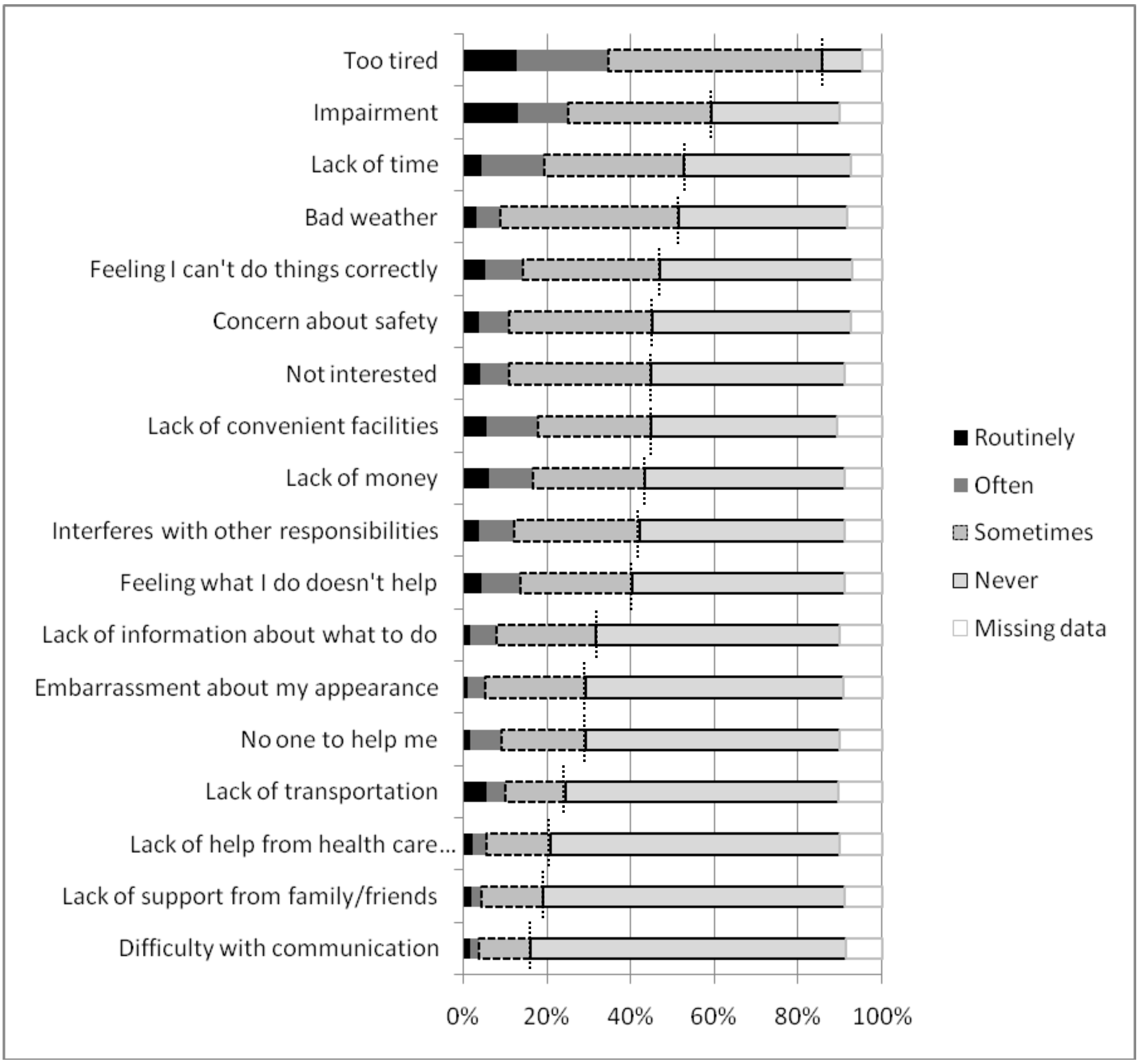
6.3.2.2 Perceived Barriers to Activity

The mean (SD) of the total score on the BHADP (n=232) was 28.9 (7.6), with a range of 18 to 72. This is only slightly lower than that reported by Stuifbergen in 1995, who reported a mean (SD) of 34.3 (7.5) with a range of 18 to 54 on the same scale.(12) Figure 6.2 displays the percentage response for each response category on each individual item of the BHADP. The items are listed in descending order with the most frequently reported perceived barrier (‘too tired’) at the top of the chart and the least frequently reported (‘difficulty with communication’) at the bottom. To help interpret the results presented in the chart, a dotted line represents the transition between an item being reported as a barrier versus not. So, all the categories to the left of the dotted line indicate an item was endorsed as a barrier experienced sometimes, often or routinely. The categories to the right of the dotted line indicate the item is either not endorsed as a barrier at all, or that no response was recorded for this item.

The most frequently reported barrier was being ‘too tired’ with 86% of the sample reporting this to be a barrier either sometimes, often or routinely. ‘Impairment’, ‘lack of time’, and ‘bad weather’ were also frequently reported barriers, with the majority of the sample (59%, 53% and 51% respectively) reporting them to be barriers to taking part in physical activity at least some of the time. Other barriers reported by a large proportion of the sample included ‘feeling I can’t do things correctly’ (47%); ‘concern about safety’ (45%); ‘feeling what I do doesn’t help’ (40%); ‘lack of information about what to do’ (32%); ‘embarrassment about my appearance’ (29%); and ‘lack of help from health care professionals’ (21%).

Figure 6.2: Percentage response for each response category on individual items of the BHADP

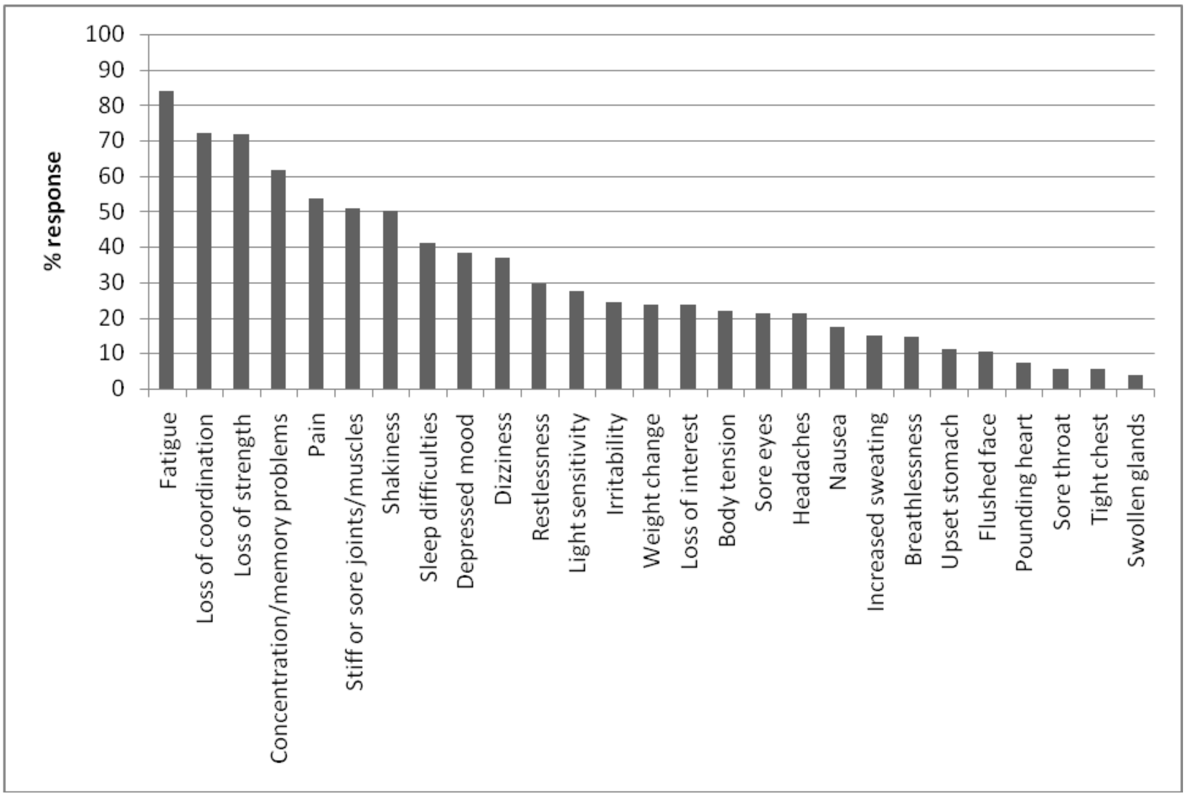
NB: The most commonly reported barriers are at the top of the figure



6.3.2.3 Health Beliefs and Illness Behaviours

Illness Identity: The mean (SD) number of symptoms attributed to MS was 8.4 (5.1), with participants attributing from 0 to 26 symptoms to their MS. Those symptoms most commonly attributed to MS included fatigue, loss of coordination, loss of strength and concentration/memory problems as shown in Figure 6.3. These symptoms are all consistent with common characteristics of MS as discussed in Chapter Two. A particularly high proportion of participants reported fatigue (84%), which is consistent with past research reporting fatigue to be one of the most frequently reported symptoms in MS.(224) There were a range of symptoms attributed to MS which in some cases may be secondary symptoms, including sore joints/muscles (51%), sleep difficulties (41%) and weight change (24%).

Figure 6.3: Percentage response of symptoms identified as relating to MS in the CBSQ



Health beliefs: The mean (SD) on the health beliefs subscales ranged from 8.2 (3.6) on the catastrophising subscale (out of a total possible score of 16) to 14.2 (4.7) on the damaging beliefs subscale (out of a total possible score of 28). The mean (SD) on each subscale cannot be directly compared due to differences in the total possible score on each subscale.

Illness behaviours: The mean (SD) on the illness behaviours subscales was 8.3 (5.1) on the avoidance behaviour subscale (out of a total possible score of 28) and 6.7 (4.2) on the all or nothing behaviour subscale (out of a total possible score of 20).

Unfortunately, the one existing publication which reports on the CBSQ (104) in people with MS did not report any summary statistics, and so no comparison can be made with regard to the similarity or difference in the prevalence of beliefs or behaviours between the two populations.

6.3.2.4 Self-efficacy

Scores on the chronic disease self-efficacy scales are very similar to scores reported in the Stanford Chronic Disease Self-Management Study,(211) with mean scores all falling slightly above the midpoint of the 10-point scale, ranging from 6.1 (2.3) on the symptom management SE scale to 7.3 (2.0) on the illness management SE scale. The mean (SD) on the MSSS was 54.0, (12.8) which is very similar to the scores reported by Rigby et al. (213) in their validation study. In their study, Rigby et al. reported a mean (SD) of 49.7 (11.4).

6.3.2.5 Fatigue

The mean (SD) of the total score on the CFQ was 16.0 (5.4) with the physical and mental fatigue scales yielding a mean (SD) of 10.6 (3.8) and 5.5 (2.3) respectively. It is difficult to put these fatigue scores into context as a number of approaches to scoring the CFQ have been adopted in the literature, making direct comparison inappropriate. In addition, the raw summary statistics have rarely been reported in previous studies using this scale in people with MS.

6.3.2.6 Disease Impact

The means (SD) on the MSIS for this sample were 46.8 (19.2) on the physical subscale and 40.0 (16.4) on the psychological subscale. This suggests that this sample report their MS to have a lower impact overall compared to those participants involved in the responsiveness study conducted by Hobart et al.(214) In their study, a mean (SD) of 64.4 (23.0) for the physical subscale and 48.4 (26.7) for the psychological subscale was reported. This could be due to the fact that a large proportion of the sample in the current study reported themselves to have a benign course of illness (n=54, 19%), compared with no participants reporting a benign course of illness in the Hobart et al. study.

6.3.2.7 Emotional Well-being

The means (SD) on the HADS were 11.25 (6.60) for the overall HADS score, 6.29 (4.13) for the anxiety subscale and 4.92 (3.52) for the depression subscale. These scores are very similar to the scores obtained previously on a NZ based MS sample.(136) A cut-off score of 13 or higher on each of the subscales has been proposed as predictive of clinical disorder 75% of the time. (225) While the mean scores on each subscale in the current sample does not indicate clinical disorder, there were participants who fell into the clinical category on both; with 2% of participants above the clinical depression cut-off and 7% above the clinical anxiety cut-off.

6.3.3 IDENTIFYING COVARIATES

Table 6.6 presents the final model resulting from the stepwise regression analyses using demographic and illness-related variables as the independent variables. The final R^2 was 0.44 (see cumulative R^2 in Table 6.6) with a significant F ratio for the final model ($F_{5,265}$=41.56, *P*<0.001), which included leg use (no use and partial), time since diagnosis, and type of MS (PPMS and SPMS). No use and partial use of legs were the strongest predictors of participation in physical activity, each accounting for 17% of variance in physical activity (see Partial R^2 in Table 6.6). Partial R^2 indicates the individual contribution of each new variable entered into the model.

Table 6.6: Final model for stepwise regression results – Identifying possible covariates

Covariates	**Order of entry into equation**	**Cumulative R^2**	**Partial R^2**	**Regression coefficient (standard error)**	**F Change**	***P***
Leg Use (No use)	1	0.17	0.17	-1.88 (0.26)	56.52	<0.001
Leg Use (Partial)	2	0.35	0.17	-0.66 (0.15)	71.24	<0.001
Time since diagnosis	3	0.39	0.04	-0.03 (0.01)	17.80	<0.001
MS Type (CPMS)	4	0.41	0.03	-0.73 (0.16)	11.71	<0.001
MS Type (SPMS)	5	0.44	0.03	-0.69 (0.20)	12.17	<0.001

Dependent variable: Total PADS-R

6.3.4 TESTING HYPOTHESES (1 AND 2)

The hypotheses being tested in the following section include:

- Those who report a higher number of perceived barriers to activity, more cognitive distortions and maladaptive behaviours, lower self-efficacy, and higher subjective fatigue will participate in significantly lower levels of physical activity than their counterparts; and
- The degree of variance in self-reported participation in physical activity accounted for by the above psychosocial variables will be significant even after controlling for important demographic and illness related variables.

6.3.4.1 Use of Assistive Devices

Use of assistive devices was significantly correlated with physical activity as measured by the PADS-R (r=-0.48, *P*<0.001). Table 6.7 presents the final model resulting from the stepwise regression analyses using a blockwise approach, with identified covariates entered into the first block using forced entry, and use of assistive devices entered into the second block in order to determine and combined and separate effects of each. The final R^2 was 0.45, with a significant F ratio for the final model ($F_{6,266}$=35.48, *P*<0.001). The illness-related variables entered as covariates were clearly the strongest predictors, accounting for combined 44% of variance in physical activity. Use of assistive devices also accounted for a significant proportion of variance over and above that of the covariates, however, only accounted for an additional 1% of variance in physical activity.

Table 6.7: Final model for stepwise regression results – Use of assistive devices (n=273)

Independent variables	**Order of entry into equation**	**Cumulative R^2**	**Partial R^2**	**Regression coefficient (standard error)**	**F Change**	***P***
Time since diagnosis MS Type (PPMS) MS Type (SPMS) Leg Use (Partial) Leg Use (No use)	1	0.44	0.44	-0.03 (0.01) -0.66 (0.15) -0.65 (0.20) -0.48 (0.17) -1.69 (0.27)	41.33	<0.001
Use of Assistive Devices	2	0.45	0.01	-0.33 (0.17)	3.98	0.047

Dependent variable: Total PADS-R

6.3.4.2 Perceived Barriers to Activity

Number of perceived barriers to activity was significantly correlated with physical activity as measured by the PADS-R (r=-0.42, *P*<0.001). Table 6.8 presents the final model resulting from the stepwise regression analyses using a blockwise approach, with identified covariates entered into the first block using forced entry, and perceived barriers to physical activity entered into the second block. The final R^2 was 0.46, with a significant F ratio for the final model ($F_{6,221}$=31.42, *P*<0.001). Once again, the illness-related variables entered as covariates were clearly the strongest predictors, accounting for 43% of variance in physical activity. Perceived barriers to activity accounted for a significant proportion of variance over and above that of the covariates, accounting for an additional 3% of variance in physical activity.

Table 6.8: Final model for stepwise regression results – Perceived barriers to activity (n=228)

Independent variables	Order of entry into equation	Cumulative R^2	Partial R^2	Regression coefficient (standard error)	F Change	*P*
Time since diagnosis MS Type (PPMS) MS Type (SPMS) Leg Use (Partial) Leg Use (No use)	1	0.43	0.43	-0.03 (0.01) -0.61 (0.16) -0.56 (0.21) -0.53 (0.16) -1.59 (0.29)	33.89	<0.001
Total BHADP Score	2	0.46	0.03	-0.03 (0.01)	11.25	<0.001

Dependent variable: Total PADS-R

6.3.4.3 Health Beliefs and Illness Behaviours

Table 6.9 displays the Pearson's correlation coefficients for the relationship between physical activity and health belief and illness behaviour variables. Fear avoidance beliefs was most highly correlated with physical activity at *r*=0.26. However, avoidance behaviour was also significantly correlated at *r*=0.24 (*P*<0.001). Damaging beliefs, catastrophising and embarrassment avoidance were also significantly correlated with physical activity (*P*<0.05). However, despite reaching significance, the correlation coefficients in Table 6.9 are low, with all coefficients being <0.3.

Table 6.9: Correlations between PADS-R and Health Beliefs and Illness Behaviours (n=224)

	PADS-R	
Illness Identity	-0.09	
Fear avoidance beliefs	-0.26	***
Damaging beliefs	-0.18	**
Catastrophising	-0.20	**
Symptom focusing	-0.08	
Embarrassment avoidance	-0.16	**
Avoidance behaviour	-0.24	***
All of nothing behaviour	0.07	

P*<0.01*P*<0.001

Table 6.10 presents the final model resulting from the stepwise regression analyses using a blockwise approach, with identified covariates entered into the first block using forced entry, and health belief and illness behaviour variables entered into the second block using a stepwise approach. The final R^2 was 0.46, with a significant F ratio for the final model ($F_{6,217}$=30.83, *P*<0.001). The only illness belief variable retained in the model was fear-avoidance beliefs, accounting for an additional 3% of variance in physical activity.

Table 6.10: Final model for stepwise regression results – Health Beliefs and Illness Behaviours

Independent variables	Order of entry into equation	Cumulative R^2	Partial R^2	Regression coefficient (standard error)	F Change	*P*
Time since diagnosis MS Type (PPMS) MS Type (SPMS) Leg Use (Partial) Leg Use (No use)	1	0.43	0.43	-0.03 (0.01) -0.65 (0.16) -0.59 (0.21) -0.54 (0.16) -1.81 (0.28)	32.62	<0.001
Fear avoidance beliefs	2	0.46	0.03	-0.05 (0.01)	12.95	<0.001

Dependent variable: Total PADS-R

6.3.4.4 Self-Efficacy

Table 6.11 displays the Pearson's correlation coefficients for the relationship between physical activity and self-efficacy variables. All self-efficacy variables were significantly correlated with physical activity (*P*<0.001), with self efficacy for exercise and household chores the most highly correlated.

Table 6.11: Correlations between PADS-R and Self Efficacy (SE – n=245)

	PADS-R
Exercise SE	0.54 ***
Illness management SE	0.36 ***
Household chores SE	0.61 ***
Leisure and recreation SE	0.45 ***
Symptom management SE	0.33 ***
MSSS	0.43 ***

****P*<0.001

Table 6.12 presents the final model resulting from the stepwise regression analyses using a blockwise approach, with identified covariates entered into the first block using forced entry, and self-efficacy variables entered into the second block using a stepwise approach. The final R^2 was 0.53, with a significant F ratio for the final model

($F_{7,237}$=37.60, $P<0.001$). Exercise and household chores self-efficacy were both retained in the model, accounting for an additional 10% of variance in physical activity between them.

Table 6.12: Final model for stepwise regression results – Self-Efficacy

Independent variables	Order of entry into equation	Cumulative R^2	Partial R^2	Regression coefficient (standard error)	F Change	*P*
Time since diagnosis MS Type (PPMS) MS Type (SPMS) Leg Use (Partial) Leg Use (No use)	1	0.43	0.43	-0.03 (0.01) -0.59 (0.15) -0.33 (0.20) -0.25 (0.15) -1.05 (0.28)	35.33	<0.001
Exercise SE	2	0.51	0.08	0.12 (0.03)	39.46	<0.001
Household chores SE	3	0.53	0.02	0.09 (0.03)	9.71	0.002

Dependent variable: Total PADS-R

6.3.4.5 Fatigue

Both physical (r=-0.24, $P<0.001$) and mental (r=-0.11, $P<0.01$) fatigue were significantly correlated with physical activity as measured by the PADS-R. Table 6.13 presents the final model resulting from the stepwise regression analyses using a blockwise approach, with identified covariates entered into the first block using forced entry, and fatigue variables entered into the second block using a stepwise approach. The final R^2 was 0.49, with a significant F ratio for the final model ($F_{7,251}$=33.86, $P<0.001$). Both physical and mental fatigues were retained in the model, accounting for an additional 4% of variance in physical activity between them.

Table 6.13: Final model for stepwise regression results – Fatigue (n=259)

Independent variables	Order of entry into equation	Cumulative R^2	Partial R^2	Regression coefficient (standard error)	F Change	*P*
Time since diagnosis MS Type (PPMS) MS Type (SPMS) Leg Use (Partial) Leg Use (No use)	1	0.45	0.45	-0.04 (0.01) -0.63 (0.15) -0.54 (0.20) -0.51 (0.15) -1.62 (0.26)	41.82	<0.001
Physical fatigue	2	0.46	0.01	-0.07 (0.02)	4.31	0.039
Mental fatigue	3	0.49	0.02	-0.10 (0.03)	11.69	<0.001

Dependent variable: Total PADS-R

6.3.4.6 Overall model – Possible Correlates of Physical Activity

Table 6.14 presents the final model resulting from the stepwise regression analyses exploring the combined effect of all important predictors identified in the previous analyses: use of assistive devices, perceived barriers to physical activity, fear avoidance beliefs, exercise and household chores self-efficacy, and physical and mental fatigue. These analyses used the same blockwise approach as previous analyses, with identified covariates entered into the first block using forced entry, and important predictor variables entered into the second block using a stepwise approach. The final R^2 was 0.53, with a significant F ratio for the final model ($F_{9,206}$=27.18, *P*<0.001).

As was the case in previous analyses, the illness-related variables entered as covariates were the strongest predictors, accounting for 42% of variance in physical activity. The final model retained a number of important predictors including exercise and household chores self-efficacy, mental fatigue and perceived barriers to physical activity. These variables accounted for an additional 12% of variance (combined effect), over and above that accounted for by the illness-related variables.

Table 6.14: Final model for stepwise regression results – Combined effect of important predictors

Independent variables	**Order of entry into equation**	**Cumulative R^2**	**Partial R^2**	**Regression coefficient (standard error)**	**F Change**	***P***
Time since diagnosis MS Type (PPMS) MS Type (SPMS) Leg Use (Partial) Leg Use (No use)	1	0.42	0.42	-0.02 (0.01) -0.55 (0.16) -0.40 (0.20) -0.18 (0.16) -1.03 (0.30)	30.17	<0.001
Exercise SE	2	0.50	0.09	0.11 (0.03)	36.35	<0.001
Household chores SE	3	0.52	0.01	0.08 (0.03)	5.99	0.015
Mental Fatigue	4	0.53	0.02	0.08 (0.03)	6.55	0.011
Total BHADP Score	5	0.54	0.01	-0.02 (0.01)	4.46	0.036

Dependent variable: Total PADS-R

6.3.4.7 Regression diagnostics and assumptions

For all regression analyses conducted to test hypotheses one and two, no influential cases were identified upon inspection of the Cook's distance statistic. All regression assumptions were met. No important multicollinearity was identified. Histograms of the dependent variable and standardised residuals appeared normal and this was confirmed with Shapiro-Wilks tests yielding non-significant values, indicating the data were not significantly different from normal. Visual inspection of scatterplots revealed no distinct patterns or funneling that would indicate important heteroscedasticity or non-linearity.

6.3.4.8 Revisiting hypotheses one and two

Hypotheses one and two were as follows:

- Those who report a higher number of perceived barriers to activity, more cognitive distortions and maladaptive behaviours, lower self-efficacy and higher subjective fatigue will participate in significantly lower levels of physical activity than their counterparts; and
- The degree of variance in self-reported participation in physical activity accounted for by the above psychosocial variables will be significant even after controlling for important demographic and illness related variables.

These hypotheses were supported only in part. Higher number of perceived barriers, lower self-efficacy and higher mental fatigue all accounted for a significant proportion of variance in physical activity behaviour, over and above that accounted for by important demographic and illness related variables. However, it should be noted that the illness-related variables identified as important covariates accounted for the largest amount of variance, accounting for 42% of variance, with psychosocial variables accounting for a smaller 12% of variance in the final model. Furthermore, contrary to hypotheses, greater cognitive distortions and maladaptive behaviours did not contribute to a significant amount of variance. These findings are discussed in detail in Chapter Eight (see page 228).

6.3.5 SECONDARY ANALYSES

The findings reported above did not support the study hypotheses, with fear avoidance beliefs being the only cognitive-behavioral variable to significantly predict participation in physical activity in the first series of analyses, and none remaining significant in the multivariable regression analyses. To aid interpretation of this finding, further analysis was carried out. First, correlation coefficients between the individual CBSQ subscales and between those subscales and physical activity engagement were examined. Five of the CBSQ subscales were found to be significantly correlated with participation in physical activity including fear avoidance beliefs (r=-0.26), damaging beliefs (r=-0.18), catastrophising (r=-0.20), embarrassment avoidance (r=-0.16) and avoidance behavior (r=-0.24). The fear-avoidance beliefs subscale was significantly correlated with each of these subscales, with correlations ranging from 0.32 (embarrassment avoidance) to 0.52 (damaging beliefs). Finally, correlations between all predictor variables entered into the multivariable regression analyses were examined and fear-avoidance beliefs found to be significantly correlated with exercise self-efficacy (r=-0.48).

6.3.6 TESTING HYPOTHESIS (3)

The hypothesis being tested in the following section is:

- Those who report lower levels of participation in physical activity will report a significantly greater perceived negative impact of MS, both physically and psychologically, and lower emotional well-being than their counterparts.

6.3.6.1 Disease impact and Emotional well-being

Table 6.15 displays the Pearson's correlation coefficient for the relationship between physical activity and the disease impact (as measured by the MSIS) and emotional well-being (as measured by the HADS).

Table 6.15: Correlations between PADS-R and disease impact and emotional well-being

		N	PADS-R	
Disease impact (MSIS)	Physical impact	250	-0.60	***
	Psychological Impact	265	-0.25	***
Emotional well-being (HADS)	Anxiety	266	-0.08	
	Depression	267	-0.41	***

****P*<0.001

Table 6.16 presents the model resulting from negative binomial regression analyses exploring the relationship between physical activity (predictor variable) and self-reported disease impact and emotional well-being. Participation in physical activity accounted for a significant proportion of variance in the physical impact of MS, as measured by the MSIS (z-score=-9.20, *P*<0.001), and a smaller (lower pseudo R2) but significant proportion of variance in the psychological impact of MS (z-score=-3.25, *P*=0.001). Participation in physical activity accounted for only a minor, non-significant proportion of variance on the anxiety subscale of the HADS (z-score=-1.12, *P*=0.26). Conversely, physical activity accounted for a significant proportion of variance on the depression subscale (z-score=-7.09, *P*<0.001) with a pseudo R2 comparable to that obtained in the model where the MSIS physical subscale was the predictor variable. The association between physical activity and both disease impact and emotional well-being was negative, indicating that as physical activity behavior increased, the perceived impact of MS and self-reported levels of anxiety and depression decreased.

Table 6.16: Regression analyses exploring participation in physical activity as a predictor for self-reported disease impact and emotional well-being

	Dependent variable			
	MSIS (physical)	**MSIS (psychological)**	**HADS (anxiety)**	**HADS (depression)**
N	250	265	266	267
Psuedo R^2	0.03	0.01	0.00	0.03
z-score	-9.20	-3.25	-1.12	-7.09
Regression coefficient (standard error)	-0.31 (0.03)	-0.14 (0.04)	-0.04 (0.03)	-0.22 (0.03)
P	<0.001	0.001	0.26	<0.001

6.3.6.2 Revisiting hypothesis three

Hypothesis three was as follows:

- Those who report lower levels of participation in physical activity will report a significantly greater perceived negative impact of MS, both physically and psychologically, and lower emotional well-being than their counterparts.

This hypothesis was supported, with lower levels of participation in physical activity found to be associated with greater disease impact (on both the physical and psychological subscales of the MSIS) and lower emotional well-being (higher levels of self-reported depression).

6.3.7 OPEN-ENDED QUESTIONS

The semi-structured questionnaire indicated a range of barriers and facilitators common to a number of participants. Common key barriers included: fatigue, balancing commitments, safety concerns, self-efficacy, concerns about others, symptomatic response, impairment, not knowing what to do, personal resources, weather, cyclical nature of MS and disinterest. Common key facilitators included: enjoyment, availability of others, social aspect, being with other people with MS, a sense of duty, attitude, use of an assistive device and belief in the benefits of physical activity. The key barriers, a descriptor summarising each, and related participant comments (to provide specific examples) are presented in Table 6.17, with the key facilitators reported in Table 6.18.

Table 6.17: Overview of responses to open-ended questions regarding perceived barriers to physical activity

Category	Description	Quotes extracted from participant responses when asked to nominate any barriers that prevent them from taking part in physical activity
Fatigue	Being too tired or fatigued to take part in physical activity	*Exhaustion - sometimes just don't have the energy* *Fatigue - just feel so tired, don't feel like doing anything* *Fatigue - I just have no energy, mentally and physically, to get going* *Tiredness - whether it be in the morning or in the afternoon I don’t have the energy to do anything physical* *Fatigue - hard to exercise when you already feel tired* *My 'batteries' go flat very quickly then I have to stop and rest to let the body recharge*
Balancing commitments	Lack of time and/or the need to balance physical activity with other commitments. This was most often linked with the need to balance engagement in physical activity with the experience of fatigue and to prioritise other commitments over physical activity.	*I am often too tired at end of working day but if I exercise before work I am fatigued at work and find it difficult to concentrate and/or complete work* *Time and energy - when working more, less time/energy to dedicate to exercise.* *Lack of time and energy. All my time and energy go towards being a 'mother' to my two preschoolers* *Fatigue - as activities for my children (11 and 9) and my husband come first* *I am working full time now and I feel fatigue takes its toll working a 40 hour week. Nothing left over for anything else.* *Time clashes - work commitments versus exercise class times* *Time - full time mum and my partner’s job has irregular long hours* *Time - I am self employed and work long hours*
Safety concerns	Concerns about the ability to participate in physical activity in a safe way. Participants frequently reported an emotional response to these safety concerns e.g. fear of injury, fear of falling.	*I have a left leg that drags, hence I fall over* *Not being able to walk safely* *Often feel fatigued after exercise - cannot drive safely home from gym - 3 km* *Fear of injury. I don't want to injure myself because I look on injury as a major step backwards* *Fear of falling/slipping in the swimming pool. I would like to go to the local pool but do not do so for this reason* *Crowded places - having to dodge or walk around items or people* *Walking. Very likely to fall - pavements are a real trap*

Category	Description	Quotes extracted from participant responses when asked to nominate any barriers that prevent them from taking part in physical activity
Self-efficacy	Loss of confidence in the ability to take part in physical activity, or to complete an activity. This also was linked to an emotional response e.g. worry, frustration, panic.	*Loss of balance causes lack of confidence* *Environment - unfamiliar environment can set body and mind into a panic* *Mountain biking - with reduced balance I've lost confidence* *I worry that I might not be able to complete the activity. I was invited to go hiking for a few days, but worried that I might not make it. I find this very frustrating.* *No longer confident to run or jog like I used to* *Loss of confidence riding a bike because my foot slips off the pedal. Not able to keep up.* *Scared I may not be able to complete the activity or exercise*
Self-consiousness /embarassment	Concerns about the perception or impact on others – this seemed related to a number of things including any of the following: embarrassment, expectations of self, showing weakness to others or concern about being a burden to others.	*Tennis - with blurry vision in one eye I can't judge position of the ball - embarrassing as I used to be a good tennis player!* *I don't want to tell people about MS, therefore won't participate in any exercise in case I can't complete whole class/game and I don't want to disappoint team members.* *Other people's reactions - don't like other people having to hassle around - to compensate, make it easier. I find it irritating if people 'fluff' around.* *Not enough disabled parks - feeling self-conscious in public places and too expensive to go privately.* *If my children try to help me - I have to cope with them seeing their mum not being able to cope.* *Depending on how demanding the exercise, if I think I can complete the exercise without falling and looking like a fool!* *Worried what people will think if I have to stop or struggle* *A lot weaker and thinner than I used to be and feel self-conscious about appearance and don't want to accept that I will not be able to do the same level of exercise I used to do*
Symptomatic response	Avoiding activity due to the symptoms that result from taking part in physical activity which were most often perceived to be related to heat sensitivity e.g. dizziness, blurred vision, tingling and so on.	*Increased body temperature - prevents aerobic exercise due to increased symptoms* *If too demanding, the risk of escalating tingling symptoms in my legs* *Blurred vision - sometimes when exercising with the heat blurs my vision in right eye* *Any exertion makes me dizzy and uncoordinated. I can't do any of the sports I used to.* *Prickly feeling with high energy exercise*

Category	**Description**	**Quotes extracted from participant responses when asked to nominate any barriers that prevent them from taking part in physical activity**
Impairment	Symptoms that were perceived to prevent participation in physical activity e.g. balance, lack of coordination, lack of mobility, pain and so on.	*Lack of coordination and balance* *Trouble with balance and very weak core muscles* *Lack of balance when moving quickly or looking from side to side* *Inability to walk or stand* *Unable to move independently* *No use of legs combined with no abdominal stability and spasticity* *I even have trouble getting into bed - pain is excruciating* *I am not a masochist. I don't like pain*
Not knowing what to do	Lack of information or advice about what exercises one can do safely and which will result in the most benefit.	*Not knowing what exercises are helpful, also how to get the most benefit when sitting in a chair when your legs don't do what you want them to do* *Exercise wise, need help with a programme* *Having the medical/physiotherapist input/knowledge to support any serious exercise at the gym would make me happier/more confident that I will not 'hurt' myself while exercising* *There doesn't seem to be anything written about how to exercise sitting down*
Personal resources	Lack of personal resources such as transport or money to take part in physical activity.	*Finances limit additional exercise* *Lack of funds/accessibility - I would like to work on my upper body strength in a gym but most are not accessible and I can't afford the membership* *Expense of joining a gym.* *Money, because with my MS, attacks are sudden, legs give out, etc. It's best to do it in a gym, but due to my finances I have trouble even affording the $2 green prescription fee plus transport!* *Lack of transport and finance*
Weather	Bad weather as a barrier to doing outdoor activity such as walking.	*Cold weather especially if windy as well* *Weather for walking*
Cyclical nature of MS	Frustration due to the cyclical nature of MS where progress is quickly lost as a result of exacerbation and residual disability makes re-engaging in physical activity difficult.	*Discouragement - so often I start on a regime, do really well and make progress and then have an attack which undoes the progress. This often means recovery of 3-6 months. Less inclined each time to do it again.*

Category	Description	Quotes extracted from participant responses when asked to nominate any barriers that prevent them from taking part in physical activity
Disinterest	A lack of interest in participating in physical activity	*I do not want to exercise!* *I've never enjoyed physical activity for its own sake*

Table 6.18: Overview of responses to open-ended questions regarding perceived facilitators to physical activity

Category	**Description**	**Quotes extracted from participant responses when asked to list any facilitators that helped them to participate in physical activity**
Enjoyment	Participants were more likely to engage in physical activity or maintain their participation if they got enjoyment from it.	*Enjoyment - exercise to music* *Enjoyment - pleasure of daily physical activity* *The promise of enjoyment and fulfillment* *Finding an activity I enjoy* *A deep love for the activities I do (rock climbing, swimming, etc)*
Availability of others	Having others available to offer support, encouragement, understanding and so on.	*Having a capable carer with me* *Having a physio encouraging me* *Encouragement from family* *Living with someone who enjoys the same activities* *Understanding family and friends* *Others to motivate me and encourage* *My partner - he is a trainer and is always encouraging and motivating* *My husband's encouragement - he will also do the exercise with me, accepts no excuses, so if I have a problem he does easy ones with me to limber me up*
Social aspect	Being able to combine physical activity with friends and family. Participating in group exercise was referred to as a facilitator by a number of people for this reason.	*The social aspect - friends are mostly understanding if I can participate at some level* *Holiday time with family - we go walking, swimming… I'm social and like doing things with other people* *Group exercise - social contact* *Group sessions* *Having someone I know with me, not because I'm weak, just for companionship* *Getting out and about and meeting different people* *Other people - when social activities combine with exercise*
Being with other people with MS	Being able to participate in physical activity with other people with MS who had similar levels of disability.	*Having like able (or not able) people around me* *Being with other people with MS - in same situation. l am a member of an MS group – I do water walking with them* *Others in 'same' boat that would like company while exercising.* *Classes of MS society mean that I am more likely to undertake activity*

Category	Description	Quotes extracted from participant responses when asked to list any facilitators that helped them to participate in physical activity
A sense of duty	Having a responsibility or a sense of duty to others making physical activity a necessity e.g. having to take a dog for a walk, or needing to (or wanting to) engage with one's children.	*My dogs need to be walked so it makes me go* *My dog is a very good reason for walking every day* *Having two active sons aged 7 and 9 means I am always participating in physical activity! I understand the need to do stuff while I am able, both for the kids and my own wellbeing.* *The dog prompts me to walk him every day* *Having young children* *Children have encouraged/prompted activity like dancing and rough and tumble* *Sense of duty and love for my family and friends*
Attitude	Having a positive state of mind and the determination to 'take control'.	*Positive attitude - attitude to life - making the most of every minute and helping others - life is a two way switch. I love life!* *Determination or self interest to keep moving* *My pig headedness!* *Getting out there and doing it; giving it a go.* *My sense of humour gets me through in whatever capacity* *Will power and positive attitude* *Determination to keep going* *The thought of taking ownership for my own wellbeing and having a margin of control over it* *My optimism*
Use of an assistive device	Having access to an assistive device which can support participating in physical activity both in terms of safety and ability.	*Four footed walking stick for balance to play indoor bowls* *Use of hiking stick enable me to walk up to an hour* *Steady myself with wheelchair for longer walks* *I play (rather bad) golf from a cart otherwise I would not be able to play* *Outdoor walking for exercise - I use a walker in the streets near my home* *I use a treadmill daily as I have something to hold and that prevents me from falling*

Category	Description	Quotes extracted from participant responses when asked to list any facilitators that helped them to participate in physical activity
Belief in the benefits of physical activity	Believing in the benefits of physical activity or in the good feeling that comes from taking part in physical activity	*I realise its doing me good. I want to be well.* *Makes me feel good* *Knowing that physical activity and exercise is good for me - body and mind* *I make myself go to the gym because I know I always feel better afterwards* *My own sense of achievement - feeling like I'm improving every day* *It helps the MS and helps me mentally* *Participating in physical activity makes me feel better in my body and in my mind.* *Feel healthier and happier* *A strong belief that physical activity is strongly linked to my health and well-being (physical and mental)* *The knowledge that increased strength derived from exercise helps with movement and balance and to maintain a normal lifestyle* *The thought that the activity just may help me live with MS*

6.4 SUMMARY

Study Four was the first study to be carried out as a part of Phase II of this doctoral research. This study aimed to explore the role that cognitive-behavioural and a range of other variables identified by previous research have in influencing physical activity engagement in people with MS; and explore the relationship that self-reported level of physical activity has to their overall well-being. The primary finding of this study was that based on the standardised measures used, self-efficacy, number of perceived barriers to activity and mental fatigue were significantly associated with participation in physical activity in people with MS. These variables accounted for a significant 12% of variance in physical activity over and above the variance accounted for by illness-related variables. However, illness-related variables (such as type of MS and use of legs) accounted for a significant 42% of variance. The large proportion of variance accounted for by these illness-related variables suggests intervention efforts may be appropriately targeted at those people more prone to inactivity, such as people with progressive forms of MS, and those with ambulatory impairments. However, factors such as self-efficacy, perceived barriers and mental fatigue are potentially more modifiable than these illness-related variables and impairment, and so may offer a useful focus for clinicians when trying to facilitate physical activity engagement in this population. Participants indicated a range of other potential barriers and facilitators to physical activity play a role in their decision to engage in physical activity in response to the open-ended questions. Given that limited research has explored the barriers and facilitators to physical activity in people with MS to date, the use of standardised measures with prescribed items may miss important information relating to physical activity engagement from the perspective of people with MS. In order to explore this in more depth, the second study of Phase II, a qualitative investigation, was carried out and is reported in the following chapter. After which, the findings of both studies are discussed in detail in the context of existing literature.

CHAPTER 7

STUDY FIVE

BARRIERS AND FACILITATORS TO ENGAGEMENT IN PHYSICAL ACTIVITY FOR PEOPLE WITH MULTIPLE SCLEROSIS: A QUALITATIVE INVESTIGATION[5]

7.1 AIMS

Study Five was the second study carried out as a part of Phase II of this doctoral research. It was included as a sub-study to the larger questionnaire study reported in the previous chapter. The main aim of this sub-study was to develop an in-depth understanding of the barriers and facilitators to engagement from the perspective of people living with the condition, and thus a qualitative design seemed most appropriate.

7.2 METHODS

Ethical approval for this sub-study was obtained at the time of obtaining full ethical approval for the larger questionnaire study (see Appendix S).

7.2.1 DESIGN

This study drew on a qualitative descriptive methodology,(227) using semi-structured interviews. This approach draws on naturalistic inquiry, or the study of something in its natural state.(227) Guba and Lincoln identified five defining features of naturalistic inquiry in their paper which discussed the distinction between a naturalistic paradigm and a rationalistic paradigm.(228) These features are presented in Table 7.1.

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[5] Study Five resulted in the fifth publication directly linked to this doctoral research (226):
Kayes, N., McPherson, K. M., Taylor, D., Schluter, P. J., & Kolt, G. (2010). Facilitators and barriers to engagement in physical activity for people with multiple sclerosis: a qualitative investigation. *Disabil Rehabil, Early online*, 1-18.

Table 7.1: Defining features of naturalistic inquiry taken from Guba and Lincoln (228)

Nature of reality	There are multiple tangible realities which can be studied and these multiple realities will inevitably diverge
The inquirer-object relationship	The inquirer and object under study interact and influence one another
The nature of truth	The aim is to develop an idiographic body of knowledge
Attribution/explanation of action	An action may be a consequence of multiple interacting factors which are best studied holistically and in their natural context
The role of values in inquiry	The inquiry is value-bound. That is, the inquiry is influenced by the inquirer's values, by the paradigm guiding the inquiry, and so on

At the time of carrying out this doctoral research, the only qualitative work in this field either explored barriers and facilitators to engagement in a specific programme (88) or explored engagement in a broader range of health behaviours. (16) None had specifically explored the barriers and facilitators to engaging in physical activity for people with MS from the perspective of the people living with the condition. Given the paucity of research in this area, there is little theoretical rationale for selecting variables for a quantitative exploration, other than what can be drawn from in other illness groups. As such, it was anticipated that qualitative data would supplement quantitative findings to aid interpretation and to highlight any variables potentially impacting the decision to take part in physical activity not already measured. The open-ended questions in Study Four, while yielding qualitative data due to them being open-ended, were a formalised, limited set of questions that did not vary between participants. In contrast, the semi-structured format of the questions used in this qualitative inquiry formed the basis of an interview guide and were used as prompts throughout the interview, allowing for flexibility in response to the person being interviewed and the interview context. This was necessary to develop a deeper understanding of factors influencing the decision to take part in physical activity for people with MS, and allowed exploration of the complexities of engagement from the perspective of those living with the condition. The goals of this study were well met by naturalistic inquiry, with the purposes described here (to obtain a deeper understanding of the *factors influencing engagement* and to explore the *complexities* *of engagement* from the *perspective of people living with the condition*) all congruent with the features outlined in Table 7.1.

Qualitative descriptive methodology draws on naturalistic inquiry in that it aims to develop a “comprehensive summary of an event in the everyday terms of those events”.(227, p.336) That is, the output of the research is kept close to the data, to the words of those being studied, to their “natural state” (p.337). Fundamental to the methodology is that those people exposed to the data (researcher or participant) agree with the resulting description.(227) Qualitative descriptive methodology is suggested to be particularly useful when a rich description, rather than ‘interpretation’, is the main goal of the study. It is acknowledged that description cannot be free from interpretation (227) given that, as Guba and Lincoln suggest, naturalistic inquiry is value-bound.(228) However, qualitative descriptive methodology simply suggests a lower level of interpretation than what one might expect in other qualitative methods of inquiry such as phenomenology. Despite some debate regarding the level of interpretation that is appropriate when using a qualitative descriptive methodology,(227,229,230) there is generally support for the approach adopted in this study, when robust methods for sampling, data collection and analysis are evident.(230)

7.2.2 PARTICIPANTS

As described in Study Four, participants were recruited through local MS Societies and one District Health Board in NZ as part of the larger questionnaire study. All those who participated in the larger study were asked to indicate on their consent form if they would also be willing to participate in an interview to explore their identified barriers and facilitators to physical activity in more depth. Of those who were willing to take part (n=183, 65%), ten were purposefully selected (151) to be interviewed aiming for diversity in self-reported disability, age, gender and type of MS. It was believed that this number of participants would allow for adequate diversity to be achieved on these characteristics, and would enable in-depth exploration of the phenomenon of interest.

In order to ensure diversity in level of disability, all consenting to be interviewed were stratified according to their level of disability (low, moderate and high disability). Responses to disability questions in the Study Four questionnaire were reviewed and used as a proxy indicator of disability for the purposes of stratification. The three items used included a) use of assistive devices; b) self reported lower limb function (no use, partial or full); and c) their score on the Guys Neurological Disability Scale (GNDS). In the questionnaire study (Study Four) the mean score on the GNDS was 15.9, therefore for the purpose of this study a score between 10 and 20 was considered moderate, <10 considered low and >20 considered high. However, rather than looking at this score in isolation, it was the combination of the three item scores that were taken into account. For example, if someone had a GNDS >20, but were ambulatory with the use of a walking aid then they were considered moderate, rather than high disability. See Table 7.2 for specific details of stratification criteria.

Table 7.2: Stratification criteria using proxy indicators of disability

Low	Moderate	High
No walking aid required	Ambulatory with the use of a walking aid	Wheelchair dependent
Full or partial use of legs	Partial use of legs	Partial or no use of legs
GNDS <10	GNDS ≥10	GNDS >20

A range of participants were then purposefully selected from each of these strata groups with the aim of achieving diversity in the other characteristics outlined earlier (age, gender, and type of MS). Given the high number of potential participants to select from, responses to semi-structured questions in the Study Four questionnaire were used to aid purposeful selection. For example, people were purposefully selected based on the key characteristics indicated above if their response to semi-structured questions indicated diverse experience and/or the potential for ‘richness’ of story.

7.2.3 PROCEDURES

Those people purposefully selected were contacted and an appointment arranged for a face-to-face interview in their home. Significant others or other persons the participant wished to have present at the interview in a support role were welcomed, however this was only taken up by one participant whose husband was present at the interview. The initial interview guide was developed by the author (NK) in consultation with the wider research team, and had not been previously pilot tested. Initially the study definition of physical activity was shared with participants in order to orient them to the phenomenon of interest (see page 29). Topics covered in the interviews included exploration of current engagement in physical activity, barriers and facilitators to physical activity and perceived impact of physical activity. It was the intention of the interviewer to keep the interviews as open-ended as possible; however prompts were used if necessary in order to gain a deeper understanding of the participants' experiences of physical activity. The nature of these prompts was generally unique to each interview situation, as the interviewer was guided by the flow of discussion. However, in some cases this included guiding participants to reflect on their pre versus post MS experiences of physical activity and identify changes in their physical activity engagement over time in order to explore the reasons for such changes in more depth. As the study progressed, issues arising from earlier interviews were explored with subsequent interviewees to allow for exploration and refinement of categories and themes that seemed to be emerging from the interviews. Interviews lasted from 60 to 90 minutes and were audio-taped and transcribed verbatim.

7.2.4 ANALYSES

Preliminary analysis took place while data collection was ongoing, so that new data and new insights could shape subsequent interviews in accord with the recommended iterative approaches to such designs.(231) Initially, transcripts were read and reread in order to become familiar with the data. Initial coding then took place through the manual coding of sentences or phrases. Following this, all transcripts were imported into QSR NVivo8,(232) a qualitative data management software package, and initial codes were examined and grouped into categories. As analysis progressed, it became apparent that many of the categories seemed to interact. To move towards disentangling this complexity, exploring the relationships in more depth and identifying key areas of tension, some of the strategies that form part of the constructivist grounded theory methodology described by Charmaz (231) were drawn upon. This included: a) the use of memos to record details of the categories and to keep track of initial thoughts about the data and any hypothesised interactions between categories; and b) engaging in a form of constant comparison where coded data were checked within and between categories and against new data as it was collected to test emerging ideas and to aid the development of themes which were derived.

As recommended by Mays and Pope and others,(233-235) a number of strategies were used to ensure rigour, including: (1) negative case analysis or searching for elements of the data that did not support or appeared contradictory to identified patterns or explanations; (2) two coded transcripts identified as being particularly information-rich being read by a second researcher (KM – primary supervisor) to ensure consistency of interpretation, and meetings held to discuss any disagreement with the aim of reaching consensus on thematic development; and (3) including illustrative quotes which corroborate interpretation throughout. In addition, a diagram was constructed to represent hypothesised interactions between themes and their proposed relationship to physical activity behaviour, which involved an iterative process of checking within and between data sources to check for any inconsistencies with the proposed theoretical model. Different iterations of the model were discussed and revised with a second researcher (KM) to ensure suggested relationships between themes and physical activity behaviour represented on the diagram were consistent with the agreed interpretation of data. Data from significant others present at the interviews were not analysed, given that the focus of inquiry as the experience of the person living with MS. However, their contributions were included in the quotes presented in the findings if they added context to what was subsequently said by the person with MS.

7.3 RESULTS

7.3.1 PARTICIPANT CHARACTERISTICS

Table 7.3 provides a summary of participant characteristics for the interview component of this study. Diversity was achieved as intended on a range of demographic and illness-related variables. Pseudonyms have been used in the place of the participants' real names to maintain their anonymity.

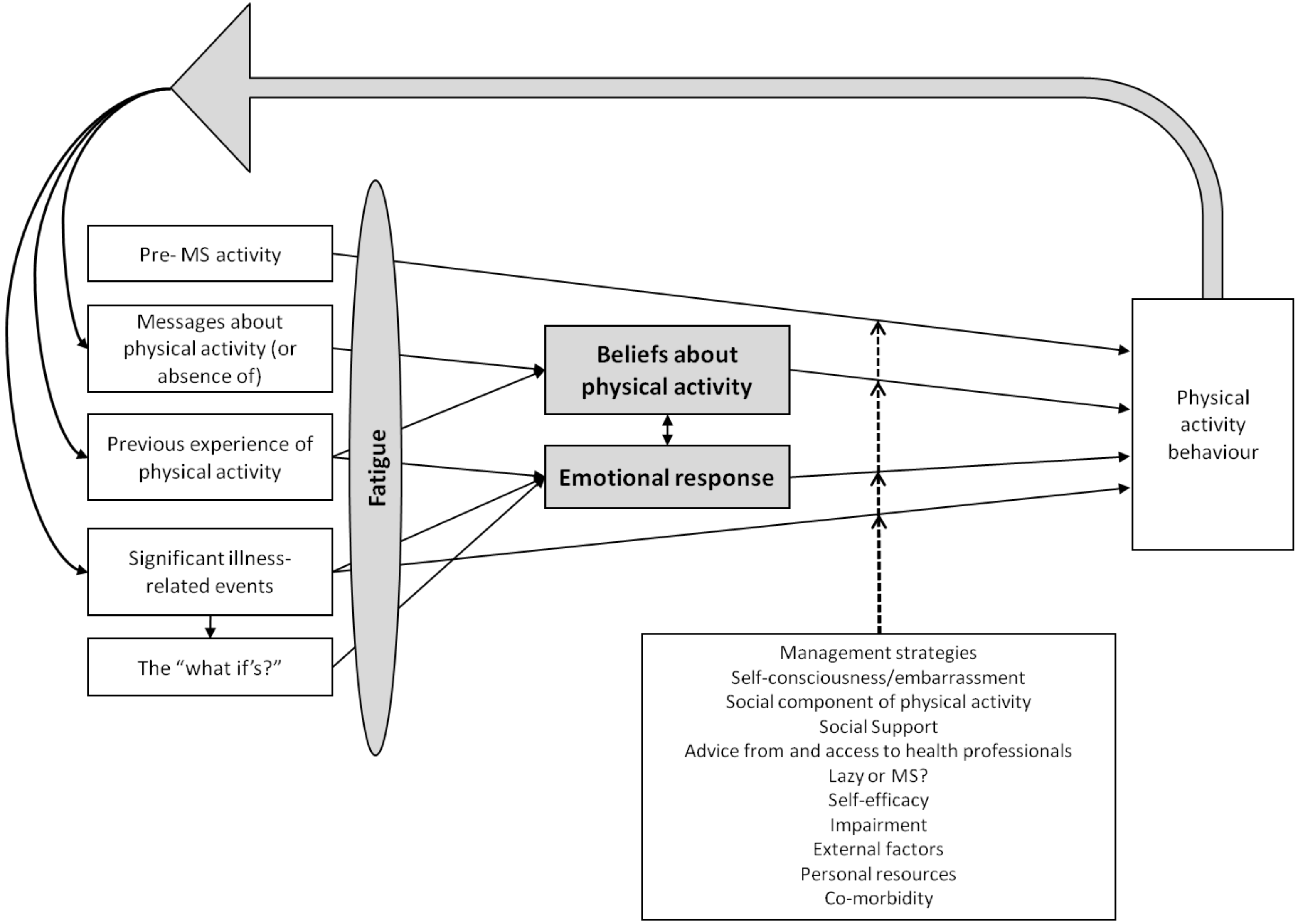
Table 7.3: Participant characteristics of Study Five

Pseudonym	Age	Gender	Type of MS	Time since diagnosis (years)	GNDS	Use of assistive devices	Leg Use	Arm Use
Irene	53	Female	PPMS	17	30	Wheelchair	Partial	Full
Teresa	34	Female	RRMS	4	11	None	Full	Full
Damien	38	Male	SPMS	3	25	None	Full	Full
Cheryl	41	Female	RRMS	4	1	Cane (outdoors)	Full	Full
Hannah	39	Female	SPMS	6	31	Cane (indoors) Wheelchair (outdoors)	Partial	Full
Julie	52	Female	RRMS	10	22	Wheelchair	No use	Partial
Sarah	43	Female	PPMS	6	18	None	Full	Full
Donna	52	Female	RRMS	11	8	None	Full	Full
Marcus	47	Male	PPMS	15	9	Walker, Cane and Wheelchair	No use	Full
John	44	Male	SPMS	12	16	Walker, Cane (outdoors)	Partial	Partial

7.3.2 INTERVIEW FINDINGS

Analysis of interview data identified numerous categories that were synthesised as a range of key themes. These themes rarely seemed to exist in isolation as influential in the decision to take part in physical activity. Instead, it seemed that a complex interaction between several themes at any one time contributed to subsequent physical activity behaviour. Throughout the findings, proposed interactions between emerging themes are discussed, representing the process of analysis and interpretation of the data. However, the final iteration of the diagrammatic representation of the analysis is first presented (Figure 7.1). While this was the endpoint of the analyses, it is provided here to allow a context for the themes and their complex interaction.

Figure 7.1: Diagrammatic representation of proposed interactions between themes identified through interviews



7.3.2.1 Beliefs about physical activity

At the centre of Figure 7.1 is the first proposed theme, *beliefs about physical activity*. This theme is deliberately placed as a central component in the figure as a representation of the strong influence that beliefs about physical activity seemed to have in influencing physical activity behaviour. There were five beliefs identified. These were:

a) The vicious cycle of activity/inactivity
b) A fine line between benefit and harm
c) Physical activity is a waste of time
d) Physical activity makes my MS worse
e) Use it or lose it

Each of these beliefs seemed to have developed as a result of previous events and experiences (depicted by the arrows leading to *beliefs about physical activity* in the figure), including:

- Messages about physical activity (or absence of); and
- Previous experiences of physical activity (post MS diagnosis) — specifically *interpretations* of these experiences.

Each of the beliefs is discussed below, with reference to how they reportedly developed.

7.3.2.1.1 The vicious cycle of activity/inactivity

This relates to the interaction between fatigue and physical activity behaviour. That is, physical activity results in increased energy levels, subsequently leading to a greater likelihood of participation in physical activity. Conversely, inactivity results in lowered energy levels and physical deconditioning, leading to further inactivity. This is similar to the cycle of pain often referred to when discussing the development of chronic pain. This participant described the cycle as they perceived it:

> *With MS you, or any of these sort of diseases, it's very easy to cop out. And then the problem is, once you have copped out once, the second time is even easier and then before long, you are not bothering at all and you are not doing any movement, you're not doing the exercise. You're finding that the days are becoming a lot more lethargic, just spending more time in bed and less time up. And the cycle just goes and accelerates that way. (John, Age 44, Secondary progressive MS)*

Very strong beliefs about this cycle were clearly described as related to the decision to take part in physical activity for some participants:

> *And because you get a lot of people who get very fatigued, I think that is the barrier to get over too. It's like... because you are tired is not a reason not to exercise... it is actually the reason to exercise. You know. (Cheryl, Age 41, Relapsing-remitting MS)*

This belief seemed to develop as a result of previous experiences of physical activity. If a person had experienced an initial positive effect of physical activity, such as an improvement in fatigue, this encouraged them to pursue further activity, intuitively leading to the belief that the impact of physical activity on fatigue was cyclical in nature.

> *Once you know that it makes you feel better, that motivates you to keep going. You know, like even when I was really ill and incredibly fatigued, I did know that even if I shuffled to the end of the block and back I felt a bit better. (Cheryl, Age 41, Relapsing-remitting MS)*

In some cases, the benefit of physical activity was not always immediately apparent. However, those who persevered through the initial, short term negative impact of physical activity reportedly experienced long term benefits.

> *With the swimming, I did have to kind of persevere a little bit because the first few weeks I felt absolutely knackered. So, most of the rest of the day you know... ummm... but I think about six months in I realised that I was overall… feeling a lot more energetic. (Cheryl, Age 41, Relapsing-remitting MS)*

When this same participant was asked what kept them going through the initial negative impact, once again, it was clear that previous experiences of physical activity played a role in the decision to keep going.

> *I am fairly bloody minded actually… and … I did... cause of the yoga experience I thought... no, this will actually be good; you have just got to get through this. (Cheryl, Age 41, Relapsing-remitting MS)*

A tension arose for people who held this belief about the vicious cycle of activity when their initial experience of fatigue impacted on their ability to engage in physical activity in the first place. They indicated that taking part in physical activity helped increase their energy levels, but they couldn't muster the energy to get going in the first place as noted by John who said:

> *It's a strange thing, if you don't do the exercise, you slowly slow down worse, but sometimes you don't have the energy to do the exercise in the first place, it's a messy conundrum… (John, Age 44, Secondary progressive MS)*

7.3.2.1.2 A fine line between benefit and harm

This belief related to the idea that there is a fine line between exercise that is beneficial and exercise that is damaging. This linked closely to the previous belief regarding the vicious cycle of activity, in that, those who recognised that one could benefit from taking part in physical activity believed in the relationship between physical activity and fatigue. However, believing in a 'fine line' between benefit and harm added a caveat — that physical activity is beneficial, so long as you kept within a certain threshold. If one crossed that threshold, then the consequences were detrimental.

> *I've discovered that there's a line between exercise that is beneficial and exercise that isn't. You know that you've gone over the line of doing more damage than good for me. (John, Age 44, Secondary progressive MS)*

This was made more complex by the fact that MS is unpredictable in nature as this participant continued to say:

> *But the problem is that the line doesn't stay stationary. It's the same with most MS people. What you did yesterday is not necessarily what you could do today, but you might be able to do twice what you did the day before tomorrow, it's a very fluid, so that level is always fluid. (John, Age 44, Secondary progressive MS)*

The language used to describe the impact of crossing the line was very powerful. This participant described what happened when he crossed the line:

> *For instance, you have a jar full of energy and that's your energy for the day and you can both waste it, or whatever, and use it up. But the problem is each day with MS that day jar size varies and you can use up all that energy that's available on the day in one foul burst… and then, you know… like I've done once before … I did two or three days of a lot of things with the girls in the school holidays, so we were very busy. We did two or three days no problem and on the fourth day I was just out of it, gone, wasted. Your body just shuts you down. (John, Age 44, Secondary progressive MS)*

Another participant used the analogy of a piece of elastic when describing her experiences:

> *It's like you have a piece of elastic, you know, knicker elastic, you know how it perishes? It will keep stretching back to its original shape if you only stretch it a small way, like about two thirds of its stretch but if you decide to stretch it all the way it never goes back, that's what I mean. (Julie, Age 52, Relapsing-remitting MS)*

Both these participants suggested extreme consequences as a result of crossing the line with the first suggesting his body 'shuts down' and the second implying that the consequences were in fact irreversible.

7.3.2.1.3 Physical activity is a waste of time

The belief that physical activity is a waste of time seemed related to previous experiences of physical activity and was at least in part linked to the degenerative nature of the illness, in that the benefits of physical activity were not always evident due to disease progression.

> *It's like having a tin can with holes punched in it, no matter how much water you pour into it, it is still pouring out. So even if you pour heaps more water in it will still pour out, you will never get anywhere. (Julie, Age 52, Relapsing-remitting MS)*

For this participant, who experienced muscle weakness, it seemed that it was an uphill battle against the nature of the symptoms she was experiencing.

> *You are trying to maintain what you haven't got. (Julie, Age 52, Relapsing-remitting MS)*

This belief was also related to the idea that it takes a long time to see benefit from physical activity, and that benefit quickly diminished with a short period of inactivity.

> *You do become weaker without even sort of blinking, really. (Sarah, Age 43, Primary progressive MS)*

> *It might take you week to become a little better, but only a day to lose it all back to where you started again. (John, Age 44, Secondary progressive MS)*

The experience of taking part in physical activity with seemingly no positive impact was linked to an *emotional response* where participants began to experience a sense of helplessness or frustration with physical activity in the absence of a positive response.

> *It feels good at the time, but when you try to do the same thing again the next day you only get a quarter of the way back, that's depressing. (Julie, Age 52, Relapsing-remitting MS)*

Emotional response is another of the central themes represented in Figure 7.1 and is discussed in more detail on page 211.

7.3.2.1.4 Physical activity makes my MS worse

This belief seemed to develop as a result of previous experiences of physical activity which the participant had believed to lead to either an exacerbation or a worsening of symptoms. For example, this participant described the development of a previous exacerbation which she clearly linked to her activity at that time.

> *I would be doing aerobics or playing touch or whatever I was doing and then I'd have tingling in my feet. My symptoms, the first symptoms are always tingling in my feet and I used to ignore it. Then I would go and do something else and then it would come up to my ankles and I'd ignore it and it would go halfway up my leg and I'd think… oh gosh I should be resting really… and slow down slightly, but still pottering around and doing everything still doing stuff but getting rid of my exercise, but still not resting enough and going to work. I was working full time then and then by the time it got halfway up my leg I knew I was in trouble. (Teresa, Age 34, Relapsing-remitting MS)*

The same participant described ceasing physical activity as a result of her symptomatic experiences while taking part in physical activity.

> *Oh my sight sometimes goes actually, that's why I had to stop. (Teresa, Age 34, Relapsing-remitting MS)*

Messages about physical activity were notable here for their absence, rather than having an influencing presence. For example, it seemed that the lack of information about the benefits of physical activity and what one may realistically expect as a result of physical activity lead people to interpret the symptoms they experienced after physical activity as a sign that they were making their MS worse. However, many described such symptoms as transient and short term, rather than a sign of a pending exacerbation. Those people who realised this seemed able to manage these symptoms in a way that enabled them to take part in physical activity.

> *Yeah, I get a bit wobbly so I sit down for an hour or so, not sit down but just don't do that for half an hour sort of thing and it usually is not too bad. (Damien, Age 38, Secondary progressive MS)*

Information about what one could expect to experience as a result of physical activity helped people to understand the symptoms they were experiencing. This was the case for those who had received messages about physical activity from people they believed to be a credible source.

> *The lady from the MS society sort of said any physical activity is good. (Damien, Age 38, Secondary progressive MS)*

> *The, ummm, neuro guy that I saw on Wednesday was saying that exercise can make you feel more positive, so, I'm sort of bearing that in mind a bit now. (Hannah, Age 39, Secondary progressive MS)*

However, such messages seemed rare:

> *I don't think the medical profession promotes exercise. You know…whether they don't see it as their job… I mean I like my neurologist… she is very good, but she would never have spoken to me about exercise and neither really did the MS nurse at the hospital. (Cheryl, Age 41, Relapsing-remitting MS)*

7.3.2.1.5 Use it or lose it

This belief related to the idea that you need to keep active or you will lose your ability to move, as described by these participants:

> *Cause if you keep moving... other than that, it will just go dead. But, you gotta keep it moving. I've realised that. (Irene, Age 53, Primary progressive MS)*

> *PARTICIPANT: I do it every day, I walk from my kitchen bench to the bathroom and that's it.*
> *INTERVIEWER: So you do that every day? And do you do that purposefully to be active or do you do that because you need to in order to get from A to B?*
> *PARTICIPANT: No, I do it so I do not lose the use of my legs. (Julie, Age 52, Relapsing-remitting MS)*

The presence of this belief was not surprising as this is a clear message given by the Auckland region MS Society, as this person articulated:

> *There's a very good phrase that is often used by other people, they use it as well [the MS society], use it or lose it. And that is really true with*

> *MS. If you don't use it you will lose it. There's no might or could be, there is - you will. (John, Age 44, Secondary progressive MS)*

7.3.2.1.6 Co-existence of conflicting beliefs

It was not uncommon for participants to ascribe to multiple, conflicting beliefs about physical activity. For example, believing that taking part in physical activity had the potential to increase energy reserves (a belief in the vicious cycle of activity), whilst also believing that there was a fine line between physical activity that is good versus not (a belief in a fine line between benefit and harm). This appeared to create quite a tension when considering physical activity engagement. This is illustrated well by the following quote where one participant described the dilemma he faced on a daily basis.

> *Using the analogy of a bottle of energy just till its run out, it's just like a car… you run out of energy, that's it. End of story. But, whether you can extend… the other thing is, with exercise you can sometimes enlarge that bottle through exercise. So you have a problem there of trying to enlarge the bottle through exercise but then not wanting to use up all the energy for the day coz you might have something else on the second half of the day to use. (John, Age 44, Secondary progressive MS)*

So, this participant appeared to believe in the vicious cycle of activity and that one can increase their energy stores through physical activity, but he also believed that a fine line existed between doing enough to experience this positive response and doing too much. Complicating matters further for people was the unpredictable nature of MS which resulted in the 'line' moving from day to day.

7.3.2.2 Emotional response

As mentioned previously, *emotional response* is the second core theme and is also placed centrally in Figure 7.1. A range of emotional responses were evident, including frustration and helplessness (as described above), anger, fear, and anxiety. These responses seemed to be linked to the following:

a) Previous experiences of physical activity;
b) Significant illness-related events; and
c) The "what ifs".

These things could be considered 'antecedents' to the emotional response. A common thread through each of these was concern about safety. This was not identified as a specific theme in Figure 7.1 as it seemed that the more important mediator was the emotional response itself. However, often it was this concern about safety that seemed to underlie the emotional response or linked the antecedents to the emotional response. Each of these antecedents is discussed in detail below with specific reference to the emotional response.

7.3.2.2.1 Previous experience of physical activity

Previous experiences of physical activity often resulted in an emotional response which seemed to impact on future decisions to take part in physical activity. One example discussed above was the sense of helplessness and frustration experienced by some participants, which seemed to stem from previous efforts to take part in physical activity not yielding the benefits they had expected.

Another commonly referred to emotional response was fear, in particular a fear or falling and/or a fear of injury. Many of those who had fallen or experienced an injury previously suggested that they had stopped taking part in physical activity, or certain activities, due to a fear that they would fall or injure themselves again. For example, this participant described a fall she had which was pivotal in her decision to stop going out for walks, an activity she had previously enjoyed doing with friends.

> *INTERVIEWER: What was the first thing that made you stop going out for those walks? Do you remember?*
> *HUSBAND: You fell over and smashed your teeth.*
> *PARTICIPANT: I tripped actually. I was crossing the road. I actually went out from work to post the letter and I crossed the road and going back I didn't pick one foot up properly and that was when I was limping. I didn't have any sticks then. But, I was just limping and walking not well enough. I tripped and I smashed my face and my teeth. (Irene, Age 53, Primary progressive MS)*
>
> *I feel I can't do it. Like I had to climb a ladder the other day, well a while ago now, to clear the drain and ended up breaking my foot because I came off the ladder. (Marcus, Age 47, Primary progressive MS)*

This participant referred to a time when she injured herself while riding a bike which she perceived may have triggered a relapse. This experience resulted in her avoiding situations where she may be vulnerable to injury, and opting for activities that were less likely to result in injury.

> *Yeah, the swimming I have been doing for about a year… partly because about a year ago I sprained my ankle while biking with the kids. I had been pretty symptom free really and the sprain set … it probably didn't start anything, but it started some symptoms in my right leg again. So, I became a bit more nervous about doing exercise where I could potentially get injured. For me, having the experience I had when I sprained the ankle, I am just aware that if I get injured the consequences for me are going to be a lot more serious than they are for somebody else… potentially. So, I just try to avoid situations where I am going to get injured really. (Cheryl, Age 41, Relapsing-remitting MS)*

Some people experienced anger or frustration with their MS when they couldn't do things as well as they would have liked, or that they used to be able to do. For example, this participant described her anger as her coordination decreased throughout an exercise class.

> *I am terrible at step - I am falling all over the place, I am so uncoordinated. At the start I am fine, as long as I am next to a fan, yep, and towards the end I just get so angry I can't get it. (Teresa, Age 34, Relapsing-remitting MS)*

7.3.2.2.2 Significant illness-related events

This theme related to the idea that significant illness-related events lead to a change in physical activity behaviour. In some cases this change in behaviour seemed to be mediated by the emotional response attached to that illness-related event. In other cases, the emotional response was not evident. Significant illness-related events referred to by participants included:

- Diagnosis;
- Exacerbation or symptom change;
- Loss of job as a result of impaired ability; and
- Transition to the use of walking aids.

Participants reported that when behaviour change occurred as a result of these events, they were not able to get themselves back to their previous level of engagement in physical activity. For example, this participant reflected on her time of diagnosis and how her emotional response to that diagnosis and other related events resulted in changes in her physical activity levels from which she had never recovered:

> *PARTICIPANT: When I was first diagnosed my world came tumbling down. I didn't do anything. I did not go to the gym… nothing. My*

> *partner decided he didn't want an MS person, he wanted a real person. So, that happened within a couple of weeks of me being diagnosed.*
> *INTERVIEWER: So, over that time, did you ever go back to the gym?*
> *PARTICIPANT: No. Just didn't. Just fell into this deep dark hole, pulled the cotton wool over me. Shut everyone out while I did my own healing. I guess.*
> *INTERVIEWER: So, 4 years later?*
> *PARTICIPANT: 4 years later. I guess, maybe I had started using the crutch then, cause that is what I thought I had to do. Umm…. and when I came out of this deep dark hole… I was still fairly tender and very sensitive and umm… I didn't want to do a lot of stuff. I just wanted to… now that I was out of the hole; I didn't want to risk getting near the edge again. You know. (Donna, Age 52, Relapsing-remitting MS)*

On the contrary, diagnosis had the opposite effect for this next participant:

> *I probably picked up… I am probably a bit more aware of making sure I get in structured exercise since I was diagnosed with MS than I was before. And, yoga is definitely something I've picked up since I've had MS, because I do find it really good to counter the stiffness in my legs. So, in many ways I am more focused on keeping fit now than I was before really. (Cheryl, Age 41, Relapsing-remitting MS)*

For this next participant, an exacerbation resulted in changing her physical activity behaviour. She described having an exacerbation which resulted in a hospital stay and how she used to walk regularly before the exacerbation, but did not return to this activity after discharge from hospital:

> *A couple of years ago I was in hospital. I used to walk then, but I became ill and then I didn't get back into walking on my own then. (Irene, Age 53, Primary progressive MS)*

This next participant used quite powerful language when describing the impact an exacerbation had on her:

> *I had a big exacerbation. And that just kind of blew me sideways again. (Donna, Age 52, Relapsing-remitting MS)*

A number of participants discussed the need to constantly re-adjust to the changing symptoms of MS and the difficulty in managing this:

> *I mean, you know, ummm….first couple of years was, you know, it would… you'd have attacks and it was quite, ummm…you'd stay a certain level. But the last, I suppose, three years… you would have an attack and you do, ummm…your level of activity reduces, but then it*

> *does sort of go back up, but not so well….so it's, you do this drop, you go up a bit and then, sort of, maybe a couple of months later you do another drop and then you come up, but maybe not so far…. (Sarah, Age 43, Primary progressive MS)*

A number of participants reported losing their job as a result of MS-related symptoms; some because their cognitive impairments impacted on their ability to do their job and others because they could no longer meet the physical demands of the job. For the most part, participants who reported losing their job never regained employment subsequent to that:

> *With that job you had to, they couldn't afford to have someone just to drive you around, so you had to drive yourself. And before that I was fibre glassing for about twelve years, you really had to see quite good detail to do that sort of stuff. When I first gave up the window stuff I thought I could go back and do that, I probably could have for six months… but now, I don't think there is any way I could sort of stick to it for eight hours a day, even two hours a day would be a mission. (Damien, Age 38, Secondary progressive MS)*

Finally, the last illness-related event that participants referred to as impacting on their engagement in physical activity was transitioning to the use of walking aids. This participant talked about her experiences:

> *When I was first diagnosed with MS, I thought to myself… you had better do something about this…. You are going to need a walking stick. So, I went and got myself a walking stick and I thought…. I am not going to use this until I have to…. But, then I started to use it and I became reliant on it, 'cause I thought that is what I was supposed to do. After a wee while… and we are talking about 5 or 6 years of using a crutch… I really did not need to use it. It was a crutch of a different sort. It was a mental crutch rather than a physical crutch. (Donna, Age 52, Relapsing-remitting MS)*

7.3.2.2.3 The "what ifs"

The "what ifs" were similar emotional responses to those discussed as a result of previous experiences of physical activity, however, they were fears or concerns that people expressed which were unfounded – that is, they were a fear about what *could* happen or what *might* happen, rather than grounded in a previous experience. So, for example some people had a *fear of falling*:

> *I think I am just a little bit nervous that I am going to fall down. (Cheryl, Age 41, Relapsing-remitting MS)*

> *No my legs were also not picking up properly, so if I couldn't walk safely there was no point. (Julie, Age 52, Relapsing-remitting MS)*

> *Even walking in a shopping mall with my crutches was very scary because the mind keeps saying… that floor is shiny, therefore it is slippery, and therefore you will fall. I know! I will keep going. No! You will fall… [using two voices] (Julie, Age 52, Relapsing-remitting MS)*

Others avoided certain activities due to concern about their ability to control their bladder and a fear that they would have 'an accident':

> *Ummm… for a long time I had a bladder and bowel problem as well and I couldn't… <u>wouldn't</u>……. go anywhere where I couldn't be real handy to a toilet. (Donna, Age 52, Relapsing-remitting MS)*

Similarly, others avoided crowded places as they were concerned for their safety:

> *I think I would probably be concerned if it was a lot of people in a small area, because you simply can't recover if somebody bumps you. You just simply can't. It is goodnight nurse…. Unless, I was hanging on to somebody and that somebody could immediately go round. If I was to go somewhere on my own and there was a crowd… I would not go. That's just it. Umm… so rock concerts are out for me. (Donna, Age 52, Relapsing-remitting MS)*

Others experienced anxiety at the thought of starting something and not being able to finish it:

> *I don't want to get over there and get stuck sort of thing and need some help. There are a few scary things. They are not the sort of things I really sit down and think about… it's just sort of stuff that just pops into your head that is probably all stupid stuff. I don't really sit down and contemplate a lot of things but they just sort of pop into your head and you make the worst case scenarios for your self don't you? (Damien, Age 38, Secondary progressive MS)*

> *With the anxiety thing I would probably get worse because I just want to get there, sort of thing. I would be sitting there thinking how am I going to get from there to here and it would probably build up even worse. (Damien, Age 38, Secondary progressive MS)*

7.3.2.3 Interactions between 'beliefs about physical activity' and 'emotional response'

Included in the diagram in Figure 7.1 is a double-ended arrow linking the two themes *beliefs about physical activity* and *emotional response*. This arrow represents the interaction between these two central themes, which has already been implied in the findings reported above. For example, for some people, previous experiences of physical activity resulted in the *belief* that physical activity is a waste of time, which was clearly linked to an *emotional response* of frustration and helplessness. The contrary also applied, where previous experiences of physical activity, which were inadvertently linked to an exacerbation, resulted in a fearful *emotional response,* which contributed to the development of the *belief* that physical activity made their MS worse.

7.3.2.4 Fatigue

Fatigue was a particularly important theme and is represented as lying along the cross-section of the diagram. This is because it came through as having the potential to influence physical activity for <u>all</u> the participants interviewed, either because it was interwoven amongst the other themes or as a theme in its own right.

7.3.2.4.1 Fatigue as a thread interwoven amongst other themes

Fatigue features in many of the themes described above. For example, in *beliefs about physical activity*, fatigue features as a thread in a number of the beliefs described by participants. For example, fatigue is core to the belief in the *vicious cycle of activity/inactivity*. Similarly, it was frequently linked to the belief that there is *a fine line between benefit and harm* as 'harm' was often conceptualised as a worsening of fatigue. In *emotional response*, if previous experiences of physical activity had resulted in a worsening of fatigue, they often resulted in *anxiety* and a *fear* of participating in physical activity in the future.

7.3.2.4.2 Fatigue as a theme in its own right

Fatigue was also clearly a theme in its own right, in that the experience of fatigue was itself perceived to be a barrier to taking part in physical activity by the majority of participants. For example, these participants tried to describe their experience of fatigue and its impact on their ability to take part in physical activity:

> *It’s overwhelming. It’s the way I’d say, you just, you don’t really care about anything but wanting to have a rest. You know, somebody could tell you really awful news and you just don’t care 'cause you just wanna put your head down and that’s how bad it feels sometimes… (Hannah, Age 39, Secondary progressive MS)*

> *So you just feel that you know, by the time you’ve got home from work, even though you’ve sat down, and you know, had an hour or so rest, it’s just, you’re a bit lifeless really by the end of day and you think… oh no, I can’t get up, because then I have to walk, think about the stairs, I’ve got to get down the stairs and then I got to go and do these exercises and then get up the stairs…I just think perhaps I might just be, just feeling a bit, you know, tired. (Sarah, Age 43, Primary progressive MS)*

> *Really heavy…. I feel as though I have got concrete blocks. That is how I feel all the time. (Donna, Age 52, Relapsing-remitting MS)*

Participants reported the need to maintain *a balancing act* as a result of their fatigue. That is, they had to balance their activities carefully in order to manage their fatigue.

> *Mainly, it’s the worry about the fatigue, if I overdo it, I get the fatigue and you know, sort of balancing the two. (Hannah, Age 39, Secondary progressive MS)*

> *I balance my life around it, you know. We had a party Saturday night… I rested most of Saturday afternoon, so that I could enjoy the evening. (Hannah, Age 39, Secondary progressive MS)*

This need to balance activity and fatigue often resulted in forfeiting activity in favour of other commitments:

> *I used to go to the MS swimming thing at Papatoetoe…but then I was finding I was too tired on Thursday then, after doing all that. I mean, it was quite hard work what we did for an hour in the pool, so I’d find that I was too tired on a Thursday, which was harming my work. Which is more…? I feel it is more important carrying on in a work place, so… (Hannah, Age 39, Secondary progressive MS)*

Related to this, participants reported only being able to participate in physical activity if the effort required to initiate engagement in activity was not too great, because if they expended too much energy at the outset, they rarely had enough energy left to actually take part in the physical activity.

> *I honestly don't think I would go swimming if I didn't have that [a disability card]. It means that I know I am going to get a park right outside the swimming pool. If I had to fight for a car park and then walk to it after I had been swimming, I just probably wouldn't do it. It's like… what do I want to use my energy for? Do I want to use my energy for a battle to find a car park, or do I want to use my energy to swim and exercise my body really well? (Cheryl, Age 41, Relapsing-remitting MS)*

> *But I mean, do what you can and somewhere that you can get to very easily without having to walk miles, you know, to go and do it, because, you know, if you have to walk a fair distance before you get there, you kind of ummm… you've used most of your energy to, you know, to actually get there before you do, before you do a workout. So, it'd be quite nice to just have something that's fairly, you know, easy, accessible. (Sarah, Age 43, Primary progressive MS)*

Furthermore, balance was required to ensure that one reserved enough energy to be able to get home and meet other responsibilities on activity completion.

> *You do have to plan a little bit as you say because like I am at the gym and so I will have to allow enough energy to get home, to be able to drive home, get inside, get the girls into bed. You know, there has to be sort of enough energy before I crash in the corner. (John, Age 44, Secondary progressive MS)*

7.3.2.5 Feedback loop

Another feature on the diagram in Figure 7.1 is the feedback loop which links physical activity behaviour with three of the themes discussed above: i) Messages about physical activity; ii) Previous experiences of physical activity; and iii) Significant illness-related events. This feedback loop represents the ongoing adjustment and readjustment in physical activity behaviour that seemed to occur each time someone was faced with any of these three things. These new experiences, in turn, resulted in an alteration in one's beliefs about physical activity or an emotional response, leading to subsequent behaviour change. It should be noted that the feedback loop does not include the "what ifs", but instead an arrow links significant illness-related events to this box. This is because it seemed that the "what ifs" were more likely to change as a result of a significant illness-related event, such as an exacerbation or symptom change, and were less likely to change in the absence of such events.

7.3.2.6 Pre-MS Activity

One theme that has not been referred to so far is pre-MS activity. There are several important things of note relating to this component. First, it seemed to stand alone. That is, there did not seem to be any logical connections between this and other themes, but rather it seemed to have the potential to have a direct effect on physical activity behaviour post-diagnosis. Second, it did not seem to be a strongly referred to theme. That is, other themes seemed to come through as having a more important influence on physical activity behaviour, often over-riding the influence that pre-MS activity might have. For example, if someone had engaged in a lot of physical activity prior to MS, it did not necessarily follow that they would continue engaging in physical activity post diagnosis; as is clear from the experiences of one participant described above whose depression resulted in disengagement post diagnosis. Finally, this theme seemed to specifically influence the type of activity one might engage in post-diagnosis rather than the decision of whether or not to participate at all in physical activity. For example, the following participant would not go to the gym, nor would she ride a horse, simply because she had never engaged in such activities previously:

> *Oh, no gym. No. Never been a gym member…..I never joined the gym. I keep myself to myself. (Irene, Age 53, Primary progressive MS)*

> *HUSBAND: I told you you should be going riding. Told her to get on a horse and do disabled riding.*
> *PARTICIPANT: I have never ridden a horse. Never.*
> *HUSBAND: I know, but when I was doing the barn….they had a lady there that had MS.*
> *PARTICIPANT: Yeah, but she might have always ridden a horse….They're big aren't they. I mean, I think you have to be that person. (Irene, Age 53, Primary progressive MS)*

This was the same participant referred to above who used to go walking, up until she was admitted to hospital as a result of an exacerbation.

7.3.2.7 Moderating variables

There were a range of themes which could be considered moderating variables in the decision to take part in physical activity. That is, there were a number of themes that seemed to impact on the strength of the influence that core themes, such as *beliefs about activity* and *emotional response*s, had on physical activity behaviour. These themes are listed at the bottom of the diagram in Figure 7.1 and their potential to influence physical activity behaviour is depicted by the dashed arrows crossing the path of the arrows linking the core themes to physical activity behaviour. Table 7.4 lists each of the themes identified as possible moderating variables, along with the categories that make up each of these themes.

Table 7.4: Themes identified as potentially ‘moderating’ the decision to take part in physical activity

Theme	Categories	Examples
Management strategies Participants reported using a range of strategies to manage the impact of physical activity on their symptoms and to prevent them ‘overdoing it’. Some of these were positive strategies which enabled increased participation; however, for some there was a risk that one may put too many limits on themselves e.g. avoiding activities they could do or ceasing activities earlier than is necessary.	I know my limits	Sometimes I feel like I could go and walk twice the distance, but if I do, that’s me out for the rest of another two days. So its best just to keep at the level I am at, keep it there. (Julie, Age 52, Relapsing-remitting MS)
	I listen to my body	I think oh gosh, I should do my vacuum cleaning and yeah… no, I am not feeling great…. Oh then, I really need to sit down. You know. I listen to my body. When my body says sit down, I sit down. (Donna, Age 52, Relapsing-remitting MS)
	Setting realistic goals	If you’ve done the distance, you’ve, you know, you had decided you’re going to do, just be sort of like happy that you’ve done that because at least it has lifted your spirits. I mean, there is no adrenaline rush or anything like that, but it’s lifted your spirits, and you feel like you’ve, you know, you’ve managed something by doing that, rather than sort of push yourself that little bit extra and then find… (Sarah, Age 43, Primary progressive MS)
	Activity planning and energy conservation	Yeah, so I do, I do my jobs differently as well, I make sure that I only do one job and have a rest, and I tend to do it more in the morning, when I’m better than in the afternoon. The afternoon I just relax, yeah… (Hannah, Age 39, Secondary progressive MS)
	Finding alternatives	I will find another way of doing it. I might do slightly less and … I guess it does limit me… in terms of... if I am not having such a good time with my legs and I go out shopping, I can’t keep that going for terribly long. That sort of thing. But, generally, I just find another way to do it rather than not do it. (Cheryl, Age 41, Relapsing-remitting MS)
	Rest	PARTICIPANT: Really tired, really tired. You have got to sit down, you have got to put the chair up, rest the legs there. That feels so much better than feet on the ground. INTERVIEWER: And how long does it normally take for you to overcome that period. So how long would you normally need to rest for? PARTICIPANT: Oh I will rest all day. (Marcus, Age 47, Primary progressive MS)

Theme	Categories	Examples
Self-consciousness/ Embarassment Some participants were concerned about how others perceived them when they took part in physical activity.	Self-conscious of disability	I thought, that was winter, so I thought I would do it a bit later [go for a walk], but people start turning up and I will get half way around [the park] and I will be all wobbling and people can see me sort of thing… when I am by myself and no one can see me I have a laugh about it, I just don't like the fact that other people can see me, and think 'look at him' sort of thing. Is he pissed or something? (Damien, Age 38, Secondary progressive MS)
	Embarrassment of taking part in physical activity with 'able-bodied' people	You can be self conscious about your body, self conscious about how little weight… you know, you're lifting these little tiddlers and you're beside this person that's lifting these weights that look like bigger than your kids are. (John, Age 44, Secondary progressive MS)
Social component of physical activity Related to the fact that some participants valued the social interaction that engagement in group activities resulted in.	No categories	I mean I used to go to the gym, I used to… I went to Contours and did some funky fit, funky dance? Funky fit. So you would dance and it's just nice that you go and you socialize… and then, all of a sudden it's kind of… that side's been taken away to a degree, because you go down stairs and there's no one to talk to. You know, if you ummm… are sort of used to being a social person, little social butterfly… Yeah, but that's been taken out… (Sarah, Age 43, Primary progressive MS)
Social support This is related to the role of social support in the decision to take part in physical activity. It was identified that social support had the potential to either facilitate or impede engagement in physical activity. For some, the presence of others meant that they were supported to engage in activity through encouragement, the provision of resources or helping with other commitments so that chosen activities could be prioritised. For others, the presence of others resulted in everything being done for them, removing the necessity of having to engage in physical activity.	Encouragement	I would have a go at anything. It's probably just someone to give me that push, probably more… this is what we are doing now, and I would probably do it. But if it was left to my own devices I probably wouldn't. (Damien, Age 38, Secondary progressive MS)
	Policing	[My husband] would tell me off when I overdo it…makes me sit down… (Hannah, Age 39, Secondary progressive MS)
	Presence of support	Every now and again, yeah, and it has to be sort of fairly short walk, I normally go with my husband and, you know, he's there for, to hold on to an arm… (Sarah, Age 43, Primary progressive MS) I don't have anybody to do anything for me and I have to do it myself. I don't have a partner; I don't have anything like that. And it's funny, because, other MS people… they say to me. How can you do this? I can't do it and I've got a husband. I don't say it, but that's the reason they can't do it is cause the have got somebody to do it for them. If they had to do it themselves…. You just do it. You know…. (Donna, Age 52, Relapsing-remitting MS)

Theme	Categories	Examples
Advice from and access to health professionals Specific advice from health professionals experienced in MS was believed to be important. For example, activities that might maximise benefit, how to carry out those activities correctly, guidance on the most appropriate equipment, and so on. Participants indicated that access to health professionals for this type of advice was limited.	No categories	You know…. I tried to sit on a swiss ball and do… you know what, I couldn't sit on it, all this wobbling around - oh dear! I'd have to strengthen up my core and, so you know, it's just having those sorts of things to run by physiotherapists that do know MS, what people that suffer with MS can and cannot do, you know, and just sort of maybe finding an activity or different equipment that we can use. (Sarah, Age 43, Primary progressive MS)
Lazy or MS? This theme is related to the idea that it is difficult to distinguish if one is simply being 'lazy', a normal feeling that many people experience, or whether one's lack of motivation is a result of the MS.	No categories	You have those limits that are put in by MS but you have also got normal person's limits where perhaps you don't want to do that, you don't feel like getting up in the morning, or it's a Monday after a hard weekend or it's a Friday and you have had a whole week of work. But you don't really feel like getting up and mowing the lawn because some sod fertilised it or whatever, you just don't feel - that's the normal person, so to deciding whether it's the MS talking or just the normal human being talking is difficult. (John, Age 44, Secondary progressive MS)
Self-efficacy This is related to the fact that much of one's expectations of ability are based on their pre-MS self and so there is an uncertainty about their ability post-MS diagnosis and a fear that they won't be able to participate at the level they used to. Many people also had a lack of confidence in their ability to achieve a certain task and so rather than attempt it and fail, they avoided that task.	Expectations of self	Well, yeah, it kind of just, you know, highlights the things that you used to do… that you can't do that anymore, so it's kind of… and that's the other thing, is that you will go and think, oh, ok, I can, I go and use this piece of equipment and then find out that you can't use it anymore. (Sarah, Age 43, Primary progressive MS)

Theme	Categories	Examples
Self-efficacy cont'd	Lack of confidence in ability	No gymnastics type work or gym. No swimming for the water is not the right temperature for me, it's way too cold, if it's hot, it's too hot, if it's my temperature, it's not the pool's temperature. So, swimming is out. I don't do any running because I can't run. I can walk about I suppose twenty metres in my walker, that's my lot. I can do two hours worth of cross stitch and my fingers give up the ghost, any kind of handwork I can last two hours and my fingers don't work. And that's it. (Julie, Age 52, Relapsing-remitting MS)
Impairment	A disconnect between mind and body	With MS it's like standing at the top of a cliff and yelling and your feet are at the bottom and the volume has gone down from when you yelled to when you hear it at the bottom and your feet go, "excuse me, run that past me again". (Julie, Age 52, Relapsing-remitting MS) I feel really, really unsteady on my feet. I feel like a foal, a new born foal. The brain just simply doesn't know where the rest of my body is. (Donna, Age 52, Relapsing-remitting MS)
	Heat sensitivity	When I was playing netball when my body would overheat I couldn't see and my eyes would go all fuzzy and I couldn't see a thing. It was terrible and so I had to stop that, because there's no fan. (Teresa, Age 34, Relapsing-remitting MS)
	Co-morbidity	MS doesn't exclude you from getting other things. It's like not an exclusive disease…stationary is not the best thing for MS… you need to try to sort of move around. If you can't move around, that starts to sieze up the body or it feels like it to me… sieze up the body and stop being able to do things. But if you move around you're damaging the treatment for cellulitus in the leg… (John, Age 44, Secondary progressive MS)

Theme	Categories	Examples
External factors	Weather	I really don't exercise very much. Particularly in winter time. I do in summer time. (Donna, Age 52, Relapsing-remitting MS)
	Accessibility	Let's go out for dinner tonight! I immediately think how far from the restaurant will we have to park? (Donna, Age 52, Relapsing-remitting MS)
	Structures to support engagement in physical activity for people with MS	I think in terms of structured exercise places, there still isn't much of an awareness of disability and including people with disability in exercise. Umm… like, I have tentatively signed up for a duathlon thing… there is nowhere on the form to say… you know… I have a disability…. there is no where I can go, look, I have some special needs, can I talk to someone about … you know, how you can meet my needs… (Cheryl, Age 41, Relapsing-remitting MS)
	Equipment for people with MS	And then you get on one of those fancy bikes that tells you 'punch in your age' and it works out how much resistance you're supposed to have and where your heart rate is supposed to be and so off you go. It was just too difficult. I just couldn't do it with the MS, so I had to adjust the age to make it sort of lose the resistance. So at the age of thirty the machine told me I was 62! (John, Age 44, Secondary progressive MS)
Personal resources	Cost	Yeah, I used to have quite an active lifestyle after work and stuff. I was always doing something, but now… it's more financial than anything. (Damien, Age 38, Secondary progressive MS)
	Time	I mean that is an issue for all women I guess with children, but you know… my… I do have to fight for it and not fight my family, but fight life pressures and go - no, I am going to do this. This is for me. I need to do it. I will feel better if I do it. (Cheryl, Age 41, Relapsing-remitting MS)

7.4 SUMMARY

Study Five was the second study to be carried out as a part of Phase II of this doctoral research. The aim of this study was to gain a deeper understanding of the barriers and facilitators to engagement in physical activity from the perspective of people living with MS. A key finding of this research is that the decision to engage in physical activity is a complex one, influenced by a number of variables which appear to interact. The most prominent themes identified which seemed to play a key role in influencing physical activity behaviour related to *beliefs about physical activity* and the *emotional response* to previous experiences of physical activity. These findings are contrary to findings from the questionnaire study (Study Four) which failed to identify cognitive-behavioural variables as a significant predictor of physical activity. A third key theme related to the role of *fatigue* in the decision to take part in physical activity both as a direct result of the experience of fatigue itself, but also with regard to the role of fatigue as it related to other key themes. These findings are discussed in more detail in Chapter Eight, comparing and contrasting findings from both this study and Study Four, and discussing them both in the context of current knowledge in the field.

CHAPTER 8

PHASE II DISCUSSION

Despite increasing evidence that physical activity is beneficial for people with MS, they have been found to engage in particularly low levels of physical activity when compared with the general population and other chronic illness groups. At the time of carrying out this doctoral research, little research had explored the barriers and facilitators to activity faced by people with MS (see Chapter Two). A greater understanding of the variables associated with engagement in physical activity could aid the development of interventions focusing on adherence. Therefore, the key aims of the second phase of this doctorate were to:

a) Explore the relationship that a range of variables, in particular health beliefs and illness behavior, have with participation in physical activity in people with MS (addressed in Study Four in a cross-sectional questionnaire study [Chapter Six]); and

b) Conduct an in-depth exploration of the barriers and facilitators to physical activity identified by people living with the condition (addressed in Study Five using a qualitative descriptive approach [Chapter Seven]).

This chapter will discuss the key findings of these studies: first, comparing and contrasting results between the two; and second, discussing the findings in the context of recent research in this field. As indicated in Chapter One, clinical implications will not be discussed here, but rather are discussed in detail in Chapter Twelve.

8.1 KEY FINDINGS

Table 8.1 summarises the key findings from each of the two studies carried out during Phase II and any contrasting findings between the two. In addition, the final row highlights how these findings augment and/or challenge existing knowledge in this field.

Table 8.1: Key findings from Phase II

	Questionnaire study (Study Four)	Qualitative investigation (Study Five)
Key findings	**Important covariates identified included:** Use of legs (partial or no use) Time since diagnosis Secondary or Primary progressive MS **Final multivariable analyses identified:** ↑exercise and household chores self-efficacy ↑mental fatigue; and ↓number of perceived barriers **To be significantly associated with:** ↑physical activity behaviour	Physical activity behaviour appears to be influenced by a number of interacting variables. **Key themes included:** Beliefs about physical activity Emotional response Fatigue The **interaction between variables** seemed particularly crucial e.g. the tension created by the co-existence of conflicting beliefs The cyclical nature of the decision to take part in physical activity that occurred over time highlighted that **decisions are constantly being reviewed and reconsidered in light of new information** (e.g. reflection on own experiences, changes in the condition, interaction with health professionals, and so on)
Contrasting findings between the two studies	The predictor accounting for the highest proportion of variance in physical activity behaviour was **exercise self-efficacy** (accounting a small, but significant 8% of variance) *None* of the measured cognitive-behavioural variables were retained in the final multivariable model	The decision to take part in physical activity is a complex one, with a **multiplicity of factors** seeming to play a role. The most striking finding was the central role of one's **perceptions and beliefs about physical activity** Self-efficacy appeared to only play a *minor* role in the way people spoke about their experiences of engagement in physical activity
Novel findings	This study is one of the first to explore the amount of variance in physical activity accounted for by frequently explored psychosocial variables **over and above that accounted for by important illness-related variables**. As such, the novel finding from this study is that despite confirming existing findings that self-efficacy, perceived barriers to physical activity and fatigue are significant predictors of physical activity in people with MS, that **the % of variance accounted for by these psychosocial variables (12%) was small compared to that accounted for by illness-related variables (42%).**	This study is the **first fully qualitative investigation** carried out to explore physical activity engagement from the perspective of people with MS. The findings highlight a number of aspects of the decision to engage in physical activity which have not been previously acknowledged in the literature, including: • That the decision is **complex, fluid,** and **individual** • The **role of self-efficacy appears less clear** than previous research has suggested • **Beliefs and perceptions about physical activity** may be important key determinants • The **role that health professionals can play** in the development of beliefs about physical activity

As highlighted in Table 8.1, the final multivariable analyses in Study Four identified greater exercise and household chores self-efficacy, greater reported mental fatigue, and lower number of perceived barriers to physical activity to be significantly associated with greater participation in physical activity, over and above the variance accounted for by illness-related factors such as type of MS and use of legs. The predictor accounting for the greatest proportion of variance in physical activity behavior was exercise self-efficacy, accounting for a significant 8% of variance over and above identified covariates. The fear avoidance beliefs subscale was the only subscale from the CBSQ found to be a significant predictor of physical activity behavior in the individual measure regression analyses. Contrary to study hypotheses, this did not retain significance when entered into the final multivariable analyses.

In contrast, Study Five found that a number of variables appeared to interact and worked to tip the decisional balance regarding physical activity engagement for people with MS, highlighting the complexity of the decision to take part in physical activity for this population. The most prominent emergent themes which seemed to play a key role in influencing physical activity behaviour related to *beliefs about physical activity* and the *emotional response* to previous experiences of physical activity, significant illness-related events, and/or concerns about what *could* or *might* happen as a result of physical activity engagement. A third key theme related to the role of *fatigue* in the decision to take part in physical activity both as a direct result of the experience of fatigue itself, but also with regard to the role of fatigue as it related to other key themes.

One of the most striking findings from Study Five was the apparent tension surrounding the decision to take part in physical activity, which seemed to be related to the co-existence of conflicting beliefs about physical activity. The example given in the findings section of Chapter Seven (see page 211) illustrates a conflict between a belief in the vicious cycle of activity and that a fine line between benefit and harm exists. So, even if there was a strong belief in the cycle of activity, if one did not have confidence in their ability to participate without crossing the ‘line’, then they invariably chose not to participate at all, or participated at such a low level that they would be unlikely to experience any benefit. Complicating matters further is the unpredictable nature of MS which results in the ‘line’ moving from day to day. This cognitive tension is something that has not been previously identified or explored in the literature, and yet it appeared to be crucial to the decision to engage (or not) in physical activity from the perspective of those taking part in this qualitative investigation.

An important question when considering these findings is to consider how they challenge and/or augment existing knowledge in this field. The final row in Table 8.1 summarises the novel findings of this phase. Regarding Study Four, the key contribution of this study to existing literature is that it is one of the first studies accounting for important illness-related variables in the exploration of factors predictive of engagement in physical activity in people with MS. The finding that self-efficacy significantly predicts participation in physical activity was not surprising given it has been linked to physical activity in this population in previous research.(12,19,20,70) The relationship between self-efficacy and physical activity in people with MS has been further confirmed more recently,(236-238) resulting in one of the first efficacy enhancing exercise programmes targeted to people with MS being piloted.(239) However, it should also be acknowledged that while accounting for the largest proportion of variance, self-efficacy only accounted for 8% of variance in physical activity, less than what has been previously reported.(19,20) Likewise, perceived barriers to activity only contributed a small, albeit significant 1% of variance. In both cases it could be argued that despite being statistically significant, neither is clinically meaningful when compared to the 42% of variance accounted for by the illness-related covariate variables. The large proportion of variance accounted for by these illness-related variables suggests that intervention efforts may make the most difference if targeted at those people more prone to inactivity, such as people with secondary and progressive forms of MS and those with ambulatory impairments. However, importantly, unlike these illness-related variables, factors such as self-efficacy, perceived barriers and mental fatigue are potentially modifiable and so may still offer a useful focus for clinicians when trying to facilitate physical activity engagement in this population.

Regarding Study Five, the key contribution of this study to existing literature is that it is the first fully qualitative study specifically designed to explore physical activity engagement from the perspective of people with MS. As a result, this study highlighted a number of key aspects of the decision to take part in physical activity that had not been previously acknowledged in existing literature. In particular, an important key finding from Study Five that is rarely given credit in the literature is the complexity of the decision to engage in physical activity. It appears from the findings of Study Five that the decision to engage in physical activity is a) influenced by a complex interaction of variables; and b) an ongoing process which is continually readjusted in light of new information and in response to changes in the condition and one’s lifestyle.

This complexity, particularly the ongoing nature of the process (depicted by the feedback loop in Figure 7.1) is a phenomenon that is yet to be acknowledged in much of the research exploring physical activity in MS to date. In fact, it has been argued that the temporal nature of the decision to engage in physical activity is an area that has been largely ignored in the broader field of behaviour change.(240) In their paper, Hall and colleagues argue that a core assumption of a large proportion of existing theoretical models of behaviour change assume intention-behaviour continuity (that is, that behaviour change will follow an intention to change), but that this assumption only holds when: “1) the behaviour in question is discrete rather than repetitive, 2) the behaviour is fully under the control of the individual, and 3) the costs and benefits of the behaviour occur at the same point in time allowing for equal temporal weighting”.(240, p.433) They argue that health protective behaviours, such as physical activity, are unlikely to meet these criteria, and instead propose a self-regulatory approach to be a more viable perspective to consider in the development of interventions targeting engagement in physical activity.

Recognition of the potential of a self-regulatory informed approach to health behaviour change is increasing.(241,242) Michie et al. assessed the effectiveness of a range of behaviour change techniques, including five self-regulation techniques, using meta-regression and found the inclusion of *self-monitoring* to be the individual technique most predictive of effective physical activity and/or nutritional strategies.(241) Added to this, they found that interventions which included *self-monitoring* combined with at least one other self-regulatory technique to be more effective at promoting behaviour change than those strategies not including this combination of techniques. Another paper recently published proposed a new theory for behaviour change, The Integrated Theory of Health Behaviour Change, drawing on a comprehensive review of the literature in this field.(242) Self-regulation skill and ability were integrated as a core component into this proposed theory and suggested such techniques to be essential to the process of implementing behaviour change. The findings of Study Five would support this view.

8.1.1 CONTRASTING FINDINGS BETWEEN STUDY FOUR AND FIVE

As highlighted above, in Study Four self-efficacy was identified to account for the largest proportion of variance in physical activity over and above that accounted for by the illness-related variables. As discussed above, though self-efficacy accounted for a small amount of variance in comparison to the illness-related variables, it was significant and is a potentially modifiable variable. Therefore, self-efficacy may offer a useful focus for intervention efforts aimed at facilitating engagement in physical activity for people with MS. Contrary to study hypotheses, the cognitive-behavioural variables measured in Study Four were not found to significantly predict physical activity in people with MS.

In contrast, the key findings in Study Five suggest cognitive-behavioural variables to play a crucial role, while self-efficacy was only vaguely referred to during the qualitative interviews. The finding that illness beliefs and illness behaviors did not significantly predict physical activity behavior was contrary to what one might intuitively expect based on previous research that has explored the role of such variables in other aspects of the illness experience in people with MS.(103,104) It is possible that cognitive-behavioral variables simply do not play a role in the decision to take part in physical activity for people with MS and one could of course argue that the findings from a small qualitative study are not generalisable and it is, therefore, not surprising that such findings do not translate to a larger quantitative study. However, given how important beliefs about activity and emotional manifestations relating to physical activity seemed to be for those interviewed in Study Five, some possible reasons for this discrepancy with what was anticipated are discussed below.

8.1.1.1 Possible multicollinearity

As indicated in Chapter Six, secondary analyses were conducted to explore the lack of significance found in Study Four in more depth. First, correlation coefficients between the individual CBSQ subscales and between those subscales and physical activity engagement were examined. While fear-avoidance was found to be the only *significant* predictor of physical activity, five of the CBSQ subscales were found to be significantly correlated with participation in physical activity. However, fear-avoidance beliefs were also found to be highly correlated with each of these subscales, with correlations ranging from 0.32 to 0.52. While these correlations were not high enough to raise concerns regarding multicollinearity (where correlations >0.8 were identified (150)), they may account for the fact that fear-avoidance beliefs was the only variable retained in the regression model when analyses were conducted on the CBSQ alone (see Table 6.10). Second, correlations between predictor variables in the multivariable regression analyses were also examined. Fear-avoidance beliefs was found to be highly correlated with exercise self-efficacy, which may explain fear-avoidance beliefs being absent in the final model where exercise self-efficacy was found to be the strongest predictor of physical activity (see Table 6.14).

8.1.1.2 Inadequate measurement of cognitive-behavioural variables

Another explanation for the contrasting findings between Study Four and Five may be that some of the items and subscales included in the CBSQ do not capture the essence of the beliefs and emotional responses as described by participants. The CBSQ is designed to measure broader illness beliefs and illness behaviors with particular reference to symptom-related cognitions and illness behaviors which are linked to symptom management. However, the beliefs identified in the qualitative component of this study were specific to physical activity. For the most part, those interviewed believed in the benefits of physical activity. However, this was tempered by the fact that they also perceived there to be a fine line between the benefit and harm of physical activity, creating a tension regarding the decision to take part in physical activity. The fear-avoidance beliefs subscale is the only subscale on the questionnaire that makes specific reference to exercise or activity, which may account for the fact that this subscale was found to be a significant predictor of physical activity when the CBSQ was considered in isolation. However, the items on this subscale focus on fear-avoidance beliefs associated with symptomatic concerns (e.g. ‘I am afraid that I will make my symptoms worse if I exercise’). While, this was a relevant concern for some people, for the most part those interviewed conceptualised their fear avoidance slightly differently. Instead of having concerns about their symptomatic response to physical activity, a number of participants referred to a fear of falling or a fear of injury. This fear seemed to stem from the concern that the consequences of such events could be detrimental to their MS, and having MS meant that they would have more difficulty bouncing back from these events. In response, a number of people reported avoiding activity so as not to put them at risk. This subtle difference underpinning the fear-avoidance belief may have contributed to this subscale not being found to be a significant predictor in the multivariable analyses. Similar nuances may also exist for other subscales, leading to them failing to be detected as a significant predictor of physical activity.

8.1.1.3 Self-efficacy - an oversimplification?

In the time since these studies were conducted, there has been an increase in research aiming to make sense of physical activity behaviour and address adherence issues in people with MS.(5,17,18,236-239,243-251) In these studies, self-efficacy is overwhelmingly the most researched construct, with a number of studies exploring some aspect of self-efficacy and/or underpinned by social-cognitive theory.(18,236-239,248-251) Indeed, one study which piloted an efficacy enhancing exercise programme in people with MS found that those in the treatment condition attended more intervention sessions, and that regardless of treatment condition, those with a stronger sense of exercise self-efficacy demonstrated greater adherence to the programme.(239) While longer term adherence to a physical activity regimen was not explored by McAuley et al., the findings were accredited as preliminary evidence of the potential for effectiveness of interventions targeting self-efficacy. However, it has been argued that it is as yet unclear what the underlying mechanism of this programme is (and more generally, physical activity behaviour in people with MS) since there is an absence of data aiming to determine whether the observed changes in self-efficacy are correlated with changes in physical activity behaviour.(249) In an effort to fill this research gap, Plow and colleagues aimed to determine whether changes in a range of psychosocial constructs (including self-efficacy) were associated with change in physical activity in response to a wellness intervention.(249) Surprisingly, they found that self-efficacy actually reduced through the course of the intervention, despite physical activity behaviour increasing. They argue that this may be in part due to their selected self-efficacy measure in that they measured confidence in overcoming barriers to exercise, in contrast to the large majority of previous work which has measured exercise self-efficacy, or confidence in performing exercise behaviours. However, it could also be argued that this finding sheds doubt on the possibility that changes in self-efficacy itself is the underlying mechanism effecting change, opening the door to other possibilities.

The absence of self-efficacy as a core theme in the qualitative study (Study Five) further corroborates the possibility that focusing *only* on self-efficacy in relation to enhancing activity and exercise may be an over-simplification. The qualitative findings indicate that while self-efficacy had a role to play, a number of other factors, which would be amenable to intervention, were identified as potentially key determinants. For example, a number of participants expressed safety concerns related to engagement in physical activity and avoided physical activity as a result. One could suggest that the lack of confidence in one's ability to engage in physical activity safely is the key underlying mechanism in this example, and thus still related to self-efficacy. However, the qualitative data would suggest that the belief that physical activity may have detrimental effects on MS symptomology or the underlying (potentially irrational) fear of injury or falling may be more influential.

8.1.2 CONSIDERING FINDINGS IN THE CONTEXT OF RECENT RESEARCH

Key findings from each of the studies are discussed in detail below in the context of existing literature in this field. Please note, where findings have been discussed in detail above, reference to them will not be repeated in this section (e.g. self-efficacy related findings).

8.1.2.1 Study Four

8.1.2.1.1 Identified covariates

The covariates identified in Study Four included lower limb function (both partial and no use of legs), type of MS (both secondary and primary MS), and time since diagnosis. The identification of lower limb function and type of MS as important covariates is consistent with previous research indicating use of a cane and primary or secondary progressive forms of MS to be associated with lower levels of physical activity.(7,244,249) Use of a cane could be considered indicative of lower limb function, however, as indicated in Chapter Six it could also be argued that the decision to use an assistive device may be influenced by a variety of factors and could be treated as a potentially modifiable variable rather than a covariate to be controlled. Identification of time since diagnosis as a covariate in Study Four is in contrast to previous work exploring demographic associates of physical activity, where time since diagnosis was not found to be significantly associated with physical activity.(244) It is possible that this finding is a reflection of an interaction between time since diagnosis and MS type. For example, Table 8.2 presents the mean (range) time since diagnosis by MS type for participants in Study Four. This information was not presented in the results, but is introduced here as it becomes relevant in the context of this discussion. The data in Table 8.2 highlights that as expected, the mean time since diagnosis is marginally higher for the both the secondary progressive and primary progressive MS subgroups in this study population. As highlighted above, people with these types of MS have been found to engage in lower levels of physical activity than their counterparts, and hence may be influencing the link between time since diagnosis and physical activity.

Table 8.2: Mean (range) time since diagnosis by MS type

MS Type	Time since diagnosis mean (range)
Benign	8.5 (0.2 – 30.0) years
Relapsing-remitting MS	9.6 (0.4 – 40.0) years
Secondary progressive MS	16.3 (0.9 – 50.0) years
Primary progressive MS	11.9 (0.0 – 34.0) years

8.1.2.1.2 Predictors of physical activity

In addition to self-efficacy, which has been discussed in detail above, fewer perceived barriers to physical activity and greater reported mental fatigue were also significantly associated to increased engagement in physical activity. The association between perceived barriers to physical activity is consistent with previous research,(12,13,16,70) which has also found a lower number of perceived barriers to be associated with greater participation in physical activity. Table 8.3 presents the top five barriers endorsed by people with MS in Study Four compared with the top five barriers endorsed in previous research.

Table 8.3: Top five barriers endorsed by participants in Study Four compared with those endorsed in previous research

Rank	Study Four of this doctoral research	Urban MS (13)	Rural MS (13)
1	Too tired	Too tired	Too tired
2	Impairment	Impairment	Impairment
3	Lack of time	Lack of time	Lack of money
4	Bad weather	Interferes with other responsibilities	Lack of convenient facilities
5	Feeling that I can't do things correctly	Lack of money	Safety concerns

The top five barriers endorsed by people with MS in Study Four were very similar to those endorsed in previous research with people with MS.(13) Table 8.3 indicates that the top two barriers are consistent across the board with 'Too tired' and 'Impairment' endorsed most frequently in the current study and in previous research. The endorsement of 'Too tired' is not surprising. This is consistent with the regression findings, where fatigue was identified as being significantly associated with physical activity behaviour. It is also consistent with participant responses to the open-ended questions in Study Four, where participants frequently suggested fatigue to be their main barrier. Impairment was also a commonly referred to barrier by participants in response to the open-ended questions. Lack of time was endorsed by both the sample in Study Four and urban people with MS in previous research. Given the sample in the questionnaire study (Study Four) was also an urban sample, this is not surprising. While the fourth and fifth ranked barriers in the questionnaire study are not consistent with those reported in previous research, their responses are not dissimilar, with barriers such as 'Interferes with other responsibilities', 'Lack of money', 'Lack of convenient facilities', and 'Safety concerns' all some of the most frequently endorsed items in the current study. In addition to the top five barriers reported here, other barriers to physical activity reported by a large proportion of the study sample included barriers such as 'feeling I can't do things correctly'; 'feeling what I do doesn't help'; 'lack of information about what to do'; and 'lack of help from health care professionals'. All of these suggest a role for health professionals and highlights the importance of ensuring that messages about physical activity engagement are clear and consistent across professions and that time is spent addressing people's concerns about physical activity engagement. This is not dissimilar to findings reported in a recent study which explored the barriers and facilitators to physical activity from the perspective of those living with a range of neurological conditions (including MS) using focus groups.(252) *Confidence in health professionals* was found to be a key theme in this study; a finding that was further corroborated in a later phase of this work using a cross-sectional survey.

There are two findings of particular interest in relation to fatigue: (1) that *mental* fatigue remained significant in the final regression model, whereas *physical* fatigue did not and; (2) that the association between mental fatigue scores and physical activity behavior scores was negative, indicating that as mental fatigue increases, so does participation in physical activity (low scores on the CFQ represent higher levels of subjective fatigue). Both of these findings are contrary to what one might intuitively expect. With regard to the first point, given that fatigue is reported to be the most disabling symptom for the large majority of people with MS,(224) one might have expected physical fatigue to play a more significant role. It is possible that this highlights a measurement problem in relation to conceptual definition of fatigue used in the CFQ. However, this scale has been used successfully in research including people with MS previously (136) and was the preferred fatigue scale of representatives of the MS Society consulted during development of this doctoral research due to its perceived face validity in comparison to other measures of fatigue. Both of these points indicate a strong conceptual basis. Alternatively, if one views fatigue as a symptomatic component of impairment, then this finding could be considered consistent with previous work which suggests that impairment itself is less predictive of outcome and adjustment in MS than one might expect; and that other, more modifiable factors such as illness perceptions, are more influential.(103) Findings from the qualitative study (Study Five) support such a view. For interview participants, while fatigue was clearly an important factor when considering engagement in physical activity, it was not necessarily the fatigue itself that contributed to choosing to take part, or not, in physical activity. Rather, one's beliefs about physical activity and how these interacted with one's experience of fatigue seemed more important. For example, many of those who believed there was a fine line between the benefit and harm of physical activity, conceptualised worsening of fatigue as 'harm'. Those who had confidence in their ability to recognise their 'tipping point' were more likely to take part in physical activity than those who did not. So, in this example, the experience of fatigue itself is not the deciding factor, but rather the individuals' beliefs about physical activity, as well as their self-efficacy beliefs.

The second point highlighted above, that increased mental fatigue was associated with increased participation in physical activity, is also perhaps less surprising in light of findings from Study Five which highlighted a number of tensions relating to the decision to take part in physical activity. It is possible that engagement in physical activity results in increased mental effort as people struggle with these tensions. This is not dissimilar to findings in previous research which reports a strong sense of personal control in MS to be associated with greater mental fatigue, suggesting that sustaining a strong sense of personal control requires considerable mental effort.(103)

8.1.2.2 Study Five

As highlighted earlier, the qualitative study described in Chapter Seven is one of only a few studies qualitatively exploring activity engagement from the perspective of people living with MS. To the researchers' knowledge, there have been only four other qualitative studies carried out relevant to physical activity engagement for people with MS to date.(16,88,253,254) Only two of these had been conducted prior to Study Five (16,88) and all were limited in their scope in comparison to the current study. One study carried out by Stuifbergen and Rogers in 1997, explored a range of health-promoting behaviours, not just physical activity,(16) the limitations of which have been discussed in Chapter Two (see page 66). Two studies explored activity engagement within the context of an activity intervention.(88,254) That is, after participants had engaged in an activity programme, interviews were carried out exploring aspects of engagement in physical activity, with the programme as a reference point to aid discussion. Focusing on engagement in a specific programme may limit the findings of these studies in two ways. First, the very fact that participants have chosen to take part and engage in an activity programme limits the breadth of experiences being explored. Second, focusing on the barriers and facilitators to engagement in a specific programme is unlikely to capture broader issues associated with activity engagement outside of that structured setting. In addition, the most recent of these studies was particularly focused on the relevance and applicability of Social Cognitive Theory and the Transactional Model of Stress and Coping to physical activity engagement in people with MS.(254) Data were analysed using a modified analytical induction approach where interview data was coded into pre-determined categories derived from these underpinning theories. While this analytical approach suited the aims and objectives of that study, given the paucity of research in this area there seems little rationale for selecting a theoretical model to underpin research, and it could be argued that doing so may limit capacity for knowledge in this area. Finally, one recent study explored the meaning of exercise to people with MS.(253) Like the two studies already described, this study only included those already engaging in an exercise programme; the limitations of which have been cited above. In addition, the authors of this paper cited Social Cognitive Theory as the conceptual framework underpinning their research and had a specified focus of motivation and exercise adherence within a social context; further limiting the scope of the study.

A more in-depth qualitative inquiry was deemed necessary to develop a better understanding of factors influencing the decision to take part in physical activity for people with MS, and to explore the complexities of engagement in physical activity for people living with the condition. Certainly, the qualitative inquiry uncovered a range of key findings that previous quantitative work has failed to identify, augmenting current knowledge in this field. Some of these have been discussed above (see page 228). The key themes are now discussed in the context of current evidence.

8.1.2.2.1 Beliefs about physical activity

As indicated above, one of the most striking findings in this qualitative investigation was the tension created by the co-existence of conflicting beliefs. One example of this has already been cited above on page 230. However, such tensions were present throughout the data. This cognitive tension is something that has not been explored previously in the literature, and yet it appeared to be crucial to decision to engage (or not) in physical activity for people with MS in Study Five. How one interpreted previous experiences of physical activity, and messages from their health professionals were also identified as important contributing factors.

8.1.2.2.2 Emotional response

A range of emotional responses to physical activity and to the illness itself were reported, which seemed to influence the decision to take part in physical activity. For example, heat sensitivity is a common symptom experienced by people with MS,(43) and a number of participants experienced disturbing symptoms when taking part in physical activity believed to be a result of overheating (such as blurred vision). While these symptoms are generally transient, many people expressed a fear that they signaled the potential for more serious damage to occur, should they continue participating. These emotional responses seemed to result in a behavioural response, such as fear-avoidance (for example avoiding physical activity due to a fear of falling). There has been some work recently published which found some specific symptoms and worsening of symptoms over time to be associated with physical activity.(17,19,247) However, this work only explored the presence or absence of symptoms as an associate to physical activity. The findings of this qualitative investigation, however, suggest that it may be less about the presence or absence of symptoms, but rather how one perceives those symptoms, and the subsequent cognitive appraisal that takes place in response to those symptoms. For example, the following symptom interpretation and cognitive appraisal could lead to avoidance of physical activity: *Physical activity has caused an exacerbation of fatigue. I need to avoid physical activity in future in order to control my fatigue*.

Emotional responses also occurred as a result of illness-related events such as an exacerbation, loss of a job due to MS-related symptoms, and so on. These kinds of events appeared to be connected to depression, or a sense of helplessness, and resulted in a change in physical activity that people found difficult to come back from. There was a perceived need to continually readjust to new levels of disability and lifestyle changes that accompanied illness-related events which people found difficult. This finding is not dissimilar to those reported in a recent qualitative study exploring the lived experienced of people diagnosed with MS in relation to exercise, where participants expressed difficulty adjusting to the progressive and changeable nature of symptoms in MS.(255) A number of participants reported losing their job due to MS-related symptoms, and of those that had lost their job, none had regained employment, likely impacting on any incidental activity which invariably comes with a workplace environment. This could help to explain previous research that found unemployment to be significantly associated with physical activity.(244)

Interestingly, not all emotional responses were a result of actual events. For example, some people experienced fear due to concerns about what might happen if they take part in physical activity, rather than the fear being a result of a specific experience. This type of fear-avoidance behaviour is similar to that described in chronic pain populations where fear-avoidance beliefs have been linked to reductions in activity.(97)

8.1.2.2.3 Fatigue

The fact that fatigue came through as a core theme is unsurprising given reports that fatigue is identified as the most disabling symptom for a large proportion of people with MS.(224) Four findings warrant further consideration here. First, managing fatigue resulted in a continual balancing act which often resulted in a trade-off being made between activities. For example, many people had to make a choice between work and leisure, between everyday activities and structured physical activity, and/or between prioritising family commitments or taking care of their own health. Second, there was a sense that one had to plan every activity carefully, resulting in a lack of spontaneity. For example: scheduling activities at the most ‘optimum’ time of day; planning rest in advance of a scheduled activity; and planning activities so as to avoid multiple activities needing to be done consecutively. Due to the unpredictable nature of MS, even when an activity had been carefully planned, there is always a risk that one might be having a particularly ‘bad day’, resulting in all planned activities being cancelled. Third, there was a weighing up of advantages and disadvantages when considering participation in a given activity. For example, agreeing to take part in an activity could be dependent on the effort required to initiate engagement in that activity. This included consideration of issues such as whether or not there is a disabled parking space available or if someone could drop you at the door. Finally, a number of participants tended to engage in behaviour as a response to their symptomatic experience, rather than attempting to exert some control over their symptoms. For example, resting in response to fatigue, but then overdoing things in the absence of fatigue. Previous research has termed this behavioural pattern ‘all or nothing behaviour’.(104)

A recent qualitative study exploring the lived experience of people with MS in relation to exercise referred to similar experiences as those described above, such as: the balancing act between the effort required to initiate an activity versus retaining enough energy to actually engage in that activity; the choice to be made between engagement in physical activity versus other competing demands; and the lack of spontaneity.(255) Similarly, another study exploring experiences of motherhood in people with MS reported similar fatigue-related findings, with some of the aspects discussed here also prevalent in that study.(256) For example, the careful balancing act and lack of spontaneity discussed here are mirrored in the ‘conserving energy’ theme reported in that study.

In an effort to manage the impact of fatigue, many participants reported adopting a range of strategies (see Table 7.4). These strategies were not dissimilar to findings reported in previous work that identified that people with MS make a range of lifestyle adjustments in order to manage their illness.(16) While engaging in some of these management strategies could result in increased participation in physical activity, some may result in the opposite occurring, and may in fact be maladaptive. For example, setting limits for oneself may result in never participating in physical activity at a level which yields maximum benefit; listening to one’s body may result in misinterpreting symptoms which are considered normal and characteristic of a natural bodily response to physical activity (such as muscle soreness or stiffness) as detrimental; and prolonged rest periods (in the absence of accompanying activity periods) may lead to physical deconditioning, making engagement in subsequent bouts of physical activity even more difficult. Recent work has reported similar themes, with one study in particular, which explored the influence of exercise on the experience of fatigue in people with relapsing-remitting MS, reporting themes such as ‘listening to your body’ and ‘reaching the edge’.(257) In their study Smith et al. suggest *listening to one’s body* to be a positive strategy, which perhaps allows people with MS to engage in physical activity confidently. The findings from the current study would agree that this strategy can be positive, but adds the caveat that *how* this strategy is utilised may be important, sometimes resulting in a more maladaptive response. Certainly, Smith et al.'s findings indicate that adoption of this strategy may differ depending on the person's level of perceived control over their fatigue, also indicating that there is some variance in how this strategy is applied.(257)

8.2 LIMITATIONS

As with any research, the findings of these studies should be considered within the context of their limitations. The questionnaire study (Study Four) was cross-sectional and so not designed to test causal relationships. Also, the results of this study should be interpreted with caution when considering the generalisability of findings because of the response rate (37%). It is possible the actual sampling frame was smaller than calculated, resulting in this response rate being marginally underestimated; a) if the overlap between the District Health Board and MS Society databases was greater than anticipated or b) if there were a greater number of deceased or misdiagnosed people in the sampling frame than we were notified of. However, as mentioned previously (see page 166), the sample is characteristic of what one might expect to see in an MS sample when sample characteristics are compared with epidemiological studies in this population,(1,152-154) and participants were recruited from multiple sources (both District Health Board and MS Society); both of which are strengths of Study Four when considering the generalisability of findings.

Another potential limitation of the questionnaire study is that no correction was made for multiple testing, and so the findings may be prone to Type I error.(150) There is much debate in the literature about the need (or not) to adjust for multiple tests.(258-260) Arguments against it include that there is a) a risk of eliminating Type I error at the expense of Type II error (260); b) the potential for publication bias due to researchers only reporting significant findings (259); and c) a general lack of clarity regarding when and how one should apply corrections, leading to a subjective decision about their use.(258) Given these arguments, and the fact that there was a theoretical rationale for the variables included and the approach taken to statistical analyses in the current study (i.e. it was not a "fishing" expedition), it was decided that adjustments for multiple testing would not be made. Rather, transparency about the approach used and possible interpretations of findings are discussed to aid the reader in making their own conclusions about the evidence presented; an approach recommended by Perneger in his 1998 paper.(260)

Study Five was a qualitative study with a relatively small sample. This sample size is consistent with qualitative methodology where the emphasis is on improving understanding of a complex phenomenon rather than generalisability per se.(261) However, future work may be necessary to test the validity of the proposed conceptual model of physical activity behaviour in people with MS in a more representative sample. In addition, the qualitative study was carried out as a sub-study to the larger quantitative study, and the target sample size predetermined, rather than data saturation defining the end-point. However, the final two interviews yielded no new categories or themes, suggesting that further interviews would have had limited impact on the findings presented here. Further, the sampling focus for this study was on inclusion of participants who could provide rich information and diversity of experience (151,227); rather than saturation necessarily being the goal.

Another important limitation to note is the role that I played as a researcher in the interpretation of findings. The decision to explore the role of cognitive-behavioural variables in physical activity engagement in Study Four clearly highlights my bias towards this perspective. It is possible that this pre-existing bias may have influenced the way I viewed and interpreted the interview data in Study Five. However, while this may be true: a) transparency about this bias from the outset should allow the reader to interpret the findings with this caution in mind; b) a number of rigour checks were adopted including a subset of transcripts being independently read and coded by a second researcher to ensure consistency of interpretation and thematic development; and c) a significant amount of raw data is deliberately included in the findings section of Chapter Seven (see page 203) so that the reader can judge for themselves the robustness of interpretation throughout.

Finally, there is much debate about mixed-methods research due to the belief that the paradigms and their underlying epistemologies are too different to be reasonably combined.(262) It could be argued that the contrast in philosophical underpinnings of the paradigms may account for the conflicting findings between the quantitative and qualitative studies observed in this phase. Certainly, the lack of clarity regarding how one goes about interpreting conflicting findings in mixed-methods research is acknowledged as a weakness of the approach.(262) However, proponents of mixed-methods research would contend that the strengths of the approach outweigh the limitations, and argue instead, that it should lead to a more complete understanding of a phenomenon than when a single method is used.(262)

8.3 CONCLUSION

In summary, the findings of this phase highlight a number of important barriers and facilitators to engagement in physical activity identified by people living with MS. There were a number of key findings which are consistent with previous research, such as the role of perceived barriers, self-efficacy and fatigue in the decision to engage in physical activity. However, this research also highlighted a number of seemingly fundamental aspects of engagement in physical activity for people with MS that previous research has failed to acknowledge, including: a) the complexity of the decision to engage in physical activity characterised by a complex interaction of a multitude of variables that differ across individuals; b) the ongoing nature of the decision making process; c) the central role of beliefs and perceptions about physical activity and related cognitive interpretations; and d) the tension created by the co-existence of conflicting beliefs.

Importantly, unlike illness-related variables, a number of the factors identified in this phase are potentially modifiable and so may offer a useful focus for the future development of interventions aiming to increase physical activity in people with MS. Such interventions should arguably be more responsive to the needs of individuals with MS, and lead to enhancing the positive effects observed in more traditional exercise and activity programmes due to their focus on long-term adherence. In response to this, Phase III of this doctorate discusses the development and pilot of an intervention which attempts to address some of the aspects identified as core to physical activity engagement in this phase.

PHASE III: FACILITATING ACTIVITY FOR WELL-BEING IN PEOPLE WITH MULTIPLE SCLEROSIS

Phase II explored the barriers and facilitators to physical activity experienced by people with MS, to gain a better understanding of physical activity engagement in this population. The key aim of Phase III is to draw on existing literature and the findings of Phase II to model an intervention aimed at facilitating physical activity engagement in people with MS. This phase consisted of two components. First, an intervention development phase; and second, a pilot study aiming to explore the acceptability of the intervention from the perspective of people with MS and their clinicians, test the feasibility of intervention delivery, and refine the intervention.

Chapter Nine reports on the first component, intervention development. Chapter Ten reports on the pilot study, the sixth and final project carried out as a part of this doctoral research. Chapter Eleven discusses the key findings from this phase and considers them in the context of recent research.

CHAPTER 9

DEVELOPING A NOVEL PROGRAMME TO PROMOTE ACTIVITY: THE FACILITATING ACTIVITY FOR WELL-BEING (FAB) PROGRAMME

9.1 A NEW APPROACH TO PHYSICAL ACTIVITY ENGAGEMENT

In response to the literature, and findings of the studies carried out to date, a programme was designed which aimed to facilitate physical activity in people with MS. Two important points of difference were incorporated into the design of the programme when compared to traditional exercise programmes that have been trialled in the past:

1) **The primary focus of the novel programme was to enhance *long term engagement* in physical activity for people with MS.**

   As highlighted in Chapter Two, previous work in this field has focused on the effectiveness of short-term exercise interventions on health outcomes for people with MS. However, such approaches have failed to improve long-term engagement in physical activity, which would arguably be more likely to result in sustainable health benefits. In response, a new programme that specifically targeted adherence issues to facilitate sustainable behaviour change was proposed. A title of Facilitating Activity for well-Being (FAB) was selected for the novel programme.

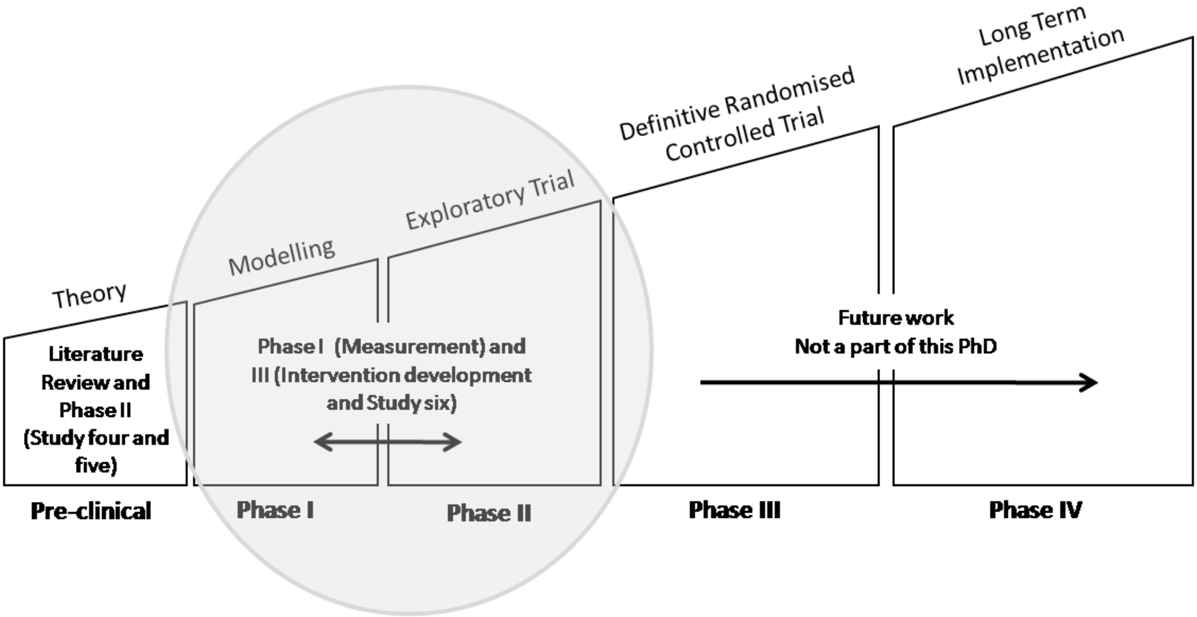
2) **As the title of the programme implies, a secondary intention was to facilitate improvements in *overall well-being* for people with MS.**

   Previous work has focused on exercise and activity likely to yield changes in cardiovascular fitness, strength and flexibility (see Chapter Two). While such changes are of interest, the key intended focus of the FAB Programme was on activity engagement to promote well-being. That is, on facilitating engagement in activities the participant wished to engage in (*meaningful* engagement) and supporting them to *live well* with their condition. This is in alignment with MS Society objectives, in NZ and elsewhere, where promoting wellness is a key theme,(263,264) and is based on the premise that supporting people to live well with their condition may have knock-on benefits to broader health outcomes.

9.2 DEVELOPMENT PROCESS

Development of the FAB Programme was informed by two frameworks: a) The framework for complex interventions proposed by the UK Medical Research Council (MRC) in 2000 (265); and b) Bartholomew et al.'s Intervention Mapping framework.(266) The MRC framework proposes five sequential and distinct phases in the development of complex interventions (Pre-clinical through to Phase IV). Figure 9.1 presents the phases as proposed by the MRC and illustrates how the phases of this doctoral study map onto this framework.

Figure 9.1: Phases of this doctoral research mapped onto the MRC framework (figure adapted from MRC (265))



As indicated in Figure 9.1, the literature review (Chapter Two) and Phase II of this research (Chapters Six to Eight) outlined the theoretical rationale and evidence base underpinning the FAB Programme; a key aspect of the *Preclinical* phase of the MRC framework. Phase I, where physical activity measurement in people with MS was explored, falls into *Phase II* of the MRC framework where design aspects relevant to a future definitive trial would be tested for feasibility, including measurement related issues. Phase III of this doctoral research is specifically concerned with *Phase I* and *Phase II* of the MRC framework. However, rather than being two separate distinctive phases as might be inferred by the separate blocks in this figure, these phases were carried out concurrently. This is consistent with the intentions of the developers of the MRC framework, who suggested that these phases could be carried out either in a linear fashion or using an iterative approach.(267) In the time since this research was carried out, a revised version of the MRC framework was developed. Given that this was not publicly available at the time of carrying out this research, the revised version is not discussed here. However, the revised framework and the similarities and differences to the approach used here are discussed further in Chapter Eleven of this thesis.

Like the MRC framework, the Intervention Mapping process places emphasis on the integration of empirical findings from the literature, relevant theoretical principles, and information collected from the target population.(266) In Intervention Mapping terms, this process is called the *needs assessment* and should become the foundation for intervention design. Unlike the MRC framework, the Intervention Mapping process also places emphasis on key stakeholder engagement from the outset, as this is considered to be crucial for successful implementation in the future.

Table 9.1 contains a matrix illustrating how the key underlying principles common to these two frameworks (theory, evidence and stakeholder engagement) map on to the stages of development of the FAB Programme, and highlights the approaches used to ensure these principles were retained throughout the development process. Each of the stages of development (structure and mode of delivery, guiding principles, content development, intervention tools, and refinement) are discussed in more detail below.

Table 9.1: Matrix illustrating how the key principles of the MRC and Intervention Mapping frameworks map onto the FAB development process

		KEY UNDERPINNING PRINCIPLES						
		THEORETICALLY DRIVEN			EVIDENCE BASED		INFORMED BY KEY STAKEHOLDER PERSPECTIVES	
		Progressive Goal Attainment Programme (PGAP) (268)	Cognitive-behavioural therapy (CBT) (95,96)	Self-regulatory theory (240,269,270)	Original research carried out as part of this doctorate (Study Four and Five)	Literature review of existing research (12,13,16,19,20)	Involvement of key stakeholders throughout	Pilot study (Study Six)
FACILITATING ACTIVITY FOR WELL-BEING (FAB) PROGRAMME	Structure and mode of delivery	✓						
	Guiding principles		✓	✓	✓	✓	✓	
	Content	✓	✓	✓	✓	✓	✓	
	Intervention tools	✓	✓	✓				
	Refinement						✓	✓

9.3 STRUCTURE AND MODE OF DELIVERY

Given that conventional approaches to activity engagement do not seem to improve long-term adherence for people with MS (see Chapter Two), an alternate approach was arguably needed. The Progressive Goal Attainment Programme (PGAP) developed by Michael Sullivan and colleagues in Canada (268) is one approach to activity engagement that appears effective for people with pain-related disability.(271) The structure and mode of delivery for the FAB Programme was informed by this approach. There are several features of PGAP which seemed sensible to adopt when taking into account the population of interest (people with MS) and the complexity that was uncovered in Phase II (Chapters Six to Eight).

A key feature of PGAP is that it *combines activity scheduling* with *management of any identified psychosocial risk factors* that have been linked with greater pain-related disability. Findings from Study Four and Five indicated a range of potentially modifiable psychosocial factors, which seemed to play a role in physical activity engagement for people with MS. Therefore, combining activity scheduling (which could be considered a more conventional activity intervention approach) with the explicit management of psychosocial barriers and facilitators to physical activity arguably had the potential to be effective for people with MS. Certainly, a recent meta-regression exploring effective techniques in healthy eating and physical activity interventions found that multi-component approaches which combine physical activity and/or nutritional strategies with a specific behaviour change component to be more effective than single-component approaches.(241)

PGAP is *delivered by an allied health professional,* a valuable feature for a number of reasons. While a clinical psychologist is likely to be more highly skilled and trained in management of psychological issues associated with engagement in physical activity, there are some issues which can be easily addressed by non-psychologists if they have the tools to do so, and with some alterations in the way they engage people. Given the shortage of clinical psychologists available for referral,(272) this approach could offer a way of engaging in discussions with people with MS about these issues as a matter of course, and would not preclude referral to a clinical psychologist if more concerning psychological issues are identified. Further, there is often a stigma associated with seeing a clinical psychologist, which could impact on a person's willingness to take up such referrals.(273) This stigma may be reduced if these issues can be addressed by an allied health professional. In the absence of a cure for MS, treatment is largely focused on symptom management, meaning that people with MS have regular contact with allied health professionals.(274) This puts those professions in an optimum position to effect change in activity behaviour. Indeed, one of the key themes prevalent in Phase II of this doctoral research was the role of the health professional in influencing physical activity behaviour. Due to the perceived credibility of health professionals, participants in Phase II implied that messages from health professionals regarding physical activity engagement (or absence of) were very powerful, highlighting it to be crucial that messages about physical activity are clear. In addition, people needed access to health professionals who had the skills and knowledge about how to engage in activity safely, which activities to engage in for optimal gain, and how to carry out those activities correctly. Therefore, an allied health professional, particularly a physiotherapist with the skills and knowledge to guide physical activity engagement, seemed most appropriate for this role.

Another important feature of PGAP is that it uses a *modular approach* to delivery. That is, while there are some core components of the programme, there is also a menu of optional modules which can be selected so that the package can be individualised to target the psychosocial risk factors of most relevance to each individual. This approach balances both the need for standardisation, and the ability of the programme to respond to needs of the individual. The ability to individualise a programme is important when working with populations where the illness trajectory is unpredictable and each person's experience of the illness is unique.(275) Furthermore, this feature seemed appropriate given the complexity regarding the decision to participate in physical activity apparent from the findings of Studies Four and Five.

Another relevant feature of PGAP is that the focus is on reducing pain-related disability rather than on impairment or the pain itself. In the context of the FAB Programme this would mean the focus is on *reducing MS-related disability*. At face value this may not seem to be a particularly important reorientation, however, this subtle change could be important in terms of how the programme is viewed by participants. For example, focusing the programme on reducing impairment may result in a different set of expectations regarding physical activity, and a tendency to avoid anything that could be perceived as having the potential to exacerbate the impairment. However, on the contrary, focusing on MS-disability may challenge the participant to take part in physical activity, in spite of their impairment. Outcome expectancies have long been associated with behaviour change and more specifically physical activity engagement, supporting the view that expectation setting is a core consideration in the development of strategies aiming to facilitate behaviour change.(276) Certainly, interventions in pain populations focusing on pain-related disability, such as interventions which place emphasis on advice to remain active in spite of impairment, have been linked to positive outcomes.(271,277,278)

9.4 GUIDING PRINCIPLES

A series of guiding principles were established to provide a broad philosophy for the FAB Programme and to ensure that the link between theory, evidence and stakeholder perspective was maintained throughout. The key influencing factors in the development of these principles is highlighted in Table 9.1. The principles were intended to define the core values of the programme, and were expected to be inherent in the content development, intervention delivery, and the strategies and resources adopted. As such, they acted as a framework to return to throughout intervention modeling. It was also intended that these principles would aid wider implementation of the FAB Programme, as training would ensure health professionals delivering the programme in practice are familiar with these guiding principles, helping to ensure the basic premise and intentions of the programme are retained. Six guiding principles were adopted, each of which are discussed in more detail below.

9.4.1 EVIDENCE-BASED

Development based on recent research findings and guided by the words of people with MS.

A key principle guiding the development of the FAB Programme was that it be grounded in current evidence regarding physical activity engagement for people with MS, and informed by the perspective of those people living with the condition. A number of strategies were utilised to ensure this during programme development and refinement. These were:

- Findings from the research carried out in Phase II (see Chapters Six to Eight) of this doctorate and other pertinent research in the field were carefully considered during content development;
- Consultation with key stakeholders was employed throughout; and
- An iterative approach to programme refinement was utilised, with piloting and refinement taking place concurrently (see Chapter Ten).

9.4.2 CHALLENGES BELIEFS AND PERCEPTIONS

Challenges individual perceptions of physical activity and explores alternative ways of thinking.

A key finding in Phase II (see page 205) was that beliefs and perceptions regarding physical activity engagement seem to play an important role in the decision to take part in physical activity for people with MS. Therefore, a key strategy adopted throughout the programme was to provide the interventionist with tools to aid identification of pre-existing notions of physical activity engagement that may be unrealistic or maladaptive, and enabling them to target and challenge those beliefs and perceptions.

9.4.3 LONG-TERM MAINTENANCE

Promotes adherence by combining activity scheduling with explicit management of the psychosocial barriers to activity.

The focus of intervention research in this field to date has been on the effectiveness of short-term physical activity and exercise interventions on health outcomes for people with MS. Despite positive results, these approaches have failed to promote long-term engagement in physical activity, as evidenced by the low levels of physical activity participation reported by people with MS (see Chapter Two). The primary focus of the FAB Programme was long-term maintenance of engagement in physical activity.

9.4.4 INDIVIDUALISED

Considers the context of the person with MS and their individual experience.

The FAB Programme adopted a modular approach to enable intervention content to be modified depending on the barriers and facilitators identified by the individual. In addition, each session can be flexibly applied to enable context-appropriate delivery. The ability to individualise the programme is important when working with a population like people with MS, where the illness trajectory is unpredictable and each person's experience of the illness is unique.

9.4.5 PARTNERSHIP

Works together with individuals to devise strategies to facilitate engagement in activity.

In order to truly understand the barriers and facilitators to engagement in physical activity experienced by an individual, FAB is based on the assumption that the participant needs to be acknowledged as an expert. A core component of the working relationship between the interventionist and the participant is working in partnership to explore their beliefs and perceptions about physical activity; identify intervention goals; decide on a module plan; and develop strategies appropriate for that individual.

9.4.6 SUPPORTED REHEARSAL

Provides a supportive environment to practice newly developed strategies.

The findings in Phase II of this doctoral research clearly highlighted that a) new experiences of engagement in physical activity have the potential to influence beliefs and perceptions about physical activity (both positively and negatively); and b) engagement in physical activity can result in an extreme emotional response. Therefore, a core component included in the FAB Programme was to allow for supported rehearsal. The reasons for this were threefold. First, supported rehearsal gives the interventionist an opportunity to manage any beliefs and perceptions resulting from engagement, to avoid the potential for misinterpretation. For example, helping participants to understand the difference between innocuous symptoms they might experience as a result of physical activity versus those that may be detrimental.

Second, any emotional response can be identified and discussed immediately. Third, any difficulties experienced or concerns regarding engagement can be discussed and addressed immediately.

9.5 CONTENT DEVELOPMENT

As discussed, content development was informed by existing theoretical and strategic approaches to behaviour change (PGAP, CBT and self-regulatory theory), and empirical evidence (original research from this doctorate and existing evidence); and was influenced by key stakeholder perspectives. The reasons for drawing on PGAP have been discussed previously so will not be addressed again here. However, the reasons for drawing on CBT and self-regulatory theory have not been explicitly addressed yet, and so this is discussed briefly here followed by a summary of the subsequent content development drawing on these theoretical approaches.

CBT is an approach based on the idea that how we think (cognition), how we feel (emotion), and how we act (behaviour) interact. The term actually describes a range of different approaches and strategies commonly used to explore aspects of this interaction that may lead to maladaptive behavioural responses.(94-96) Given the interaction between cognitions (*beliefs about activity*), emotion (*emotional response*), and behaviour (*engagement in physical activity*) evident from the findings of Phase II of this research, it would seem appropriate to draw on some of the existing strategies used in CBT to address this in people with MS.

Self-regulation theory suggests that most human behaviour is goal directed and that success in achieving desired goals determined by one’s ability to regulate their cognitions, emotions and behaviour. Further to this, it suggests that motivation, affect, and goal attainment are closely related.(269) This has important implications with regard to physical activity behaviour for people with MS, some of which have already been suggested by Hall and colleagues in the presentation of their social neuroscience perspective of physical activity.(240) First, engagement in physical activity is a self-regulatory activity. Second, self-regulatory behaviour requires executive abilities. Third, people with MS often have cognitive impairment and may suffer from affective disorders (103) which could impair their executive functioning and therefore their ability to successfully engage in physical activity goals. Fourth, it is likely that the frustration and learned helplessness experienced by people with MS (due to the progressive nature of the condition and concerning symptomatic response to physical activity) may lead to negative consequences with regard to motivation, affect and ultimately goal-directed activity. Explicit management of goal-directed behaviour is therefore an important component considered in the FAB approach. Furthermore, Emmons suggests "The most adaptive form of self-regulatory behaviour may be to select concrete, manageable goals that are linked to personally meaningful, higher-order representations".(279, p.54) This is consistent with the focus of the FAB Programme on facilitating activity for well-being and encouraging engagement in meaningful activity rather than focusing specifically on physical health benefit.

The FAB Programme adopted a modular approach with a series of core modules (anticipated to be relevant to all participants) and a series of optional modules (selected depending on the barriers and facilitators most relevant to the individual participant). The modular structure of the programme at this first stage of development is presented in Figure 9.2.

Figure 9.2: First version of the FAB programme

As can be seen from this figure, this first version of the programme was developed to include eight weekly sessions with four core modules (green segments) and four optional modules (blue segments). The black arrow in the centre of the figure represents the start and finish of the programme. The green arrow surrounding the figure and the arrows moving out at weeks II and III and then in again at weeks IV to VIII highlight the fact that goal setting, activity scheduling and fatigue management are reviewed and monitored in subsequent weeks. This feature is also consistent with self-regulatory theory, where review and monitoring is considered an important requirement of goal-directed activity.(280-282)

9.5.1 CORE MODULES

The key aim of the FAB Programme was to e*nhance long term engagement in physical activity* by combining activity scheduling with active management of identified barriers and facilitators to physical activity. In total, there are four core modules, each developed with this emphasis in mind. A summary of the key components of these core modules, along with the key influencing factors in their development are presented in Table 9.2.

Table 9.2: Sumary of core module content development

Core module	Key components	Key influences
Week I: **Introductory session**	Knowledge exchange Developing a therapeutic relationship Identifying personal barriers to engagement in physical activity	• Guiding principles (*Individualised, Partnership*) • Key stakeholder perspectives
Week II: **Goal setting and activity scheduling**	Setting programme goals Introducing activity scheduling	• Self regulatory theory • PGAP activity scheduling approach
Week III: **Fatigue management**	Identifying patterns of behaviour potentially contributing to fatigue Introducing the cognitive behavioural model of fatigue Developing fatigue management plan	• Findings from this doctoral research • Cognitive behavioural theory • Guiding principles (*Challenges current thinking*)
Week VIII: **Maintaining the FAB Programme**	Review Considering future engagement	• Self-regulatory theory • Guiding principles (*Long term maintenance*)

9.5.2 OPTIONAL MODULES

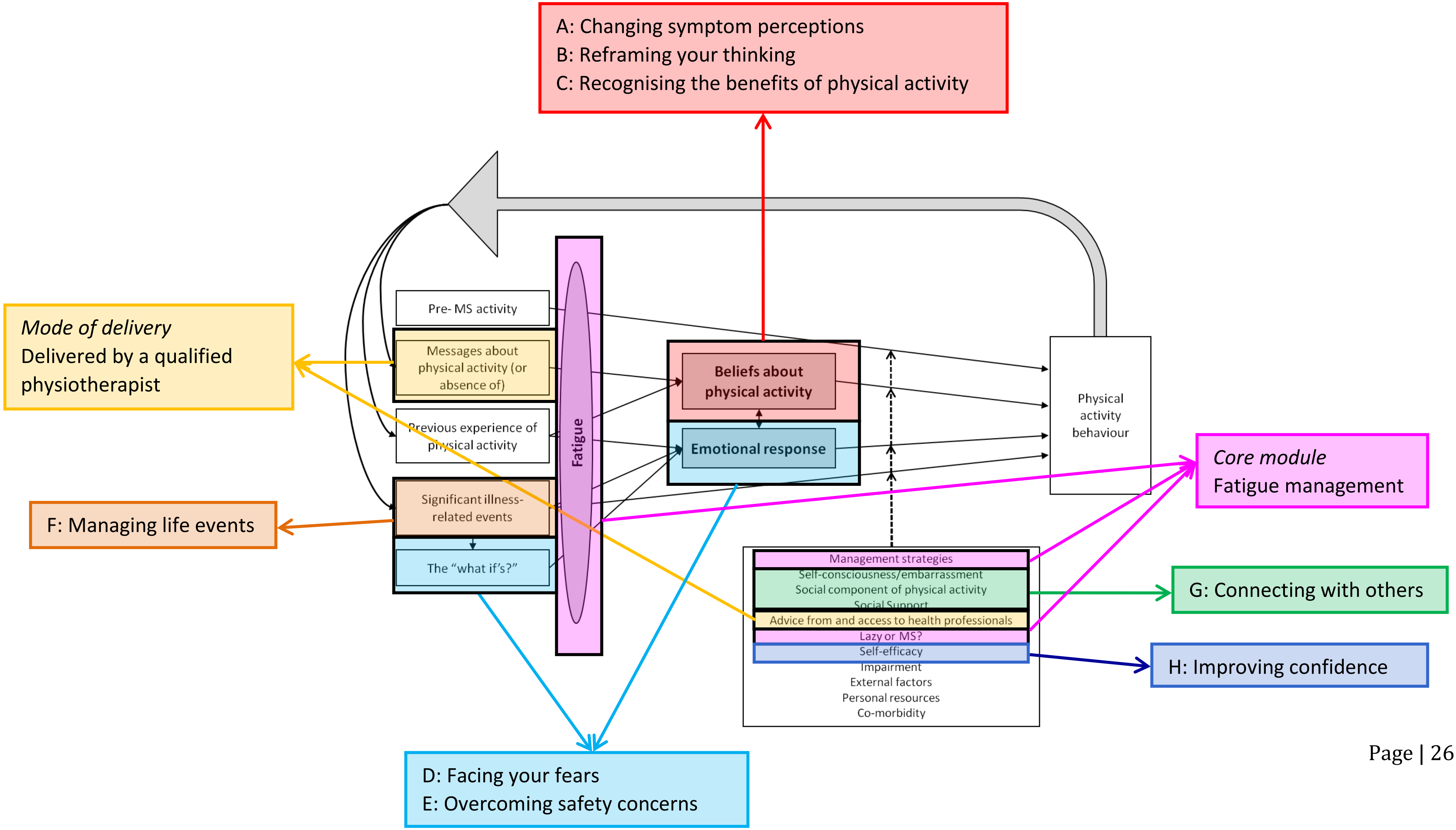
Optional modules were developed in response to the findings from Phase II of this research and with consideration of previous research in this field. In total, eight optional modules were developed which can be selected depending on the individual needs of the participant. The optional modules developed and their key components are presented in Table 9.3.

Table 9.3: Summary of optional module content development

Optional module	Key components
A: Changing symptom perceptions	Identifying existing symptoms and causal attributions
	Discussing the link between symptom perceptions and behaviour
	Considering alternative explanations for the symptoms experienced and discussing how this might impact on behaviour
B: Reframing your thinking	Identifying some of the thoughts that may be contributing to the participants inactivity
	Discussing some alternative ways of thinking
C: Recognising the benefits of physical activity	Discussing the participants previous experiences of physical activity, to identify what might be contributing to their negative perceptions regarding the benefits of physical activity
	Drawing on literature to discuss their experiences in the context of literature that highlights the importance of physical activity engagement
D: Facing your fears	Identifying any feared activities
	Discussing reasons why the participant fears those activities
	Choosing one activity to work on with the participant, with the aim of gradually exposing them to the activity without risk of harm
E: Overcoming safety concerns	Identifying any existing safety concerns with the participant
	Discussing some possible strategies for how one might overcome these safety concerns
F: Managing life events	Identifying previous events that have resulted in a change in physical activity behaviour for the participant
	Discussing the reasons for the change in behaviour
	Considering which events are likely to happen again in the future, and developing a plan for how one might manage this in the future
G: Connecting with others	Identifying why connecting with others is important to the participant
	Developing an action plan for connecting with others
H: Improving confidence	Identifying activities the participant does not feel confident doing
	Facilitating the participant to carry out the activity in a supportive environment, utilising strategies to enhance their confidence
	Identifying strategies the participant can test out on their own designed to enhance confidence

Figure 9.3 illustrates how each optional module maps onto the findings from Phase II of this research (see Figure 7.1 for original version of this figure).

Figure 9.3: Optional modules as they map onto findings from Phase II of this doctoral research



As is illustrated in Figure 9.3, Phase II findings primarily influenced the development of optional modules, with the exception of two key findings. First, fatigue management was introduced as a core module (rather than an optional one), as it seemed to be key to physical activity engagement for all those interviewed. Second, Phase II findings regarding the influence of health professionals informed the mode of delivery.

Note that there are a number of findings included in Figure 9.3 that are not captured in the optional modules that were developed, including pre-MS activity, previous experience of physical activity, impairment, external factors, personal resources, and co-morbidity. The reason for this is that the focus of the intervention was kept to factors thought to be amenable to change. Therefore, rather than being the key focus of an optional module, information relevant to these factors was considered to provide important context for intervention delivery.

A full programme manual, detailing the full content of each of the modules described above, is included in Appendix Z. Rather than include multiple versions of the programme manual, the appendix presents the version of the manual as fully revised on completion of the pilot study. Details of all revisions are included in Chapter Ten.

9.6 INTERVENTION TOOLS

A number of intervention tools were developed to assist delivery of the programme. These were developed with three things in mind: 1) to act as a toolbox for clinicians to draw from throughout the intervention; 2) to ensure treatment fidelity; and 3) to enable participants to learn strategies they could draw from in the future due to the key focus of the programme being on enhancing long term engagement in physical activity. The rationale for and examples of the main intervention tools are discussed below.

9.6.1 PROGRAMME MANUAL

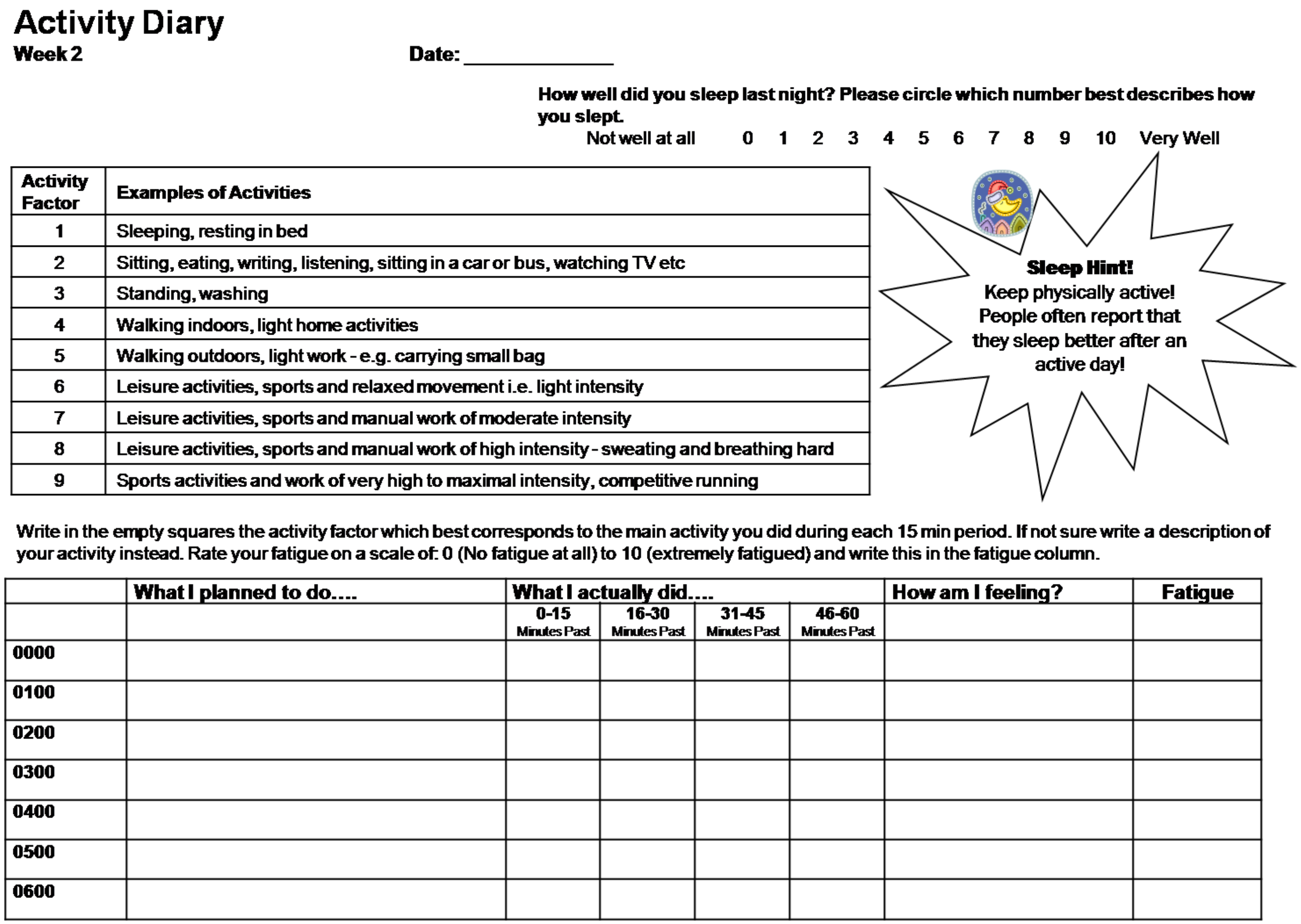
The programme manual was designed with the clinician in mind, and included: a) an introduction to the programme and its guiding principles; b) a summary of the programme structure; c) a detailed discussion of each module including the aims and objectives of the module, the rationale for development (including any theoretical influences), and a guideline for carrying out that module with the participant; and d) a series of appendices with a range of resources to assist with programme delivery (discussed in more detail below). As highlighted above, the most up-to-date version of the programme manual is included in Appendix Z.

9.6.2 ACTIVITY DIARY

In order to carry out the activity scheduling component of the programme, an activity diary was developed for participants to complete throughout the course of the programme. The activity diary is an important component of the programme. It gives the participant and the physiotherapist a clear picture of the participant's daily routine and what activities they currently take part in. This is particularly important as it helps to ensure the programme is tailored to meet the needs of that individual participant. Further, a key component of the programme is activity scheduling, and the success of activity scheduling depends on completion of the activity diary to allow for review and monitoring of scheduled activities throughout the intervention. A further benefit of utilising the activity diary as a monitoring tool is that it highlights changes the participant has made over the course of the programme; a form of positive feedback for the participant. As indicated earlier, it is also in keeping with self-regulatory theory where self-monitoring and review are considered to be essential components of self-regulation according to Carver and Scheier's control theory.(280,281) Indeed, as indicated earlier in Chapter Eight, Michie et al. found the inclusion of self-monitoring techniques to be the strongest predictor of effective physical activity and/or nutritional strategies in their meta-regression, particularly when combined with at least one other self-regulatory technique.(241)

An example of the original activity diary is presented in Figure 9.4. This figure shows that there were a number of components included in this activity diary which ask participants to rate how well they slept the previous night, what activities they planned to do, what they actually did, to describe how they are feeling throughout the day, and to rate their fatigue on a scale of 0 to 10. In addition, included on every diary page there was an activity, nutrition or sleep hint. The format of the activity diary (recording activities every 15 minutes and coding their activities according to the type of activity carried out) was developed in response to previous research which has found this format to be valid and closely approximating daily total energy expenditure.(283) Therefore, it was thought that as well as being an important intervention tool, this activity diary could also couple as a research tool and allow monitoring of intervention effects in future research.

Figure 9.4: Original version of the activity diary



Activity Diary

Week 2 **Date:** ______________

How well did you sleep last night? Please circle which number best describes how you slept.

Not well at all 0 1 2 3 4 5 6 7 8 9 10 Very Well

Activity Factor	Examples of Activities
1	Sleeping, resting in bed
2	Sitting, eating, writing, listening, sitting in a car or bus, watching TV etc
3	Standing, washing
4	Walking indoors, light home activities
5	Walking outdoors, light work - e.g. carrying small bag
6	Leisure activities, sports and relaxed movement i.e. light intensity
7	Leisure activities, sports and manual work of moderate intensity
8	Leisure activities, sports and manual work of high intensity - sweating and breathing hard
9	Sports activities and work of very high to maximal intensity, competitive running

Sleep Hint!
Keep physically active!
People often report that
they sleep better after an
active day!

Write in the empty squares the activity factor which best corresponds to the main activity you did during each 15 min period. If not sure write a description of your activity instead. Rate your fatigue on a scale of: 0 (No fatigue at all) to 10 (extremely fatigued) and write this in the fatigue column.

	What I planned to do....	What I actually did....				How am I feeling?	Fatigue
		0-15 Minutes Past	16-30 Minutes Past	31-45 Minutes Past	46-60 Minutes Past		
0000							
0100							
0200							
0300							
0400							
0500							
0600							

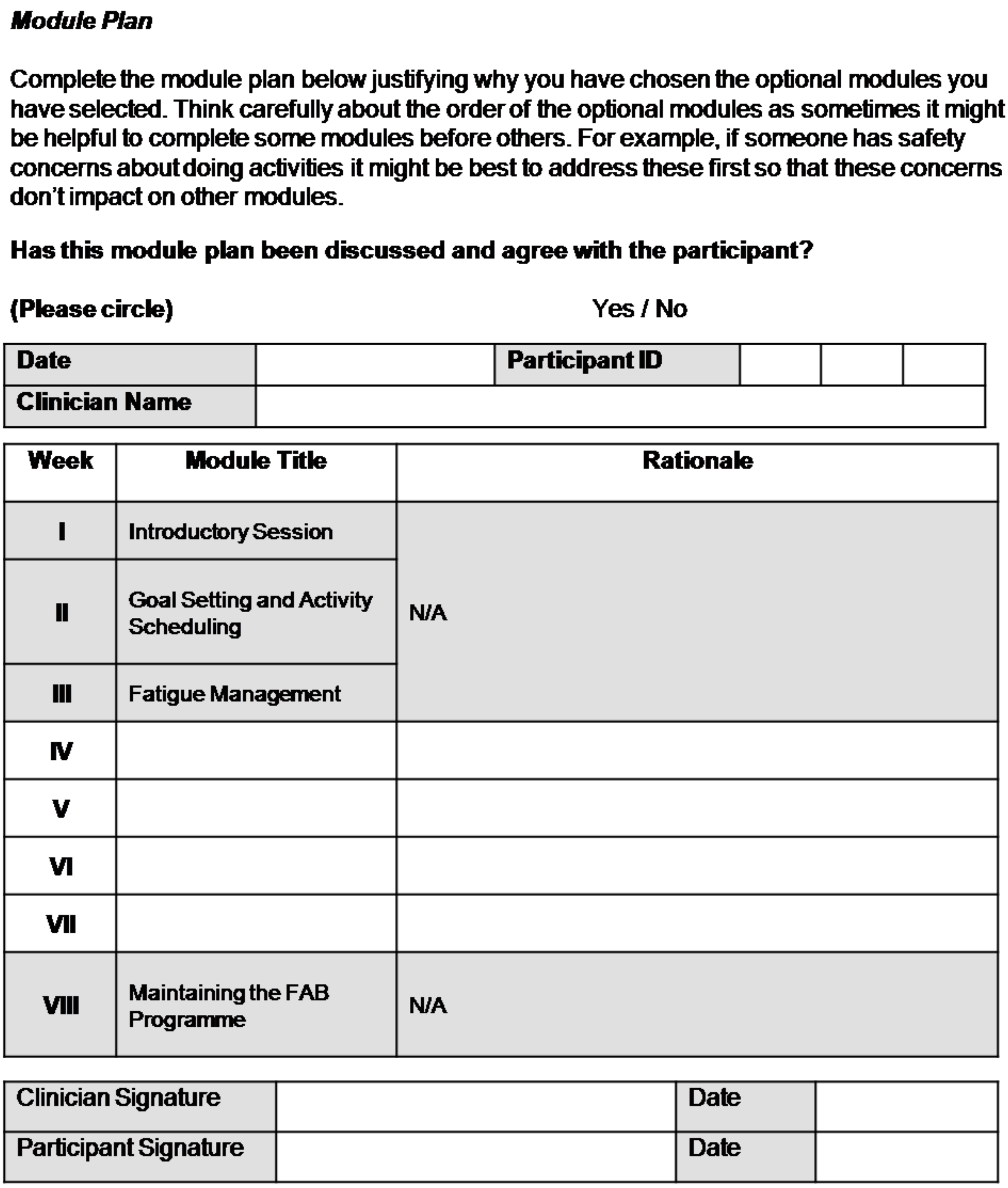
9.6.3 SCREENING QUESTIONNAIRE

The screening questionnaire was intended as an initial exploration into the barriers to engagement that may be relevant to the participant, to be completed in Week 1. Once the screening questionnaire is completed, the clinician can explore some of the answers in more detail with the participant during their exploratory interview. The screening tool includes questions about a range of demographic and illness-related variables, and a series of standardised questionnaires similar to those used in Phase II of this research. These were The Barriers to Health Promoting Activities for Disabled Persons Scale (90); The Cognitive and Behavioural Responses to Symptoms Questionnaire (CBSQ) (104,205); and a selection of the most relevant Self-Efficacy for Chronic Diseases Scales (211) (e.g. exercise and household chores self-efficacy). Note that the CBSQ was included in the screening questionnaire even though analyses in Phase II of this research failed to identify any of the variables measured in this questionnaire as associates of physical activity. The reason for its inclusion is that: a) there are as yet no other measures available which aim to capture the existence of potentially maladaptive beliefs and behavioural patterns; and b) in the absence of a better measure, and given that the questionnaire is only being used to inform module selection rather than to compare across individuals, it was thought that some of the individual items on this questionnaire would offer some insight into participants beliefs and perceptions about physical activity. This would then act as a stimulus for discussion in the more in-depth exploratory interview.

9.6.4 MODULE PLAN

In response to the exploration in Week I, clinicians develop an individualised module plan for their participant (that is, selecting relevant optional modules to cover throughout the programme). The draft plan is then presented to the participant for their approval with a rationale for selection of specific modules. The purpose of this is that it allows the participant the opportunity to amend the module plan if they disagree with the proposed plan (maintaining a partnership approach), and helps to ensure transparency of process with the participant (e.g. a method of expectation setting). Also, the plan is signed off by both the clinician and the participant, and acts as a behavioural contract and a symbol of the commitment agreed by both parties.(284) An example of a module plan is presented in Figure 9.5.

Figure 9.5: Example of module plan



Module Plan

Complete the module plan below justifying why you have chosen the optional modules you have selected. Think carefully about the order of the optional modules as sometimes it might be helpful to complete some modules before others. For example, if someone has safety concerns about doing activities it might be best to address these first so that these concerns don't impact on other modules.

Has this module plan been discussed and agree with the participant?

(Please circle) Yes / No

Date		**Participant ID**			
Clinician Name					

Week	**Module Title**	**Rationale**
I	Introductory Session	N/A
II	Goal Setting and Activity Scheduling	
III	Fatigue Management	
IV		
V		
VI		
VII		
VIII	Maintaining the FAB Programme	N/A

Clinician Signature		Date	
Participant Signature		Date	

9.6.5 GOAL ATTAINMENT SCALING

Clinicians also used Goal attainment scaling (GAS) (285) to negotiate the programme and weekly activity goals. The benefits of using GAS are that the goals are negotiated with the participant (in keeping with the guiding principles of the programme), and the GAS structure allows the goal to be broken down into different levels of goal attainment. If it is true that motivation, affect and goal attainment are closely related (as self-regulation theory suggests), then continuously failing to achieve ones goals can have a negative effect on mood, emotion and the ability to work towards and achieve further goals. The benefit of being able to consider different levels of goal attainment is it helps to highlight small levels of achievement in a goal, even if the highest level of the goal attainment has not been achieved. GAS has been recommended as a useful tool for this type of goal setting in people with MS (286) and is an approach that can be carried out in a one-off session, as would be the case in this instance.

9.6.6 MODULE WORKSHEETS

A range of module worksheets were developed to facilitate discussion with participants during programme sessions. Examples of these worksheets are included in the programme manual in Appendix Z.

9.7 OTHER KEY DEVELOPMENT CONSIDERATIONS

In addition to the development process outlined above, there were some additional key development considerations, which are discussed below.

9.7.1 GETTING BUY-IN FROM KEY STAKEHOLDERS

There were some aspects of the programme that were specifically designed to facilitate buy-in from key stakeholders – in this case people with MS and clinicians working with them. One key consideration was the language adopted throughout the programme manual. For example, it was thought to be important to keep the language positive in the manual, so all the module titles are deliberately positively phrased (e.g. ‘Facing your fears’ instead of ‘Fear avoidance’; and ‘Reframing your thinking’ instead of ‘Negative beliefs’). Another consideration was the image of the programme. For example, it was thought to be important to ensure the image attached to the programme was in keeping with the underlying focus of the programme (activity engagement), but is one that people with MS can relate to. At the time of designing the programme, members of our research team were invited to an art exhibition organised by the MS Society in Auckland entitled ‘Art for MS’. The art at this exhibition was created by people whose lives have been touched by MS, enabling us to look for a piece of artwork that could be adopted as the image for this programme. Figure 9.6 presents the image that was decided on. This original painting was purchased and the image reprinted with the permission of the artist, Jayne Hillam, a woman with MS. Jayne kindly agreed to let us use her creation as the image for the FAB Programme. We believed this painting in particular captured the spirit of the programme with the figures in the painting signifying movement and action.

Figure 9.6: Image of the FAB progamme painted by Jayne Hillam

9.7.2 OTHER DELIVERY ASPECTS

A final key decision in the development of the FAB Programme was consideration of the best location for carrying out the programme. It was decided that the programme would be home-based for a number of reasons including the following:

- A home-based programme would allow for a better understanding of the individual’s environment which may help to better understand some of the barriers to engagement participants describe;

- Given the focus of the programme on long term engagement in physical activity, it seemed important to support engagement in a participant's usual context rather than rely on translation from the clinic to the home environment, which can present its own difficulties (287);
- Participants in Phase II reported a range of barriers to engagement relating to accessibility and lack of convenient facilities so it was considered important that engagement in the programme did not create similar barriers; and
- Having a home-based programme would allow for involvement of family members or other significant others if the participant wished them to be involved.

9.8 REFINEMENT

The final phase of development of the FAB Programme was refinement. In order to refine the programme a pilot study was carried out (Study Six). This pilot study and resulting revisions to the programme are described in the following chapter (Chapter Ten).

CHAPTER 10

STUDY SIX

FACILITATING ACTIVITY FOR WELL-BEING IN PEOPLE WITH MULTIPLE SCLEROSIS: A PILOT STUDY

10.1 AIMS

Study six was the final study carried out as part of this doctoral research. As indicated in Chapter Nine, Study Six was developed as part of the refinement phase of FAB Programme development and so is linked to Phase III of this research, with the overarching objective of facilitating physical activity in people with MS. Specifically; the key aims of this study were to:

(1) Explore the acceptability of the Facilitating Activity for well-Being (FAB) Programme in people with MS and their clinicians;
(2) Test the feasibility of the programme; and
(3) Refine the programme.

10.2 METHODS

Ethical approval for this study was obtained from the Northern X Health and Disability Ethics Committee in NZ (see Appendix AA).

10.2.1 DESIGN

This was a pilot study using the same qualitative descriptive design as described earlier in Chapter Seven (see page 196). Multiple data collection methods were used, including: a) review of intervention and supervision notes; b) face to face interviews with people with MS; and c) focus groups with clinicians involved in intervention delivery. Intervention delivery took place over two phases, to allow for an iterative approach to refining the intervention in response to participant feedback.

10.2.2 PARTICIPANTS

10.2.2.1 People with MS

Convenience sampling was used to select participants for this pilot study. Initially, details of all those who had a definite diagnosis of MS and lived within a 15km radius of AUT University were extracted from the participant database from study four. Proximity to the study centre was added as an inclusion criterion to limit the cost of travel (in terms of both time and money) for intervention delivery. In order to ensure diversity in level of disability, potential participants were stratified into groups (low, moderate and high disability) using the same approach as that described in Study Five (see page 198). Names of people in each stratum were then randomised using http://www.random.org/lists/ and potential participants were invited to take part in the pilot study in this random order. The first five in each stratum were invited in the first instance, and then one by one thereafter until n=6 (in total) eligible and consenting participants were identified. Participants were excluded if they had experienced a relapse within one month of baseline, had a medical condition precluding their participation in physical activity, and/or had engaged in regular and intensive physical activity in the three months prior to baseline (defined as at least three times per week at 30 minutes or more a time).

The target sample size was six potential participants to balance the competing demands of resource constraints and the goals of the pilot study. Since the final phase of this doctoral research was not externally funded, the clinicians delivering the FAB Programme were recruited from AUT University (see below for more detail). This meant that clinician time was limited. Accounting for this, a sample size of six was believed to be a manageable number of participants. The aim of the pilot study was to explore the acceptability and feasibility of the programme, and to refine the programme further. It was thought that data from six participants would be sufficient to meet these aims, and would allow room for some diversity in level of disability and type of MS.

10.2.2.2 Clinicians

Physiotherapists on staff at AUT University who had experience of working with neurological conditions and had the time to commit to intervention delivery were invited to take part in the study. Three clinicians expressed an interest and were trained in intervention delivery. Training included a two hour group session where the programme and the underpinning principles of the approach were introduced, and the content and intent of each module discussed. After this group session, clinicians were encouraged to spend some self-directed time working through the programme manual before meeting individually with the principal investigator. The number of individual training sessions conducted with each clinician varied depending on how comfortable they were with the intervention process and content (ranging from one to three sessions, at a maximum of one hour per session). In these individual sessions, clinicians were encouraged to role-play key sessions and discuss any questions or concerns they had regarding intervention delivery. Participating clinicians were then entered on a list in random order (using http://www.random.org/lists/) to enable unbiased allocation of consenting participants to individual clinicians.

10.2.3 PROCEDURES

Potential participants with MS identified using the process described above were sent an invitation to participate (see Appendix BB) and a participant information sheet (see Appendix CC). Those interested in taking part were invited to call the study free phone number for further information about the study, and to complete eligibility screening (see Appendix DD). In order to screen for any medical conditions that would preclude participation, the modified version of the Physical Activity Readiness Questionnaire (PAR-Q) (184) was included in the screening process. If participants answered ‘yes’ to any of the questions on the PAR-Q, then medical clearance was obtained from their general practitioner before taking part in the pilot. Once eligibility was confirmed, participants were allocated to one of the three clinicians in the order predetermined by the randomisation process described above. Participant details were then passed on to the clinicians, who contacted their allocated person with MS to arrange for their first intervention visit.

At the beginning of the first intervention visit, the clinician revisited the information sheet with their participant and discussed any outstanding concerns the participant had. If they were happy to continue, participants completed and signed the study consent form (see Appendix EE) before engaging in the intervention process. Intervention delivery was carried out over two waves (see 10.2.6 below for further explanation of this).

10.2.4 DATA COLLECTION

10.2.4.1 Intervention monitoring

Clinicians completed a report after each weekly session (see Appendix FF) and intervention progress was discussed and notes taken at supervision sessions held between each intervention visit. Weekly reports involved recording information regarding session length, participant engagement in the session, adequacy of resources for the session, what the clinician liked and did not like about the session and what they thought could be improved. During supervision sessions, clinicians reported on their previous session, discussed any difficulties they were having, and possible approaches for the next session were identified. Any areas of concern regarding content and delivery of the programme to be considered during programme revisions were noted. On intervention completion, clinicians also completed a final report asking for their overall feedback on some specific aspects of the programme (see Appendix GG).

10.2.4.2 Participant interviews

Participants were interviewed twice throughout the programme; once midway through and then again on programme completion. These interviews were semi-structured with some quite specific questions regarding feasibility of the programme (e.g. session and programme length, venue for delivery, attributes of the interventionist) and some more open ended questions exploring the participant's experiences of taking part in the intervention and perceived impact of the intervention on their daily lives, in order to gauge the acceptability of the programme. These face to face interviews took place in the participant's home. Interviews lasted from 30 to 60 minutes and were audio-taped and transcribed.

10.2.4.3 Clinician focus groups

Clinicians took part in two focus groups; one on completion of the first wave of intervention delivery and then again after the second wave of intervention delivery. These focus groups explored the clinicians’ perspectives regarding acceptability of the programme. Questions and prompts were used to stimulate discussion including the following: What did you like about the programme? What did you not like about the programme? How do you think the programme impacted on your client? What type of client do you think would be most suited to this programme? How did you find delivering this programme as a physiotherapist? Focus groups lasted from 60 to 90 minutes and were audio-taped and transcribed.

10.2.5 ANALYSES

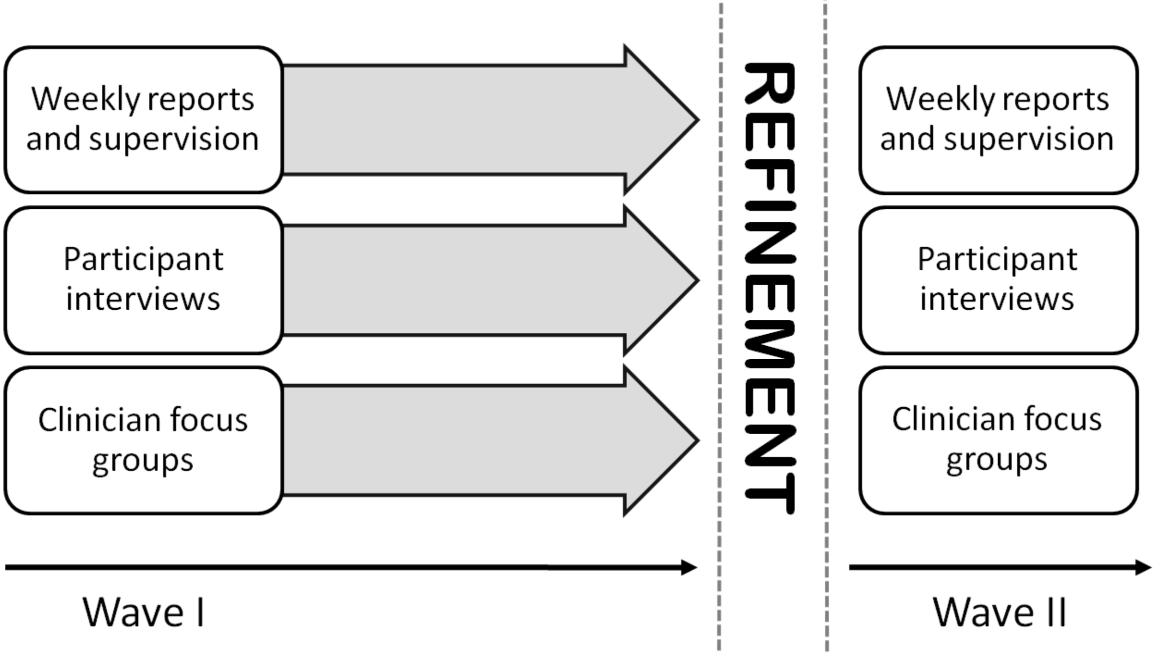
Interview and focus group transcripts were analysed using a qualitative descriptive approach to content analysis, where the link between codes, categories and the raw data is kept relatively transparent.(227) Initially, transcripts were read and reread to become familiar with the data and note any early indication of patterns in the text by recording and commenting on these in the margins.(151) Transcripts were then imported into QSR NVivo8,(232) where a more systematic approach to coding took place informed by early understandings of the data. Coded sections of the data were then pasted into a word document to enable comparison between codes and to identify any similarities or differences, and instances where codes could be grouped together into categories, representing themes in the data. Data was examined within and between different perspectives (clinicians and people with MS) throughout the analytical process to identify any parallels or nuances between perspectives. Relevant quotes were selected to illustrate established codes and categories and presented to a second researcher (KM) to verify that the coding scheme made sense and was reflective of the data.

10.2.6 REFINEMENT OF THE PROGRAMME

As indicated earlier, intervention delivery was carried out in two waves. The reasons for this were twofold: a) to make the most of the resources available for carrying out this study (i.e. only three clinicians were engaged in intervention delivery);

and b) so that refinements could be made to the programme. The refinement process is illustrated in Figure 10.1 which shows that the intervention was initially delivered to the first set of eligible and consenting participants in Wave I. Findings from that phase of intervention delivery then informed refinements to the programme, after which the newly revised programme was delivered to remaining participants (Wave II). This approach enabled exploration of the feasibility and acceptability of the revised programme.

Figure 10.1: Illustrating two waves of intervention delivery incorporating programme refinement



10.3 RESULTS

Of the 282 participants with a definite diagnosis of MS who took part in Study Four, n=36 were considered for participation for this pilot study due to their proximity to AUT University. In total, invitations were posted to n=20 participants. Of these, two were returned by NZ post as 'addressee unknown' leaving n=18 potential participants. Six people responded to these invitations, all of whom were eligible and consenting.

Three clinicians were recruited to deliver the intervention to two participants each (one in each intervention wave). One of the clinicians had to withdraw after the first wave of intervention delivery due to competing commitments, leaving only two clinicians available for intervention delivery in the second wave, neither of whom could commit any further time to the study. As a result, the participant who was allocated to the withdrawing clinician for Wave II also had to be withdrawn from the study, leaving five remaining participants.

10.3.1 PARTICIPANT CHARACTERISTICS

Table 10.1 provides a summary of participant characteristics for the five people with MS who took part in this pilot study.

Table 10.1: Participant characteristics – people with MS

Pseudonym	Gender	Age	Ethnicity	Type of MS	Time since diagnosis (years)	Use of assistive device	Use of arms	Use of legs	Proxy indicator of disability
Mellissa	Female	52	European	RRMS	10	Yes	Partial	No use	High
Steven	Male	37	European	SPMS	6	No	Partial	Partial	Low
Mark	Male	38	European	SPMS	13	Yes	Partial	Partial	Moderate
Duncan	Male	55	European	PPMS	4	Yes	Full	Partial	Moderate
Dianne	Female	60	European	PPMS	2	No	Full	Partial	Low

Table 10.2 provides a summary of participant characteristics for the clinicians responsible for intervention delivery in this pilot study.

Table 10.2: Participant characteristics - clinicians

Clinician	Gender	Age	Postgraduate qualifications	Years as a registered physiotherapist	Years experience of working with neurological conditions
001	Female	35	BHSc (Physiotherapy)	3	3
002	Female	31	BHSc (Physiotherapy) PostgradDip (Rehabilitation)	8	5
*003	Female	44	Diploma in Physiotherapy (UK)	23	10

*Withdrew after Wave I of intervention delivery

10.3.2 ACCEPTABILITY

10.3.2.1 People with MS

Reports from participants in both waves of intervention delivery suggested the FAB Programme was highly acceptable to people with MS, with a range of positive feedback. Discussion regarding acceptability of the programme centred on the following core themes:

a) The therapeutic encounter;
b) The role of the therapist and qualities of the therapist most valued by participants; and
c) Key attributes of the programme with regard to mode of delivery.

Each of these is discussed in more detail below.

10.3.2.1.1 The therapeutic encounter

One aspect of the programme which seemed to be key to the acceptability of the programme was the emphasis placed on the development of a strong therapeutic relationship. A number of participants enjoyed having the time to develop a relationship with their clinician and reported that it gave the clinician a chance to really get to know them. They felt this helped to ensure the programme was truly tailored to their needs.

> *It is important because you need to know the person otherwise you will start to chart impossible things. (Mellissa, Age 52, Relapsing-remitting MS)*

Several participants referred to the session length, which was longer than one would routinely have in a physiotherapy session. They suggested that having this longer session gave them time to feel comfortable enough to express themselves and talk about aspects of their experience in detail, which a shorter session may not have allowed.

> *By the time the end of the session has come that's when you start getting down to the nitty gritty, and if you make the sessions too short, you never get to the nitty gritty because there's not enough time or you don't feel comfortable enough, or things don't come up like they should do. (Mellissa, Age 52, Relapsing-remitting MS)*

Participants seemed to enjoy being able to talk to someone about their experiences and felt the nature of the programme enabled them to be themselves.

> *I mean, to be honest, it was good to have someone to sit down and talk to. Emotionally, you know. I didn't have to… she didn't have to put on any… tickets… you know any airs and graces…. (Steven, Age 37, Secondary progressive MS)*

One participant indicated that his clinician helped him to feel positive about his ability to engage in physical activity and to work towards his mutually agreed goals.

> *I always feel very positive after I have spoken to [the clinician]…you know, she… I feel really and I feel really ooohh arragh… you know, and then next morning I was up! I had a good sleep; I didn't feel like I had to get up at any time, like I was probably up at nine o'clock. I went down to the gym first, and then I went down to the bowling club… (Steven, Age 37, Secondary progressive MS)*

10.3.2.1.2 The role of the therapist and qualities of the therapist most valued by participants

Participants liked the fact that the programme was run by a qualified physiotherapist with experience of working with neurological populations, and highlighted a number of reasons why they perceived this to be important. Firstly, it seemed to give the programme credibility:

> *I know this sounds bad, well no it sounds good…because she was a neuro physio I probably thought, oh yes, she knows what she is on about, you know? (Steven, Age 37, Secondary progressive MS)*

This same participant also suggested that this promoted a sense of accountability on his part.

> *It's just not like Mickey Mouse turning up and doing it. You know. It's like, okay, she must know something. And … I am prepared to give it a decent shot. (Steven, Age 37, Secondary progressive MS)*

For others, it was about the fact that the clinician had an understanding of MS and its potential impact.

> *PARTICIPANT: Yeah, I thought she was good, yeah. She knows about the brain…the issues with MS….*
> *INTERVIEWER: So her knowledge of MS was useful?*
> *PARTICIPANT: The actual practical knowledge of what it does to your brain. So, that was good. I just don't know how well people do understand MS. Certainly they know the actual… what it does… but how it feels… the feeling we have. It is like being shorted out all the time. Messages aren't going through properly. It is quite hard to describe. (Mark, Age 38, Secondary progressive MS)*

Some saw the combined knowledge of MS and physical activity as a positive and a rare opportunity to discuss their questions and concerns about physical activity.

> *It was good that she did know about certain things. Like the physio side. I knew I could ask her about certain things, like Tai chi and stuff like this. It was good… her knowledge was good. Just like… if I do this... will I be…? I picked her brains a little bit over certain things. (Dianne, Age 60, Primary progressive MS)*

10.3.2.1.3 Key attributes of the programme with regard to mode of delivery

There were a number of aspects relating to mode of delivery highlighted as important by participants that seemed to contribute to the overall acceptability of the programme. The participants liked that the programme was delivered in the home (as opposed to being delivered in a clinic or over the phone). They cited a number of reasons why they thought home-based was an acceptable method of delivery. The most important of these seemed to be that the clinician was exposed to the participant's real-world living environment and could see for themselves the difficulties they faced with regard to engagement in physical activity. For example, one participant indicated it would have been impossible to explain to the clinician why she could not get outside independently. However, because the clinician was at her home and could observe her attempts, they could identify the difficulty and discuss ways of solving the problems she was experiencing together.

> *When I said to her I cannot walk, wheel up my wheelchair ramp and open my lift door all at the same time - she couldn't see why… we went downstairs and I said I'll show you …so she could see the problems I had. (Mellissa, Age 52, Relapsing-remitting MS)*

Another participant felt that he took it more seriously than he might have otherwise because it was home-based:

> *PARTICIPANT: Maybe I took it more seriously at home though…*
> *INTERVIEWER: Why do you say that?*
> *PARTICIPANT: Because the person has made the effort to come here… you are thinking shivers, that is really… and cause I would say… "oh, I can come and see you". Maybe in hindsight it was because I could take onus a bit off me… I have gone to see them; I have done my side… I don't really have to do this. But, if they come here I am thinking, if they spend a bit of time here, I had better do what they say. (Steven, Age 37, Secondary progressive MS)*

In this example, the participant suggested that having the clinician make the effort to come to his home and spend time working with him had made him feel accountable and encouraged him to engage in the programme. The same participant highlighted that the regular (weekly) face to face contact also acted as a motivator for him.

> *I kind of liked that [the clinician] came every week. It was like… it got you more motivated 'cause you knew someone was coming and you'd think… oh, I'd better do something! I don't want to turn up at the meeting or at the review and say, look I've done nothing all week! (Steven, Age 37, Secondary progressive MS)*

In this example, the participant was motivated by the regular weekly sessions and the fact that each session started with a review of the previous week's goals. He did not want to look bad when the clinician came back and so was keen to ensure he had done the things he had agreed with the clinician previously. While this seemed to be related to the need for self-preservation, it seemed to also be related, at least in part, to the strength of the therapeutic relationship. That is, due to the relationship the clinician had established with the participant, the participant seemed to want to please her through his engagement in the programme.

Another important aspect of the regular weekly sessions identified by participants was the fact that it promoted a sense routine and structure to their day. For example, this participant highlighted the fact that when one is not engaging in regular vocational activities it can be easy to let oneself fall into an unhealthy pattern of inactivity. He suggested the regular weekly appointments had helped to reinstate some structure into his day.

> *That's probably quite good for us because I mean, especially when we are not working, it's very easy to fall into a rut and I suppose I have always been a kind of active person, and even today, like I wake up in the morning, get up and go oh I've got an appointment, I've got X at one and I've got X at four…(Steven, Age 37, Secondary progressive MS)*

10.3.2.2 Clinicians

The clinicians also reported FAB to be highly acceptable, but challenging to their conventional practice methods. For example, one clinician who was relatively new to practice said:

> *CLINICIAN: I thoroughly enjoyed it… there were just also aspects about it that were really difficult.*
> *GROUP FACILITATOR: So, challenging the way you were practicing, but also nice…?*
> *CLINICIAN: Yeah. I mean, it is challenging in good ways and challenging in 'oh my god' ways. (Clinician 001)*

However, rather than seeing the challenging aspects as a negative thing, they seemed to perceive the challenge as a good thing, as a way of developing themselves as a clinician.

> *CLINICIAN: But, my initial impression from looking at it was really exciting! This is going to be a really good challenge for me, as a new clinician. (Clinician 001)*

10.3.2.2.1 A paradigm shift

What was clear from all three clinicians who took part in this pilot study was that the FAB programme was a paradigm shift to them due to there being an increased focus on engagement. This related to both the emphasis on therapeutic relationship, and the personalised barrier management which was at the heart of the programme.

One clinician reported that she had felt slightly outside her comfort zone when engaging with her clients in the FAB way:

> *It was only in the last session [where the participant said]… 'I have to do this and I am finding it a bit difficult'… so there was an opportunity and we did stuff. We did some lunges and a bit of strengthening and technique… and that was when I was able to be a 'physio' and I definitely felt more comfortable … my role… I was able to do my normal role. (Clinician 002)*

However, the clinicians also reported seeing value in the FAB approach and seemed to believe it to be important to incorporate into routine practice, albeit a mind-shift.

> *I still have this feeling of novice practitioner, both in physiotherapy and with dealing with this [the FAB Programme] because it was quite different, and it's something I know I need to be able to incorporate in my physiotherapy practice, but it is a really different way of thinking about approaching an intervention. (Clinician 001)*

One clinician suggested that despite the programme clearly requiring a shift in her way of engaging with people, it had the potential to result in positive outcomes for the client, particularly with regard to long-term engagement in physical activity.

> *It is more focused on talking than doing and I would probably be more focused the opposite way as a physio. But, what I learnt from her made what I did physically more effective for long term compliance or continuance… I think. Whereas, I think in the past I might have rushed in a bit more quickly… maybe got better performance on the spot, but maybe not as much longevity. So, it can be a little bit frustrating because as physios we just want to get in there and do… but it made me work in a slightly different paradigm I think. (Clinician 003)*

The clinicians who took part in this pilot study believed themselves to be relatively holistic practitioners, and for the most part seemed to see the paradigm shift required to successfully deliver the FAB Programme as a positive step for physiotherapy. However, they did voice their concerns about the impact that this paradigm shift might have on the potential for wider implementation. They were concerned that other physiotherapists might be less enthusiastic about the change in emphasis from "doing" to "talking".

> *For some reason there's this real block around… we do physical stuff and we'll spend time on a physical stuff, but as soon as we're getting into talking about stuff… we're not doing our job. (Clinician 002)*

10.3.2.3 Time to develop a strong therapeutic relationship

Like their clients, one aspect of the programme clinicians seemed to particularly like was having the time to get to know their clients and develop a strong therapeutic relationship with them.

> *I think the nature of the programme forced you to maintain that in-depth communication role... and I think as a physio… especially community physio you are on a tight timeframe so I would need to push her to keep to half an hour. So, if you need to keep someone to half an hour you can't establish the same depth of communication. So, I think it did form a deeper bond… a more significant bond. (Clinician 003)*

> *What was really good about it was… the opportunity to spend the time to really nut things out and talk about things and things would come up that just wouldn't have come up before…. So those kinds of things were really great and led you down a path that probably would be more productive. (Clinician 002)*

Clinicians seemed to enjoy the fact that the programme had enabled them to engage with their clients about things that they ordinarily would not have had the time to incorporate into their sessions. For example, this clinician indicated that while she sees fatigue management as an important thing to consider when prescribing an activity programme for someone, and wholly appropriate in her role as a physiotherapist to be engaging with someone on such issues, she admits that she rarely has the time to do that in her clinical sessions.

> *He [the participant] had a very clear goal of wanting to incorporate the gym more into his day and we were going to start with doing some core strengthening exercises… and if I had gone in there as a physio to his home to do that then that is what we would have done. We probably would have worked around how to fit that into his day, but... how do you manage the fatigue so that you can… you know… it won't have had that because there wouldn't have been the time. So, it is not a case of not wanting to do that as a physiotherapist, it is completely appropriate… you are just not given the space to do that. (Clinician 001)*

10.3.2.4 Challenging scope of practice

Clinicians expressed a concern that the content in some modules (e.g. the *Reframing your thinking* module) gave them a sense that they were pushing the boundaries of their scope of practice. They were concerned that to some extent these modules required them to engage with the client in a psychotherapeutic way, for which they are not trained.

> *CLINICIAN 001: In the context of helping someone explore how they think about themselves, and how to change how they think about themselves, that's a fairly big psychological thing that people spend their whole degree doing, you know, several years of clinical practice.*
> *GROUP FACILITATOR: Did you feel you were being called upon to try to get people to change their cognitions too much?*
> *CLINICIAN 001: Well, if we are asking people to reframe their thinking, then…*
> *CLINICIAN 002: Yeah, for that one, I think so… I'm not sure if we have the tools to do it well.*

There was acknowledgement that it may possible to facilitate a change in thinking utilising the skills one has as a physiotherapist by targeting the physical manifestation believed to be reinforcing a particular perception or maladaptive belief. For example, this clinician describes how she can see that targeting *physical* aspects (e.g. balance and mobility) may result in changes in *psychological* states (e.g. confidence to engage in activity safely or without being self-conscious about others' perceptions) without necessarily having to utilise psychotherapeutic techniques that one is not trained to use.

> *Like if somebody's… one of the things they're struggling with is how they're perceived by other people and a component of that is because of balance limitations, then I can help them improve their mobility, so that they can start to think more positively about their safety, so that is going to contribute to them reframing their thinking about what they do. (Clinician 001)*

However, it was felt that the role that one plays as a physiotherapist in facilitating a change in thinking could have been made clearer:

> *Maybe it needs to be stated somewhere, about using your physio skills… certainly with the first person, I was feeling like I wanted to do more physio stuff and I wasn't sure how it fitted. So, I think being more*

> *specific that it's ok to be a physio, but in addition to that, you've got few other tools… (Clinician 002)*

In addition, it was highlighted that there needs to be a clear process for referral to a psychologist should it become clear that things are moving outside ones scope of practice and area of expertise.

> *It's just knowing where the line is, I guess. Knowing what's expected of the physio and having it written down somewhere that the opportunity to refer on is there. I think that would make a difference. (Clinician 002)*

This was believed to be important for a number of reasons, not the least of which included safety and ethical considerations. A key consideration was that it was felt to be important that when things came up that were outside the clinician's scope of practice, that the client felt they were being addressed and not ignored by the clinician.

> *I'd feel better it if I had identified things and then done a referral or knew that someone was dealing with that, because it was important to them and I feel like I've completely…'cause I don't have the skills to deal with that… that I've missed that bit. (Clinician 002)*

10.3.2.5 Perceived benefits

Despite this pilot study not exploring the effectiveness of the programme, both participants and clinicians suggested that the programme had resulted in a range of benefits with regard to physical activity engagement. One participant who was largely dependent on a wheelchair and had difficulty with some of the most basic activities of daily living at the beginning of the programme (e.g. transfers, making a cup of tea, showering) reported some small but important changes in activity engagement.

> *I already can turn myself walking, and I'm standing at the shower rail, I'm standing to make myself cups of tea or coffee. (Mellissa, Age 52, Relapsing-remitting MS)*

This participant identified the key change for her was that she had previously believed she could not do certain activities, but that the programme forced her to challenge those beliefs by enabling her to 'give things a go' in a supportive environment. Once she realised she could actually do more than she had thought, her confidence seemed to increase, giving her the incentive to do more.

> *INTERVIEWER: What kinds of things did you like most about it [the programme]?*
> *PARTICIPANT: Having a go with things, realising I can do more than I thought I could… I had thought I couldn't do some stuff and I had a go and yeah I can do that.*
> *INTERVIEWER: And so how did that impact on you? Being able to do things that you hadn't thought you could do?*
> *PARTICIPANT: It was good, gave me more incentive. (Mellissa, Age 52, Relapsing-remitting MS)*

The clinician working with this client admitted having particularly low expectations of what the programme could do to support this participant, given her level of dependency, and so was surprised by how much they had achieved.

> *You know, my expectations were relatively low so we achieved more than I thought we would… actually … in view of how disabled she was and how long the condition had been going and how little she could achieve. (Clinician 003)*

One participant suggested that the programme helped him to make physical activity a part of his daily routine.

> *PARTICIPANT: I still do the exercise every night now… last three, four weeks I've been doing the exercises at night, every night, without being pushed to do it. I know that when I get up from TV, take my cup back to the sink, do my exercises and then go to bed. (Duncan, Age 55, Primary progressive MS)*

Interestingly, this participant admitted that he was yet to see the benefits of the exercises he had been doing, but remained positive about his engagement. This suggests the programme may have had some success in helping this participant to engage in positive cognitive appraisal when evaluating the advantages and disadvantages of carrying out his exercise regime.

> *I don't feel any benefit for having done them, like the exercise, I don't feel any benefit at all… but if I hadn't done them, would I have felt worse because I hadn't done them? I don't know. (Duncan, Age 55, Primary progressive MS)*

Another participant suggested the programme had helped her to engage in activities she could do with the resources she has.

> *One of the main reasons why I'm not doing one of the things I want to do, which is use a rowing machine, is because of the cost of hiring it. So, I didn't ever imagine that this programme was going to help me*

> *with the cost of that. Obviously I can't get around that, but what it has done is to get me into Tai Chi which is good. (Dianne, Age 60, Primary progressive MS)*

This same participant indicated that while Tai Chi was something she had been thinking about trying for a while, she had not done anything more about it. The programme helped her to initiate engagement.

> *It sort of encouraged me to start Tai Chi… I've been thinking about it for so long and haven't done anything about it, so yes, that's good. Yeah, basically, that's what I like about it… it's forced me to do something….it does encourage you to be active. We all know we should be active, but that's sometimes not enough… (Dianne, Age 60, Primary progressive MS)*

Another participant also highlighted the fact that the programme helped him initiate activity goals he had previously had difficulty initiating and indicated that now that he is over that first initiation barrier, he is likely to continue engaging in that activity.

> *I have actually joined the bowling club and that is different for me, in that I will utilise it now that I have joined it. (Steven, Age 37, Secondary progressive MS)*

This participant had several goals, all of which were related to engaging in leisure-time physical activity (e.g. bowling and fishing) rather than structured exercise activities. He liked that the programme had supported him to engage in these kinds of activities which were more meaningful to him, due to them being activities that were an important part of his lifestyle and which allowed him to engage with his friends and family.

> *I've got a mate who is into it too [fishing], which is good because we both bought the same kind of rod. And 'cause he is around, that really makes me go… Dad is into fishing as well, which is quite good too. I went out Boxing Day with him – did a bit of surf casting and stuff. (Steven, Age 37, Secondary progressive MS)*

He also indicated that had the programme been focused strictly on engagement in more structured exercise activities he would have been unlikely to continue with those activities post-programme.

> *I think that… I think I can say… if [the clinician] did those things [prescribed exercises] during that course… I probably would have done*

> *them then [for the duration of the programme]… but then I definitely wouldn't have carried them on. (Steven, Age 37, Secondary progressive MS)*

However, he could see himself continuing with the leisure-time activities:

> *Who knows…? I might carry on playing bowls and go to the commonwealth games…. [laughing]. (Steven, Age 37, Secondary progressive MS)*

10.3.3 FEASIBILITY

While the feedback regarding the guiding principles and content of the programme was very positive, there were some feasibility-related comments, particularly with regard to the structure of the programme, the time commitment involved and intervention delivery tools, which needed consideration.

10.3.3.1 Structure of the programme

10.3.3.1.1 Introductory session

The clinicians had some concerns about the intensity of the introductory session suggesting that they had to cover too much material in this session. During the first wave, the introductory session included introducing the programme, getting to know the participant, completing the screening questionnaire and carrying out an in-depth interview exploring the barriers and facilitators to activity engagement for that participant. The clinicians found that this resulted in a very lengthy session which was overwhelming for the participants.

10.3.3.1.2 Follow-up

Both clinicians and participants identified that having a follow-up of some kind would add to the programme. They suggested the inclusion of the follow-up was a way of reviewing how things had gone with the activity goals once the clinician ceased their weekly sessions. They believed this would give the clinician the opportunity to discuss any difficulties and concerns the participant had with longer term engagement.

> *When you join the gym for a year… you never go. So, I was wondering like… let us go for four months and then maybe do it for six weeks and then after five months or something, do a follow-up… 'cause I think a lot of people have good intentions and then it is like a lot of things… probably waver a bit. (Steven, Age 37, Secondary progressive MS)*

There were a number of options for addressing this discussed, including:

a) Having a staged intervention process where a period of engagement is following by an independent period, followed by another period of engagement, and so on:

> *I was just wondering if you could almost install a sort of self-review period. So, you do four or five weeks and then you have a break for 2 or 3 weeks and then you come back to it and say… okay, what was difficult about you putting those things in place? Let's work on that. (Clinician 001)*

b) Having a one-off follow-up session a few weeks post-intervention:

> *I think that it would be good to have a follow-up four to six weeks after the end of the programme to see how much of what you think has been established has actually been established. (Clinician 003)*

c) Having regular follow-ups for a period of time post-intervention:

> *And if they could come back once a month to refresh your memory and retest you once a month you'd realised that have you dropped any or have you gained any. (Mellissa, Age 52, Relapsing-remitting MS)*

10.3.3.1.3 Flexibility

In some instances the clinicians felt that the programme structure did not allow enough flexibility.

> *I suppose I did feel that, you know, following my exploratory interview that I was trying to fit them into boxes just to fill out, you know, a certain number of modules, but… was really like scratching to try and name each week as a particular topic to be covered. (Clinician 001)*

It was always the intention that the programme be flexibly applied. For example, if the fatigue management session takes two weeks rather than one, then the clinician could just reduce the number of optional modules they deliver. If only one optional module is relevant for a participant, then it is wholly appropriate to only focus on this, and reduce the overall length of the programme if necessary. However, the clinicians did not really feel they had license to be flexible, partly because they were concerned about how that would impact on treatment fidelity in the context of research:

> *I mean, I did feel I wanted to, I felt, as a pilot study, I wanted to follow the plan, so you've got an idea of how it works… (Clinician 001)*

This aside, they also commented they did not think the ability to be flexible was transparent enough in the programme manual.

10.3.3.2 Time commitment

All the clinicians expressed a concern about the time commitment involved in delivering the programme. For example, this clinician indicated that each weekly session had taken up to a half day in total by the time she accounted for preparation time, travel, the session itself, and then weekly reporting. Some of this was partly due to the nature of the participant she had been working with, but there was still some concern regarding the overall time commitment.

> *I think one thing that jumped out at me was the time commitment. It was probably taking me in the beginning an hour to read through things to make sure I knew what I was going to go and do… and then the actual doing… I spend two hours with my person at a time. I'd spend an hour just reviewing things. And then I would go onto the next bit. That is just the person I am working with I think. And then it is probably about half an hour at the end. So, that time commitment is quite a lot. And the travel as well I guess. But, it's half a day, I guess. (Clinician 001)*

However, the same clinician acknowledged that a lot of the time commitment would likely be reduced the more familiar one became with programme and its contents. She also acknowledged that she could not be sure that one could cut down specific sessions without losing important information.

> *I do think part of it is me being unfamiliar with the programme. So, like with anything… if I knew, was more onto it about what was required… then I wouldn't need that prep time… I don't know whether you would be able to cut down the amount of time with the person – without losing a lot of useful information. (Clinician 001)*

A second clinician agreed that more experience in delivering the programme should result in less preparation time.

> *I think it might be just a ten minute reminder and then I would be away. It is more reading through and knowing what the key points are… Like, I already feel that if I did it again, that bit would be quicker. (Clinician 002)*

This was confirmed when weekly reports from both phases were collated and the average session length was seen to reduce from an average session length of 84 minutes in phase I (with sessions ranging from 50 to 120 minutes in length) to 61 minutes in phase II (ranging from 45 to 70 minutes). In this small sample, figures like this should be interpreted with caution; however, they do support a trend towards reduced session length in phase II.

10.3.3.3 Intervention delivery tools

Both the participants and the clinicians had several comments relating to several of the intervention delivery tools. Some of these comments are discussed below.

10.3.3.3.1 Activity diary

The activity diary was the subject of much discussion by both participants and clinicians. For those participants engaged in the first wave of intervention delivery, for the most part the activity diary was a source of frustration, with all participants and clinicians believing the activity diary to be too intensive.

> *I want to cross out the whole lot and forget it. (Mellissa, Age 52, Relapsing-remitting MS)*

> *I just thought… that diary… was a nightmare! (Steven, Age 37, Secondary progressive MS)*

> *It is a bit tedious and a bit hard to fill out (Mark, Age 38, Secondary progressive MS)*

In some cases, participants resorted to using their own strategies for recording activities, which impacted on the accuracy of the activity diary. For example, this participant talked about sitting down and completing chunks of the diary retrospectively, relying on her ability to recall past activities:

> *I am not going to walk around with a paper and pen constantly in my hand, so I had to remember an hour's worth and just write down a blanket hour's lot of activity. (Mellissa, Age 52, Relapsing-remitting MS)*

Other participants stopped using the diary completely or used it in such a way that made it impossible to use the diary as a review tool during sessions, minimising the true potential of the diary as an intervention tool. For example, this participant stopped using the diary component of the tool part way through the intervention, after which he only used it to plan his daily activities.

> *I changed it in the end… to just putting down specific things I had to do. (Steven, Age 37, Secondary progressive MS)*

Despite this frustration, participants did indicate some positive aspects of the tool, highlighting the possibility that in the right format, the activity diary has the potential to be a useful tool.

> *I think it is giving me a sense of achievement, because you can chart the achievement. (Mellissa, Age 52, Relapsing-remitting MS)*

> *I think the activity diary was quite beneficial if I had used it the way it should have been used. The idea was quite good. I might have been able to see a few things happening in there. So, I would not say it is wrong. (Mark, Age 38, Secondary progressive MS)*

Both participants and clinicians had some ideas about how the diary could be modified to make it more acceptable and feasible. For example, the participants highlighted that reporting on larger blocks of activity, rather than 15 minute blocks may help.

> *You have to have it in an hour block and not every quarter of an hour. (Mellissa, Age 52, Relapsing-remitting MS)*

> *Well, like… do it in four hour blocks maybe? (Steven, Age 37, Secondary progressive MS)*

One participant who had dyslexia was keen to see the diary available in different formats:

> *INTERVIEWER: Like if you could have the perfect activity diary to complete, what would it look like?*
> *PARTICIPANT: Probably if you just spoke into something really*
> *INTERVIEWER: So, some sort of a Dictaphone instead of writing anything down?*
> *PARTICIPANT: Well, maybe even if you have voice recognition software that you could write it down for me just by talking that'd be good.*
> *(Mark, Age 38, Secondary progressive MS)*

One concern is that participants did not always seem to have a clear understanding of the purpose of the activity diary and its role in the programme. They saw the diary as a burden, rather than a therapeutic tool as it was intended.

> *I just realised I actually don't know much about the activity diary to be honest… (Steven, Age 37, Secondary progressive MS)*

This highlights the importance of explaining the purpose of each intervention tool and helping participants to understand their importance to facilitate buy-in to the process.

10.3.3.3.2 Fatigue rating

All the participants also reported difficulty with the fatigue rating. There was confusion about what each rating on the fatigue scale should equate to and whether it related to one's own experience of fatigue versus a global understanding of each level of fatigue.

> *Does it relate to the worldwide version of exhaustion or your personal exhaustion? (Mellissa, Age 52, Relapsing-remitting MS)*

Some participants found it difficult to rate their fatigue on a scale without a reference point to compare it with:

> *It's quite hard to gauge it against something that you've not done before. (Mark, Age 38, Secondary progressive MS)*

There was also concern that the rating might be misinterpreted as there was a sense that the fatigue experienced by participants was misunderstood by people generally.

> *It's not like usual fatigue of people… it's more like a heaviness and your legs become heavy, they become buzzy and they become burny, burning sensations and all sorts of stuff… (Mark, Age 38, Secondary progressive MS)*

The participants suggested that one way to improve the fatigue rating would be to have descriptors which participants could refer to.

> *Maybe if you had a list of a few different symptoms. (Mark, Age 38, Secondary progressive MS)*

This participant developed his ideas about the fatigue rating during his sessions. His clinician reported the outcome of those discussions saying that he had indicated that it would be good for participants to develop their own rating scale with personal descriptors reflecting their own experience of fatigue which could then act as anchors at different points on the scale.

> *Having a session where you establish a thermometer… he thought that was really important. 'Cause he found it so hard to do. (Clinician 001)*

10.3.3.3.3 Programme manual

The clinicians had some difficulty navigating the manual at times, particularly in the first wave of intervention delivery when they were still getting to grips with the content of the programme.

> *I guess it's a bit to fish through isn't it? It did take a little bit of searching through to find things. (Clinician 002)*

They highlighted a number of aspects of the programme manual which could be improved to make it easier to navigate. For example, one suggestion was that it would help to have a checklist of the key things required to cover in each weekly session:

> *I do think the whole thing needs to be slightly repackaged so it is a lot easier to find what you are doing. I would like a checklist… of week one… have you done this, this and this? (Clinician 003)*

10.3.3.3.4 Worksheets

The clinicians believed the worksheets were useful resources and facilitated discussion relating to the barriers they had identified. However, they suggested the worksheets were most effectively used as an intervention tool when they could leave a copy with the participant so they could continue to work on and refer to it in between intervention sessions.

> *I mean, I needed duplicates of things because I needed to take a copy for myself as a record as well as leave something preferably with them, or what I was doing. (Clinician 001)*

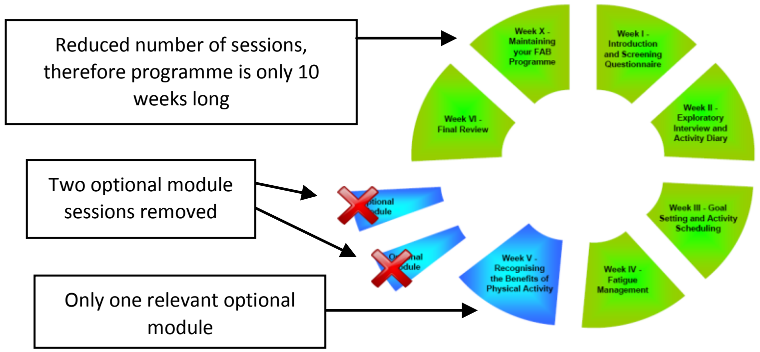
In order to leave a copy with the participant and retain a copy themselves, the clinicians invariably had to resort to writing out the worksheet twice during an intervention period, which was onerous and time consuming, or making do with just one copy, which was not considered ideal either.

> *I mean, I write quickly… I don't print. I mean it is really hard to write within an hour and a half. I wouldn't have had the time… to actually write out something legible for him and retain a copy for me. Anything that you want duplicates of… it is just not going to happen if you are writing it out double. (Clinician 001)*

10.3.4 REFINING THE INTERVENTION

In response to the feedback from participants and clinicians after Wave I of intervention delivery, a range of amendments were made to the programme so they could be piloted during Wave II of intervention delivery. Table 10.3 outlines these amendments and includes a summary of participant and clinician feedback to the revised approach. Given that participants in Wave II were not privy to previous versions of the programme, it was difficult for them to comment on the changes. Hence, the feedback presented in Table 10.3 is from clinicians only.

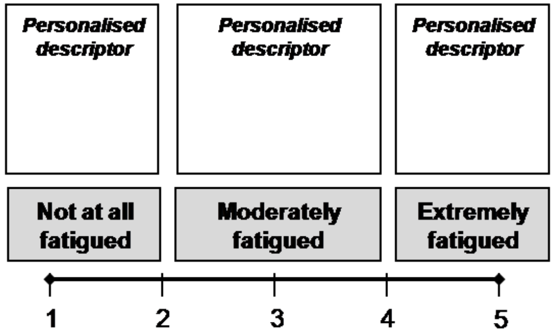
Table 10.3: Amendments made to the FAB programme in response to Wave I feedback

Key amendments		**Feedback in Wave II**
Structure of the programme		
Introductory session	The introductory session was split into two weekly sessions as follows: Week I - Introduction and screening questionnaire Week II - Exploratory interview and activity diary	*It was helpful to split the session in half [introductory session] as the whole would have been huge! (Clinician 003)*
Follow-up	A follow-up session was added resulting in an eight week programme and a review session at week twelve.	*Meeting up with him after so many weeks, that was good. It is quite nice… you are weaning yourself off slightly too. (Clinician 002)*
Flexibility	A series of examples were added to the manual to show how the structure of the programme could be flexibly applied to meet the individual needs of participants. *Example:* The important sessions for this participant are the activity scheduling and the fatigue management. The only relevant optional module after these sessions is the 'Recognising the benefits of physical activity' module. Therefore, their FAB Programme could look as follows:  	*I adapted it…and one thing I think was better was I felt I could do that. This time I was more open to making it suit the person, rather than trying to squeeze them in one of these [modules]. (Clinician 002)*

<table>
<tr><th colspan="2">Key amendments</th><th>Feedback in Wave II</th></tr>
<tr><td colspan="3"><i>Intervention delivery tools</i></td></tr>
<tr><td><i>Activity diary</i></td><td>The activity diary was simplified in the following ways:

Participants only need to record their activity each hour (v every 15 minutes);
They only record activities during usual waking hours (between 0600 and 2100 at most);
They only write a description of their activity (v coding their activities as well); and
They only report their fatigue levels three times a day (morning, afternoon and evening)

<i>Example of simplified diary:</i>
<table>
<tr><th></th><th>What I plan to do….</th><th>What I did….</th><th>Fatigue</th></tr>
<tr><td>0600</td><td></td><td></td><td rowspan="6"><u>Morning</u>
1=Not at all fatigued
5=Extremely fatigued</td></tr>
<tr><td>0700</td><td></td><td></td></tr>
<tr><td>0800</td><td></td><td></td></tr>
<tr><td>0900</td><td></td><td></td></tr>
<tr><td>1000</td><td></td><td></td></tr>
<tr><td>1100</td><td></td><td></td></tr>
<tr><td>1200</td><td></td><td></td><td rowspan="4"><u>Afternoon</u>
1=Not at all fatigued
5=Extremely fatigued</td></tr>
<tr><td>1300</td><td></td><td></td></tr>
<tr><td>1400</td><td></td><td></td></tr>
<tr><td>…</td><td></td><td></td></tr>
</table></td><td>The clinicians believed the changes improved the activity diary:
<blockquote><i>Heaps better! (Clinician 002)</i></blockquote>
They also indicated that the new, simplified format enabled them to make better use of the diary as a monitoring tool and to facilitate discussion regarding activity engagement throughout the programme:
<blockquote><i>It was much easier to see visually… so she was actually more aware of… “Okay well, I actually wanted to do a walk, I didn’t do that…now, why didn’t I do that?” (Clinician 001)</i></blockquote>
Finally, they reported a behaviour change on their part relating to the way they communicated with their participants about the diary, likely to have an impact on participant buy-in.
<blockquote><i>I think one thing that I probably didn’t do so much last time, and I did more this time, was really demonstrating how important the diary is… (Clinician 002)</i></blockquote></td></tr>
</table>

Key amendments		Feedback in Wave II
Fatigue rating	A personalised fatigue rating was developed which enabled participants to add their own descriptors relating to their own experience of fatigue to each anchor point on the scale. The development of this personalised scale was incorporated into week II of the programme so that it could be referred back to during subsequent diary completions. 	*He very easily filled out the fatigue stuff, that was heaps better… (Clinician 002)*
Programme manual	A number of changes were made to the programme manual to improve clarity and make it more user-friendly for the clinicians. The changes included: • Inserting coloured tabs in at key sections to allow for easy navigation • Bullet-pointing the core aims for each module on the front page of each module section • Including a pie chart alongside the core aims to give an indication of how long each component of the module is anticipated to take to aid clinician planning and highlight where the emphasis of the session should be • Including a summary sheet of the key things to cover in each module at the beginning of the module section as a quick reference guide to module content and the resources required for that module 	*I did find it helpful; because it made it clearer for me what needed to be covered in the session and I don't think this was so apparent in the first draft. (Clinician 001)* *It was definitely clearer and I understood the main points more. (Clinician 002)*

Key amendments		**Feedback in Wave II**
Worksheets	To enable clinicians to leave a copy of any worksheets completed during the session, the clinicians were each given a duplicates book where they could keep notes and use when completing worksheets. This allowed them to give the original to the participant themselves and retain the copy for their own records.	*No feedback related specifically to this amendment.*

The feedback included in Table 10.3 suggests that the changes were positively received by clinicians. This was further confirmed when information from the weekly session reports were collated and examined over the two waves of intervention delivery. For example, in these weekly reports the clinicians rated how well they perceived their client to engage in each session on a 5 point likert scale (1=Not at all engaged; 5=Extremely engaged). These engagement ratings improved from an average of 4 during Wave I to 4.7 in Wave II, indicating increased engagement in Wave II. While it is possible that this was partly due to the individual participants included at each wave, the feedback in Table 10.3 indicates that it may also be reflective of the programme amendments. It should be noted however that this engagement rating was developed specifically for this study and so is not standardised and has not been formally tested. For these reasons and also due to the small sample, these figures should be interpreted with caution. Similarly, for each session, clinicians were asked whether the resources for each session were adequate by circling ‘Yes’, ‘No’ or ‘In part’. Clinicians agreed that the resources were appropriate 78% of the time in Wave I and 87% of the time in Wave II.

Furthermore, while there seemed to be a significant amount of concern regarding some aspects of the programme such as the activity diary and fatigue rating for Wave I participants, this was less evident for those in Wave II. Rather, feedback on those aspects of the programme appeared more positive.

> *I found anyway, when you’ve got to write things down it makes it a bit different than just doing things and getting up in the morning and doing whatever, and having some reason to get up. (Duncan, Age 55, Primary progressive MS)*
>
> *I knew I had to go for a walk every couple of days, I did my exercise at night and all that sort of thing... if it wasn’t written down I wouldn’t do it. (Duncan, Age 55, Primary progressive MS)*
>
> *I wouldn’t say I enjoyed it the most, but I found the most useful was writing down when I did exercise. (Dianne, Age 60, Primary progressive MS)*

While the clinicians were positive about the amendments and seemed to enjoy delivering the programme in Wave II, they had outstanding concerns about the impact the *paradigm shift* and perceptions regarding *scope of practice* might have on wider implementation of the programme.

> *My biggest concern is a little bit around what we were talking about before, that I think we're both [the clinicians engaged in this study] very open, and holistic and open to thinking outside the square. I think it's not for all physios. (Clinician 002)*

10.4 SUMMARY

Study Six was the final study to be carried out as a part of this doctoral research and makes up a key part of Phase III. This pilot study aimed to explore the acceptability and feasibility of the FAB programme to people with MS and their clinicians; and refine the programme in response to participant feedback. The FAB Programme was found to be acceptable to both people with MS and their clinicians. In particular, both appreciated the emphasis and priority that the FAB Programme gave to ensuring the development of a strong therapeutic relationship. People with MS also liked that the programme was delivered by a qualified physiotherapist with experience of working with neurological conditions. They believed that this added credibility to the programme. Finally, they liked that the programme was home-based and therefore context-appropriate. Despite seeing value in the approach, clinicians did express some concerns regarding the paradigm shift from “doing” to “talking”. They indicated that this shift in the way they work is challenging to conventional practice methods and may impact on the success of wider implementation in the future. Furthermore, they suggested that some of the psychologically-informed aspects of the programme may be pushing the boundaries of their scope of practice. Regarding feasibility, there were a number of minor issues identified during the first wave of intervention delivery. However, refinements were made in response to this feedback and subsequently tested in Wave II. Clinician feedback after Wave II was positive. While impact was not formally tested, a range of perceived benefits were reported by participants, indicating that the FAB Programme has potential as a strategy for facilitating physical activity engagement in people with MS.

CHAPTER 11

PHASE III DISCUSSION

Chapter Two highlighted evidence that people with MS have been consistently found to engage in particularly low levels of physical activity when compared with the general population and other chronic illness groups, contributing to the onset of secondary conditions, reduced physical functioning, worsening mental health and social isolation. While traditional exercise programmes have been found to have beneficial effects on a range of health outcomes, changes in physical activity are rarely maintained in the long term. In Phase II of this doctoral research, it was found that engagement in physical activity is influenced by a complex interaction of factors for people with MS, including personal beliefs about physical activity, and emotional response to previous experiences of activity. An intervention designed to explicitly manage personal barriers to activity engagement, with a focus on long term maintenance of physical activity, should arguably result in considerable health gains, and be likely to enhance the positive effects achievable in more traditional exercise programmes. Phase III was the final phase of this doctorate and aimed to move towards such a programme by developing a novel, theoretically driven, evidence-based approach to activity engagement for people with MS; and then pilot testing this approach to assess its acceptability to people with MS and their clinicians, identify any feasibility issues, and further refine the intervention protocol.

11.1 KEY FINDINGS

Table 11.1 highlights the key findings from the pilot study (Study Six) carried out during Phase III.

Table 11.1: Key findings from pilot study

<table>
<tr><th></th><th>People with MS</th><th>Clinicians</th></tr>
<tr><td>Acceptability</td><td>People with MS found the FAB Programme acceptable and in particular liked:
• The emphasis on and time to develop a **strong therapeutic relationship**;
• That it was delivered by a qualified physiotherapist with **expert knowledge in and an understanding of MS**; and
• That it was **home-based**, ensuring it was context-appropriate.</td><td>Clinicians found the FAB Programme to be acceptable, but challenging. In particular they liked:
• Having the **time to develop a strong therapeutic relationship** and get to know their client.
They believed the contents of the programme required a **paradigm shift**, moving away from ‘doing’ to ‘talking’. Despite being challenged by this, they saw value in the approach and indicated they would like to see it incorporated into routine practice.
However, they also had some concerns including:
• The potential impact a paradigm shift would have on the success of wider implementation as they believed that **not all physiotherapists would be so open to this** approach; and
• Concern about engaging in a psychologically-informed way and **pushing the boundaries of one’s scope of practice**.</td></tr>
<tr><td rowspan="3">Feasibility</td><td colspan="2">Both people with MS and clinicians were positive regarding the *guiding principles* and *content* of the programme, but highlighted some areas for refinement relating to *programme structure* and *intervention delivery*.</td></tr>
<tr><td>*People with MS commented that:*
• They would have benefited from a **follow-up** session;
• The **activity diary was too complex** and needed simplifying; and
• The **fatigue rating was not self-explanatory and was too generic**. There was a preference for a personalised fatigue rating.</td><td>*Clinicians commented that:*
• The **introductory session was too long**;
• A **follow-up** session would have been useful;
• The intended **flexibility** of the programme needed to be more explicit;
• The programme was **time intensive**, though this could improve with increased familiarity;
• The programme manual could be **re-packaged for ease of reference**; and
• The ability to duplicate worksheets during sessions would have been useful.</td></tr>
<tr><td colspan="2">Refinements were made in response to this feedback and tested on subsequent participants in Phase II of intervention delivery. Feedback on these modifications was positive.</td></tr>
<tr><td>Perceived benefits</td><td colspan="2">Despite not formally testing effectiveness, clinicians and people with MS identified a range of perceived benefits including:
• Challenging beliefs about one’s ability resulting in increased confidence in engaging in physical activity;
• Helping participants to make physical activity a part of their daily routine;
• Facilitating participants to initiate engagement in physical activity; and
• Helping participants to engage in meaningful activities.</td></tr>
</table>

Table 11.1 highlights the FAB Programme was acceptable to both people with MS and their clinicians. A number of feasibility issues were identified; however refinements made in response to this feedback were received positively. Furthermore, both clinicians and people with MS identified a range of perceived benefits relating to activity engagement, indicating the programme has potential for effectiveness. Perhaps the most noteworthy findings related to the clinician feedback regarding the *paradigm shift* required to engage with people in the way intended by the FAB Programme, and their concerns about the risk that some of the content of the programme pushes the boundaries of their *scope of practice*. These findings are discussed in more detail below.

11.1.1 A MIND SHIFT REQUIRED FOR CLINICIANS?

11.1.1.1 A paradigm shift

All three clinicians who took part in the pilot study enjoyed having the time to talk with their participants and get to know them, particularly as they suggested that this enabled them to develop a stronger therapeutic relationship than they would ordinarily have in a typical clinical environment due to time constraints. However, despite this positive feedback, there was a sense that they were somewhat unsettled by the emphasis placed on “talking” and engaging with the client versus actually “doing”, due to the mind-shift that this required. In particular, the two least experienced clinicians were concerned about this, not for themselves, but because they believed that this shift in focus may make it difficult to get buy-in from other clinicians when considering wider implementation of the FAB Programme in the future.

This finding is not dissimilar to those reported recently in a pilot study of two novel approaches to goal setting, where clinicians also commented on the need for a mind-shift to take place due to emphasis on “talking” rather than “doing”.(288) In that study, the clinicians were also concerned about the perceptions clients would have of therapy if they spent too much time engaging with them in discussion. This was also implied by one of the clinicians in the current study who suggested that there was a perception that if one spent too much time “talking” versus “doing” then you were not doing your job (see page 288). However, this concern was not mirrored by the participants in this study who particularly enjoyed the time the clinicians spent getting to know them. One participant even suggested that this was an essential component of the programme, which helped to ensure the programme goals were relevant and appropriate to her and that the time spent focusing on this knowledge exchange gave her the opportunity to really get to the 'nitty gritty' rather than being limited to a superficial exchange (see page 283). Further, research investigating a range of perspectives on what contributes to quality of care suggests that technical competence needs to be balanced with a human approach to care,(289) supporting the underpinning principles of the FAB Programme which call for an individualised approach and partnership.

In 2000, Jensen and colleagues published the findings of a qualitative study which aimed to identify what characterised 'expert' practice in physiotherapy.(290) In this study, a range of data was obtained from 12 physiotherapists identified as experts by their peers, and synthesised into a theoretical model of expert practice in physiotherapy. They found that one of the key distinguishing features of an expert was the centrality of the patient. That is, they considered the patient to be an important source of knowledge, and the knowledge required to treat the patient moved beyond movement and function to understanding the patient and their personal context. Further, collaboration with the patient was considered crucial. This is relevant to the findings of this pilot study for a number of reasons. First, perhaps the transition from "doing" to "talking" is something that occurs naturally as clinicians become more experienced. Therefore, a novice clinician may find gaining competence in this sort of approach to be a steeper learning curve than a more experienced clinician might. This is supported in the findings of this study, where the least experienced clinicians seemed more concerned about this shift in the way of working than the more experienced clinician. Second, the FAB Programme could be seen as an intervention not only targeting behaviour change on the part of the client, but also on the part of the clinician; in that it may provide the clinician with the tools and resources to engage with the client in a more personalised way. Given that this skill is considered a key characteristic of being an expert physiotherapist, a formalised approach, such as the FAB Programme, which facilitates this type of skill development, may have positive implications for the quality of care provided by physiotherapists. Finally, the FAB

Programme was structured in a way that allows time for getting to know the client and establishing therapeutic relationship. Jenson and colleagues suggested that allocating time in practice environments for this type of engagement may be one way of improving related professional competence.(290)

11.1.1.2 Scope of practice

The clinicians also indicated feeling a little apprehensive about the some of the content of the FAB Programme, due to concerns that the psychological nature of some aspects of the programme pushed them to the boundaries of their scope of practice. In particular clinicians were concerned with modules such as the ‘Reframing your thinking’ module, where the purpose is to challenge potentially maladaptive beliefs and help participants to consider alternative ways of thinking. It is true that it would be unsafe to expect a physiotherapist to engage with a client in a psychotherapeutic way given that they are not trained to do so. However, the intention of the FAB Programme was not to make physiotherapists quasi-psychologists. Whether they mean to or not, physiotherapists have the potential to influence their client’s beliefs and perceptions about physical activity and their subsequent behaviour.(291) It is possible that ignorance of their potential role in shaping behaviour could result in them unwittingly having a negative impact on behaviour. The FAB Programme, therefore, aimed to make that process more explicit and encourage the clinician to consider their role more closely.

Psychologically informed interventions are not new to physiotherapy, particularly in the chronic pain field,(98,268,271,292,293) and it has been argued that applying psychology could enhance physiotherapy practice.(294) Harding and Williams proposed a number of ways that a physiotherapist could use psychology to enhance their practice in chronic pain patients,(293,294) which are similar to those proposed in the FAB Programme. Examples included using pacing and scheduling to ensure that engagement in activity is not symptom dependent; using education and evidence to help the patient weigh up the advantages and disadvantages of behaviour change; recording progress to reinforce improvements; and challenging unhelpful cognitions by helping participants engage in physical activity in a way that allows the patient to gather their own evidence that they can engage in physical activity without detrimental effect. Similar strategies have been incorporated into the FAB Programme. For example, rather than intervene directly with a catastrophising thought, the FAB Programme was designed for the physiotherapist to use their skills and knowledge to deal with the *physical manifestation* that is *contributing* to that thought.

This raises a number of implications for the FAB Programme. First, previous work in chronic pain would suggest that drawing on psychology to enhance physiotherapy practice is acceptable and can be incorporated into practice in a way that does not need to challenge scope of practice.(293,295) Second, the fact that clinicians participating in this pilot study raised concerns about scope of practice indicated there is some work to be done on the FAB Programme to ensure that the language used does not imply that one needs to engage in a psychotherapeutic way. Instead, it should be emphasised that the intention is for clinicians to explicitly utilise their skills and expertise as a physiotherapist (including listening and talking) to challenge unhelpful beliefs. Third, concern about scope of practice highlighted the possibility that there will be times when engaging with clients on these issues may raise some concerns about the client's psychological state, the management of which goes beyond the expertise of the physiotherapist. Therefore, the FAB Programme should explicitly address this by identifying what the triggers for referral might be, and how one should manage the referral process if it should become apparent that it is necessary.

11.2 CONSIDERING THE FAB PROGRAMME IN THE CONTEXT OF RECENT TRIALS

Since carrying out this pilot study, a small number of trials have been published exploring the efficacy of a variety of interventions aiming to increase health-promoting behaviour in people with MS.(239,243,296,297) Two of the programmes reported in these studies targeted health-promoting behaviours more generally (not just physical activity),(296,297) while the other two were designed to target physical activity behaviour specifically.(239,243) The interventions and mode of delivery were diverse and included telephone-based motivational interviewing (296); a group-based health promotion education (297); a group wellness intervention paired with prescribed home exercises (243); and an efficacy enhancing intervention drawing on social cognitive theory paired with an exercise programme.(239) The effects observed in these trials were variable, with the telephone counseling and health promotion education both finding significantly greater improvements in health promoting behaviours than controls,(296,297) the group wellness intervention resulting in improvements, but not significantly different from controls,(243) and the efficacy enhancing intervention trended towards greater improvement in exercise adherence when compared to controls, but this was not significant.(239)

These studies are relevant to the FAB Programme for a number of reasons. First, they highlight increasing interest in facilitating people with MS to live well with their condition, further confirming the need for a programme like the FAB Programme, to explicitly address this important issue. Second, as well as this topic being of interest to researchers and practitioners, it seems to be something people with MS themselves are grappling with. For example, in the telephone counseling intervention,(296) participants self-selected their target health promotion behaviour. Increased physical activity was cited to be the most commonly expressed goal with 59% and 78% selecting it as their goal in the treatment and control groups respectively. Finally, the FAB Programme offers quite a different approach with regard to mode of delivery and activity engagement when compared with the approaches used in these trials. It is possible that many of the key features incorporated into the FAB Programme may help overcome some of the limitations cited in those papers. Examples include:

- All but one of the trials only included people with MS who could walk independently, with or without an assistive device, thereby limiting the generalisability of findings only to people with mild to moderate disability.(239,243,296) In contrast, the FAB pilot study included people with MS with a range of disability including one participant with severe disability who found the programme to be acceptable, and despite low expectations on the part of the clinician, reported what appeared to be personally meaningful changes in physical activity behaviour (see page 290).
- With the exception of the telephone counseling programme, all the programmes were carried out in a group setting.(239,243,297) McAuley and colleagues who reported having considerable difficulties recruiting people into their programme and then retaining them through the programme suggested

that an individualised, home-based programme may yield more positive effects than those observed in their trial.(239) Certainly, one of the features participants in the FAB pilot study liked the most was the fact that it was home-based and individualised and therefore relevant and context-appropriate. This is in line with findings of Phase II of this research, which suggested that the decision to engage in physical activity is influenced by a complex interaction of factors that seems unique to each person, supporting the need for a personalised approach to barrier management.

- The two interventions targeting physical activity behaviour incorporated a structured exercise programme into their intervention.(239,243) In contrast, in the FAB Programme, activity goals are self-selected in an effort to ensure they are meaningful to the individual person with MS. This was received positively by participants in the FAB pilot study, with one participant even reporting that he believed he would be more likely to continue activity engagement post-programme, as a result of the focus on meaningful engagement (see page 292). Clearly this is yet to be tested, but the focus on meaningful engagement is a distinguishing feature of the FAB Programme which may have the potential to result in enhanced outcomes.
- McAuley and colleagues made the point that the recruitment difficulties they experienced may, at least in part, be due to the historical view of health professionals that people with MS should rest.(239) As a result they make a call for recognition that MS health care providers have a responsibility to promote physical activity engagement in people with MS. The FAB Programme addressed this through the engagement of qualified physiotherapists in intervention delivery, thereby formalising the role that health care practitioners, such as physiotherapists, have in facilitating physical activity in people with MS. Feedback from participants in the pilot study suggested this played a key role in the perceived acceptability of the programme with participants, indicating that having experts in physical activity who understood MS increased the credibility of the programme and promoted accountability on their part (see page 283).

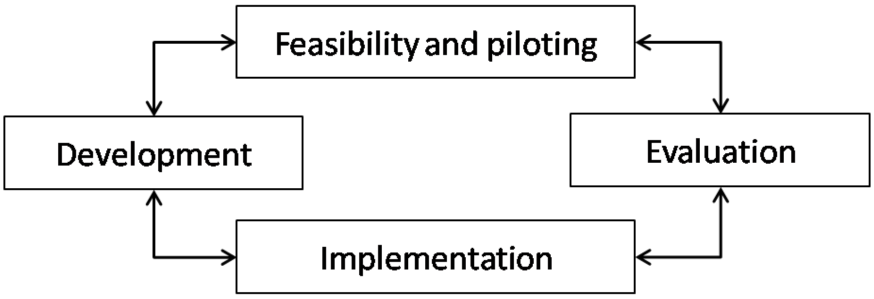
The points discussed above highlight a number of key distinguishing features of the FAB Programme which have not yet been tested for efficacy or effectiveness in people with MS. These include that it: a) was targeted to people with all levels of disability; b) utilised a personalised approach to barrier management; c) was home-based; d) targeted meaningful engagement in physical activity; and e) was delivered by qualified physiotherapists experienced in working with neurological conditions. It is possible that these key features, which draw on evidence, have the potential to result in longer term engagement in physical activity and enhanced health outcomes for people with MS, when compared to existing approaches discussed here.

11.3 FAB PROGRAMME LIMITATIONS

11.3.1.1 Revised Medical Research Council framework

In 2008, the Medical Research Council revised their guidelines in response to critics' concerns regarding limitations of the framework which largely centered on a) the inference of the 2000 framework that one would work through the phases in a linear fashion in keeping with phases traditionally applied to drug development; b) that full standardisation of protocol may not be appropriate, or even possible, in a complex intervention; and c) that a thorough process evaluation is important for successful implementation.(298) As a result, the revised guidelines propose a cyclical approach to intervention development and evaluation (see Figure 11.1).

Figure 11.1: Revised MRC framework (figure adapted from Craig et al.(298))



Given that the earlier framework guided the development of the FAB Programme, it seemed important to consider whether or not the revised framework highlighted any potential flaws in development process. Table 11.2 illustrates the key aspects of the framework relevant to intervention development and the processes used in the FAB Programme in order to assess how consistent they were.

Table 11.2: Checking for consistency between the revised MRC framework and development of the FAB programme

Revised MRC framework	FAB Programme development
The revised framework considers development to include three processes: 1) Identifying the evidence base; 2) Identifying or developing theory; and 3) Modeling process and outcomes.	The FAB Programme was a theoretically driven, evidence-based approach informed by existing literature in the field and research carried out through this doctorate (*Identifying evidence base* and *Identifying or developing theory*) The pilot study enabled consideration of requirements for successful intervention delivery e.g. necessary training for clinicians, supervision required, utility of intervention tools and resources, and logistics of carrying out the intervention. Furthermore, it helped to identify the types of activity goals likely to be self-selected by people with MS which would assist in identification of appropriate outcome measures, should a full definitive trial be carried out (*Modeling process and outcomes*)
Intervention development and evaluation should be cyclical in nature	Intervention development was iterative with findings from the pilot study informing further refinement of the FAB Programme
Full standardisation of protocol is not always appropriate	Due to findings from Phase II of this research which highlighted the complexity of the decision to engage in physical activity, the FAB Programme adopted a modular approach to intervention delivery, which allowed for both standardisation and individualization

Table 11.2 highlights that while this revised framework was not available during the intervention development phase of this project, the process adopted during FAB Programme development was congruent with the new guidelines. At face value, it could be interpreted that congruency with the revised guidelines indicates the development to be in violation of the original guidelines. However, the key components of the revised framework indicated in the left-hand column of Table 11.2 were arguably an intention of the original framework, and the revised framework simply makes this more explicit. For example, despite the inference that the original MRC framework proposed sequential phases, an alternative iterative approach to

carrying out the phases (as adopted in the FAB Programme development) had been previously suggested.(267) This iterative alternative appears closely aligned with the cyclical process proposed in the revised framework.

11.3.1.2 Cost-effectiveness

A possible limitation of the FAB Programme is its potential cost-effectiveness given that it is a home-based, individualised, time-intensive approach. Home-based, individualised approaches are inevitably more costly than clinic-based sessions (due to the cost of travel) or a group-based alternative. Regarding the time-intensiveness of the approach, feedback after Wave II of intervention delivery in the pilot study suggested that the clinician preparation time reduced as one became more familiar with the programme content. However, the average session length (45 to 70 minutes in Wave II of intervention delivery) is still longer than what one would normally expect in a clinic-based session largely due to the emphasis on therapeutic relationship. Given the likelihood that the FAB Programme would be more costly than usual care for people with MS, cost-effectiveness analyses would need to indicate the FAB Programme to yield greater benefit than usual care, to account for the higher cost. A decision would then have to be made about whether or not the degree of benefit over and above that of usual care is worthy of the higher cost before wider implementation could be considered.(299) It has been argued that a simple cost-effectiveness analysis cannot help answer such questions, inevitably resulting in a judgment call being made regarding which intervention to fund.(299) In response, it has been proposed that a cost-benefit analysis that accounts for the broader societal costs of no intervention versus intervention over the long term would be appropriate. Having found the FAB Programme to be acceptable and to produce qualitative benefits for people with MS, one hypothesis would be that investing in the FAB Programme may result in longer term engagement in physical activity, in turn producing health benefits and leading to reduced health care utilisation in the long term. Testing this hypothesis with appropriate cost-benefit analyses is a key question for future research, to inform decisions as to whether wider implementation would be warranted.

11.3.1.3 Potential for over-reliance on therapeutic relationship

One of the key findings of the pilot study was that emphasis on therapeutic relationship seemed to be an important factor in the perceived acceptability of the programme, from the perspective of both people with MS and their clinicians. It may be that the therapeutic relationship itself was what kept people engaged throughout intervention delivery. It is possible, in practice, once a clinician disengages and leaves the participant to manage on their own, they may fail to maintain their engagement due to the departure of their motivator. In this study, participants commented that they felt accountable due to the fact that someone was taking the time to come to their home; that they did not want to let the clinician down by having not worked on their goals in between sessions; and that the weekly sessions acted as a deadline to get things done by (see page 285). All these comments suggest a strong reliance on the weekly sessions and the clinician being present. One aim of the FAB Programme is to help people learn the skills and develop the resources to continue to engage in physical activity independently. The possibility of over-reliance on therapeutic relationship further highlights the importance of emphasising this key component, and the need to carefully manage the process of withdrawing from participants upon programme completion. Furthermore, it is clear that including a long term follow-up would be crucial when carrying out a more definitive trial to assess the impact the programme has on longer term engagement, and to discount the effects of therapeutic relationship.

11.4 PILOT STUDY LIMITATIONS

There are a number of limitations which should be taken into account when considering the findings of this pilot study. First, convenience sampling was used to identify potential participants, and only a small number of people with MS (n=5) took part in this study. Both of these factors may limit the generalisability of the findings. A selection of people who took part in Phase II of this doctoral research were invited to take part in the pilot study. It is possible that those people who had participated in this earlier phase were those who already had an interest in physical activity and may have been more likely to engage in the FAB Programme than those who did not participate.

In addition, people were only invited to take part if they lived within a 15km radius of AUT University, limiting the generalisability of the sample further. While small numbers and limited generalisability are important to consider, keeping the findings of the pilot study in context; they are not crucial elements with the study aims in mind. The aims of the pilot study were to explore the acceptability and feasibility of the FAB approach and further refine the programme; therefore diversity in the sample was given priority over a larger, more generalisable sample. A reasonable level of diversity was achieved as intended on a number of participant characteristics including gender, age, type of MS, use of aids and level of disability (see Table 10.1 on page 281).

Second, all the clinicians who took part in this pilot study were working at AUT in research and teaching roles. It could be argued that those physiotherapists working in research and teaching are by their very nature interested in new ways of working and so more likely to engage in a novel programme like the FAB Programme. All three clinicians self-reported being open to a holistic way of working which may have resulted in more buy-in to the FAB approach than one might expect if a more diverse sample of clinicians were included. Furthermore, the clinicians were colleagues with an interest in the topic with, it could be argued, a vested interest in the research outcome; potentially biasing their feedback. Testing of the FAB Programme in a wider range of clinicians from different practice environments will be important to rule out any of these potential biases.

Finally, this pilot study was not designed to test effectiveness. As a result there was no control group and/or blinding. Therefore, while reports of the perceived benefits of the FAB Programme suggest the programme has potential for effectiveness, further testing using a randomised controlled trial design is required to confirm this.

11.5 CONCLUSION

The FAB Programme was found to be acceptable to both people with MS and their clinicians, and a range of perceived benefits were reported. A number of feasibility issues were identified in Wave I of intervention delivery; however feedback on the refined programme delivered in Wave II was positive. One of the most interesting findings from this pilot study was that engagement was an issue for both participants (with regard to engaging in physical activity) and clinicians (with regard to engaging in a new way of working). This highlighted the need to address the beliefs of practitioners, as well as people with MS, especially given that buy-in from clinicians will be important for wider implementation. Another thing to be mindful of when considering wider implementation is clinician concerns regarding scope of practice. The FAB Programme needs to be further refined to ensure clarity regarding the clinician's role in delivering this psychologically-informed intervention, including how they could use their existing skills and knowledge to challenge potentially unhelpful beliefs, while working within their scope of practice.

CHAPTER 12

SYNTHESIS, DISCUSSION AND CONCLUSIONS

12.1 REVISITING THE AIMS AND OBJECTIVES OF THIS DOCTORAL RESEARCH

As highlighted in Chapter Two, the benefits of physical activity have been well established in people with MS. Despite this, people with MS engage in relatively low levels of activity when compared with healthy adults (including those deemed to live a sedentary lifestyle) and other chronic illness groups. This inactivity has been linked to a range of negative health outcomes for people with MS, leaving them vulnerable to a range of secondary conditions, social isolation and diminished general well-being. At the time of carrying out this research, little research had explored activity engagement in this population other than that carried out by two specific research groups which were found to be subject to a range of limitations, potentially limiting the capacity for knowledge about this important topic. As such, the key aims of this doctoral research were to:

(1) Gain a more in-depth understanding of the barriers and facilitators to physical activity from the perspective of people with MS;
(2) Use findings from this doctoral research and from previous research to inform the development of a theoretically driven, evidence based programme to facilitate activity engagement for people with MS; and
(3) Explore the acceptability and feasibility of the programme in people with MS and their clinicians.

In the process of developing a research proposal designed to address these aims, it became evident that a major limitation of research in this field to date was the lack of a valid and reliable measure of physical activity relevant to people with MS. This finding led to the introduction of a fourth aim, which needed to be addressed first:

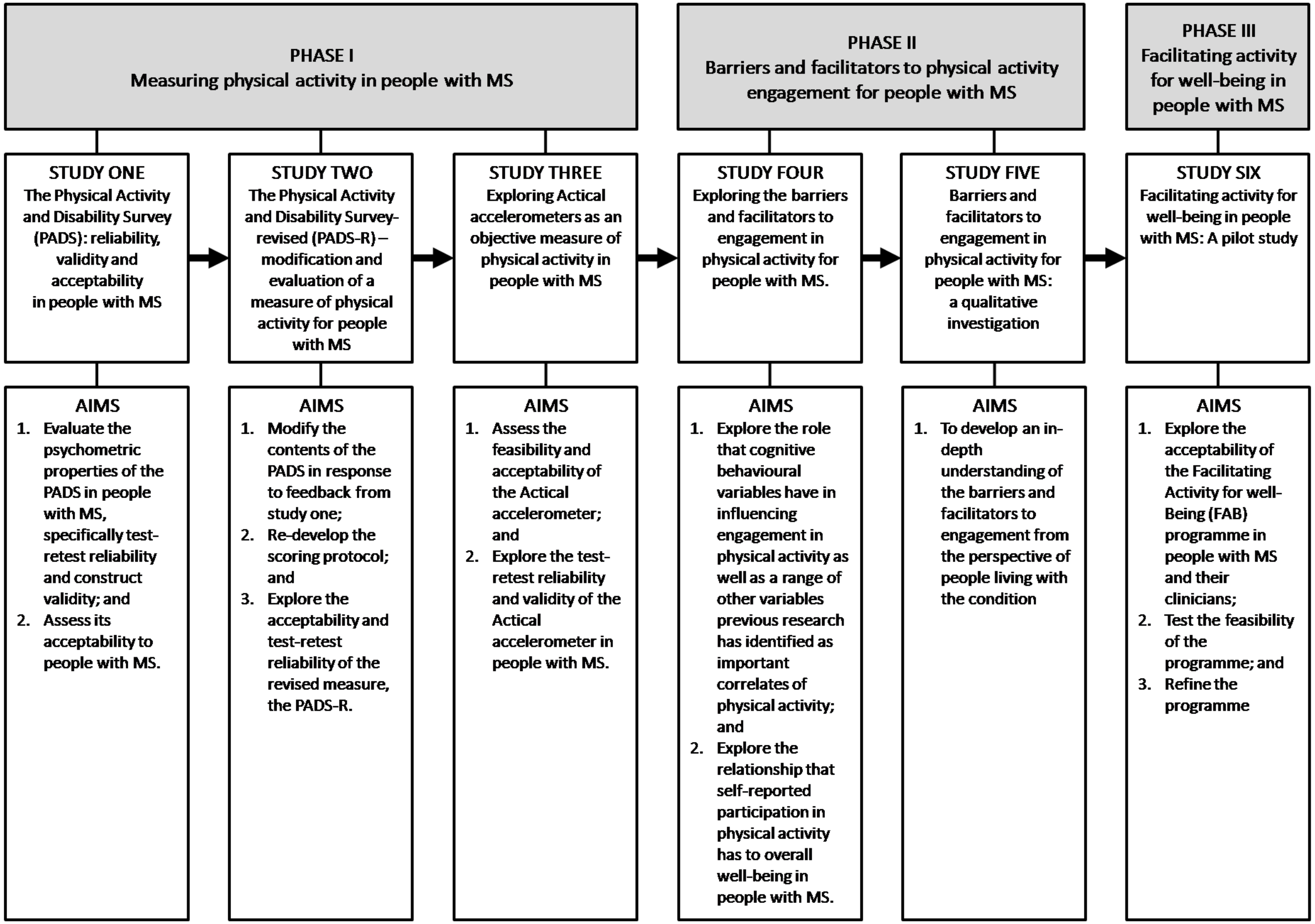
(4) To explore physical activity measurement in people with MS and identify an appropriate measure of physical activity to utilise in subsequent phases.

In order to achieve these four aims, three related phases of work were undertaken, incorporating six specific studies:

Phase I	Measuring physical activity in people with MS (aim 4)
Phase II	Barriers and facilitators to physical activity engagement for people with MS (aim 1)
Phase III	Facilitating activity for well-being in people with MS (aims 2 and 3)

An overview of the key aims and objectives of each of the six studies associated with these three phases are included in Figure 12.1.

Figure 12.1: Overview of the phases and studies incorporated into this doctoral research



PHASE I
Measuring physical activity in people with MS

STUDY ONE
The Physical Activity and Disability Survey (PADS): reliability, validity and acceptability in people with MS

AIMS
1. Evaluate the psychometric properties of the PADS in people with MS, specifically test-retest reliability and construct validity; and
2. Assess its acceptability to people with MS.

STUDY TWO
The Physical Activity and Disability Survey-revised (PADS-R) – modification and evaluation of a measure of physical activity for people with MS

AIMS
1. Modify the contents of the PADS in response to feedback from study one;
2. Re-develop the scoring protocol; and
3. Explore the acceptability and test-retest reliability of the revised measure, the PADS-R.

STUDY THREE
Exploring Actical accelerometers as an objective measure of physical activity in people with MS

AIMS
1. Assess the feasibility and acceptability of the Actical accelerometer; and
2. Explore the test-retest reliability and validity of the Actical accelerometer in people with MS.

PHASE II
Barriers and facilitators to physical activity engagement for people with MS

STUDY FOUR
Exploring the barriers and facilitators to engagement in physical activity for people with MS.

AIMS
1. Explore the role that cognitive behavioural variables have in influencing engagement in physical activity as well as a range of other variables previous research has identified as important correlates of physical activity; and
2. Explore the relationship that self-reported participation in physical activity has to overall well-being in people with MS.

STUDY FIVE
Barriers and facilitators to engagement in physical activity for people with MS: a qualitative investigation

AIMS
1. To develop an in-depth understanding of the barriers and facilitators to engagement from the perspective of people living with the condition

PHASE III
Facilitating activity for well-being in people with MS

STUDY SIX
Facilitating activity for well-being in people with MS: A pilot study

AIMS
1. Explore the acceptability of the Facilitating Activity for well-Being (FAB) programme in people with MS and their clinicians;
2. Test the feasibility of the programme; and
3. Refine the programme

12.2 NOVEL FINDINGS

The specific findings of each study carried out as a part of this doctoral research are discussed in detail in the context of existing literature in the discussion chapters at the end of each phase (Chapters Five, Eight and Eleven). This chapter is focused specifically on discussing how the research findings have challenged and/or augmented current knowledge regarding physical activity measurement and engagement in people with MS. The research carried out as a part of this doctorate has contributed to knowledge regarding physical activity and MS through having:

a) Improved measurement of physical activity in people with MS, both conceptually (Phase I and II) and psychometrically (Phase I);
b) Increased understanding of physical activity behaviour in people with MS and factors linked to their physical activity engagement (Phase II and III); and
c) Developed a theoretically sound, evidence-based intervention designed to facilitate long-term physical activity engagement in people with MS (Phase III).

Each of these contributions is discussed in more detail here.

12.2.1 IMPROVED MEASUREMENT OF PHYSICAL ACTIVITY IN PEOPLE WITH MULTIPLE SCLEROSIS

Findings from this doctoral research resulted in the development of a conceptually sound measure of physical activity for people with MS, the PADS-R. Consultation with people with MS throughout the development and refinement of this measure led to the development of a robust self-report measure that was found to be highly acceptable to people with MS. The PADS-R also displayed good content and face validity from the perspective of people living with the condition, and acceptable test-retest reliability. While future work is necessary to explore other important psychometric properties such as criterion validity and responsiveness, the PADS-R is arguably the most psychometrically sound measure of physical activity for people with MS currently available.

As well as advancing self-report physical activity measurement for people with MS, Phase I also explored objective measurement of physical activity in people with

MS using accelerometers. The findings from this exploration cast doubt on the prevailing assumption that accelerometry may be a more robust alternative to self-report measurement of physical activity in this population. Despite their intuitive appeal, Actical accelerometers did not appear to be a valid and reliable measure of physical activity in people with MS, particularly when attempting to measure a range of free-living physical activities.

Accelerometers have grown in popularity as an objective measure of physical activity, particularly in the general population.(143,179,180) They are thought to offer several important advantages for measuring physical activity in comparatively sedentary populations, such as people living with a chronic disabling condition like MS, as they have been shown to be sensitive in detecting varying levels of activity at the lower end of the physical activity spectrum (73); detect movement in multiple planes (179); and, in the case of the Actical accelerometer, are compact and waterproof and therefore can be worn in a variety of land-based and aquatic activities.(141) A range of accelerometers have been used previously with people experiencing illness and disability. However, despite their widespread use, at the time of carrying out this doctoral research little attention had been given to their acceptability in these populations and their ability to reliably detect the amount and intensity of activity.

While the limitations of self-report measures of physical activity have been debated extensively (22,140,159,163,164) with a range of biases identified, such as social desirability bias (165,166) and recall bias,(155,158) little attention has been given to the potential limitations of their ‘objective’ counterparts. There seems to be an underlying assumption that if an ‘objective’ measure is available, it should be the preferred option and that they are, by their very nature, robust and invariant across populations.(175) Interestingly, a number of the papers referred to in Chapter Five, published data which indicated high variability in the accelerometer measures being testing.(197,198) Despite this, the authors of these papers continued to be positive about these devices, advocating them to be a good measure of physical activity in people with MS.

The results of Phase I challenged existing assumptions that objective measurement is by its very nature superior to self-report. The Actical accelerometer was found to be subject to a range of limitations including poor overall test-retest reliability and validity. In particular, the ability of the accelerometer to measure free-living activities accurately and reliably in people with MS came into question. On the contrary, the self report measure (PADS-R) appeared to be a more conceptually sound measure of physical activity; seemed more able to capture activities at the low end of the activity spectrum; and demonstrated better test-retest reliability than the Actical accelerometer.

Research has demonstrated repeatedly that people with MS are a particularly sedentary population (7) who engage in relatively low levels of structured exercise and leisure-time physical activity. In addition, the findings of the qualitative investigation in Phase II (Study Five) indicated that engagement in physical activity for people with MS is a balancing act, where engagement in one activity often takes place at the expense of another. As a result of this balancing act, a number of people highlighted that work and household-related activities generally took priority over activities which were perceived to be more self-indulgent (e.g. leisure and exercise activity). For both these reasons, it is imperative that a measure aiming to capture physical activity in this population can accurately and reliably measure free-living physical activity, particularly activities at the low end of the activity spectrum, such as general household activity and incidental physical activity. As yet, based on the findings of Phase I and other recent research in this field, there remains insufficient evidence to suggest that accelerometry devices can do this.

12.2.2 INCREASED UNDERSTANDING OF PHYSICAL ACTIVITY BEHAVIOUR IN PEOPLE WITH MULTIPLE SCLEROSIS

Physical activity engagement in people with MS continues to be problematic. Despite an increasing amount of research in this field in recent years,(5,17,18,181,239,243-246,254,300) a recently published study reported that people with MS continue to engage in low levels of physical activity.(301) A key contribution of the research carried out in this doctorate is that it offers further understanding of physical activity behaviour in people with MS from a new perspective, both theoretically and methodologically. From a theoretical perspective, this research was the first to explore physical activity engagement in people with MS from a cognitive-behavioural perspective. From a methodological perspective there were a number of aspects of this doctoral work which distinguish it from existing research. First, Study Four was one of the first to explore the amount of variance in physical activity accounted for by frequently explored psychosocial variables *over and above that accounted for by important illness-related variables*. Second, Study Five was one of the first fully qualitative studies designed to explore physical activity engagement from the perspective of people with MS. Finally, the qualitative study (Study Five) and the pilot study (Study Six) offered some insight into the perspectives of health professionals regarding their role in addressing issues of activity engagement in people with MS.

This in-depth exploration has led to a range of novel findings, which augment existing knowledge in this field. First, despite findings from the questionnaire study failing to identify cognitive-behavioural variables as important predictors of physical activity, the qualitative inquiry clearly indicated that beliefs and perceptions about physical activity may be important key determinants of physical activity behaviour in people with MS. This was further confirmed with findings from the pilot study, indicating the FAB programme (underpinned by cognitive-behavioural principles) was highly acceptable to people with MS and their clinicians.

Second, findings from the questionnaire study (Study Four) identified self-efficacy, perceived barriers to physical activity and fatigue to be significant predictors of physical activity in people with MS. This in itself is not new knowledge, as it simply confirms what has already been reported in the literature.(12,13,16,19,20,245,302) However, the interesting finding is that these psychosocial variables accounted for 12% of variance in physical activity behaviour. This is arguably small compared to that accounted for by illness-related variables (42%), such as type of MS and use of legs. This raised two key points of interest: 1) that a key focus of future intervention work may be to target people with secondary and primary progressive forms of MS and those with mobility-related impairments; and 2) that while previous work has highlighted self-efficacy to be a key determinant of physical activity behaviour in people with MS,(18-20) when accounting for illness-related variables, the role of self-efficacy appears less certain. This was further confirmed by the qualitative findings in Study Five where self-efficacy was not identified as a key theme when physical activity engagement was explored from the perspective of people living with MS. This finding indicates that it is possible that focusing only on self-efficacy in an effort to facilitate behaviour change in people with MS may be an over-simplification. This notion was discussed in Chapter Eight.

Third, the qualitative investigation highlighted a number of aspects of the decision to engage in physical activity which have not been previously acknowledged in the literature. That is, the decision to engage in physical activity appears to be influenced by an interaction of factors and is *complex, fluid and individual*. While the factors reported to contribute to physical activity behaviour appeared to be consistent across those interviewed (such as beliefs about physical activity, emotional response, fatigue, and so on), the way in which these factors interacted or *how* they influenced activity engagement seemed to be unique to each individual. In addition, the decision to engage in physical activity was not a one-off event; but rather a fluid process where the decision was continually reassessed in light of new information and personal experiences of physical activity. As discussed in Chapter Eight (see page 231) these findings challenge the notion of intention-behaviour continuity and instead support the potential role of a self-regulatory model of physical activity behaviour in this population.

Finally, the qualitative study (Study Five) highlighted the potential role that health professionals play in shaping physical activity behaviour in people with MS. For example, previous messages about physical activity (or the absence of), particularly those from health professionals, appeared to influence subsequent engagement in physical activity for people with MS. The findings from the pilot study (Study Six) linked with this, offering some insight into the perspectives of health professionals regarding their perceived role in addressing issues of activity engagement in people with MS.

One of the most striking findings from the pilot study was that the novel intervention brought the challenge of facilitating clinicians to engage in new ways of working. Clinicians participating in the pilot study reported in Chapter Ten highlighted two potential barriers to uptake by physiotherapists if wider implementation of the FAB programme was sought: 1) the *paradigm shift* the programme requires with greater emphasis on “doing” versus “talking”; and 2) the risk of clinician perceptions that the FAB programme requires them to move beyond their *scope of practice*. These findings indicate that while the focus of the FAB programme is targeted at facilitating engagement of people with MS in physical activity, facilitating engagement of clinicians in delivery of the FAB programme may be just as crucial to the success of the programme. These findings are not dissimilar to a previous study where two new approaches to goal setting were piloted in people with traumatic brain injury.(288) In that study clinicians also voiced a concern about the mind shift required to engage in those new ways of working. There was also some anxiety expressed about how these new methods of engagement would be perceived by patients. For example, what if their patients thought they weren't doing their job if priority was given "talking" versus "doing"? On the contrary, feedback from participants in Phase III of this doctoral research would suggest that patients would likely be amenable to this change in practice.

There is a growing body of literature which explores the beliefs and attitudes of health professionals and the impact they have on how one engages with their patients and the resulting effect on treatment adherence.(303-306) For example, one study found that despite increasing evidence, and professional standards highlighting the importance of a nurse's role in patient education upon discharge to improve treatment adherence, that a group of nurses interviewed did not believe education was their responsibility; did not believe patients wanted to know about their medication; and did not appreciate the potential impact education would have on subsequent adherence.(306) Similarly, a more recent study exploring attitudes of physiotherapists regarding exercise and knee osteoarthritis found that clinicians saw exercise adherence as the patient's responsibility, not the therapist's.(305) Another study exploring knowledge, attitudes and use of adherence-related strategies in nurses found that poor knowledge about medications was associated with negative attitudes about medication, and that both poor knowledge and negative attitudes were associated with difficulty utilising adherence-related strategies with their patients.(304) One important component regarding adoption of a specific intervention strategy by a health professional that has been discussed in the literature is their self-efficacy, or their belief in their ability to carry out a given treatment. For example, a recent study found that a clinician's belief that they had the adequate skills and knowledge to enhance patient adherence was most predictive of their subsequent efforts to utilise adherence-enhancing strategies in their practice.(303)

All of these studies highlight the importance of practitioner beliefs, knowledge and attitudes about a treatment with regard to both their own engagement in intervention delivery and the potential knock-on effect this could have on treatment adherence on the part of the patient. This highlights the importance of overcoming any impact that beliefs and perceptions on the part of the clinician about a *paradigm shift* and *scope of practice*. Based on findings of this previous research, there is a risk that beliefs and perceptions like this may result in clinicians either not seeing delivery of the FAB programme as aligned with their role as a physiotherapist and/or not adhering to the evidence-based principles of the FAB programme. Given that people with MS identified that health professionals have a role in influencing their decisions regarding physical activity engagement, further understanding of clinician perceptions regarding their role offers an important contribution to this field of research.

12.2.3 THE DEVELOPMENT OF A NOVEL INTERVENTION FOR PHYSICAL ACTIVITY ENGAGEMENT IN PEOPLE WITH MULTIPLE SCLEROSIS

A key addition to the field of activity engagement for people with MS that can be attributed to this doctoral research is the development of a novel approach to activity engagement for people with MS, the FAB programme. The FAB programme is a theoretically driven, evidence-based approach to activity engagement designed specifically for people with MS. It integrates the findings highlighted above to ensure it is responsive to the needs of people with MS and is acceptable to both people with MS and their clinicians. As highlighted in Chapter Nine, there are several novel features incorporated into the FAB programme which make it different to existing intervention approaches. Of particular note is that:

(1) It uses a modular approach to delivery, balancing the need for both standardisation and individualisation; and
(2) It is a psychologically informed intervention delivered by a physiotherapist.

In his 2008 paper, Russell Glasgow argued that the type of evidence most needed to advance behavioural medicine is that which is *contextual, practical and robust*.(307) He argues that the perceived superiority of the randomised controlled trial and the reductionist approach of controlling for all potential confounders have led to a focus on internal validity of interventions, often at the expense of external validity. As a result, translation of evidence into practice has been plagued with difficulties due to the complexity inherent in a real world environment. A major strength of the FAB programme is that it is *contextual, practical and robust.* For example, key stakeholders, such as representatives from the MS Society, people with MS, and clinicians have been engaged in the research from its early conception and have influenced content, development and refinement. Further, in the pilot study (see Chapter Ten), participants were purposefully sampled for diversity in a range of variables such as level of disability, type of MS and gender in order to explore the utility and acceptability of the approach in a sample that is representative of the complexity evident in the real world. Finally, the modular approach to delivery allows for a balance between treatment fidelity and the need for a person and context-appropriate approach.

12.3 CLINICAL IMPLICATIONS

There are a number of clinical implications of note arising from this doctoral research discussed further here.

12.3.1 MEASURING PHYSICAL ACTIVITY IN PEOPLE WITH MULTIPLE SCLEROSIS

While the PADS-R is likely to be subject to the same limitations that other self-report measures of physical activity are (e.g. recall bias), it appears to be an appropriate measure for use in studies exploring physical activity in people with MS and potentially other people experiencing disability. A notable strength of the PADS-R is that it is a conceptually sound measure, developed in consultation with, and specifically for, people with MS.

Regarding measurement of physical activity using accelerometers in people with MS, findings from this research suggest Actical accelerometers should be used with caution in people with MS and potentially other people with chronic disabling conditions. This caution is particularly relevant when intending to measure more sedentary or free-living activities in these populations. Design and development of accelerometry devices has predominately occurred in healthy populations and, due to the growing popularity of such devices; the technology has been adopted for use in illness and disability populations. The findings from Phase I highlighted, at least in the case of Actical accelerometers, that the measurement properties of these devices do not necessarily hold for populations they have not been designed for. The problem with this is that inappropriate use of these devices may lead to study findings, service evaluations, or individual client outcomes being misinterpreted or misrepresented. For example, if we believe that an accelerometer measures free-living activity, but actually it only measures more vigorous or purposeful, rhythmical activities then we may conclude that no change has occurred, when in fact meaningful change may have occurred in activities which require more subtle movements than can be detected with the accelerometer. Or if a change is observed it is unlikely to be a reflection of the true change that has occurred across all free-living activities, but rather just a subset of activities. There are several possible repercussions of misinterpreting or misrepresenting a finding, which could include resource allocation shifts from an intervention type that is effective to one that is not effective, impeding the advancement of knowledge in rehabilitation, or worse, making clinical decisions based on inaccurate data. This doctoral research has highlighted that the accuracy and reliability of accelerometry-based devices cannot be assumed across populations. Therefore, researchers and practitioners would be well advised to ensure their device of choice has been well validated and is stable in their population of interest before using them in future research and practice.

An overarching issue this raises is that it could be argued that viewing measures as a dichotomy (‘objective’ or not), is not helpful when selecting a measurement tool. A more useful approach to measure selection would be to first determine if a measure is fit for its required purpose, and only after this has been established should one consider the relative merits of the measures that have been identified. When considering if a measure is fit for purpose, there are a number of things one might consider, including: the specific question or purpose of evaluation; the population being measured; and the context in which measurement is taking place. In some circumstances it may be that a self-report measure would be best fit for purpose, in other circumstances, an objective measure may be the most appropriate choice. Alternatively, an ‘objective’ measure and a self-report measure may in fact measure similar but distinct components of a construct, in which case there is value in using both. As such, a combination of *both* methods of measurement may be the most robust approach. Whatever the case, the findings of this doctoral research suggest that it may be misguided to assume a measure to be more robust due to its purported objectivity. Therefore, an alternative approach to measure selection is warranted.

12.3.2 PHYSICAL ACTIVITY ENGAGEMENT IN PEOPLE WITH MULTIPLE SCLEROSIS

A better understanding of the experiences of physical activity, and perceptions regarding engagement in physical activity for people living with MS should arguably lead to the development of programmes more responsive to the needs of individuals with MS, such as that developed in Phase III (the FAB programme). Most importantly, clinicians working with this population should be aware that decisions about engagement in physical activity are complex, made more complex by the unpredictable nature of MS; and that each person's experience of the illness is unique. As such, clinicians attempting to engage their clients in a physical activity programme may be more effective if they avoid oversimplifying the complexity, typifying it as simply a 'lack of self-efficacy', and consider adopting a personalised approach to barrier management. In addition, they could arguably invest time exploring and addressing personal beliefs about physical activity and any unfounded or irrational emotional responses to physical activity.

Health professionals may also benefit from considering the role they themselves play in influencing the development of beliefs about physical activity in this patient group. People with MS highlighted the importance of previous messages about physical activity (or the absence of) in influencing subsequent physical activity engagement, particularly messages received from health professionals. Supporting this finding in the qualitative study, the questionnaire study also highlighted this as an issue. For example, as highlighted in Chapter Six (page 173), barriers to physical activity reported by a large proportion of the sample included 'feeling I can't do things correctly' (47%); 'concern about safety' (45%); 'feeling what I do doesn't help' (40%); 'lack of information about what to do' (32%); and 'lack of help from health care professionals' (21%). All of these suggest a role for health professionals and highlights the importance of ensuring that messages about physical activity engagement are clear and consistent across professions, and that time is spent addressing people's concerns about physical activity engagement in an effort to avoid the development of unhelpful beliefs about physical activity.

Given the important role that health professionals could play in setting expectations regarding engagement in physical activity and addressing personal barriers to engagement, there may be implications for their training and education. It could be argued that strategies for engagement and the complexity of behaviour change in complex disabling conditions, such as MS, should become a core component of the training and education for health professionals at both an undergraduate and postgraduate level.

12.3.3 FACILITATING PHYSICAL ACTIVITY ENGAGEMENT IN PEOPLE WITH MULTIPLE SCLEROSIS

As highlighted earlier, findings from the questionnaire study (Study Four) indicated that targeting interventions at secondary and primary progressive forms of MS and those with mobility-related impairment would be wise. Intervention studies to date have predominantly targeted ambulatory people with MS.(239,243,296,297) This may be partly due to the difficulties of measuring physical activity in those with mobility impairments with studies exploring physical activity measures in people with MS including only those who are independently mobile.(5,114,139,181,197-199) The development of the PADS-R measure in Phase I of this research has helped to alleviate this measurement problem somewhat, making it possible to include people with mobility-related impairments, such as wheelchair users, in physical activity research. Furthermore, the FAB Programme was developed with the intention of addressing activity for people with MS with a diverse range of illness severity and was found to be acceptable event to the most impaired participant (largely dependent on a wheelchair) who took part in the pilot study (Study Six).

The pilot study found the FAB Programme to be highly acceptable to both people with MS and their clinicians, and refinements made as a result of the pilot study should improve the feasibility and utility of the approach. While there is much research to be done before wider implementation of the FAB Programme would be advised (see Section 12.4 below), the pilot study suggested that the FAB Programme has the potential to facilitate physical activity in people with MS with participants reporting a range of perceived benefits. Furthermore, despite the absence of empirical evidence that the FAB Programme is more effective than alternative approaches, it would arguably make sense to use an approach that is theoretically sound and evidence-based.(308) Interventions which facilitate populations, like people with MS, to engage in physical activity, are likely to enhance the positive effects achievable in more traditional exercise programmes through their focus on engagement and adherence. Furthermore, they have the potential to result in significant improvements in physical, social and psychological outcomes for people with MS.

If FAB were found to be effective, it would also be important to ensure adequate training for delivery of the FAB Programme to ensure treatment fidelity and alignment with the underlying principles of the programme; and to ensure clinicians delivering the programme establish confidence in their ability to deliver the programme. In the absence of a cure for MS, input from health professionals is largely centred on symptom management, frequently making allied health professionals the main point of contact that people with MS have at the interface of formal health care.(274) Therefore, buy-in from these professionals would be crucial to successful implementation of the FAB Programme.

This issue is broader than the FAB Programme alone. The findings of the pilot study regarding engagement of clinicians in a new way of working are likely to be just as applicable to other new interventions and strategies. Therefore, service delivery managers attempting to implement new strategies in their own health care environment should be mindful of this. Based on the findings of this doctoral research, it is recommended that stakeholders be engaged in intervention development and implementation from the outset, and that implementation plans are devised which pre-empt and counter any potential barriers to implementation. In addition, adequate training and education regarding the new approach should be ensured.

12.4 RECOMMENDATIONS FOR FUTURE RESEARCH

There are a number of areas where future research would be warranted in this field. These are discussed below.

12.4.1 MEASURING PHYSICAL ACTIVITY IN PEOPLE WITH MULTIPLE SCLEROSIS

More research is needed in the field of physical activity measurement in people with MS and likely other chronic disabling conditions. As highlighted in Chapter Five, further research should explore the validity and responsiveness of the PADS-R. Further research exploring the development of accelerometry devices (or other devices) that can better capture physical activity across the spectrum for use with disabled people is also warranted. Specific features of such a device include that it be designed to a) capture slow walking speeds and a range of free-living activities (as well as more vigorous activities); and b) capture physical activity in a diverse population e.g. wheelchair users and ambulatory people. It is possible that accelerometry technology will not be able to meet these requirements, in which case innovation in engineering may be necessary to further objective measurement of physical activity in complex disabling conditions like MS. However, it is possible that even if the technology could be developed to conceive of such a device, that the resulting device may be too cumbersome or complicated for use. Therefore, another important area for research would be to further explore the relative merits of a self-report measure and an accelerometry based device, and determine if they are in fact measuring similar but distinct components of physical activity. If they are, then a combined approach to activity measurement (including both a self-report measure and accelerometer) may offer important advantages, and should be further explored.

12.4.2 PHYSICAL ACTIVITY ENGAGEMENT IN PEOPLE WITH MULTIPLE SCLEROSIS

Figure 7.1 (see page 204) presented a diagrammatic representation of proposed interactions between themes identified through the interviews carried out as a part of the qualitative study (Study Five). It is possible that it could have been considered premature to develop an intervention based on these qualitative findings before quantitatively testing the proposed interactions in order to confirm generalisability of findings. Future research could explore these proposed interrelationships further.

As highlighted in Chapter Eight (see page 234), the CBSQ did not appear to capture the essence of the beliefs and perceptions about physical activity that people with MS described in the qualitative study. As a result, this may have contributed to the fact that cognitive-behavioural variables were not identified as a key associate of physical activity in the earlier questionnaire study (Study Four). Future research could further explore beliefs and perceptions about physical activity relevant to a range of chronic disabling conditions, to inform the development of a new measure aimed at capturing beliefs and perceptions specific to physical activity.

Given the discrepancy between the findings presented here and existing research, which suggests self-efficacy plays a key role in physical activity engagement; future research could further explore the underlying mechanisms of self-efficacy. For example, the qualitative study highlighted the possibility that it may be the underlying beliefs and perceptions about physical activity which contribute to self-efficacy; or one's confidence in their own ability to engage in physical activity. Exploring this notion further may help to make efforts to enhance self-efficacy more effective.

12.4.3 FACILITATING PHYSICAL ACTIVITY ENGAGEMENT IN PEOPLE WITH MULTIPLE SCLEROSIS

As highlighted in Chapter Eleven, the FAB Programme arguably requires further development to optimise buy-in from clinicians. This could include any or all of the following:

- Revisiting the language used in the programme so that it is more familiar to clinicians;
- Revising module content to include examples of ways that clinicians can influence beliefs and perceptions about physical activity using their existing skills, and without needing to work outside of their scope practice;
- Acknowledging the possibility that addressing personal beliefs about physical activity may raise psychological concerns, the management of which sit outside of the clinicians scope of practice; and/or

- Pre-empting concerns regarding FAB going beyond allied health professional scope of practice by explicitly identifying what the triggers for referral to psychological services might be, and how one should manage the referral process should it become apparent that it is necessary.

Following this, the next step for the FAB Programme would be to evaluate the effectiveness of the approach in a full definitive trial. As highlighted in Chapter Eleven (see page 318), in order to truly explore the effectiveness of the FAB Programme to facilitate longer term engagement in physical activity, long-term follow-up in a future trial is necessary. None of the published trials to date focusing on engagement in health promoting behaviours have included such follow-up, with the exception of one that included a three month follow-up assessment for the treatment group only.(297) Future research should make this a priority. Further, the majority of existing research is limited to ambulatory people with MS, yet, it is increasingly identified that those with progressive forms of illness have lower levels of physical activity (see Chapter Two and Study Four findings). In order to ensure that the trial is *contextual, practical and robust,* as proposed by Glasgow, 2008,(307) the methods should allow the recruitment of a representative sample that reflects the diversity evident in the MS population, and includes all types of MS and all levels of disability. Finally, as highlighted in Chapter Eleven (see page 317), incorporating a cost-benefit analysis into a trial of the FAB Programme would be important prior to future wider implementation.

Should a definitive trial find the FAB Programme to be effective, it may be worth considering development of alternative versions of the FAB Programme which can be offered. For example, a brief version of the FAB Programme could possibly be developed and incorporated into everyday practice. Alternatively, a group-based version may be a viable alternative for some people with MS, for whom social connection is important. The challenge of both of these options would be ensuring that the underlying principles of the FAB Programme are maintained. For example, if a brief version were developed, adequate time would still be needed to allow identification of personal barriers to engagement in physical activity. Likewise, if a group-based version is developed, consideration of how to best incorporate individual experiences of physical activity engagement and the potential for an individualised module plan would be needed.

Finally, another key area for future research would be to explore how the FAB Programme can be developed for different target populations. For example, future research exploring barriers and facilitators to engagement in other chronic disabling conditions may highlight a range of other individual modules which could be developed relevant to those populations. In addition to this, it would be worth exploring whether other clinicians may be well placed to deliver the FAB Programme. For example, occupational therapists or nurses.

12.5 CONCLUSION

Despite clear evidence that exercise and activity is beneficial for people with MS, actual participation in activity remains low.(7,301) This inactivity contributes to the onset of secondary conditions, reduced physical functioning, worsening mental health, and social isolation in people with MS.(7,31,33) While we know that exercise and physical activity are beneficial: physically, psychologically and socially; this knowledge is irrelevant if we are unable to support people with MS to engage in physical activity. The research carried out for this doctorate has contributed to knowledge by:

a) Improving measurement of physical activity in people with MS, both conceptually (Phase I and II) and psychometrically (Phase I);
b) Increasing understanding of physical activity behaviour in people with MS and factors linked to their physical activity engagement (Phase II and III); and
c) Integrating information from previous research, Phase I and II to inform the development of a theoretically sound, evidence-based intervention designed to facilitate long-term physical activity engagement in people with MS (Phase III).

The burden of a condition such as MS on the individual, their family and society is enormous. The development of an intervention, such as the FAB Programme, which facilitates people with MS to engage in physical activity should result in considerable health gains, and is likely to enhance the positive effects achievable in more traditional exercise programmes (6) due to the expectation that adherence will improve.(7)

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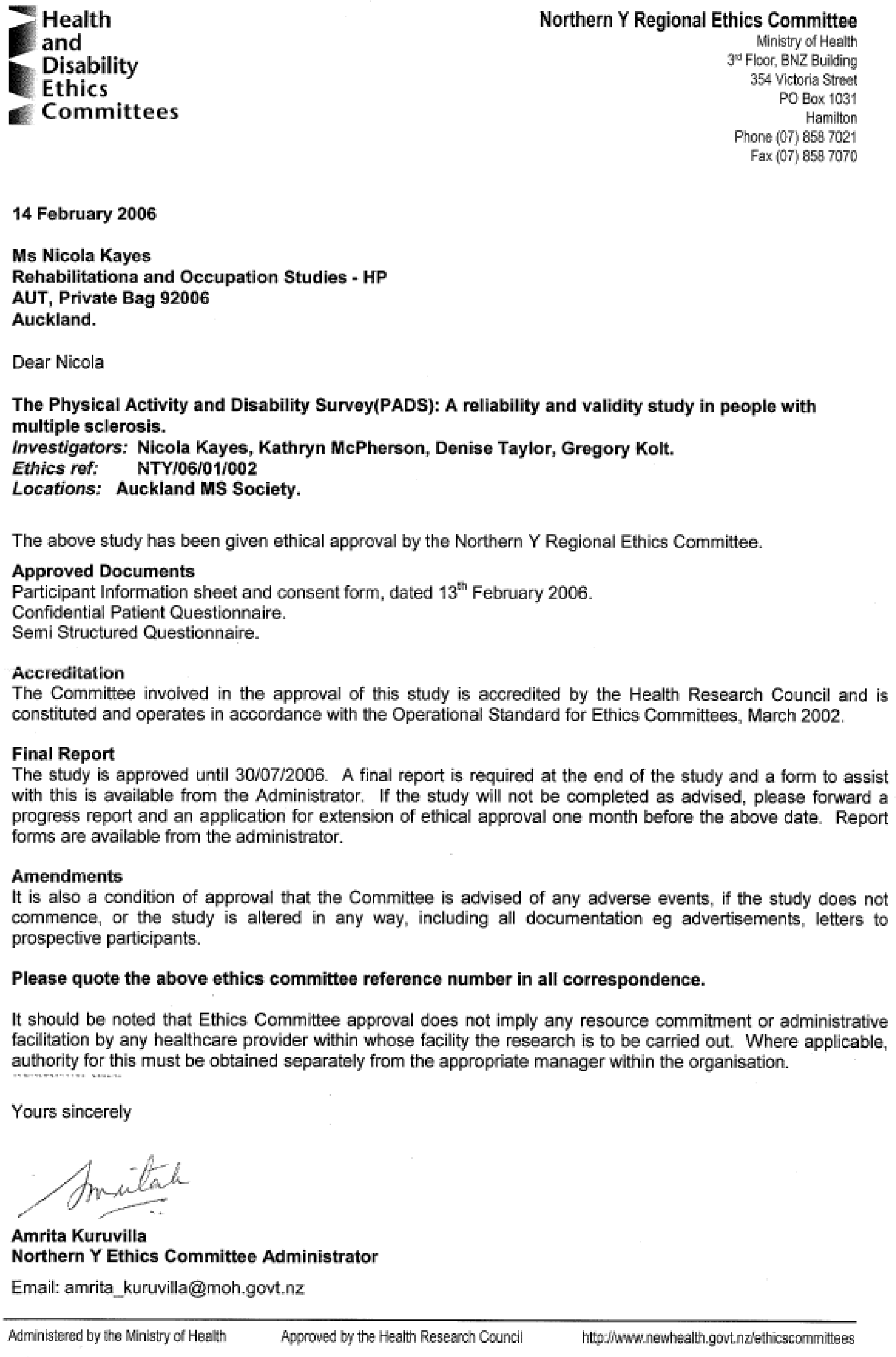
APPENDICES

APPENDIX A

Ethical approval for Study One



Health
and
Disability
Ethics
Committees

Northern Y Regional Ethics Committee
Ministry of Health
3rd Floor, BNZ Building
354 Victoria Street
PO Box 1031
Hamilton
Phone (07) 858 7021
Fax (07) 858 7070

14 February 2006

Ms Nicola Kayes
Rehabilitationa and Occupation Studies - HP
AUT, Private Bag 92006
Auckland.

Dear Nicola

The Physical Activity and Disability Survey(PADS): A reliability and validity study in people with multiple sclerosis.
Investigators: **Nicola Kayes, Kathryn McPherson, Denise Taylor, Gregory Kolt.**
Ethics ref: **NTY/06/01/002**
Locations: **Auckland MS Society.**

The above study has been given ethical approval by the Northern Y Regional Ethics Committee.

Approved Documents
Participant Information sheet and consent form, dated 13th February 2006.
Confidential Patient Questionnaire.
Semi Structured Questionnaire.

Accreditation
The Committee involved in the approval of this study is accredited by the Health Research Council and is constituted and operates in accordance with the Operational Standard for Ethics Committees, March 2002.

Final Report
The study is approved until 30/07/2006. A final report is required at the end of the study and a form to assist with this is available from the Administrator. If the study will not be completed as advised, please forward a progress report and an application for extension of ethical approval one month before the above date. Report forms are available from the administrator.

Amendments
It is also a condition of approval that the Committee is advised of any adverse events, if the study does not commence, or the study is altered in any way, including all documentation eg advertisements, letters to prospective participants.

Please quote the above ethics committee reference number in all correspondence.

It should be noted that Ethics Committee approval does not imply any resource commitment or administrative facilitation by any healthcare provider within whose facility the research is to be carried out. Where applicable, authority for this must be obtained separately from the appropriate manager within the organisation.

Yours sincerely

Amrita Kuruvilla
Northern Y Ethics Committee Administrator

Email: amrita_kuruvilla@moh.govt.nz

Administered by the Ministry of Health   Approved by the Health Research Council   http://www.newhealth.govt.nz/ethicscommittees

APPENDIX B

Cover letter from MS Society – Study One

Date

Xxxxx
Xxxxx
Xxxxx
Xxxxx

Dear XXXXXX

The Multiple Sclerosis Society of Auckland is currently working with researchers at the Auckland University of Technology (AUT) on some research looking at physical activity in people with Multiple Sclerosis (MS).

Enclosed is some information about a small study that we would like to give you the opportunity to participate in. There are no blood tests, x-rays or other procedures involved, and more details are in the information sheet.

Also enclosed is a consent form and a stamped self-addressed envelope. If you would like to take part in this study, then please complete the consent form and post it to the researchers at the AUT in the envelope provided.

In order to protect your Privacy, we have mailed this letter to you directly from the MS Auckland offices. Please post your reply, using the envelope provided, directly to the researchers at AUT. Please note that:

- The Society has not divulged your name and address to AUT or the researchers
- Your reply goes directly to the Researchers and MS Auckland are not informed of the names and addresses of those that choose to participate

The Society endorses this study as useful to people with MS.

Yours sincerely

Gary McMahon
GENERAL MANAGER

APPENDIX C

Participant information sheet – Study One

Participant Information Sheet

Measuring physical activity in people with Multiple Sclerosis (MS)

Invitation

Kia ora, talofa lava and hello, you are invited to take part in a study looking at measuring physical activity in people with MS. Please remember that:

- Your participation in this study is entirely voluntary (your choice). You do not have to take part in this study, and if you choose not to take part this will in no way affect your future health care.
- If you do agree to take part you are free to withdraw at any time, without having to give a reason. This will in no way affect your future health care.

This information sheet will explain the research study. Please feel free to ask about anything you do not understand or if you have questions at anytime.

What is the purpose of the study?

We are trying to find out if a new questionnaire designed to measure physical activity in people with chronic health conditions, the Physical Activity Disability Scale (PADS), is suitable and consistent over time in people with Multiple Sclerosis (MS).

How are people chosen to be asked to be part of the study?

A random sample of people have been selected from the MS Society of Auckland database. We have asked the MS Society of Auckland to send this letter on our behalf. The first 30 people who consent to participate in this research will be included in the study. The MS Society of Auckland supports this research.

Who is eligible to participate?

You are eligible to participate if you have been given a definite diagnosis of MS and are able to communicate with the researchers. We would like people with varying levels of participation in activity and so you are eligible to participate in this research regardless of your current level of mobility.

What happens in the study?

You will be visited by a researcher in your home and asked to wear an activity monitor for a period of 7 days, while you continue your usual daily activities. The activity monitor itself is a small device that can be worn on a belt around your waist or on your wrist like a wristwatch. It does not cause any pain as it sits on your skin. During this visit the researcher will also help you complete a short questionnaire, which will take approximately 10 minutes to complete. At the end of the 7 days the researcher will collect the accelerometer and help you to complete the same questionnaire again. You will also be asked to take part in a short interview (about 15-20 minutes) so that we are able to hear your thoughts about using the questionnaire and accelerometer.

What are the risks of this study?

There should not be any risk to you from this study. It is possible that you may find the questionnaire completion and interview tiring, but we will try to minimise this for you by going at your own pace and giving you the opportunity to take a break at any time if you desire.

How will this study help?

The information we gain from this study will help us to understand how well the PADS measures physical activity in people with MS. If results indicate that the PADS is an accurate and reliable measure of physical activity for people with chronic health conditions then we will be able to do more research to gain a better understanding of the impact that activity or inactivity has in those populations.

What are the costs of participating in the project?

There will not be any cost to you except your time, approximately two hours in total over the three visits we make to you.

How will my privacy be protected?

All information you give will be kept confidential and your name will not be known to anyone but the researcher. We will keep the information locked in a cabinet. Any reports will make sure that you cannot be identified. The researchers are independent of the MS Society of Auckland and so we have no access to their records. Likewise, representatives of the Society will have no access to individual data collected for the purpose of this study. A summary of the results will be made available to the MS Society of Auckland and the wider community. However, no individual's will be identifiable from this summary.

What will happen with the results?

We hope that the results of this study will be publishable in a neuro-rehabilitation journal. The results of this study will also inform the choice of questionnaire we use to measure physical activity in future studies in people with chronic health conditions.

Will I be able to have a copy of the results?

If you would like a summary of the results they will be sent to you at the end of the study (about 6 months after your final visit). Usually there is a delay between collecting information and letting people know about the results.

If you have any concerns or questions?

If you have any questions please feel free to contact one of the researchers:

Named researcher	Nicola Kayes	Phone: (09) 921-9999 ext. 7309 E-mail: nkayes@aut.ac.nz
Or	Kathryn McPherson	Phone: (09) 921-9999 ext. 7110 E-mail: katmcphe@aut.ac.nz
	Denise Taylor	Phone (09) 921-9999 ext. 7080 E-mail: detaylor@aut.ac.nz

If you have any queries or concerns regarding your rights as a participant in this study you may wish to contact a Health and Disability Advocate: Phone 08004ADNET (0800 423 638)

Other local services:	Auckland MS Society	Phone: (09) 845 5921

Statement of Approval
This study has received ethical approval from the Northern Y Regional Ethics Committee.

APPENDIX D

Consent form – Study One

Consent Form

Measuring physical activity in people with Multiple Sclerosis (MS)

Principal Investigator: Nicola Kayes Phone: 921 9999 ext. 7309

- I have read or had read to me, and I understand, the information sheet dated (13/02/06) for volunteers taking part in the study looking at a physical activity questionnaire, the Physical Activity Disability Scale (PADS), in people with MS. I have had the opportunity to ask questions. I am satisfied with the answers I have been given.
- I have had the opportunity to use family/whanau support or a friend to help me ask questions and understand the study.
- I understand that taking part is entirely voluntary (my choice) and that I may withdraw from the study at any time and this will in no way affect my future health care.
- I understand that my participation in this study is confidential and that no material which could identify me will be used in any reports on this study.
- I understand that the study will be stopped if it should appear harmful to me.
- I have had time to consider whether to take part and I know who to contact if I have any questions about the study.

	Please Tick
I wish to receive: A summary of the results	Yes ○ No ○

I ____ (print full name)
consent to take part in this study.

Signed _____________________________ Date ______________________

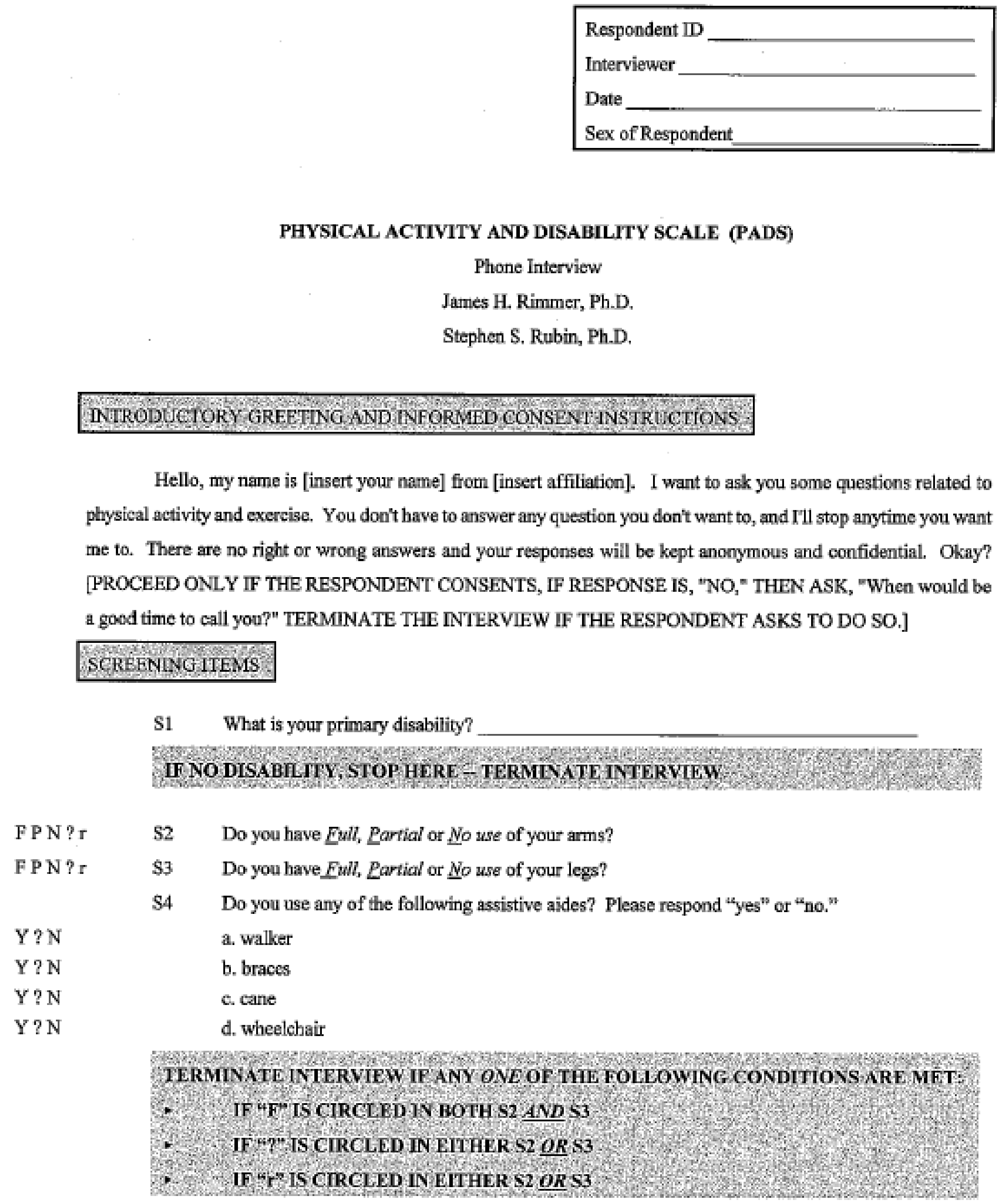
Participant Contact Details:

……

……

APPENDIX E

Original Physical Activity Disability Survey



Respondent ID ____________________
Interviewer ____________________
Date ____________________
Sex of Respondent ____________________

PHYSICAL ACTIVITY AND DISABILITY SCALE (PADS)

Phone Interview
James H. Rimmer, Ph.D.
Stephen S. Rubin, Ph.D.

INTRODUCTORY GREETING AND INFORMED CONSENT INSTRUCTIONS

Hello, my name is [insert your name] from [insert affiliation]. I want to ask you some questions related to physical activity and exercise. You don't have to answer any question you don't want to, and I'll stop anytime you want me to. There are no right or wrong answers and your responses will be kept anonymous and confidential. Okay? [PROCEED ONLY IF THE RESPONDENT CONSENTS, IF RESPONSE IS, "NO," THEN ASK, "When would be a good time to call you?" TERMINATE THE INTERVIEW IF THE RESPONDENT ASKS TO DO SO.]

SCREENING ITEMS

S1 What is your primary disability? ____________________

IF NO DISABILITY, STOP HERE – TERMINATE INTERVIEW

F P N ? r S2 Do you have *Full*, *Partial* or *No use* of your arms?
F P N ? r S3 Do you have *Full*, *Partial* or *No use* of your legs?
S4 Do you use any of the following assistive aides? Please respond "yes" or "no."
Y ? N a. walker
Y ? N b. braces
Y ? N c. cane
Y ? N d. wheelchair

TERMINATE INTERVIEW IF ANY *ONE* OF THE FOLLOWING CONDITIONS ARE MET:

- **IF "F" IS CIRCLED IN BOTH S2 *AND* S3**
- **IF "?" IS CIRCLED IN EITHER S2 *OR* S3**
- **IF "r" IS CIRCLED IN EITHER S2 *OR* S3**

I. EXERCISE

Y ? N 1.00 Do you currently exercise?

GO TO QUESTION 2.00, SCORE EXERCISE TOTAL -5

1.01 What kind of exercises do you do? **A = .3 S = .2 F = .1** **NOTE:** if < 1 day/week, multiply number given by .25

Activity	Type (**A, S, F**)	assigned value	days/week	min/day	months/yr	Totals
			x	x	x	x **.1 =**
			x	x	x	x **.1 =**
			x	x	x	x **.1 =**
			x	x	x	x **.1 =**

Aerobic Total (add all type "A" Totals) ________ *(SCORE Aerobic)*

Strength Total (add all type "S" Totals) ________ *(SCORE Strength)*

Flexibility Total (add all type "F" Totals) ________ *(SCORE Flexibility)*

SCORE Aerobic + SCORE Strength + SCORE Flexibility = ______________ **(SCORE 1)**

M ? L 1.02 Have you been exercising for More than one year or Less than one year?

"M" = + 5, "L" = 0

____
(SCORE 2)

1 2 3 ? 1.03 On a scale of 1 to 3, with 1 describing a light exercise program where you don't sweat, 2 describing a moderate exercise program where you breathe a little harder and may possibly sweat, and 3 describing a vigorous exercise program where you breathe hard and sweat, how would you rate the average intensity of your exercise program?

"1" = +5, "2" = +10, "3" = +20

____
(SCORE 3)

I. EXERCISE TOTAL

________	+	________	+	________	=	________
(SCORE 1)		**(SCORE 2)**		**(SCORE 3)**		**(SCORE A)**

II. LEISURE-TIME PHYSICAL ACTIVITY (LTPA)

Y ? N 2.00 Do you currently participate in any sports, recreational, or leisure activities?

GO TO QUESTION 3.00, SCORE LTPA TOTAL 0

2.01 What type of activities do you do?. **Endurance (E) = .3 Non-Endurance (NE) = .15**

NOTE: if < 1 day/week, multiply number given by .25

Activity	Type (E, NE)	assigned value	days/week	min/day	months/yr	Totals
			x	x	x	x .1 =
			x	x	x	x .1 =
			x	x	x	x .1 =
			x	x	x	x .1 =

Endurance Total (add all type "E" Totals) ________ **(SCORE 4)**

Non-Endurance Total (add all type "NE" Totals) ________ **(SCORE 5)**

II. LTPA TOTAL

________ + ________ = ________

(SCORE 4) (SCORE 5) (SCORE B)

III. GENERAL ACTIVITY

1 2 3 ? 3.00 From Monday through Friday, how many waking hours a day do you usually spend inside your home?

[1] Less than 6 hours a day, [2] 6 to 10 hours a day, or [3] More than 10 hours a day.

"1" = +2 , "2" = 0, "3" = -2

(SCORE 6) ____________

1 2 3 ? 3.01 On Saturday and Sunday, how many waking hours a day do you usually spend inside your home?

[1] Less than 6 hours a day, [2] 6 to 10 hours a day, or [3] More than 10 hours a day.

"1" = +1, "2" = 0, "3" = -1

(SCORE 7) ____________

3.02 On average, how many hours a day do you sleep including naps? ____________

3.03 On average, how many hours a day are you sitting or lying down, excluding sleeping ? ____________

ADD 3.02 + 3.03 = ____________

"23-24 hours" = -20, "20-22 hours" = -10, "< 20 hours" = 0

(SCORE 8) ____________

Y ? E 3.04 Are most of your indoor household activities done by <u>Y</u>ou or someone <u>E</u>lse?

GO TO QUESTION 3.06. SCORE HOUSEHOLD ACTIVITY TOTAL -5.

3.05 Please list all the household activities you do and the number of minutes a week you spend on each activity.

Activity	min/week

HOUSEHOLD ACTIVITY TOTAL

Total min/week ________ **x .01 =** ____________ **(SCORE 9)**

Y ? N 3.06 Do you do any outdoor household activities such as gardening?

GO TO QUESTION 3.08, SCORE OUTDOOR ACTIVITY TOTAL 0

3.07 Please list all the outdoor activities you do. **NOTE:** if < 1 day/week, multiply number given by .25

Activity	Score	days/week	min/day	months/yr	Totals
	.05	x	x	x	x .1 =
	.05	x	x	x	x .1 =
	.05	x	x	x	x .1 =
	.05	x	x	x	x .1 =

OUTDOOR ACTIVITY TOTAL
(Sum Totals of All Activities)

______
(SCORE 10)

W S F ? 3.08 Do you perform activities of daily living such as dressing and bathing Without assistance, with Some assistance, or with Full assistance?

"W" = 0, "S" = -5, "F" = -10

______
(SCORE 11)

III. GENERAL ACTIVITY TOTAL

______ + ______ + ______ + ______ + ______ + ______ = ______
(SCORE 6) (SCORE 7) (SCORE 8) (SCORE 9) (SCORE 10) (SCORE 11) (SCORE C)

IV. THERAPY

Y ? N 4.00 Do you currently receive Physical or Occupational Therapy?

GO TO QUESTION 5.00, SCORE THERAPY TOTAL 0

4.01 How many days a week do you receive therapy? ________ **x 1.0 =** ________ **(SCORE 12)**

4.02 How long does each therapy session usually last? ______________ **(Convert to minutes)**

x .10 = ______________

(SCORE 13)

IV. THERAPY TOTAL

________ + ________ = ________

(SCORE 12) **(SCORE 13)** **(SCORE D)**

V. EMPLOYMENT

E N R ? 5.00 Are you currently Employed, Not employed, or Retired?

GO TO QUESTION 6.00, SCORE EMPLOYMENT TOTAL -5

M D S ? 5.01 For most of your workday, do you Move around, stanD, or Sit?

"M" = +5, "D" = +0, " S" = -5

____
(SCORE 14)

Y ? N 5.02 Do you climb any stairs during the workday?

5.02a How many flights of stairs do you climb? ___________

5.02b How many times a day do you climb these stairs? ___________

___________ x ___________ x .3 = ___________
(5.02a) (5.02b) (SCORE 15)

Y ? N 5.03 In your transportation to and from work, do you get any physical activity?

SCORE TRANSPORTATION ACTIVITY TOTAL -2

5.04 What type of activity do you do?

Activity	Score		days/week		min/day		months/yr		Totals
____________________	.15	x	________	x	________	x	________	x .1 =	________
____________________	.15	x	________	x	________	x	________	x .1 =	________
____________________	.15	x	________	x	________	x	________	x .1 =	________
____________________	.15	x	________	x	________	x	________	x .1 =	________

TRANSPORTATION ACTIVITY TOTAL

(Sum Totals of All Activities)

____
(SCORE 16)

V. EMPLOYMENT TOTAL

________ + ________ + ________ = ________
(SCORE 14) (SCORE 15) (SCORE 16) (SCORE E)

PROCEED WITH SECTION VI - WHEELCHAIR USERS <u>ONLY</u>

IF THE "S4" SCREENING ITEM RESPONSE TO "WHEELCHAIR (d)" WAS "Y," PROCEED, OTHERWISE, SCORE A "0" IN WHEELCHAIR USER TOTAL AND GO TO SECTION VII.

IF APPLICABLE

[Closing Remarks] Thank you for taking the time to complete this survey.

— END OF SURVEY—SUM RAW SCORE TOTALS

VI. WHEELCHAIR USERS

6.00 How many years have you used a wheelchair?____________ **x -1.0 = ____________ (SCORE 17)**

1 2 3 ? 6.01 During the time that you are awake, do you spend [1] all of the day in your wheelchair, [2] most of the day in your wheelchair, or [3] just a few hours a day in your wheelchair?

"1" = -5, "2" = -2, "3" = -1 ________________(SCORE 18)

M ? P 6.02 Do you primarily use a <u>M</u>anual or a <u>P</u>owered wheelchair?

"M" = +5.0, "P" = -10 ____________(SCORE 19)

O ? S 5.02a Do you usually push your <u>O</u>wn wheelchair or does <u>S</u>omeone usually push you? **"O" = +2, "S" = -2 ____________ (SCORE 20)**

L ? M 5.02b On average, how many minutes a day do you push yourself in your wheelchair? <u>L</u>ess than 60 minutes or <u>M</u>ore than 60 minutes?

"L" = -10, "M" = +10 ____________(SCORE 21)

VI. WHEELCHAIR USER TOTAL

________	+	________	+	________	+	________	+	________	=	________
(SCORE 17)		**(SCORE 18)**		**(SCORE 19)**		**(SCORE 20)**		**(SCORE 21)**		**(SCORE F)**

[Closing Remarks] Thank you for taking the time to complete this survey.

— END OF SURVEY—SUM RAW SCORE TOTALS

VII. TOTAL RAW SCORE

SECTION RAW SCORE TOTALS

(SCORE A) ________ +

(SCORE B) ________ +

(SCORE C) ________ +

(SCORE D) ________ +

(SCORE E) ________ +

(SCORE F) ________ +

TOTAL RAW SCORE ____________

APPENDIX F

Semi-structured questions – Study One

1. How did you find completing the activity questionnaire? (I.e. was it easy to understand the questions and complete?)
2. Do you feel the questions in the activity questionnaire enabled you to give an accurate picture of the activities you participate in (explain)?
3. Were there any activities that you currently participate in that you were not asked about in the questionnaire?
4. How did you find wearing the activity monitor (I.e. how comfortable was it to wear? Were there times when it irritated you?)?
5. Did you wear the activity monitor for the whole seven days?
6. At what times did you **not** wear the activity monitor?
7. What were your reasons for taking off the activity monitor at these times?
8. Do you feel you changed your level of activity in any way as a result of wearing the activity monitor (explain)?
9. In the past week while you have had the activity monitor on, have you felt any **positive** benefits of activity?
10. In the past week, while you have had the activity monitor on, have you felt any **negative** effects of activity?
11. Is there anything else you would like to tell about the activity questionnaire or the activity monitor?
12. In general, how does taking part in activity or exercise impact on you **whilst you are actually doing it**?
13. In general, does taking part in activity or exercise have any impact on you **after you have finished** (e.g. that evening or the next day)?

APPENDIX G

Participant instructions for accelerometer use – Study One

- You are encouraged to wear the activity monitor 24 hours a day for 7 days
- It is important that the monitor is worn on your LEFT HIP BONE with the ARROW POINTING UP ↑ towards your head to enable accurate data capture
- The activity monitor belt should be worn flat against your skin however if this causes irritation it can be worn over a thin layer of clothing ie underwear/ singlet
- The activity monitor is encouraged to be worn at all times and is designed to tolerate activities including sleeping, showering, swimming and vigorous sports
- If worn in the shower it is advised that you pat dry (with towel) the activity monitor, the belt and your underlying skin to minimise any irritation
- In the event that you wish to remove the activity monitor please press the asterisk ***** button in the middle of the device to help indicate this action

Please note: it would be highly beneficial for this study if the monitor is worn whilst in the shower, however if this becomes uncomfortable or intolerable it is your decision on whether to or not. If removed during showering please put activity monitor on IMMEDIATELY afterwards.

APPENDIX H

Ethical approval for Study Two – Physical Activity Disability Survey-Revised (PADS-R) scoring development

Health
and
Disability
Ethics
Committees

Northern Y Regional Ethics Committee
Ministry of Health
3rd Floor, BNZ Building
354 Victoria Street
PO Box 1031
Hamilton
Phone (07) 858 7021
Fax (07) 858 7070

18 July 2006

Ms Nicola Kayes
Rehabilitation and Occupation Studies - HP
AUT, Private Bag 92006
Auckland.

Dear Nicola

The Physical Activity and Disability Survey(PADS): A reliability and validity study in people with multiple sclerosis.
Investigators: **Nicola Kayes, Kathryn McPherson, Denise Taylor, Gregory Kolt.**
Ethics ref: **NTY/06/01/002**
Locations: **Auckland MS Society.**

Thank you for your letter dated 13 July 2006 informing the committee of the intention to extend the study to another group of people with MS using the same methodology and requesting extension of ethical approval until the completion date.

The additional time required to complete the study was noted and the Chairperson under delegated authority gave approval to extend the study until 30 September 2006.

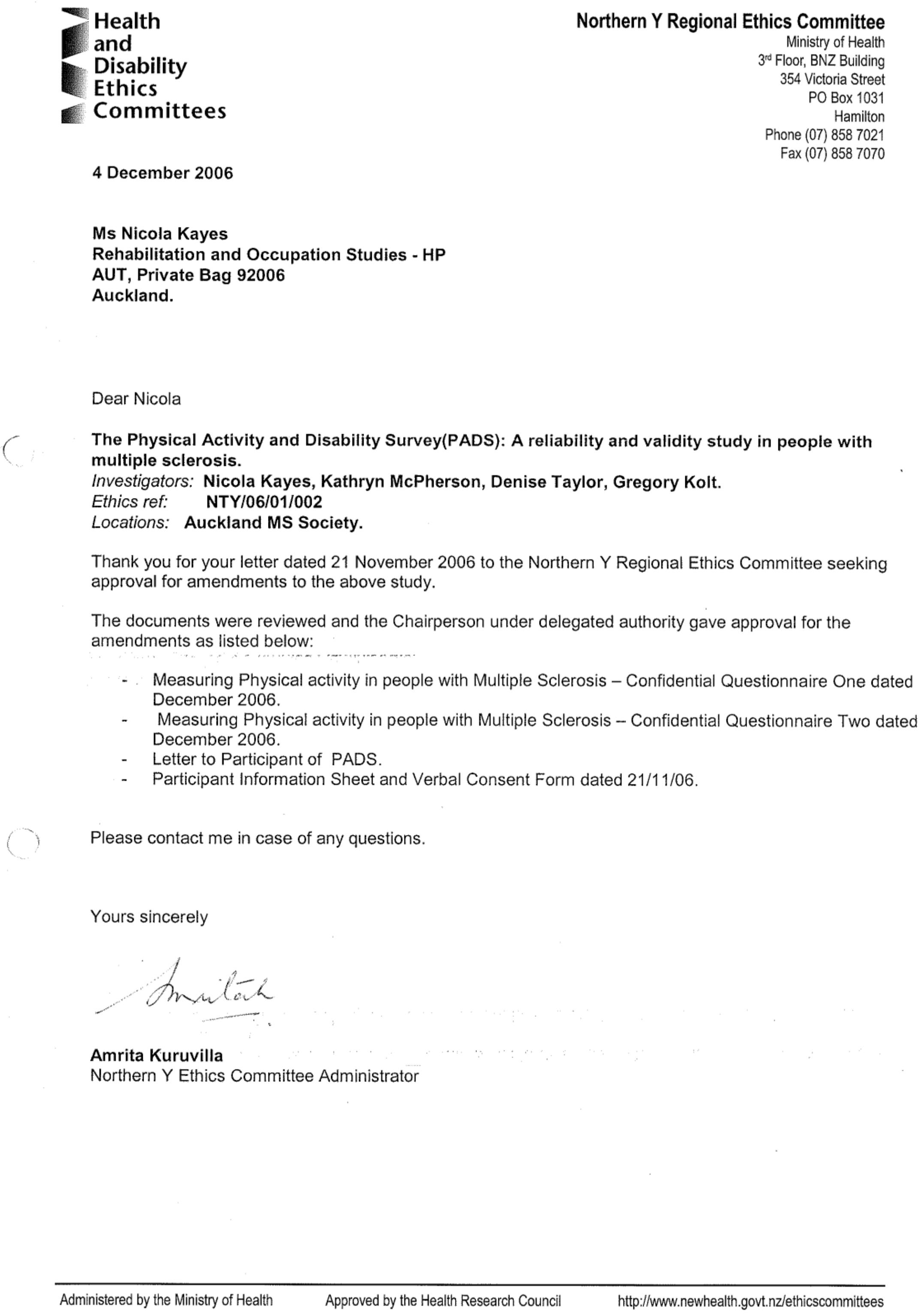
Yours sincerely

Amrita Kuruvilla
Northern Y Ethics Committee Administrator

Administered by the Ministry of Health Approved by the Health Research Council http://www.newhealth.govt.nz/ethicscommittees

APPENDIX I

Ethical approval for Study Two – PADS-R acceptability and reliability assessment



Health
and
Disability
Ethics
Committees

Northern Y Regional Ethics Committee
Ministry of Health
3rd Floor, BNZ Building
354 Victoria Street
PO Box 1031
Hamilton
Phone (07) 858 7021
Fax (07) 858 7070

4 December 2006

Ms Nicola Kayes
Rehabilitation and Occupation Studies - HP
AUT, Private Bag 92006
Auckland.

Dear Nicola

The Physical Activity and Disability Survey(PADS): A reliability and validity study in people with multiple sclerosis.
Investigators: **Nicola Kayes, Kathryn McPherson, Denise Taylor, Gregory Kolt.**
Ethics ref: **NTY/06/01/002**
Locations: **Auckland MS Society.**

Thank you for your letter dated 21 November 2006 to the Northern Y Regional Ethics Committee seeking approval for amendments to the above study.

The documents were reviewed and the Chairperson under delegated authority gave approval for the amendments as listed below:

- Measuring Physical activity in people with Multiple Sclerosis – Confidential Questionnaire One dated December 2006.
- Measuring Physical activity in people with Multiple Sclerosis – Confidential Questionnaire Two dated December 2006.
- Letter to Participant of PADS.
- Participant Information Sheet and Verbal Consent Form dated 21/11/06.

Please contact me in case of any questions.

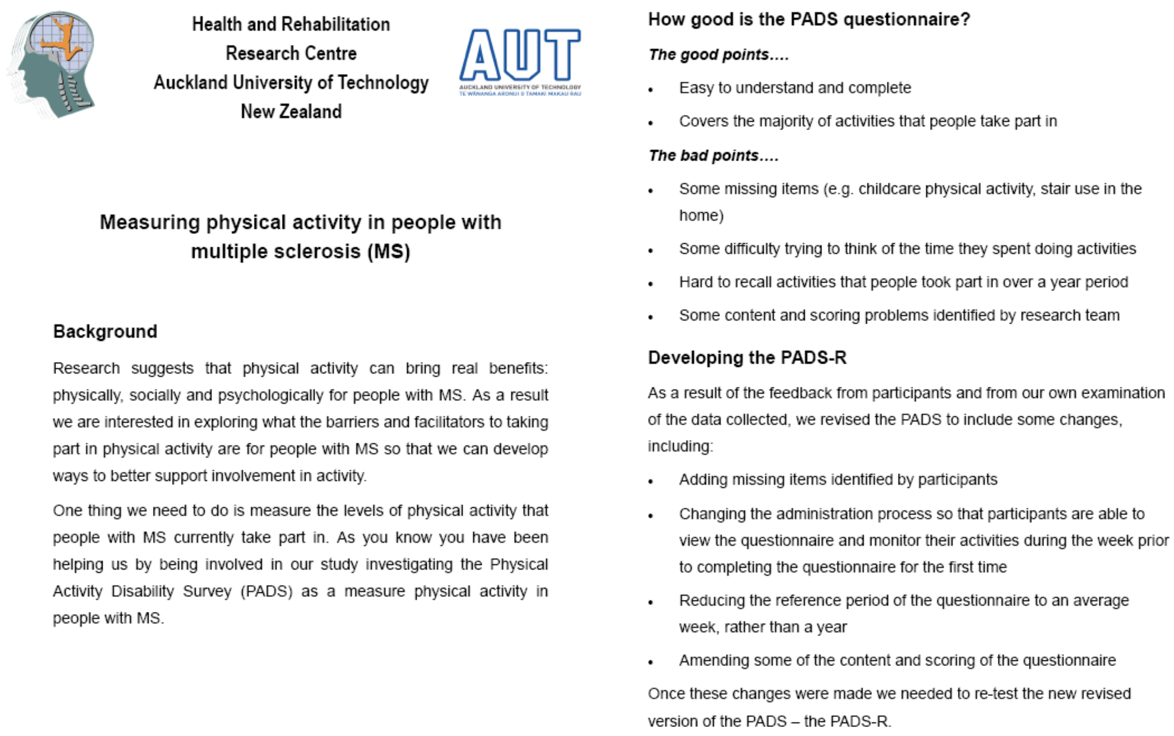
Yours sincerely

Amrita Kuruvilla
Northern Y Ethics Committee Administrator

Administered by the Ministry of Health Approved by the Health Research Council http://www.newhealth.govt.nz/ethicscommittees

APPENDIX J

Summary of findings for Study One and PADS-R field testing



**Health and Rehabilitation
Research Centre
Auckland University of Technology
New Zealand**

AUT
AUCKLAND UNIVERSITY OF TECHNOLOGY
TE WĀNANGA ARONUI O TAMAKI MAKAU RAU

Measuring physical activity in people with multiple sclerosis (MS)

Background

Research suggests that physical activity can bring real benefits: physically, socially and psychologically for people with MS. As a result we are interested in exploring what the barriers and facilitators to taking part in physical activity are for people with MS so that we can develop ways to better support involvement in activity.

One thing we need to do is measure the levels of physical activity that people with MS currently take part in. As you know you have been helping us by being involved in our study investigating the Physical Activity Disability Survey (PADS) as a measure physical activity in people with MS.

How good is the PADS questionnaire?

The good points….

- Easy to understand and complete
- Covers the majority of activities that people take part in

The bad points….

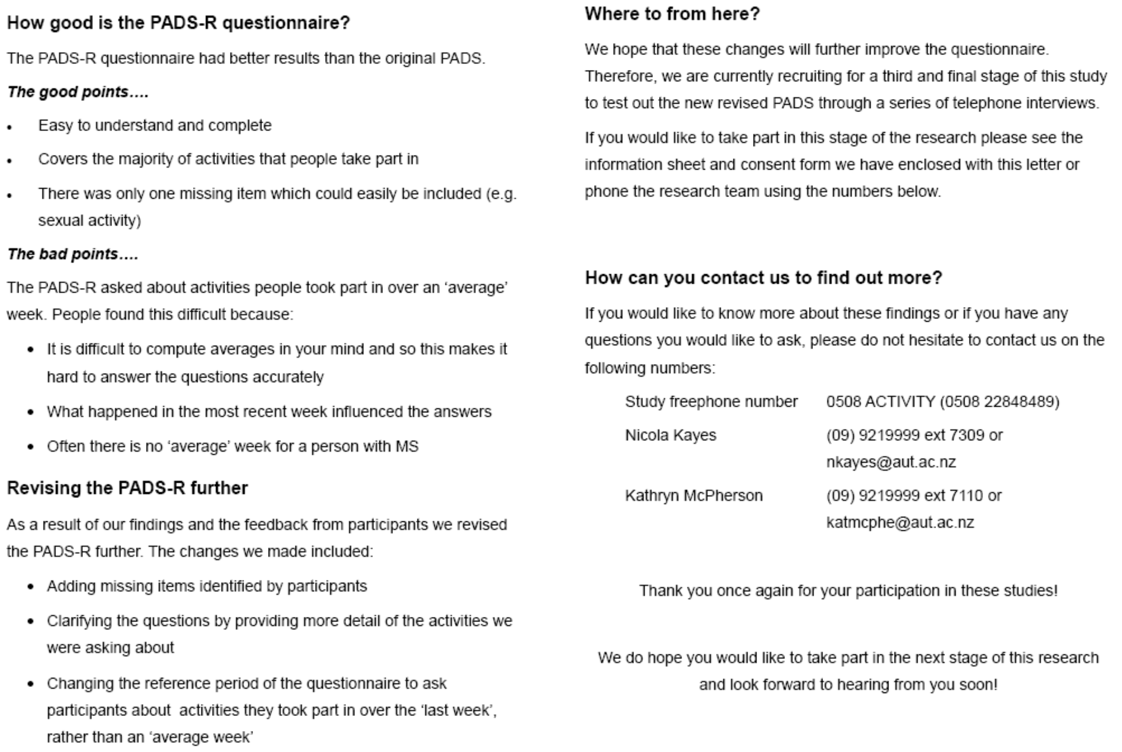
- Some missing items (e.g. childcare physical activity, stair use in the home)
- Some difficulty trying to think of the time they spent doing activities
- Hard to recall activities that people took part in over a year period
- Some content and scoring problems identified by research team

Developing the PADS-R

As a result of the feedback from participants and from our own examination of the data collected, we revised the PADS to include some changes, including:

- Adding missing items identified by participants
- Changing the administration process so that participants are able to view the questionnaire and monitor their activities during the week prior to completing the questionnaire for the first time
- Reducing the reference period of the questionnaire to an average week, rather than a year
- Amending some of the content and scoring of the questionnaire

Once these changes were made we needed to re-test the new revised version of the PADS – the PADS-R.



How good is the PADS-R questionnaire?

The PADS-R questionnaire had better results than the original PADS.

The good points….

- Easy to understand and complete
- Covers the majority of activities that people take part in
- There was only one missing item which could easily be included (e.g. sexual activity)

The bad points….

The PADS-R asked about activities people took part in over an 'average' week. People found this difficult because:

- It is difficult to compute averages in your mind and so this makes it hard to answer the questions accurately
- What happened in the most recent week influenced the answers
- Often there is no 'average' week for a person with MS

Revising the PADS-R further

As a result of our findings and the feedback from participants we revised the PADS-R further. The changes we made included:

- Adding missing items identified by participants
- Clarifying the questions by providing more detail of the activities we were asking about
- Changing the reference period of the questionnaire to ask participants about activities they took part in over the 'last week', rather than an 'average week'

Where to from here?

We hope that these changes will further improve the questionnaire. Therefore, we are currently recruiting for a third and final stage of this study to test out the new revised PADS through a series of telephone interviews.

If you would like to take part in this stage of the research please see the information sheet and consent form we have enclosed with this letter or phone the research team using the numbers below.

How can you contact us to find out more?

If you would like to know more about these findings or if you have any questions you would like to ask, please do not hesitate to contact us on the following numbers:

Study freephone number	0508 ACTIVITY (0508 22848489)
Nicola Kayes	(09) 9219999 ext 7309 or nkayes@aut.ac.nz
Kathryn McPherson	(09) 9219999 ext 7110 or katmcphe@aut.ac.nz

Thank you once again for your participation in these studies!

We do hope you would like to take part in the next stage of this research and look forward to hearing from you soon!

APPENDIX K

Invitation to take part – Study Two

Date

Xxxxx
Xxxxx
Xxxxx
Xxxxx

Dear xxxxx

Thank you for participating in our research recently, exploring the acceptability of the Physical Activity Disability Survey (PADS) for use in people with Multiple Sclerosis. I enclose a summary of the findings from this study for your information.

As a result of the findings of this study and particularly with regards to your feedback we have made some revisions to the questionnaire. **We would value your comments on these revisions and as such, would like to invite you to participate in a further study to pilot these revisions.**

What would happen if you decide to take part?

You would complete the questionnaire via telephone survey twice with three days between each time. This will take approximately 30 minutes each time.

What do I need to do if I want to take part?

If you wish to take part, you can either:

(1) Phone myself on (09) 921 9999 ext. 7309 or Marta Leete on 0508 22848489 (0508 ACTIVITY) to give your consent verbally and to arrange a time to complete the questionnaire over the telephone.

(2) Complete and sign the enclosed consent form and return to us in the prepaid envelope provided.

I have enclosed a copy of the information sheet for you, which has more details about this study. If you would like further clarification or if you have any questions, please do not hesitate to contact me on (09) 921 9999 ext. 7309.

If you decide you would not like to take part in this pilot, I would like to take this opportunity to thank for your participation to date and for your support of our research. Your feedback has been instrumental in getting us to this point.

Regards,

Nicola Kayes
Research Officer

APPENDIX L

Participant information sheet – Study Two

AUCKLAND UNIVERSITY OF TECHNOLOGY
TE WĀNANGA ARONUI O TAMAKI MAKAU RAU

Participant Information Sheet

Measuring physical activity in people with Multiple Sclerosis (MS)

Invitation

Kia ora, talofa lava and hello, you are invited to take part in a study looking at measuring physical activity in people with MS. Please remember that:

- Your participation in this study is entirely voluntary (your choice). You do not have to take part in this study, and if you choose not to take part this will in no way affect your future health care.
- If you do agree to take part you are free to withdraw at any time, without having to give a reason. This will in no way affect your future health care.

This information sheet will explain the research study. Please feel free to ask about anything you do not understand or if you have questions at anytime.

What is the purpose of the study?

We are trying to find out if a new revised questionnaire designed to measure physical activity in people with chronic health conditions, the Physical Activity Disability Scale - Revised (PADS-R), is suitable and consistent over time in people with Multiple Sclerosis (MS).

How are people chosen to be asked to be part of the study?

People who recently took part and gave feedback on the original Physical Activity Disability Scale (PADS) have been asked to pilot this new revised version.

Who is eligible to participate?

You are eligible to participate if you have been given a definite diagnosis of MS and are able to communicate with the researchers. We would like people with varying levels of participation in activity and so you are eligible to participate in this research regardless of your current level of mobility.

What do I need to do if I want to take part?

If you would like to take part then you can either:

(1) Phone the research team on free phone 0508 22848489 (0508 ACTIVITY) to complete a verbal consent form over the phone; or
(2) Complete the enclosed consent form and return it to the research team in the prepaid envelope provided

What happens in the study?

Once we have received your signed consent we will arrange a time to complete the revised questionnaire over the telephone with you. This will take approximately 30 minutes. We will then arrange to complete the questionnaire with you a second time three days later.

What are the risks of this study?

There should not be any risk to you from this study. It is possible that you may find the questionnaire completion tiring, but we will try to minimise this for you by going at your own pace and giving you the opportunity to take a break at any time if you desire.

How will this study help?

The information we gain from this study will help us to ensure that the new revised questionnaire is easy to understand and complete and that it is a reliable measure of physical activity for people with chronic health conditions. We will be able to do more research to gain a better understanding of the impact that activity or inactivity has in those populations.

What are the costs of participating in the project?

There will not be any cost to you except your time, approximately one hour in total over the two telephone interviews.

How will my privacy be protected?

All information you give will be kept confidential and your name will not be known to anyone but the researcher. We will keep the information locked in a cabinet. Any reports will make sure that you cannot be identified. A summary of the results will be made available to the MS Society of Auckland and the wider community. However, no individual's will be identifiable from this summary.

What will happen with the results?

We hope that the results of this study will be publishable in a neuro-rehabilitation journal. The results of this study will also inform the choice of questionnaire we use to measure physical activity in future studies in people with chronic health conditions.

Will I be able to have a copy of the results?

If you would like a summary of the results they will be sent to you at the end of the study. Usually there is a delay between collecting information and letting people know about the results.

If you have any concerns or questions?

If you have any questions please feel free to contact one of the researchers on 0508 22848489 (0508 ACTIVITY) or on the following numbers:

Named researcher

	Nicola Kayes	Phone: (09) 921-9999 ext. 7309 E-mail: nkayes@aut.ac.nz
Or		
	Marta Leete	Phone 050822848489 (0508 ACTIVITY) E-mail: mleete@aut.ac.nz
	Kathryn McPherson	Phone: (09) 921-9999 ext. 7110 E-mail: katmcphe@aut.ac.nz

If you have any queries or concerns regarding your rights as a participant in this study you may wish to contact a Health and Disability Advocate: Phone 08004ADNET (0800 423 638)

Other local services: Auckland MS Society Phone: (09) 845 5921

Statement of Approval

This study has received ethical approval from the Northern Y Regional Ethics Committee.

APPENDIX M

Consent form – Study Two

AUCKLAND UNIVERSITY OF TECHNOLOGY
TE WĀNANGA ARONUI O TAMAKI MAKAU RAU

Consent Form

Measuring physical activity in people with Multiple Sclerosis (MS)

Principal Investigator:	Nicola Kayes	Phone: 921 9999 ext. 7309
Research Assistant:	Marta Leete	Phone: 0508 22848489 (0508 ACTIVITY)

- I have read or had read to me, and I understand, the information sheet dated 21/11/06 for volunteers taking part in the study looking at the revised physical activity questionnaire, the Physical Activity Disability Scale - Revised (PADS-R), in people with MS. I have had the opportunity to ask questions. I am satisfied with the answers I have been given.
- I have had the opportunity to use family/whanau support or a friend to help me ask questions and understand the study.
- I understand that taking part is entirely voluntary (my choice) and that I may withdraw from the study at any time and this will in no way affect my future health care.
- I understand that my participation in this study is confidential and that no material which could identify me will be used in any reports on this study.
- I understand that the study will be stopped if it should appear harmful to me.
- I have had time to consider whether to take part and I know who to contact if I have any questions about the study.

I consent to taking part in this research	Yes ○ No ○ *Please tick*
I wish to receive a summary of the results	Yes ○ No ○ *Please tick*

Full Name			
Address			
Phone	(Home)	(Mobile)	
Signature		Date	

APPENDIX N

Final revised version of the PADS-R

The Physical Activity Disability Survey (PADS)
Revised Version (August 2007)

This questionnaire asks you questions about the types of **exercise** and **physical activities** you participated in over the **last week** and the time you spent doing these activities.

If you compared the activities you took part in over the **last week** to the activities you would take part in on a **typical week**, would you say you did (please circle):

Much less than usual	Less than usual	About the same as usual	More than usual	Much more than usual
1	2	3	4	5

1. EXERCISE

Did you exercise in the **last week**? Exercise is any activity you do on a regular basis for the primary purpose of increasing or maintaining fitness. Please note: this does not include activities you do for leisure or recreation.

YES		NO	

If NO, please go to question 2

If YES, what kind of exercise did you do?

Please list the exercise activities below that you did in the **last week** for the primary purpose of maintaining or improving your health and fitness. For each activity indicate the activity type and intensity (using the keys below), how many days per week you did the activity and how many minutes per day.

Activity types
A = Aerobic Exercise (aerobic activities are those exercises done for a sustained period of time which result in an increase in your heart rate and breathing rate e.g. walking, jogging, attending an aerobics class, bicycling, etc)
S = Strength Exercise (strength activities e.g. lifting weights or using elastic bands or weight training machines, pilates, core body strengthening & stability, tai chi, etc)
F = Flexibility Exercise (flexibility refers to activities that involve muscle stretching e.g. yoga, etc)

Intensity
L = Light activities - don’t sweat or breathe heavily
M = Moderate activities - breathe a little harder and may sweat
V = Vigorous activities - breathe hard and sweat

Activity Type (A, S or F)	Activity	Days/ Week	Minutes/ Day	Intensity (L, M or V)

Exercise Matrix

	Light	*Moderate*	*Vigorous*
Flexibility	*1*	*2*	*4*
Strength	*2*	*4*	*8*
Aerobic	*3*	*6*	*12*

Activity Score (for each activity listed) = Days/week x Minutes/day x Exercise Matrix Score

Total Exercise Score = sum of all Activity Scores

SCORE 1 *= ln(Total Exercise Score/60)+0.1)*

2. LEISURE TIME PHYSICAL ACTIVITY

Did you participate in any sports, recreational, or leisure time activities in the **last week**? These activities may not necessarily result in sustained increases in heart rate and breathing rate. Examples include hiking, boating, skiing, dancing, bowling and sports activities.

YES		NO	

If NO, please go to question 3

If YES, what type of activities did you do?

Please list **the leisure time physical activities** below that you did in the **last week** for leisure or recreation. For each activity indicate the activity type and intensity (using the keys below), how many days per week you did the activity and how many minutes per day. **Do not list activities here that you have already listed previously in this questionnaire.**

Activity types

E = Endurance (endurance activities are leisure time physical activities that you maintain for a sustained period of time that make you sweat and breathe a little harder than usual e.g. tramping/hiking, tennis, dancing, skiing, sports fishing, sexual activity, etc)

NE = Non-Endurance (non-endurance activities are leisure time physical activities that you might do in shorter bouts of activity and/or do not cause you to sweat and breathe a little harder e.g. boating, fishing by the jetty, bowling, etc)

Intensity

L = Light activities - don’t sweat or breathe heavily

M = Moderate activities - breathe a little harder and may sweat

V = Vigorous activities - breathe hard and sweat

Activity Type (E or NE)	Activity	Days/ Week	Minutes/ Day	Intensity (L, M or V)

Leisure Time Physical Activity (LTPA) Matrix

	Light	*Moderate*	*Vigorous*
Non-endurance	*1*	*2*	*4*
Endurance	*2*	*4*	*8*

Activity Score (for each activity listed) = Days/week x Minutes/day x LTPA Matrix Score
Total LTPA Score = sum of all Activity Scores
***SCORE 2** = ln(Total LTPA Score/60)+0.1)*

3. GENERAL ACTIVITY

3.1 From **Monday through Friday last week**, how many **waking hours a day** did you spend inside your home (please tick one)?

Less than 6 hours a day	4
6 to 8 hours a day	3
9 to 10 hours a day	2
11 to 12 hours a day	1
13 hours or more	0

3.1:
Less than 6 hours a day = 4
6 to 8 hours a day = 3
9 to 10 hours a day = 2
11 to 12 hours a day = 1
13 hours or more = 0

3.2 On **Saturday and Sunday last week**, how many **waking hours a day** did you spend inside your home (please tick one)?

Less than 6 hours a day	4
6 to 8 hours a day	3
9 to 10 hours a day	2
11 to 12 hours a day	1
13 hours or more	0

3.2:	*Less than 6 hours a day =*	*4*
	6 to 8 hours a day =	*3*
	9 to 10 hours a day =	*2*
	11 to 12 hours a day =	*1*
	13 hours or more =	*0*

SCORE 3 *= (3.1 + 3.2)/2*

3.3 During the **last week**, how many **hours a day** did you sleep including naps?

	HOURS

3.4 During the **last week**, how many **hours a day** were you sitting or lying down (including work), but excluding sleeping?

	HOURS

SCORE 4 *= 24 - (3.3 + 3.4)*

3.5 During the **last week** did you do any **indoor** household activities, such as cleaning, food preparation, childcare activities, etc?

YES		NO	

If NO, please go to question 3.6

If **YES,** please list all the **indoor** activities that required some **physical activity** (e.g. cleaning, hanging washing, food preparation, etc) that you did in the **last week.** Please also include here any physical activities you did as a part of your role as caregiver (e.g. parenting activities). For each activity indicate how many days per week you did the activity and how many minutes per day. **Do not list activities here that you have already listed previously in this questionnaire.**

Activity	Days/Week	Minutes/Day

Activity Score (for each activity listed) = Days/week x Minutes/day
Indoor Activity Score = sum of all Activity Scores
***SCORE 5** = ln(Indoor Activity Score/60)+0.1)*

3.6 During the **last week** did you do any **outdoor** household activities, such as gardening, walking to and from shops, etc?

YES		NO	

If NO, please go to question 3.7
If **YES,** please list all the **outdoor** activities that required some **physical activity** (e.g. gardening, mowing lawns, walking to shops) that you did in the **last week**. For each activity indicate how many days per week you did the activity and how many minutes per day. **Do not list activities here that you have already listed previously in this questionnaire.**

Activity	Days/Week	Minutes/Day

Activity Score (for each activity listed) = Days/week x Minutes/day
Ourdoor Activity Score = sum of all Activity Scores
***SCORE 6** = ln(Outdoor Activity Score/60)+0.1)*

3.7 During the **last week** did you climb any stairs at home?

YES		NO	

If NO, please go to question 3.8

3.7a If **YES,** how many flights of stairs do you have at home (one flight of stairs is 5-10 steps)?

	FLIGHTS

3.7b If **YES,** how many times a day did you climb these stairs in the **last week**?

	TIMES A DAY

Total Flights = 3.7a x 3.7b

SCORE 7*:*	*No flights =*	*0*
	1-6 flights/day =	*1*
	7-10 flights/day =	*2*
	11+ flights/day =	*3*

3.8 How much assistance do you need to perform activities of daily living, such as dressing and bathing (please tick one)?

Without assistance	2
Some assistance	1
Full assistance	0

SCORE 8*:*	*Without assistance =*	*2*
	Some assistance =	*1*
	Full assistance =	*0*

4. THERAPY

During the **last week** did you receive physiotherapy or occupational therapy or another type of therapy that involves physical activity? **If you have already listed therapy related activities previously in this questionnaire, DO NOT complete this section.**

YES		NO	

If NO, please go to question 5

How many days a week did you receive a therapy that involved physical activity in the **last week**?

	DAYS/WEEK

How long did each activity-based therapy session last?

	MINUTES

SCORE 9: *No therapy =* *0*
1 session/week = *1*
2+ sessions/week = *2*

5. EMPLOYMENT/SCHOOL

Are you currently employed, participate in any volunteer work or do you attend School?

Employed/Attend School/Volunteer Work	
Not employed/Do not attend school/ Do not do any volunteer work	
Retired	

If you are NOT EMPLOYED, DO NOT ATTEND SCHOOL, DO NOT DO ANY VOLUNTEER WORK or ARE RETIRED, please go to question 6

5.1 For most of your work/school day, do you:

Move around	2
Stand	1
Sit	0

SCORE 10: *Move around =* *2*
Stand = *1*
Sit = *0*
Not employed = *0*

5.2 During the **last week** did you climb any stairs whilst at work/school?

YES		NO	

If NO, please go to question 5.3

5.2a If **YES,** how many flights of stairs do you have at work/school (one flight of stairs is 5-10 steps)?

	FLIGHTS

5.2b If **YES,** how many times a day did you climb these stairs in the **last week**?

	TIMES A DAY

Total Flights = 5.2a x 5.2b
SCORE 11*:* *Not employed =* *0*
No flights = *0*
1-6 flights/day = *1*
7-10 flights/day = *2*
11+ flights/day = *3*

5.3 During the **last week** did you get any **physical activity** in your transportation to and from work/school (e.g. walking to work)?

YES		NO	

If NO, please go to question 6

If **YES**, please list all the transportation physical activity you did in the **last week** (e.g. walking or wheeling a wheelchair to and from work). For each activity indicate how many days per week you did the activity and how many minutes per day. **Do not list activities here that you have already listed previously in this questionnaire.**

Activity	**Days/Week**	**Minutes/Day**

Activity Score (for each activity listed) = Days/week x Minutes/day
Transport Activity score = sum of all Activity Scores
SCORE 12 *=* *Not employed =* *0*
No transport activity = *0*
1 to 60 minutes/week = *1*
61+ minutes/week = *2*

6. WHEELCHAIR USERS

During the last week did you use a wheelchair?

YES		NO	

If NO, stop this questionnaire

If **YES**, during the time that you were awake, how much time a day did you spend in your wheelchair in the **last week** (please tick one)?

All day	
Most of the day	
A few hours	

What type of wheelchair did you primarily use in the **last week** (please tick one)?

Manual	
Power	

If POWER WHEELCHAIR, stop this questionnaire

If **MANUAL,** did you push your own wheelchair at any time during the **last week**?

YES		NO	

If NO, stop this questionnaire

If **YES**, on average, how many minutes a day did you push yourself in your wheelchair in the **last week**?

Less than 60 minutes	
60 minutes or more	

SCORE 13 *=*	*No wheelchair use =*	*0*
	Pushed for less than 60 =	*1*
	Pushed for 60 minutes or more =	*2*

SCORING SUBSCALES

EXER/LTPA (***SCORE A***) = (0.7071((*SCORE 1* - 0.535)/2.344)) +
(0.7071((*SCORE 2* + 1.571)/1.643))

GENERAL (***SCORE B***) = (0.3748((*SCORE 3* - 2.031)/1.338)) +
(0.4481((*SCORE 4* - 8.350)/4.977)) +
(0.4399((*SCORE 5* - 1.314)/1.962)) +
(0.3811((*SCORE 6* + 0.490)/1.742)) +
(0.3045((*SCORE 7* - 0.914)/1.108)) +
(0.4766((*SCORE 8* - 1.704)/0.585))

THERAPY (***SCORE C***) = *SCORE 9*

EMPLOYMENT (***SCORE D***) = (0.6021((*SCORE 10* - 0.301)/0.704)) +
(0.6290((*SCORE 11* - 0.351)/0.783)) +
(0.4918((*SCORE 12* - 0.099)/0.374))

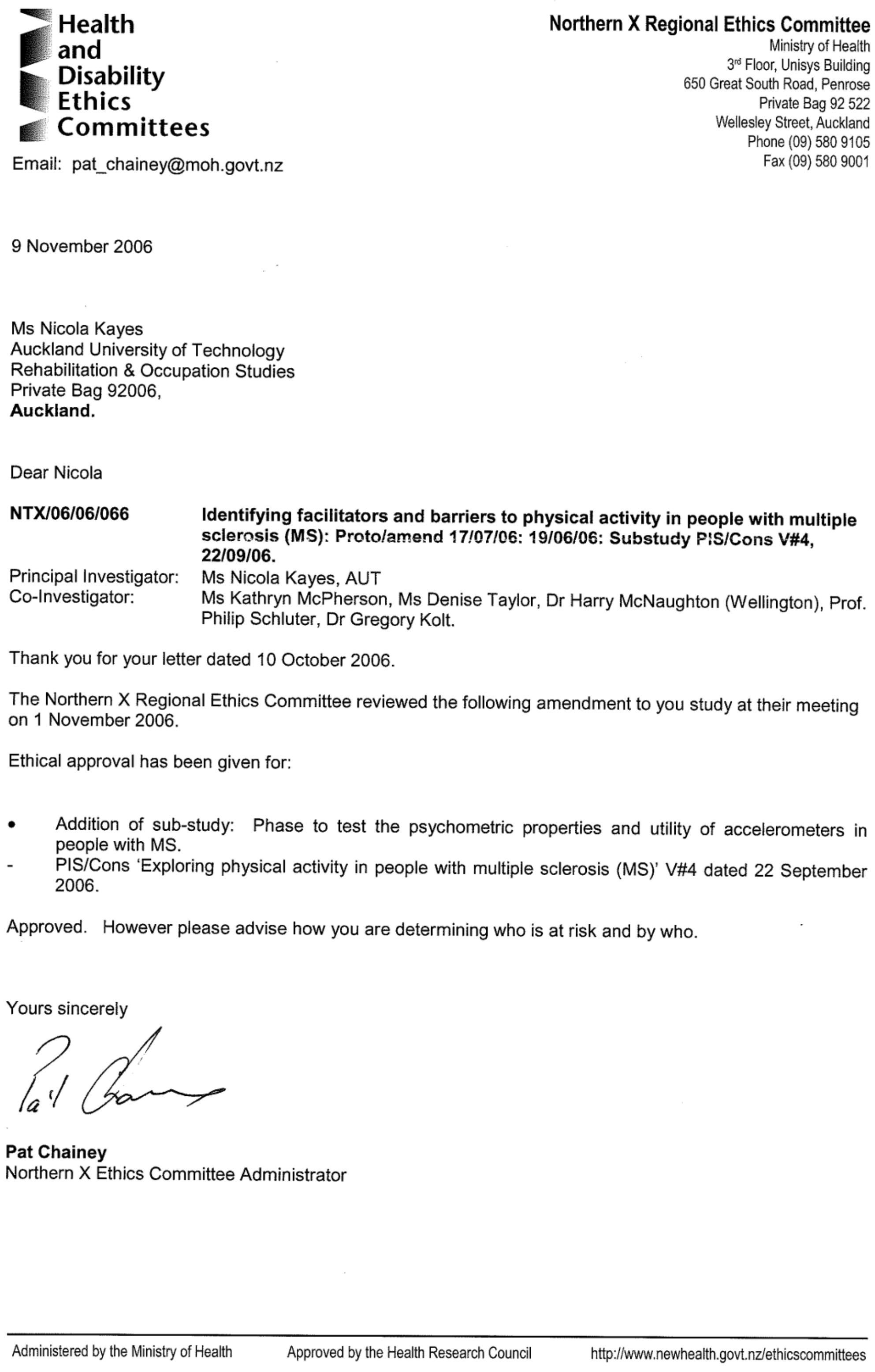
WHEELCHAIR (***SCORE E***) = *SCORE 13*

TOTAL SCORE

TOTAL PADS-R = (0.5349(*SCORE A*/1.074)) +
(0.6369(*SCORE B*/1.540)) +
(-0.0967((*SCORE C* - 0.104)/0.378)) +
(0.5005(*SCORE D*/1.184)) +
(-0.2198(*SCORE E* - 0.165)/0.497))

APPENDIX O

Ethical approval for Study Three



Health
and
Disability
Ethics
Committees

Email: pat_chainey@moh.govt.nz

Northern X Regional Ethics Committee
Ministry of Health
3rd Floor, Unisys Building
650 Great South Road, Penrose
Private Bag 92 522
Wellesley Street, Auckland
Phone (09) 580 9105
Fax (09) 580 9001

9 November 2006

Ms Nicola Kayes
Auckland University of Technology
Rehabilitation & Occupation Studies
Private Bag 92006,
Auckland.

Dear Nicola

NTX/06/06/066	**Identifying facilitators and barriers to physical activity in people with multiple sclerosis (MS): Proto/amend 17/07/06: 19/06/06: Substudy PIS/Cons V#4, 22/09/06.**
Principal Investigator:	Ms Nicola Kayes, AUT
Co-Investigator:	Ms Kathryn McPherson, Ms Denise Taylor, Dr Harry McNaughton (Wellington), Prof. Philip Schluter, Dr Gregory Kolt.

Thank you for your letter dated 10 October 2006.

The Northern X Regional Ethics Committee reviewed the following amendment to you study at their meeting on 1 November 2006.

Ethical approval has been given for:

- Addition of sub-study: Phase to test the psychometric properties and utility of accelerometers in people with MS.
- PIS/Cons 'Exploring physical activity in people with multiple sclerosis (MS)' V#4 dated 22 September 2006.

Approved. However please advise how you are determining who is at risk and by who.

Yours sincerely

Pat Chainey
Northern X Ethics Committee Administrator

Administered by the Ministry of Health Approved by the Health Research Council http://www.newhealth.govt.nz/ethicscommittees

APPENDIX P

Accelerometer testing protocol

Prior to participant arriving
Set up the testing area – placing a chair at the start point of each activity
Make sure the randomised activities have been entered onto the testing record
Attach completed PAR-Q to testing record
Enter ID code onto both the PAR-Q and testing record
Load the participant's details onto the accelerometer using the Actical software
Make sure all old files on the HR monitor are deleted
Synchronise the HR monitor with the computer clock
Once participant arrives – take them to the table to sit down
Explain to the participant why we are doing this testing and what will happen while they are at AUT – Include the following…. • They will be fitted with a HR monitor and Activity monitor • They will be asked to do a variety of activities • They will asked not to talk during the activities as it affects their HR • If they need a break at any time, let us know • Explain the Borg RPE to them
Get the participant to complete any missing data on their questionnaire
Get the participant to sign the completed PAR-Q
Record the participants date of birth, gender and medications
Record what footwear the person is wearing during testing
Ask the participant to complete their pre-testing fatigue rating
Ask the participant to rate the impact of their condition compared to last week (second testing session only)
Get the person to stand up
Fit the activity monitor - On the iliac crest of their left hip, with the arrow pointing upwards Record where the accelerometer is fitted on the record sheet
Fit the HR monitor - Make sure HR monitor is wet before fitting
Take the participants height and weight
Go to the chair at the start of the first activity and get the participant to sit down
Press the marker button on the activity monitor twice AND Start the HR monitor
Record the participants resting heart rate
Begin testing using the instruction sheet for each activity

After testing
Ask the participant to complete their post-testing fatigue rating
Ask the participant to rate the accelerometer and record any comments they make
Write down any comments you have that will need to be considered when analysing the data
COLLECT ALL EQUIPMENT FROM THE PARTICIPANT

APPENDIX Q

Standardised activity instructions – Accelerometer testing

Newspaper reading instructions

Get the participant to sit in the chair at the table with the newspaper

Instruct the participant as follows:

"The object of this activity is to read the newspaper for five minutes."

"Are you ready to do that?"

When the participant is ready, position them with the vacuum cleaner within the vacuuming area:

"OK, I am going to press the button on your activity monitor and the HR monitor and you can start reading the newspaper when I tell you to GO."

Press the **activity monitor button TWICE**; and

Get ready to press the lap button on the HR monitor AND start the stopwatch. When you are ready tell the participant:

"OK, ready, GO" (press the **lap button and start stopwatch on GO**)

When the time is up, say this:

"STOP!"

Walk over to the participant as quickly as you can. When you reach them:

1. Press the **lap button** on the HR monitor immediately
2. Press the **marker button** on the activity monitor **TWICE**
3. Get the person to sit down while they return to resting heart rate (RHR). **Press the lap button on the HR monitor AGAIN once they have reached RHR.**
4. Record the **Borg RPE**
5. Record if the participant had the **newspaper** lying flat whilst reading, or if they held the newspaper up in their hands
6. Offer the participant a **drink of water**

Washing instructions

Get the participant to sit in the chair by the washing area

Instruct the participant as follows:

"The object of this activity is to first hang each item in the washing basket on the washing line one by one and then take each item off and fold it one by one.

If you are doing washing at home – would you normally have the basket up at waist level or on the floor?"

<Place the basket where they would normally have it at home –
***record this on the record sheet*>**

"Are you ready to do that?"

When the participant is ready, position them by the basket and washing line:

"OK, I am going to press the button on your activity monitor and the HR monitor and you can start when I tell you to GO."

Press the **activity monitor button TWICE**; and

Get ready to press the lap button on the HR monitor AND start the stopwatch. When you are ready tell the participant:

"OK, ready, GO" (press the **lap button and start stopwatch on GO**)

When the participant has completed the activity:

1. **Stop the stopwatch**
2. Press the **lap button** on the HR monitor immediately
3. Press the **marker button** on the activity monitor **TWICE**
4. Get the person to sit down while they return to resting heart rate (RHR). **Press the lap button on the HR monitor AGAIN once they have reached RHR.**
5. Record the **time on the stopwatch**
6. Record the **Borg RPE**

Vacuuming instructions

Get the participant to sit in the chair by the vacuuming area

Instruct the participant as follows:

“The object of this activity is to vacuum this area of the floor for five minutes. You are permitted to stop, and to rest as necessary. You may lean against the wall while resting, but resume vacuuming as soon as you are able.

Five minutes is a long time so you are likely to cover this floor area several times in this time. Just carry on until I tell you to stop”

“Are you ready to do that?”

When the participant is ready, position them with the vacuum cleaner within the vacuuming area:

“OK, I am going to press the button on your activity monitor and the HR monitor and you can start vacuuming when I tell you to GO.”

Press the **activity monitor button TWICE**; and

Get ready to press the lap button on the HR monitor AND start the stopwatch. When you are ready tell the participant:

“OK, ready, GO” (press the **lap button and start stopwatch on GO**)

When the time is 15 seconds from completion, say this:

“In a moment I’m going to tell you to stop. When I do, just stop right where you are and I will come to you”

When the time is up, say this:

“STOP!”

Remind the person to stay where they are and to not move. You will come to them.

Walk over to the participant as quickly as you can, taking a chair with you. When you reach them:

1. Press the **lap button** on the HR monitor immediately
2. Press the **marker button** on the activity monitor **TWICE**
3. Get the person to sit down while they return to resting heart rate (RHR). **Press the lap button on the HR monitor AGAIN once they have reached RHR.**
4. Record the **Borg RPE**
5. Offer the participant a **drink of water**

IF the person stops before the 5 minutes is up, **stop the stopwatch** and do the **5 steps** outlined above. IN addition to this, record the **time stopped** and **why** they stopped on the record sheet.

30 second stair climb instructions

Get the participant to sit in the chair by the stair climb area

---

Instruct the participant as follows:

"The object of this activity is to walk up and down this flight of stairs for 30 seconds. You are permitted to stop, and to rest as necessary. You may lean against the wall while resting, but resume climbing as soon as you are able."

"Which side of the stairs would you prefer to use for this activity?"

"Are you ready to do that?"

When the participant is ready, position them at the bottom of the stairs:

"OK, I am going to press the button on your activity monitor and the HR monitor and you can start climbing when I tell you to GO."

Press the **activity monitor button TWICE**; and
Get ready to press the lap button on the HR monitor AND start the stopwatch. When you are ready tell the participant:

"OK, ready, GO" (press the **lap button and start stopwatch on GO**)

When the time is 15 seconds from completion, say this:

"In a moment I'm going to tell you to stop. When I do, just stop right where you are and I will come to you"

When the time is up, say this:

"STOP!"

Remind the person to stay where they are and to not move. You will come to them.

Walk over to the participant as quickly as you can. When you reach them:

1. Press the **lap button** on the HR monitor immediately
2. Press the **marker button** on the activity monitor **TWICE**
3. Record the **the number of flights** the participant has climbed during that activity
4. Lead the person to the bottom of the stairs and get them to sit down while they return to resting heart rate (RHR). **Press the lap button on the HR monitor AGAIN once they have reached RHR.**
5. Record the **Borg RPE**
6. Offer the participant a **drink of water**

IF the person stops before the 1 minute is up, **stop the stopwatch** and do the **6 steps** outlined above. IN addition to this, record the **time stopped** and **why** they stopped on the record sheet.

30 second chair stand instructions

Get the participant to sit in the chair ready for the chair stand activity.

Instruct the participant as follows:

"The object of this activity is for you to stand up and down from the chair as many times as possible over 30 seconds. However, there are a couple of things I need you to think about while you do this:

Firstly, I want you to keep your arms folded during this activity

Secondly, you need to stand completely uprightly and sit all the way back down each time you do it."

<demonstrate>

"I will be timing you for 30 seconds and so will let you know when you can start and when to stop. When I tell you to stop, stay where you are "

"Are you ready to do that?"

When the participant is ready, position them with the vacuum cleaner within the vacuuming area:

"OK, I am going to press the button on your activity monitor and the HR monitor and you can start the activity when I tell you to GO."

Press the **activity monitor button TWICE**; and

Get ready to press the lap button on the HR monitor AND start the stopwatch. When you are ready tell the participant:

"OK, ready, GO" (press the **lap button and start stopwatch on GO**)

When the time is up, say this:

"STOP!"

1. Press the **lap button** on the HR monitor immediately
2. Press the **marker button** on the activity monitor **TWICE**
3. Get the person to sit down while they return to resting heart rate (RHR). **Press the lap button on the HR monitor AGAIN once they have reached RHR.**
4. Record the **Borg RPE** and the **No. of chair stands** on the record sheet
5. Offer the participant a **drink of water**

6MWT instructions

Get the participant to sit in the chair at the start line

Instruct the participant as follows:

"The object of this test is to walk as far as possible for 6 minutes. You will walk back and forth in this hallway. Six minutes is a long time to walk, so you will be exerting yourself. You will probably get out of breath or become exhausted. You are permitted to slow down, to stop, and to rest as necessary. You may lean against the wall while resting, but resume walking as soon as you are able.

You should be walking back and forth around the cones. You should pivot briskly around the cones and continue back the other way without hesitation. Now I'm going to show you. Please watch the way I turn without hesitation"

<demonstrate>

"I am going keep track of the number of laps you complete. I will mark my worksheet each time you turn around at this starting line"

"Are you ready to do that?"

When the participant is ready, position them at the starting line:

"OK, remember that the object is to walk as far as possible for 6 minutes, but don't run or jog. I am going to press the button on your activity monitor and the HR monitor and you can start walking when I tell you to GO."

Press the **activity monitor button TWICE**; and

Get ready to press the lap button on the HR monitor AND start the stopwatch. When you are ready tell the participant:

"OK, ready, GO" (press the **lap button and start stopwatch on GO**)

DO NOT WALK WITH THE PARTICIPANT

DO NOT TALK WITH THE PARTICIPANT WHILE THEY ARE WALKING EXCEPT TO USE THE STANDARD PHRASES OF ENCOURAGEMENT

Each time the participant returns to the starting line, mark down on your record sheet that they have done a lap. Let the participant see you do it. Exaggerate your movement when making this mark.

Use the following standard phrases of encouragement. Use an even tone of voice:

1. After the first minute: **"You are doing well. You have 5 minutes to go"**
2. After second minute: **"Keep up the good work. You have 4 minutes to go"**
3. After third minute: **"You are doing well. You are halfway done"**
4. After fourth minute**: "Keep up the good work. You have 2 minutes to go"**
5. After fifth minute: **"You are doing well. You have only 1 minute to go"**

If the participant stops walking during the test and needs a rest, say this:

"You can lean against the wall if you would like: then continue walking whenever you feel able". DO NOT STOP THE TIMER.

If the participant stops before the 6 minutes are up and refuses to continue (of if you decide they should not continue), wheel the chair over for the participant to sit on, discontinue the walk, and note on the record the distance, the time stopped, and the reason for stopping prematurely.

When the time is 15 seconds from completion, say this:

"In a moment I'm going to tell you to stop. When I do, just stop right where you are and I will come to you"

When the time is up, say this:

"STOP!"

Remind the person to stay where they are and to not move. You will come to them.

Walk over to the participant as quickly as you can, taking a chair with you. When you reach them:

1. Press the **lap button** on the HR monitor immediately
2. Press the **marker button** on the activity monitor **<u>TWICE</u>**
3. **Mark the spot** where they stopped by placing a piece of tape on the floor
4. Get the person to sit down while they return to resting heart rate (RHR). **Press the lap button on the HR monitor <u>AGAIN</u> once they have reached RHR.**
5. Record the **Borg RPE**
6. Record the number of laps from the tick marks on the record sheet and work out the additional distance covered using the 3m markers on the corridor wall. **Calculate total distance walked**, rounding to the nearest metre and record it on the worksheet.
7. Offer the participant a **drink of water**

IF the person stops before the 6 minutes is up, **stop the stopwatch** and do the **7 steps** outlined above. IN addition to this, record the **time stopped** and **why** they stopped on the record sheet.

APPENDIX R

Accelerometer testing record

Code				

Date			

Assessment Number: __________

Height		CENTREMETRES
Weight		KILOGRAMS

Date of Birth		**Gender**	

Resting Heart Rate	

List any medications

Accelerometer fitting	Is the accelerometer fitted: Underneath the clothes / over a thin layer of clothing *(please circle)*
Footwear	Is the participant wearing footwear during testing? YES / NO *(please circle)*

Pre-testing Fatigue rating
Please place an "X" through this line to indicate how fatigued you are feeling RIGHT NOW. Not at all fatigued ________________________________ Extremely fatigued

Second Testing Session ONLY				
Thinking about the impact of your condition on you today, how would you compare it to **last week** (please circle):				
Much worse than last week	A little worse than last week	The same as last week	A little better than last week	Much better than last week

Marker	Activity	Event	Average HR	Peak HR	Total Activity Counts
1	**Start testing**				
2	1	Activity 1 start			
3		Activity 1 end			
4		Activity 1 RHR			
5	2	Activity 2 start			
6		Activity 2 end			
7		Activity 2 RHR			
8	3	Activity 3 start			
9		Activity 3 end			
10		Activity 3 RHR			
11	4	Activity 4 start			
12		Activity 4 end			
13		Activity 4 RHR			
14	5	Activity 5 start			
15		Activity 5 end			
16		Activity 5 RHR			
14	6 6MWT	Activity 6 start			
15		Activity 6 end			
16		Activity 6 RHR			
17	**Finish testing**				
COLLECT EQUIPMENT FROM THE PARTICIPANT					

30 Second Chair Stand

			No. Chair Stands
Note: If participant is fully standing or on their way back down to sitting at 30 seconds – this counts as 1 chair stand. If the participant is on their way to standing position – this counts as 0.			
	Borg RPE		Aids Use

Reading Newspaper

Did the participant have the newspaper: In their hands / Laying flat on the table *(please circle)* Does the participant ever experience any spasms? YES/NO *(please circle)* If Yes, did they experience any whilst reading the newspaper? YES/NO *(please circle)* If Yes, how many did they experience?			
	Borg RPE		Aids Use

Washing

			TIME STOPPED
Did the participant have the washing basket: At waist level / On the floor *(please circle)*			
	Borg RPE		Aids Use

Vacuuming

Did the participant: Vacuum continuously for 5 minutes / Stop to rest *(please circle)* If they stopped to rest – how many times did they stop?			
If stopped prematurely			TIME STOPPED
Why?			
	Borg RPE		Aids Use

Climbing stairs

Did the participant: Walk up and down the stairs continuously for 30 seconds / Stop to rest *(please circle)* If they stopped to rest – how many times did they stop?			
Note: Going up and down the stairs once = 2 flights			FLIGHT MARKS
If stopped prematurely			TIME STOPPED
Why?			
	FLIGHTS	¼ ½ ¾ *(please circle)*	PARTIAL FLIGHT
	Borg RPE		Aids Use

6 Minute Walk Test Results

			LAP MARKS
If stopped prematurely			TIME STOPPED
Why?			
	LAPS		ADDITIONAL DISTANCE
	Borg RPE		Aids Use

At the end of testing:

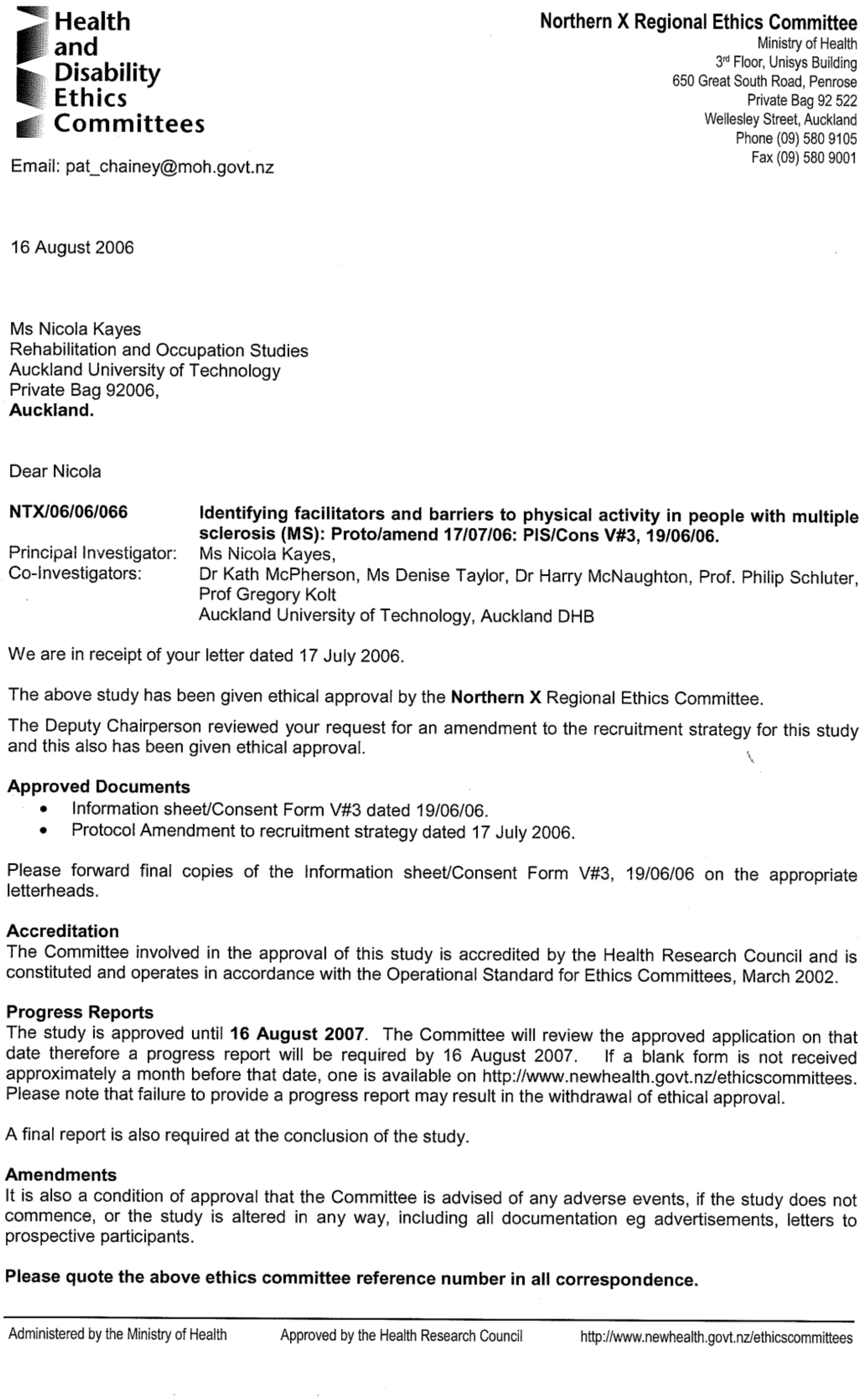
Post-testing Fatigue rating
Please place an “X” through this line to indicate how fatigued you are feeling RIGHT NOW. ____ Not at all fatigued Extremely fatigued

Please rate on the following scale how comfortable you felt the accelerometer was to wear? *(please circle)* *Not at all comfortable* 1 2 3 4 5 *Very comfortable*
Do you have any comments with regards to how comfortable you found the accelerometer to wear?
Do you (the researcher) have any comments to add? (for example – anything of note about the persons gait (e.g. foot drop), etc should go in here)

DON'T FORGET TO COLLECT ALL EQUIPMENT FROM THE PARTICIPANT

APPENDIX S

Ethical approval for Studies Four and Five



**Health
and
Disability
Ethics
Committees**

Email: pat_chainey@moh.govt.nz

Northern X Regional Ethics Committee
Ministry of Health
3rd Floor, Unisys Building
650 Great South Road, Penrose
Private Bag 92 522
Wellesley Street, Auckland
Phone (09) 580 9105
Fax (09) 580 9001

16 August 2006

Ms Nicola Kayes
Rehabilitation and Occupation Studies
Auckland University of Technology
Private Bag 92006,
Auckland.

Dear Nicola

NTX/06/06/066	**Identifying facilitators and barriers to physical activity in people with multiple sclerosis (MS): Proto/amend 17/07/06: PIS/Cons V#3, 19/06/06.**
Principal Investigator:	Ms Nicola Kayes,
Co-Investigators:	Dr Kath McPherson, Ms Denise Taylor, Dr Harry McNaughton, Prof. Philip Schluter, Prof Gregory Kolt Auckland University of Technology, Auckland DHB

We are in receipt of your letter dated 17 July 2006.

The above study has been given ethical approval by the **Northern X** Regional Ethics Committee.

The Deputy Chairperson reviewed your request for an amendment to the recruitment strategy for this study and this also has been given ethical approval.

Approved Documents

- Information sheet/Consent Form V#3 dated 19/06/06.
- Protocol Amendment to recruitment strategy dated 17 July 2006.

Please forward final copies of the Information sheet/Consent Form V#3, 19/06/06 on the appropriate letterheads.

Accreditation
The Committee involved in the approval of this study is accredited by the Health Research Council and is constituted and operates in accordance with the Operational Standard for Ethics Committees, March 2002.

Progress Reports
The study is approved until **16 August 2007**. The Committee will review the approved application on that date therefore a progress report will be required by 16 August 2007. If a blank form is not received approximately a month before that date, one is available on http://www.newhealth.govt.nz/ethicscommittees. Please note that failure to provide a progress report may result in the withdrawal of ethical approval.

A final report is also required at the conclusion of the study.

Amendments
It is also a condition of approval that the Committee is advised of any adverse events, if the study does not commence, or the study is altered in any way, including all documentation eg advertisements, letters to prospective participants.

Please quote the above ethics committee reference number in all correspondence.

Administered by the Ministry of Health   Approved by the Health Research Council   http://www.newhealth.govt.nz/ethicscommittees

It should be noted that Ethics Committee approval does not imply any resource commitment or administrative facilitation by any healthcare provider within whose facility the research is to be carried out. Where applicable, authority for this must be obtained separately from the appropriate manager within the organisation.

Yours sincerely

Pat Cha

Pat Chainey
Northern X Ethics Committee Administrator

Cc: ADHB Research Office A+A+3510

APPENDIX T

Introductory letter – Study Three, Four and Five

AUT
AUCKLAND UNIVERSITY OF TECHNOLOGY
TE WĀNANGA ARONUI O TAMAKI MAKAU RAU

Date

Xxxxx
Xxxxx
Xxxxx

Dear XXXXXX

The [Multiple Sclerosis Society of Auckland / MS Nurses at Auckland City Hospital] is currently working with researchers at the Auckland University of Technology (AUT) on some research exploring physical activity in people with Multiple Sclerosis (MS).

We would like to give you the opportunity to participate in their study.

There are three parts to this study and you can choose which parts you wish to take part in, if any at all. Below is a brief description of each of the three parts. However, in a few days time you will receive an information pack about this research. If you are interested in participating, this pack will also include a consent form for you to complete and indicate your willingness to be involved.

The three parts include:

1. Questionnaire

This questionnaire is designed to explore the kinds of things that make it difficult or easy for you to participate in activity. If you wish to participate in this part of the study, you will be able to complete the questionnaire over the telephone with a member of our research or you can complete the questionnaire yourself and post it to us in a prepaid envelope which will be provided.

2. Interview

In addition to the questionnaire, you may also consent to being contacted for a more in-depth interview. The interview will be held at a time and place that is convenient to you and will take approximately one hour. The researchers will only select a small number of people to actually participate in this interview for the purpose of exploring in more detail the questionnaire findings.

3. Accelerometer testing

Finally, you may also consent to being contacted to participate in a third component designed to test the effectiveness of accelerometers in measuring physical activity in people with MS. An accelerometer is a small portable device, similar to a pedometer, designed to measure motion and acceleration. It can be attached to a waistband which is then worn around the waist like a belt. Those who consent to being involved in this part of the study will be asked to attend two sessions at Auckland University of Technology (AUT) where you will be asked to complete a selection of activities while wearing the accelerometer. Each session will last approximately two hours and will be scheduled seven days apart. Your transport costs will be covered to and from AUT.

Please remember to keep an eye out for the information pack that will be posted to you in a few days time to learn more about this research.

Please note the [MS Societies / MS nurses at Auckland City Hospital] have their own databases and in order to protect your privacy, we are unable to cross check our database with theirs. If you are on both databases you may have received this invitation twice. If this is the case and you want to participate, you only need to complete the questionnaire ONCE.

We have mailed this letter to you directly from the [MS Nurses offices / MS Auckland offices]. Please note that:

- The [MS nurses / MS Society] have not divulged your name and address to AUT or the researchers
- The [MS nurses / MS Society] are not informed of the names and addresses of those that choose to participate

The [MS nurses / Society] fully endorses this study as useful to people with MS.

Yours sincerely

[Gary McMahon / Kamlesh Nand]
[GENERAL MANAGER / MS SPECIALIST NURSE]

APPENDIX U

Information pack cover letter – Study Three, Four and Five

AUCKLAND UNIVERSITY OF TECHNOLOGY
TE WĀNANGA ARONUI O TAMAKI MAKAU RAU

Date

Xxxxx
Xxxxx
Xxxxx
Xxxxx

Dear XXXXXX

You will have received a letter from us recently with information about some research we are currently working on with researchers at the Auckland University of Technology (AUT), exploring physical activity in people with Multiple Sclerosis (MS).

We would like to give you the opportunity to participate in their study.

As mentioned in our previous letter there are three parts to this study. Below is a brief description of each of these parts, along with information on how you can participate. However, we have enclosed a more detailed information sheet for you to read.

The three parts include:

1. Questionnaire

This questionnaire is designed to explore the kinds of things that make it difficult or easy for you to participate in activity. If you wish to participate in this part of the study, there are two ways you can do this:

Complete the enclosed questionnaire:
If you prefer this option, please complete the enclosed consent form and questionnaire and return to the research team in the stamped self-addressed envelope provided.

Complete the questionnaire via telephone interview
If you prefer this option, phone 0508 ACTIVITY (0508 2284 8489) and arrange for a time convenient to you to complete the questionnaire over the phone. The researchers will complete a verbal consent form over the phone with you.

2. Interview

In addition to the questionnaire, you may also consent to being contacted for a more in-depth interview. The interview will be held at a time and place that is convenient to you and will take approximately one hour. The researchers will only select a small number of people to actually participate in this interview for the purpose of exploring in more detail the questionnaire findings. **If you wish to take part in the interview, you can indicate this on the enclosed consent form and return to us in the stamped, self-addressed envelope provided.**

3. Accelerometer testing

Finally, you may also consent to being contacted to participate in a third component designed to test the effectiveness of accelerometers in measuring physical activity in people with MS. An accelerometer is a small portable device, similar to a pedometer, designed to measure motion and acceleration. It can be attached to a waistband which is then worn around the waist like a belt. Those who consent to being involved in this part of the study will be asked to attend two sessions at Auckland University of Technology (AUT) where you will be asked to complete a selection of activities while wearing the accelerometer. Each session will last approximately two hours and will be scheduled seven days apart. Your transport costs will be covered to and from AUT. **If you wish to take part in the accelerometer testing, you can indicate this on the enclosed consent form and return to us in the stamped, self-addressed envelope provided.**

Please note the [MS Societies / MS nurses at Auckland City Hospital] have their own databases and in order to protect your privacy, we are unable to cross check our database with theirs. If you are on both databases you may have received this invitation twice. If this is the case and you want to participate, you only need to complete the questionnaire ONCE.

We have mailed this letter to you directly from the [MS Nurses offices / MS Auckland offices]. Please note that:

- The [MS nurses / MS Society] have not divulged your name and address to AUT or the researchers
- The [MS nurses / MS Society] are not informed of the names and addresses of those that choose to participate

The [MS nurses / Society] fully endorses this study as useful to people with MS.

Yours sincerely

[Gary McMahon / Kamlesh Nand]
[GENERAL MANAGER / MS SPECIALIST NURSE]

APPENDIX V

Participant information sheet – Study Three, Four and Five

Participant Information Sheet

Exploring physical activity in people with Multiple Sclerosis (MS)

Principal Investigator	Nicola Kayes	Phone: 921 9999 ext. 7309

Invitation

You are invited to take part in a study exploring physical activity in people with MS. Please remember that:

- Your participation in this study is entirely voluntary (your choice). You do not have to take part in this study, and if you choose not to take part this will in no way affect your future health care.
- If you do agree to take part you are free to withdraw at any time, without having to give a reason. This will in no way affect your future health care.

This information sheet will explain the research study. However, if you would like to go through this information sheet with someone in person or if you have any questions about anything you do not understand then please contact the research team on **0508 ACTIVITY (0508 22848489).**

What is the purpose of the study?

We are trying to find out physical activity in people with MS. There are two parts to this research:

Part One aims to learn more about things that help or make it hard for people with MS to take part in activity.

Part Two aims to test how effective a portable physical activity monitor (accelerometer) is at measuring physical activity in people with MS.

How are people chosen to be asked to be part of the study?

Anyone whose details are on the North Shore MS Society database, the MS nurses database at the Auckland City Hospital and the MS Society of Auckland database have been sent an information pack about this study. The MS nurses and the MS societies have sent this information pack on our behalf.

Who is eligible to participate?

Part One – Questionnaire and Interviews

You are able to take part in this part of the study if you have been given a definite diagnosis of MS by a neurologist and are able to communicate with the researchers. We would like to survey people with varying levels of participation in activity and so you are eligible to participate in this research regardless of your current level of mobility.

Part Two – Accelerometer Testing
You are able to take part in this part of the study if you have been given a definite diagnosis of MS by a neurologist and are able to communicate with the researchers. You must be independently mobile (with or without an assistive device). You cannot participate if you have any unstable cardiovascular disease or any other serious illness that precludes you from taking part.

What happens in the study?
If you would like to participate in this study, there are three ways you can do this:

Part One

1. You can complete the questionnaire enclosed – the questionnaire asks you questions about your current level of participation in activity, your current health and well-being and the MS-related symptoms you are currently experiencing.
2. You can take part in an in-depth interview

Part Two

3. You can take part in two sessions at the Auckland University of Technology (AUT) where you will be asked to complete a variety of everyday tasks and activities whilst wearing an accelerometer.

1. If you want to complete the questionnaire:
You can complete the questionnaire via telephone interview
If you prefer this option, phone **0508 ACTIVITY (0508 22848489)** and arrange for a time convenient to you to complete the questionnaire over the phone. The researchers will complete a verbal consent form over the phone with you.

OR:

You can complete the questionnaire yourself:
If you prefer this option, complete both the consent form and questionnaire and return to the research team in the stamped self-addressed envelope provided.

2. If you wish to be considered to take part in a more in-depth interview
You may indicate on the consent form if you are happy to be contacted to take part in an in depth interview, exploring the barriers and facilitators to activity in more detail. We will select only ten consenting participants, with a range of activity levels and disability, to take part in these interviews. We will arrange a time and place that is convenient to you to conduct the interviews. These interviews will be audio-taped and transcribed.

3. If you wish to be considered to take part in the sessions at AUT
You may also indicate on the consent form if you are happy to be contacted to take part in the sessions at AUT. We will select thirty consenting participants to take part in these sessions. The sessions will be arranged at a time convenient to you and will be held seven days apart. Your transport costs to and from AUT will be covered. During these sessions you will complete a variety of everyday tasks and activities, such as reading the newspaper, making a cup of tea, vacuum cleaning, climbing stairs, walking a marked out route around campus, water exercises, travelling in a car for 5 minutes and sitting quietly for 5 minutes. You will also complete some standardised including a 6 minute walk test, 10 metre walk test, and a 30 second chair stand test.

What are the risks of this study?

There should not be any risk to you from this study. However, you may find answering some of the questions difficult due to the sensitive nature of some questions. If you find completing the questionnaire distressing and would like to discuss this with someone, then please phone the research team on the study 0800 number so that we are able to refer you as appropriate. You may also phone other local services, such as your local MS Society or the Health and Disability Advocate (numbers provided at the bottom of this information sheet). It is also possible that you may find the questionnaire completion, interview and AUT sessions tiring, but we will try to minimise this for you by going at your own pace and giving you the opportunity to take a break at any time if you desire. If you feel unable to complete one or more of the activities during the AUT sessions, then please advise the researcher who will be with you throughout the session.

How will this study help?

The information we gain from this study will help us to find out about the activity levels of people with MS and what the barriers and facilitators are to participating in activity from your perspective. The results of this study will help us to look at how best to develop an intervention aimed at explicitly managing the barriers and facilitators to activity. Facilitating participation in activity for people with complex neurological conditions such as MS will contribute to reduced risk of secondary impairments as well as enhanced functional, psychological and social outcomes.

What are the costs of participating in the project?

There will not be any cost to you except your time. The questionnaire should take approximately 60 to 90 minutes to complete. If you participate in the interview it will last for approximately one hour. If you participate in the two sessions at AUT they will last for approximately two hours each.

How will my privacy be protected?

All information you give us will be kept confidential and your name will not be known to anyone but the researcher. Your questionnaire will be given a code and the answers you give in the questionnaire will not be able to be tracked back to you. We will keep the consent forms and questionnaires locked in a cabinet, in separate locations. Any reports will make sure that you cannot be identified. The researchers are independent of the MS Society and the MS Nurses and so we have no access to their records. Likewise, representatives of the Society and MS Nurses will have no access to individual data collected for the purpose of this study. A summary of the results will be made available to the MS Society, MS nurses and the wider community. However, no individual's will be identifiable from this summary.

What will happen with the results?

We hope that the results of this study will be publishable in a neuro-rehabilitation journal. The results of this study will also inform the development of an intervention, aiming to support people with MS to participate in activity, which will be tested in a future study.

Will I be able to have a copy of the results?

If you would like a summary of the results they will be sent to you at the end of the study (about 6 months after completion of the study). Usually there is a delay between collecting information and letting people know about the results.

Compensation

No harm is likely to happen to you from taking part in this study. However, in the unlikely event of a physical injury as a result of your participation in this study, you may be covered by ACC under the Injury Prevention, Rehabilitation and Compensation Act. ACC cover is not automatic and your case will need to be assessed by ACC according to the provisions of the 2002 Injury Prevention, Rehabilitation and Compensation Act. If your claim is accepted by ACC, you still might not get any compensation. This depends on a number of factors such as whether you are an earner or non-earner. ACC usually provides only partial reimbursement of costs and expenses and there may be no lump sum compensation payable. There is no cover for mental injury unless it is a result of physical injury. If you have ACC cover, generally this will affect your right to sue the investigators. If you have any questions about ACC, contact your nearest ACC office.

If you have any concerns or questions?
If you have any questions please feel free to contact one of the researchers:
Study freephone number 0508 ACTIVITY (0508 22848489)

Named researcher	Nicola Kayes	Phone: (09) 921-9999 ext. 7309 E-mail: nkayes@aut.ac.nz
Or	Kathryn McPherson	Phone: (09) 921-9999 ext. 7110 E-mail: katmcphe@aut.ac.nz
	Denise Taylor	Phone (09) 921-9999 ext. 7080 E-mail: detaylor@aut.ac.nz

If you have any queries or concerns regarding your rights as a participant in this study you may wish to contact a Health and Disability Advocate - Phone 0800-555-050

Other local services:	MS Society of Auckland	Phone: (09) 845 5921
	North Shore MS Society	Phone: (09) 4431153

Statement of Approval
This study has received ethical approval from the Northern X Regional Ethics Committee.

APPENDIX W

Consent form – Study Three, Four and Five

Consent Form

Exploring physical activity in people with Multiple Sclerosis (MS)

Principal Investigator	Nicola Kayes	Phone: 921 9999 ext. 7309

- I have read or had read to me, and I understand, the information sheet dated 22/09/06 for volunteers taking part in the study exploring physical activity in people with MS. I have had the opportunity to ask questions. I am satisfied with the answers I have been given.
- I have had the opportunity to use family/whanau support or a friend to help me ask questions and understand the study.
- I understand that taking part is entirely voluntary (my choice) and that I may withdraw from the study at any time and this will in no way affect my future health care.
- I understand that my participation in this study is confidential and that no material which could identify me will be used in any reports on this study.
- I understand that the study will be stopped if it should appear harmful to me.
- I understand the compensation provisions for this study.
- I have had time to consider whether to take part and I know who to contact if I have any questions about the study.

Please complete the following:

I consent to taking part in this research and ……. Have enclosed a completed questionnaire **OR** Would like to complete the questionnaire via a telephone interview (Please provide a telephone number below or contact us on **0508 ACTIVITY (0508 22848489)** *(please circle that which applies)*	
I wish to receive a summary of the results	Yes ○ No ○ *Please tick*
I consent to being contacted to participate in an in depth interview	Yes ○ No ○ *Please tick*
I consent to being contacted to participate in two accelerometer testing sessions at AUT	Yes ○ No ○ *Please tick*
If I participate in an in depth interview, I consent to my interview being audio-taped and transcribed **If Yes:** I wish to have the audio-tape returned to me on completion of the study (**If No:** please note the audio-tape will be destroyed)	Yes ○ No ○ *Please tick* Yes ○ No ○ *Please tick*

Full Name			
Address			
Phone	(Home)	(Mobile)	
Signature		Date	

APPENDIX X

Participant questionnaire – Study Four

Code				

Date			

BARRIERS AND FACILITATORS TO ACTIVITY IN PEOPLE WITH MULTIPLE SCLEROSIS (MS)
Confidential Patient Questionnaire

- It is important to note that there are no right or wrong answers to these questions.
- Please try to complete the questionnaire as honestly as possible and answer all the questions.
- If you find it hard to keep your mind on the statements, take a short break.
- The questionnaire is made up of ten different questionnaires and so sometimes you may feel the questions are repeating themselves. Please try to be patient with this and answer all the questions.
- If you need any help to complete this questionnaire please contact the research team on freephone: **0508 ACTIVITY (0508 22848489)**
- Thank you for taking the time to complete this questionnaire

This questionnaire is completely CONFIDENTIAL

What is your gender?

FEMALE		MALE	

How old are you?

YEARS	

What ethnic group or groups do you identify with?

Are you presently unemployed because of your health?

YES		NO	

Are you currently receiving financial compensation or disability payment for your Multiples Sclerosis?

YES		NO		Decision Pending	

Has a neurologist confirmed your diagnosis of Multiple Sclerosis?

YES		NO	

How long ago was a <u>definite</u> diagnosis of Multiple Sclerosis confirmed?

YEARS		MONTHS	

Which of the following best describes your patterns of MS (please tick the <u>one box</u> that best applies)?

Separate attacks with a sudden onset, followed by a gradual resolution, no permanent disability.	
Separate attacks with a sudden onset, followed by gradual resolution, residual disability between attacks.	
Sudden onset, initially separate attacks, followed by a progressive deterioration.	
Slow onset with a progressive deterioration.	
Other (please specify):	

Are you currently in remission?

YES		NO	

Assistive Devices (Please tick all that apply)

	Indoors	Outdoors
Walker		
Braces		
Cane		
Wheelchair		

Use of Arms (Please tick one)

Full	
Partial	
No Use	

Use of Legs (Please tick one)

Full	
Partial	
No Use	

Thinking about the impact of your condition on your life, over the **last week,** how would you compare it to a **typical week** (please circle):

Much worse than usual	A little worse than usual	The same as usual	A little better than usual	Much better than usual
1	2	3	4	5

Questionnaire One

This questionnaire asks you questions about the types of **exercise** and **physical activities** you participated in over the **last week** and the time you spent doing these activities.

If you compared the activities you took part in over the **last week** to the activities you would take part in on a **typical week**, would you say you did (please circle):

Much less than usual	Less than usual	About the same as usual	More than usual	Much more than usual
1	2	3	4	5

2. EXERCISE

1.1 Did you exercise in the **last week**? Exercise is any activity you do on a regular basis for the primary purpose of increasing or maintaining fitness. Please note: this does not include activities you do for leisure or recreation.

YES		NO	

If NO, please go to question 2

1.2 What kind of exercise did you do?

Please list the exercise activities below that you did in the **last week** for the primary purpose of maintaining or improving your health and fitness. For each activity indicate the activity type (using the key below), how many days per week you did the activity and how many minutes per day.

Activity types
A = Aerobic Exercise (aerobics are those exercises done for a sustained period of time which result in an increase in your heart rate and breathing rate e.g. walking, jogging, attending an aerobics class, bicycling, etc)
S = Strength Exercise (strength activities e.g. lifting weights or using elastic bands or weight training machines, pilates, core body strengthening & stability, tai chi, etc)
F = Flexibility Exercise (flexibility refers to activities that involve muscle stretching e.g. yoga, etc)

Please also indicate the intensity level for each activity that you list here using the key below:

Intensity
L = Light activities - don’t sweat or breathe heavily
M = Moderate activities - breathe a little harder and may sweat
V = Vigorous activities - breathe hard and sweat

Activity Type (A, S or F)	Activity	Days/ Week	Minutes/ Day	Intensity (L, M or V)

1.3 **Overall**, how would you describe the **average** intensity of the exercise you did over the **last week** (please tick one)?

Light exercise: Don't sweat or breathe heavily	
Moderate exercise: Breathe a little harder and may sweat	
Vigorous: Breathe hard and sweat	

2. LEISURE TIME PHYSICAL ACTIVITY

2.1 Did you participate in any sports, recreational, or leisure time activities in the **last week**? These activities may not necessarily result in sustained increases in heart rate and breathing rate. Examples include hiking, boating, skiing, dancing, bowling and sports activities.

YES		NO	

If NO, please go to question 3

2.2 What type of activities did you do?

Please list **the leisure time physical activities** below that you did in the **last week** for leisure or recreation. For each activity indicate the activity type (using the key below), how many days per week you did the activity and how many minutes per day. **Do not list activities here that you have already listed previously in this questionnaire.**

Activity types

E = Endurance (endurance activities are leisure time physical activities that you maintain for a sustained period of time that make you sweat and breathe a little harder than usual e.g. tramping/hiking, tennis, dancing, skiing, sports fishing, sexual activity, etc)

NE = Non-Endurance (non-endurance activities are leisure time physical activities that you might do in shorter bouts of activity and/or do not cause you to sweat and breathe a little harder e.g. boating, fishing by the jetty, bowling, etc)

Please also indicate the intensity level for each activity that you list here using the key below:

Intensity
L = Light activities - don't sweat or breathe heavily
M = Moderate activities - breathe a little harder and may sweat
V = Vigorous activities - breathe hard and sweat

Activity Type (E or NE)	Activity	Days/ Week	Minutes/ Day	Intensity (L, M or V)

2.3 **Overall**, how would you describe the **average** intensity of the leisure time physical activities you did over the **last week** (please tick one)?

Light exercise: Don't sweat or breathe heavily	
Moderate exercise: Breathe a little harder and may sweat	
Vigorous: Breathe hard and sweat	

3. GENERAL ACTIVITY

3.1 From **Monday through Friday last week**, how many **waking hours a day** did you spend inside your home (please tick one)?

Less than 6 hours a day	
6 to 8 hours a day	
9 to 10 hours a day	
11 to 12 hours a day	
13 hours or more	

3.2 On **Saturday and Sunday last week**, how many **waking hours a day** did you spend inside your home (please tick one)?

Less than 6 hours a day	
6 to 8 hours a day	
9 to 10 hours a day	
11 to 12 hours a day	
13 hours or more	

3.3 During the **last week**, how many **hours a day** did you sleep including naps?

	HOURS

3.4 During the **last week**, how many **hours a day** were you sitting or lying down (including work), but excluding sleeping?

	HOURS

3.5 During the **last week** did you do any **indoor** household activities, such as cleaning, food preparation, childcare activities, etc?

YES		NO	

If NO, please go to question 3.6

If **YES,** please list all the **indoor** activities that required some **physical activity** (e.g. cleaning, hanging washing, food preparation, etc) that you did in the **last week.** Please also include here any physical activities you did as a part of your role as caregiver (e.g. parenting activities). For each activity indicate how many days per week you did the activity and how many minutes per day. **Do not list activities here that you have already listed previously in this questionnaire.**

Activity	**Days/Week**	**Minutes/Day**

3.6 During the **last week** did you do any **outdoor** household activities, such as gardening, walking to and from shops, etc?

YES		NO	

If NO, please go to question 3.7

If **YES,** please list all the **outdoor** activities that required some **physical activity** (e.g. gardening, mowing lawns, walking to shops) that you did in the **last week**. For each activity indicate how many days per week you did the activity and how many minutes per day. **Do not list activities here that you have already listed previously in this questionnaire.**

Activity	**Days/Week**	**Minutes/Day**

3.7 During the **last week** did you climb any stairs at home?

YES		NO	

If NO, please go to question 3.8

If **YES,** how many flights of stairs do you have at home (one flight of stairs is 5-10 steps)?

	FLIGHTS

If **YES,** how many times a day did you climb these stairs in the **last week**?

	TIMES A DAY

3.8 How much assistance do you need to perform activities of daily living, such as dressing and bathing (please tick one)?

Without assistance	
Some assistance	
Full assistance	

4. THERAPY

4.1 During the **last week** did you receive physiotherapy or occupational therapy or another type of therapy that involves physical activity? **If you have already listed therapy related activities previously in this questionnaire, DO NOT complete this section.**

YES		NO	

If NO, please go to question 5

4.2 How many days a week did you receive a therapy that involved physical activity in the **last week**?

	DAYS/WEEK

4.3 How long did each activity-based therapy session last?

	MINUTES

5. EMPLOYMENT/SCHOOL

5.1 Are you currently employed, participate in any volunteer work or do you attend School?

Employed/Attend School/Volunteer Work	
Not employed/Do not attend school/ Do not do any volunteer work	
Retired	

If you are NOT EMPLOYED, DO NOT ATTEND SCHOOL, DO NOT DO ANY VOLUNTEER WORK or ARE RETIRED, please go to question 6

5.2 For most of your work/school day, do you:

Move around	
Stand	
Sit	

5.3 During the **last week** did you climb any stairs whilst at work/school?

YES		NO	

If NO, please go to question 5.4

If **YES,** how many flights of stairs do you have at work/school (one flight of stairs is 5-10 steps)?

	FLIGHTS

If **YES,** how many times a day did you climb these stairs in the **last week**?

	TIMES A DAY

5.4 During the **last week** did you get any **physical activity** in your transportation to and from work/school (e.g. walking to work)?

YES		NO	

If NO, please go to question 6

If **YES**, please list all the transportation physical activity you did in the **last week** (e.g. walking or wheeling a wheelchair to and from work). For each activity indicate how many days per week you did the activity and how many minutes per day. **Do not list activities here that you have already listed previously in this questionnaire.**

Activity	**Days/Week**	**Minutes/Day**

6. WHEELCHAIR USERS

6.1 During the last week did you use a wheelchair?

YES		NO	

If NO, stop this questionnaire

If **YES**, during the time that you were awake, how much time a day did you spend in your wheelchair in the **last week** (please tick one)?

All day	
Most of the day	
A few hours	

6.2 What type of wheelchair did you primarily use in the **last week** (please tick one)?

Manual	
Power	

If POWER WHEELCHAIR, stop this questionnaire

If **MANUAL,** did you push your own wheelchair at any time during the **last week**?

YES		NO	

If NO, stop this questionnaire

If **YES**, on average, how many minutes a day did you push yourself in your wheelchair in the **last week**?

Less than 60 minutes	
60 minutes or more	

Questionnaire Two

Sometimes people have problems doing what they want to do to stay healthy. Please tick which best indicates how much each of these problems keeps you from participating in exercise or physical activity.

		NEVER	SOMETIMES	OFTEN	ROUTINELY
1.	Lack of convenient facilities				
2.	Too tired				
3.	Lack of transportation				
4.	Feeling what I do doesn’t help				
5.	Lack of money				
6.	Impairment				
7.	No one to help me				
8.	Not interested				
9.	Lack of information about what to do				
10.	Embarrassment about my appearance				
11.	Concern about safety				
12.	Lack of support from family/friends				
13.	Interferes with other responsibilities				
14.	Lack of time				
15.	Feeling I can’t do things correctly				
16.	Difficulty with communication				
17.	Bad weather				
18.	Lack of help from health care professionals				

Questionnaire Three

Listed below are a number of symptoms that you may have experienced since your illness. Read the instructions at the top of each column carefully as they ask you different questions in relation to your symptoms.

		Please tick the box in this column if you have experienced the symptom SINCE your illness began	**Tick ONE of the columns below for each symptom by choosing what you think the symptom is MOST related too**		
			This symptom is related to my illness	***This symptom is related to stress***	***This symptom is related to my lack of fitness or inactivity***
1.	Pain				
2.	Sore throat				
3.	Nausea				
4.	Breathlessness				
5.	Flushed face				
6.	Weight change				
7.	Fatigue				
8.	Shakiness				
9.	Swollen glands				
10.	Stiff or sore joints/muscles				
11.	Loss of coordination				
12.	Depressed mood				
13.	Body tension				
14.	Light sensitivity				
15.	Restlessness				
16.	Sore eyes				
17.	Pounding heart				
18.	Irritability				
19.	Headaches				
20.	Upset stomach				
21.	Sleep difficulties				
22.	Increased sweating				

		Please tick the box in this column if you have experienced the symptom SINCE your illness began	Tick ONE of the columns below for each symptom by choosing what you think the symptom is MOST related too		
			This symptom is related to my illness	*This symptom is related to stress*	*This symptom is related to my lack of fitness or inactivity*
23.	Dizziness				
24.	Tight chest				
25.	Loss of strength				
26.	Loss of interest				
27.	Concentration/ memory problems				

Please indicate how much you agree or disagree with the following statements about your current symptoms by ticking the appropriate box.

	VIEWS ABOUT YOUR SYMPTOMS	STRONGLY DISAGREE	DISAGREE	NEITHER AGREE NOR DISAGREE	AGREE	STRONGLY AGREE
FA1	I am afraid that I will make my symptoms worse if I exercise					
FA2(R)	My symptoms would be relieved if I were to exercise					
FA3	Avoiding unnecessary activities is the safest thing I can do to prevent my symptoms from worsening					
FA4	The severity of my symptoms must mean there is something serious going on in my body					
FA9(R)	Even though I experience symptoms, I don't think they are actually harming me					
FA10	When I experience symptoms, my body is telling me that there is something seriously wrong.					
FA12	Physical activity makes my symptoms worse					
FA14	Doing less helps symptoms					
FA15	Symptoms are a signal that I am damaging myself					
FA16	I am afraid I will have more symptoms if I am not careful					

FA17	I should avoid exercise when I have symptoms					
	VIEWS ABOUT YOUR SYMPTOMS	STRONGLY DISAGREE	DISAGREE	NEITHER AGREE NOR DISAGREE	AGREE	STRONGLY AGREE
C1	I worry that I may become permanently bedridden because of my symptoms					
C2	I think that if my symptoms get too severe they may never decrease					
C3	If I push myself too hard I will collapse					
C4	My illness is awful and I feel that it overwhelms me					
C5	If I overdo things it will cause a major relapse					
C6	I will never feel right again					
SF1	When I experience symptoms, I think about them constantly					
SF2	I worry when I am experiencing symptoms					
SF3	When I am experiencing symptoms it is difficult for me to think of anything else					
SF5	I think a great deal about my symptoms					
SF9	My symptoms are always at the back of my mind					
SF12	I spend a lot of time thinking about my illness					
EA1	I am embarrassed about my symptoms					
EA2	I worry that people will think badly of me because of my symptoms					
EA3	The embarrassing nature of my symptoms prevents me from doing things					
EA4	I avoid social situations because I am scared my symptoms will get out of control					
EA5	I am ashamed of my symptoms					
EA6	My symptoms have the potential to make me look foolish in front of other people					

We are interested in how you respond to or manage your symptoms at the moment. Listed below are a number of different responses that people may have to their symptoms. Please indicate how often you respond in the following ways by ticking the appropriate box. Choose the most accurate answer for YOU, not what you think "most people" would say or do.

	MANANGING SYMPTOMS	NEVER	SOMETIMES	QUITE OFTEN	VERY OFTEN	ALL THE TIME
L2	I stay in bed to control my symptoms					
L3	When I experience symptoms, I rest.					
L4	I tend to avoid activities that make my symptoms worse					
L7	I tend to nap during the day to control my symptoms					
AL1	I tend to overdo things when I feel energetic					
AL2	I find myself rushing to get things done before I crash					
AL3	I tend to overdo things and then rest up for a while					
AL4	I tend to do a lot on a good day and rest on a bad day					
L9	I sleep when I'm tired in order to control my symptoms					
L10	I avoid making social arrangements in case I'm not up to it.					
L11	I avoid exerting myself in order to control my symptoms					
AL5	I'm a bit all or nothing when it comes to doing things					
L13	I avoid stressful situations					

Which of the following best describes the nature of your symptoms (please tick one):

My symptoms are physical	My symptoms are mainly physical	Both physical and psychological factors are involved in my symptoms	My symptoms are mainly psychological	My symptoms are psychological in nature

Questionnaire Four

The following questions are designed to help us to know how you feel. Please read each item carefully and **tick** one of the replies below each item which comes closest to how you have been feeling during the last week. Don’t take too long over your replies; your immediate reaction to each item will probably be more accurate than a long thought out response.

1. I feel tense or ‘wound-up’:	
Most of the time	
A lot of the time	
From time to time, occasionally	
Not at all	

2 (R). I still enjoy the things I used to enjoy:	
Definitely as much	
Not quite as much	
Only a little	
Hardly at all	

3. I get a sort of frightening feeling as if something awful is about to happen:	
Very definitely and quite badly	
Yes, but not too badly	
A little, but it doesn’t worry me	
Not at all	

4 (R). I can laugh and see the funny side of things:	
As much as I always could	
Not quite as much now	
Definitely not so much now	
Not at all	

5. Worrying thoughts go through my mind:	
A great deal of the time	
A lot of the time	
From time to time, but not too ofte	
Only occasionally	

6. I feel cheerful:	
Not at all	
Not often	
Sometimes	
Most of the time	

7 (R). I can sit at ease and feel relaxed:	
Definitely	
Usually	
Not often	
Not at all	

8. I feel as if I am slowed down:	
Nearly all the time	
Very often	
Sometimes	
Not at all	

9 (R). I get a sort of frightened feeling like ‘butterflies’ in the stomach:	
Not at all	
Occasionally	
Quite often	
Very often	

10. I have lost interest in my appearance:	
Definitely	
I don’t take as much care as I shoul	
I may not take quite as much care as ever	
I take just as much care as ever	

11. I feel restless as if I have to be on the move:	
Very much indeed	
Quite a lot	
Not very much	
Not at all	

12 (R). I look forward with enjoyment to things:	
As much as I ever did	
Rather less than I used to	
Definitely less than I used to	
Hardly at all	

13. I get sudden feelings of panic:	
Very often indeed	
Quite often	
Not very often	
Not at all	

14 (R). I can enjoy a good book or radio or TV programme:	
Often	
Sometimes	
Not often	
Very seldom	

Questionnaire Five

We would like to know how confident you are in doing certain activities. For each of the following questions, please **circle** the number that best corresponds to your confidence that you can do the tasks regularly at the present time.

Exercise

1.	How confident are you that you can do gentle exercises for muscle strength and flexibility three to four times a week?	Not at all confident Totally confident 1 2 3 4 5 6 7 8 9 10
2.	How confident are you that you can do aerobic exercise such as walking, swimming, or bicycling three to four times a week?	Not at all confident Totally confident 1 2 3 4 5 6 7 8 9 10
3.	How confident are you that you can exercise without making symptoms worse?	Not at all confident Totally confident 1 2 3 4 5 6 7 8 9 10

Managing your illness

1.	Having an illness often means doing different tasks and activities to manage your condition. How confident are you that you can do all the things necessary to manage your condition on a regular basis?	Not at all confident Totally confident 1 2 3 4 5 6 7 8 9 10
2.	How confident are you that you can judge when the changes in your illness mean you should visit a doctor?	Not at all confident Totally confident 1 2 3 4 5 6 7 8 9 10
3.	How confident are you that you can do the different tasks and activities needed to manage your health condition so as to reduce your need to see a doctor?	Not at all confident Totally confident 1 2 3 4 5 6 7 8 9 10
4.	How confident are you that you can reduce the emotional distress caused by your health condition so that it does not affect your everyday life?	Not at all confident Totally confident 1 2 3 4 5 6 7 8 9 10
5.	How confident are you that you can do things other than just taking medication to reduce how much your illness effects your everyday life?	Not at all confident Totally confident 1 2 3 4 5 6 7 8 9 10

Household chores

1.	How confident are you that you can complete your household chores, such as vacuuming and gardening, despite your health problems?	Not at all confident Totally confident 1 2 3 4 5 6 7 8 9 10
2.	How confident are you that you can get your errands done despite your health problems?	Not at all confident Totally confident 1 2 3 4 5 6 7 8 9 10
3.	How confident are you that you can get your shopping done despite your health problems?	Not at all confident Totally confident 1 2 3 4 5 6 7 8 9 10

Leisure and Recreation

1.	How confident are you that you can continue to do your hobbies and recreation?	Not at all confident Totally confident 1 2 3 4 5 6 7 8 9 10
2.	How confident are you that you can continue to do the things you like to do with friends and family? (such as social visits or recreation)	Not at all confident Totally confident 1 2 3 4 5 6 7 8 9 10

Managing your symptoms

1.	How confident are you that you can reduce your physical discomfort or pain?	Not at all confident Totally confident 1 2 3 4 5 6 7 8 9 10
2.	How confident are you that you can keep the fatigue caused by your illness from interfering with the things you want to do?	Not at all confident Totally confident 1 2 3 4 5 6 7 8 9 10
3.	How confident are you that you can keep the physical pain or discomfort of your illness from interfering with the things you want to do?	Not at all confident Totally confident 1 2 3 4 5 6 7 8 9 10
4.	How confident are you that you can keep any other symptoms or health problems you have from interfering with the things you want to do?	Not at all confident Totally confident 1 2 3 4 5 6 7 8 9 10
5.	How confident are you that you can control any symptoms or health problems you have so that they don't interfere with the things you want to do?	Not at all confident Totally confident 1 2 3 4 5 6 7 8 9 10

Questionnaire Six

	FATIGUE	BETTER THAN USUSAL	NO MORE THAN USUAL	WORSE THAT USUAL	MUCH WORSE THAN USUAL
P1	Do you have problems with tiredness?				
P2	Do you need to rest more?				
P3	Do you feel sleepy or drowsy?				
P4	Do you have problems starting things?				
P5	Do you start things without difficulty but get weak as you go on?				
P6	Are you lacking in energy?				
P7	Do you have less strength in your muscles?				
P8	Do you feel weak?				
M1	Do you have difficulty concentrating?				
M2	Do you have problems thinking clearly?				
M3	Do you make slips of the tongue when speaking?				
M4	Do you find it more difficult to find the correct work?				
M5	How is your memory?				
M6	Have you lost interest in the things you used to do?				

Questionnaire Seven

The following questions ask for your views about the impact of MS on your day to day life **during the past two weeks.**

In the past two weeks, how much has your MS limited your ability to…….

		NOT AT ALL	A LITTLE	MODERATELY	QUITE A BIT	EXTREMELY
MSIS1	Do physically demanding tasks?					
MSIS2	Grip things tightly (e.g. turning on taps)?					
MSIS3	Carry things?					

In the past two weeks, how much have you been bothered by…..

		NOT AT ALL	A LITTLE	MODERATELY	QUITE A BIT	EXTREMELY
MSIS4	Problems with your balance?					
MSIS5	Difficulties moving about indoors?					
MSIS6	Being clumsy?					
MSIS7	Stiffness?					
MSIS8	Heavy arms and/or legs?					
MSIS9	Tremor of your arms or legs?					
MSIS10	Spasms in your limbs?					
MSIS11	Your body not doing what you want it to do?					
MSIS12	Having to depend on others to do things for you?					
MSIS13	Limitations in your social and leisure activities at home?					
MSIS14	Being stuck at home more than you would like to be?					

		NOT AT ALL	A LITTLE	MODERATELY	QUITE A BIT	EXTREMELY
MSIS15	Difficulties using your hands in everyday tasks?					
MSIS16	Having to cut down the amount of time you spent on work or other daily activities?					
MSIS17	Problems with using transport (e.g. car, bus, train, taxi, etc.)?					
MSIS18	Taking longer to do things?					
MSIS19	Difficulty doing things spontaneously (e.g. going out on the spur of the moment)?					
MSIS20	Needing to go to the toilet urgently?					
MSIS21	Feeling unwell?					
MSIS22	Problems sleeping?					
MSIS23	Feeling mentally fatigued?					
MSIS24	Worries related to your MS?					
MSIS25	Feeling anxious or tense?					
MSIS26	Feeling irritable, impatient, or short tempered?					
MSIS27	Problems concentrating?					
MSIS28	Lack of confidence?					
MSIS29	Feeling depressed?					

Questionnaire Eight

		STRONGLY DISAGREE 1	2	3	4	5	STRONGLY AGREE 6
SE1	I am confident when meeting new people and going to new places						
SE2	I find that the things I do during the day make me feel happy and satisfied						
SE3	I sometimes have thoughts about whether my condition will get worse						
SE4	Sometimes I feel embarrassed in public places						
SE5	I like not having to (or the thought of not having to) go to work						
SE6	Planning for the future helps me to cope with my illness						
SE7	I can keep my MS from interfering with time spent with my friends and family						
SE8	I have as much independence as I feel I need						
SE9	Sometimes I feel inadequate as a person because of my condition						
SE10	I often feel a failure in things that I try to do						
SE11	There are things that I can do to help control my fatigue						
SE12	I often feel that MS controls my life						
SE13	I can usually do what I want to do when I want to do it						
SE14	I feel that my social life would be better if I did not have MS						

Questionnaire Nine

The following questions refer to you. Most of the questions can be answered directly by you, and ask your opinion. However, some questions specifically ask for the opinion of another person. Therefore, it is important that a friend, relative or carer also helps you to complete this part of the questionnaire if at all possible.

Please describe your relationship to the person who is going to help you complete this part of the questionnaire?	

	MEMORY AND CONCENTRATION	YES	NO
1	Do you have any problems with your memory or your ability to concentrate and work things out?		
2	**If 'No' to Q1:** Do you family or friends think you have such a problem?		
	If answer to <u>either</u> of the questions (1 or 2) is 'Yes':		
3	Do you need to use lists or other aids to help you overcome this problem?		
4	Do you need help from other people to plan your daily affairs or to work out simple finances?		

To the helper, or other person:
Is the person fully oriented in time, place and person?

Yes, fully.	Yes, partially.	No, totally disorientated.
Any comments?		

	MOOD	YES	NO
1	Have you been feeling anxious, irritable, depressed, or had any mood swings during the last month? (If 'yes', please write your problem below)		
	To other person:		
2	Does the person have euphoria (being over happy) or emotional lability (crying or laughing too easily)?		
	If answer to <u>either</u> of the questions (1 or 2) is 'Yes':		
3	Have you/has the person had this problem most days?		
4	Has this problem affected your ability to do **any** of your usual activities?		
	If 'Yes' to Q4:		
5	Has this problem been severe enough to prevent you from doing **all** usual activities?		

6	Have you been admitted to hospital for treatment of your mood problem during the last month?		
What problem has been experienced?			

	VISION	YES	NO
1	Do you have any problems with your vision?		
If 'Yes' to Q1:			
2	Can you read normal newspaper print (with ordinary glasses if worn, but not magnifying lenses)?		
If 'No' to Q2:			
3	Can you read large newspaper print?		
4	Can you count your fingers if you hold your hand out in front of you?		
5	Can you see your hand move in front of you?		
Any comments?			

	SPEECH AND COMMUNICATION	YES	NO
1	Do you have any problems with your speech?		
To other person:			
2	Do you think the person has any problem with their speech?		
If the answer to either of the questions (1 or 2) is 'Yes':			
3	Do you have this problem most days?		
4	Do you have this problem all the time and in every sentence?		
5	Do you need to write things down, use sign language, or use a communication aid?		
To other person:			
6	Is the person able to communicate effectively?		
Any comments?			

	SWALLOWING	YES	NO
1	Do you have to take care when swallowing solids or fluids?		
If 'Yes' to Q1:			
2	Do you have to take care with most meals?		
3	Do you choke during most meals?		
4	Does your food require special preparation (e.g. mashing) to modify its consistency?		
5	Do you have a feeding tube (nasogastric tube or gastrostomy tube)?		
Any comments?			

	ARMS AND HANDS	YES	NO
1	Do you have any problems with your arms or hands?		
If 'Yes' to Q1: **Please describe your problem below.**			
2	Do you have any difficulty doing **any** of your zips or buttons?		
2a	**If 'Yes' to Q2:** Are you able to do **all** of your zips and buttons?		
3	Do you have any difficulty in washing **or** brushing your hair?		
3a	**If 'Yes' to Q3:** Are you able to wash **and** brush your hair?		
4	Do you have any difficulty in using a knife and fork **together**?		
4a	**If 'Yes' to Q4:** Are you able to use a knife and fork together?		
5	Do you have any difficulty in handling **small** coins?		
5a	**If 'Yes; to Q5:** Are you able to handle **small** coins?		
6	**If unable to use hands for any of above activities:** Can you use your hands for anything at all?		
What problem(s) do you have with your arms and hands?			

	MOBILITY	YES	NO
1	Do you have any problems with your walking?		
To other person:			
1a	Does the person have any problems with their walking?		
If the answer to either of the questions (1 or 1a) is 'Yes':			
2	Do you use a walking aid?		
3	How do you usually get around outdoors:		
3a	Without aid?		
3b	**Or** With one stick or crutch, or holding someone's arm?		
3c	**Or** With two sticks or crutches, a walking frame, or one stick or crutch **and** someone's arm?		
3d	**Or** With a wheelchair?		
4	Can you stand and walk a few steps with help?		
Any comments?			

	BLADDER	YES	NO
1	Do you have any problems with your bladder?		
2	Are you currently on any treatment for such problems?		
3	Do you have to rush to the toilet, go frequently, or have difficulty in starting to pass urine?		
4	Have you been incontinent in the last month?		
5	Have you been incontinent every week?		
6	Have you been incontinent every day?		
7	Do you use a catheter (tube) to empty your bladder?		
8	Do you have a permanent catheter (tube) in the bladder, or, if a man, do you use a sheath to catch your urine?		
Any comments?			

	BOWELS	YES	NO
1	Do you have any problems with your bowel movements?		
If 'Yes' to Q1:			
1a	Do you suffer from constipation?		
2	Are you on any treatment for your bowels?		
3	Do you take laxatives or use suppositories for constipation?		
4	Do you need to use enemas for constipation?		
5	Do you need to evacuate your bowels by hand?		
6	Do you have to rush to the toilet to open your bowels?		
7	Have you had any bowel accidents (been incontinent of faeces) in the last month?		

8	Have you had bowel accidents every week?		
Any comments?			

	FATIGUE	YES	NO
1	Have you been feeling tired or getting tired easily during the last month?		
If 'Yes' to Q1:			
2	Have you been feeling tired or getting tired easily most days?		
3	Has this tiredness affected your ability to do **any** of your usual activities?		
4	Has the tiredness been severe enough to prevent you from doing **all** your usual activities?		
5	Has the tiredness been severe enough to confine you to bed and prevent you from doing **all** physical and mental activities?		
Any comments?			

	SEXUAL ACTIVITIES	YES	NO
1	Do you have any problems in relation to your sexual function?		
If 'Yes' to Q1:			
2	Do you have any problems in finding or satisfying a sexual partner?		
3	Is your sexual drive (desire) reduced?		
4	Is your sexual function affected by any physical problem such as loss of sensation, pain, weakness, spasms, catheterisation or incontinence?		
5	Do you have any difficulty with: (men) erection or ejaculation? (women) vaginal lubrication or orgasm?		
6	Do any of these difficulties totally prevent any sexual activities?		
Any comments?			

OTHER DISABILITIES

Do you have any other problems due to multiple sclerosis (MS) which have not been mentioned so far (such as: pain, spasms, dizziness)?

If 'Yes', please answer below:

What is the worst other problem?	

		YES	**NO**
1	Have you had this problem most days during the last month?		
2	Has this problem affected your ability to do **any** of your usual activities?		
3	Has this problem been severe enough to prevent you from doing **all** your usual activities, or to make you stay in bed all the time?		
4	Have you been admitted to hospital for this problem in the last year?		

Any comments?

Questionnaire Ten

1. What would you say is the main thing that stops you from participating in physical activity or exercise (please explain)?
2. Please list any other barriers that you feel prevent you from participating in physical activity or exercise (please explain)?
3. What would you say is the main thing that helps you to participate in physical activity or exercise (please explain)?
4. Please list any other facilitators that help you to participate in physical activity or exercise (please explain)?
5. In general, how does taking part in physical activity or exercise impact on you **whilst you are actually doing it**?
6. In general, does taking part in physical activity or exercise have any impact on you **after you have finished** (e.g. that evening or the next day)?

Thank you for taking the time to complete this questionnaire!

APPENDIX Y

Reminder letter – Study Three, Four and Five

AUCKLAND UNIVERSITY OF TECHNOLOGY
TE WĀNANGA ARONUI O TAMAKI MAKAU RAU

Date

Xxxxx
Xxxxx
Xxxxx
Xxxxx

Dear XXXXXX

You will have received a letter from us recently with information about some research we are currently working on with researchers at the Auckland University of Technology (AUT), exploring physical activity in people with Multiple Sclerosis (MS).

If you have already been in contact with the researchers then please ignore this letter. However, if not, then we would like to give you another opportunity to participate in the study.

As mentioned in our previous letter there are three parts to this study. Below is a brief description of each of these parts, along with information on how you can participate. However, we have enclosed a more detailed information sheet for you to read.

The three parts include:

1. <u>Questionnaire</u>

This questionnaire is designed to explore the kinds of things that make it difficult or easy for you to participate in activity. If you wish to participate in this part of the study, there are two ways you can do this:

Complete the enclosed questionnaire:
If you prefer this option, please complete the enclosed consent form and questionnaire and return to the research team in the stamped self-addressed envelope provided.
Complete the questionnaire via telephone interview
If you prefer this option, phone 0508 ACTIVITY (0508 2284 8489) and arrange for a time convenient to you to complete the questionnaire over the phone. The researchers will complete a verbal consent form over the phone with you.

2. Interview

In addition to the questionnaire, you may also consent to being contacted for a more in-depth interview. The interview will be held at a time and place that is convenient to you and will take approximately one hour. The researchers will only select a small number of people to actually participate in this interview for the purpose of exploring in more detail the questionnaire findings. **If you wish to take part in the interview, you can indicate this on the enclosed consent form and return to us in the stamped, self-addressed envelope provided.**

3. Accelerometer testing

Finally, you may also consent to being contacted to participate in a third component designed to test the effectiveness of accelerometers in measuring physical activity in people with MS. An accelerometer is a small portable device, similar to a pedometer, designed to measure motion and acceleration. It can be attached to a waistband which is then worn around the waist like a belt. Those who consent to being involved in this part of the study will be asked to attend two sessions at Auckland University of Technology (AUT) where you will be asked to complete a selection of activities while wearing the accelerometer. Each session will last approximately two hours and will be scheduled seven days apart. Your transport costs will be covered to and from AUT. **If you wish to take part in the accelerometer testing, you can indicate this on the enclosed consent form and return to us in the stamped, self-addressed envelope provided.**

Please note the [MS Societies / MS nurses at Auckland City Hospital] have their own databases and in order to protect your privacy, we are unable to cross check our database with theirs. If you are on both databases you may have received this invitation twice. If this is the case and you want to participate, you only need to complete the questionnaire ONCE.

We have mailed this letter to you directly from the [MS Nurses offices / MS Auckland offices]. Please note that:

- The [MS nurses / MS Society] have not divulged your name and address to AUT or the researchers
- The [MS nurses / MS Society] are not informed of the names and addresses of those that choose to participate

The [MS nurses / Society] fully endorses this study as useful to people with MS.

Yours sincerely

[Gary McMahon / Kamlesh Nand]
[GENERAL MANAGER / MS SPECIALIST NURSE]

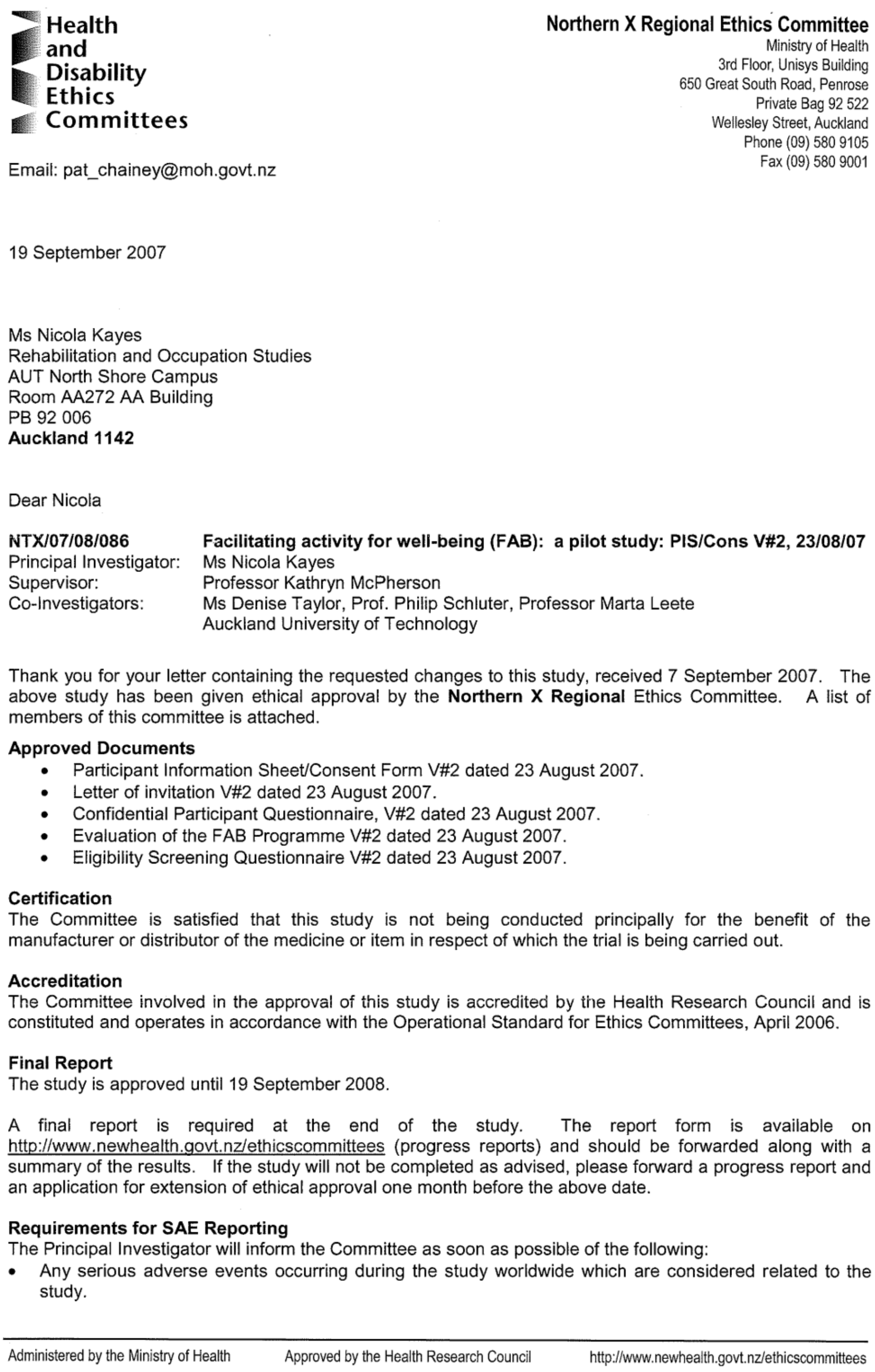
APPENDIX Z

Facilitating activity for well-being (FAB) Programme Manual

See CD-Rom accompanying this PhD (attached to the back cover of this document)

APPENDIX AA

Ethical approval for Study Six



Health
and
Disability
Ethics
Committees

Email: pat_chainey@moh.govt.nz

Northern X Regional Ethics Committee
Ministry of Health
3rd Floor, Unisys Building
650 Great South Road, Penrose
Private Bag 92 522
Wellesley Street, Auckland
Phone (09) 580 9105
Fax (09) 580 9001

19 September 2007

Ms Nicola Kayes
Rehabilitation and Occupation Studies
AUT North Shore Campus
Room AA272 AA Building
PB 92 006
Auckland 1142

Dear Nicola

NTX/07/08/086	**Facilitating activity for well-being (FAB): a pilot study: PIS/Cons V#2, 23/08/07**
Principal Investigator:	Ms Nicola Kayes
Supervisor:	Professor Kathryn McPherson
Co-Investigators:	Ms Denise Taylor, Prof. Philip Schluter, Professor Marta Leete Auckland University of Technology

Thank you for your letter containing the requested changes to this study, received 7 September 2007. The above study has been given ethical approval by the **Northern X Regional** Ethics Committee. A list of members of this committee is attached.

Approved Documents
- Participant Information Sheet/Consent Form V#2 dated 23 August 2007.
- Letter of invitation V#2 dated 23 August 2007.
- Confidential Participant Questionnaire, V#2 dated 23 August 2007.
- Evaluation of the FAB Programme V#2 dated 23 August 2007.
- Eligibility Screening Questionnaire V#2 dated 23 August 2007.

Certification
The Committee is satisfied that this study is not being conducted principally for the benefit of the manufacturer or distributor of the medicine or item in respect of which the trial is being carried out.

Accreditation
The Committee involved in the approval of this study is accredited by the Health Research Council and is constituted and operates in accordance with the Operational Standard for Ethics Committees, April 2006.

Final Report
The study is approved until 19 September 2008.

A final report is required at the end of the study. The report form is available on http://www.newhealth.govt.nz/ethicscommittees (progress reports) and should be forwarded along with a summary of the results. If the study will not be completed as advised, please forward a progress report and an application for extension of ethical approval one month before the above date.

Requirements for SAE Reporting
The Principal Investigator will inform the Committee as soon as possible of the following:
- Any serious adverse events occurring during the study worldwide which are considered related to the study.

All SAE reports must be signed by the Principal Investigator and include a comment on whether he/she considers there are any ethical issues relating to this study continuing due to this adverse event. It is assumed by signing the report, the Principal Investigator has undertaken to ensure that all New Zealand investigators are made aware of the event.

Amendments
All amendments (including advertisements and Posters) to the study must be advised to the Committee prior to their implementation, except in the case where immediate implementation is required for reasons of safety. In such cases the Committee must be notified as soon as possible of the change.

Please quote the above ethics committee reference number in all correspondence.

The Principal Investigator is responsible for advising any other study sites of approvals and all other correspondence with the Ethics Committee.

It should be noted that Ethics Committee approval does not imply any resource commitment or administrative facilitation by any healthcare provider within whose facility the research is to be carried out. Where applicable, authority for this must be obtained separately from the appropriate manager within the organisation.

Yours sincerely

Pat Chainey
Administrator
Northern X Regional Ethics Committee

Cc: AUT Research Office.

APPENDIX BB

Invitation letter – Study Six

AUCKLAND UNIVERSITY OF TECHNOLOGY
TE WĀNANGA ARONUI O TAMAKI MAKAU RAU

Date

Xxxxx
Xxxxx
Xxxxx
Xxxxx

Dear xxxxx

You are invited……

Thank you for taking part in our recent research exploring the barriers and facilitators to physical activity for people with Multiple Sclerosis (MS). As a result of all the information we gathered throughout this research we are developing a programme for people with MS, designed to help them to be more physically active. The programme aims to work with people, helping them to overcome specific barriers to activity that they experience.

We would like to invite you to take part in a small pilot study of this programme to help us develop the programme further. The aim of this pilot study is to test out the feasibility and acceptability of the programme and get your feedback on it so that we can further refine the programme to meet your needs.

So, if you:

- **Have a definite diagnosis of MS; AND**
- **Would like to be more physically active, but find it difficult**

Then, phone us now at either of the following numbers:

Nicola Kayes	**(09) 921 9999 ext 7309**
Marta Leete	**0508 ACTIVITY (0508 22848489)**

… so that we can tell you more about this pilot study and check your eligibility to take part.

You will find an information sheet enclosed if you would like to read more about what this pilot study involves.

We look forward to hearing from you soon.

Regards,

Nicola Kayes
Research Officer

APPENDIX CC

Particiant information sheet– Study Six

Participant Information Sheet

Facilitating Activity for well-Being (FAB):
A Pilot Study in people with Multiple Sclerosis (MS)

Principal Investigator	Nicola Kayes	Phone: 921 9999 ext. 7309

Invitation

You are invited to take part in a pilot study aiming to test the feasibility and acceptability of a programme designed to facilitate people with MS to take part in physical activity. It is important to note that:

- Your participation in this study is entirely voluntary (your choice). You do not have to take part in this study, and if you choose not to take part, this will in no way affect your future health care.
- If you do agree to take part, you are free to withdraw at any time, without having to give a reason. This will in no way affect your future health care.
- If you choose to withdraw from the study, you may request that any data collected from you is also withdrawn.

This information sheet will explain the research study. However, if you would like to go through this information sheet with someone in person or if you have any questions about anything you do not understand, then please contact the research team on **0508 ACTIVITY (0508 22848489).**

What is the purpose of the study?

We have been doing a lot of research exploring what makes it difficult for people with MS to take part in physical activity and what would help them to take part. As a result of this research, we are developing a programme designed to facilitate people with MS to take part in physical activity and to help them overcome the barriers to activity they experience. This pilot study aims to test out this new programme and get your feedback on it. This is an important step in the development of this programme to ensure that it is feasible and acceptable to people with MS. Your feedback will help us to refine the programme further.

How are people chosen to be asked to be part of the study?

All those who took part in our recent research have been screened for eligibility and sorted into three groups depending on their level of disability. We have invited random selections of potential participants from each of these groups to take part in this pilot study.

Who is eligible to participate?

You are able to take part in this part of the study if you:

(1) Have been given a definite diagnosis of MS by a neurologist;
(2) Are able to communicate with the researchers; and
(3) Live within approximately 15km of AUT University, Akoranga Campus.

You will not be eligible to take part if you:

(1) Have experienced a relapse within the last month;
(2) Have a medical condition that precludes your participation; and
(3) Have engaged in regular and intensive physical activity in the last three months (at least three times per week for 30 minutes or more at a time).

We will need to obtain medical clearance from your GP if you have experienced any of the following:

- Asthma
- Diabetes
- Heart Problems
- If you are taking any medication for blood pressure or a heart condition
- If you ever get light headed or dizzy while exercising
- If you know of any other reason why you should not participate in exercise or physical activity

What happens in the study?

If you would like to participate in this pilot study, you should phone the research team on freephone **0508 ACTIVITY (0508 22848489).**

They will tell you more about the study and ask a series of questions to check your eligibility to participate. If you are eligible to participate and if you are still interested in participating, the researcher will obtain your signed consent and schedule you in to take part in the programme.

The programme

The programme has one main aim:

To assist you to take part in physical activity by explicitly managing any barriers to physical activity that you face and to help you overcome them.

The programme will take place in your home or at an alternative location of your choice if you prefer. It will be run by a qualified physiotherapist who will schedule time to see you once a week for eight weeks. Each weekly session will take between one to two hours to complete and will take place at a time that is convenient to you.

The first weekly session will be an introductory session where the physiotherapist will introduce the programme to you and spend some time getting to know you. During this session, you will be asked to complete a questionnaire so the physiotherapist can learn more about what kinds of things make it difficult for you to take part in physical activity. They will also conduct an initial interview to get to know you in more depth and gain a clearer understanding of your situation so that the content of the programme can be individualised for you. They may record this initial interview so that they can ensure they retain all the information you give them.

The sessions subsequent to this first session will focus on helping you to incorporate physical activity into your daily life and helping you overcome some of the difficulties you discussed in your first session. Your physiotherapist will work with you on developing some strategies to help you with this and will practice these strategies with you.

In addition to these weekly sessions you will be asked to do some home-based tasks in-between the sessions. These will include:

- Keeping an activity diary of your daily activities throughout the eight weeks. This will take approximately 30 minutes each day.

- Practising any strategies you might have discussed in your weekly session to help you overcome some of the difficulties you face when taking part in physical activity. You will usually be able to incorporate these strategies into your normal daily routine.
- In addition, you may occasionally be required to do some preparation for the following weekly session.

Your feedback

Halfway through the programme (at four weeks) we will ask you to take part in an interview to get your feedback on the programme to date. This will take approximately 30 minutes and will be held at a time and place that is convenient to you. In addition, on completion of the programme (at eight weeks), we will ask you to complete a short questionnaire to provide us with some feedback about the sessions. We will also ask you to take part in another interview to allow us to explore your feedback in more depth. The questionnaire and interview will take approximately one hour in total and will be held at a time and place that is convenient to you. We would also like to record the interviews so that we can ensure we retain all the information you give us.

What are the risks of this study?

There should not be any risk to you taking part in this pilot study. However, if you do not normally do any physical activity, you may find that your body has a natural physiological response to it (e.g. muscle soreness).

However, if you find that you experience a reaction to the activities you are doing that is beyond what you would normally expect OR if you have any other concerns that you would like to discuss, please:

Either: Discuss this with your physiotherapist during your next session

Or: Phone a member of the research team on **0508 ACTIVITY (0508 22848489)**

Or: Phone other local services, such as your local MS Society or the Health and Disability Advocate (numbers provided at the bottom of this information sheet).

How will this study help?

Facilitating people with complex neurological conditions such as MS to participate in physical activity will contribute to reduced risk of secondary impairments. It will also contribute to enhanced functional, psychological and social outcomes.

What are the costs of participating in the project?

There will not be any cost to you.

As noted above, your time commitment includes a one to two hour session per week for eight weeks; approximately 30 minutes a day to complete your activity diary; a 30 minute interview halfway through the programme and a one hour session to complete a short questionnaire and interview on completion of the programme. Other home-based tasks should be easily incorporated into your daily routine.

Any travel costs associated with the study will be reimbursed to you either by petrol or taxi voucher. In addition, we will also reimburse any costs that may be incurred if you need to see your GP to gain medical clearance to take part in the study.

How will my privacy be protected?

All information you give us will be kept confidential and your name will not be known to anyone but the researcher and the physiotherapist running the programme. Your questionnaire and interview transcript will be given a code and the answers you give in the questionnaire will not be able to be tracked back to you. We will keep the consent forms, audiotapes/CDs, questionnaires and interview transcripts locked in a cabinet, in separate locations. If you wish to have a copy of your interview audiotapes/CDs and transcripts on completion of the study; you will be able to indicate this on the consent form. Any reports will make sure that you cannot be identified. A summary of the results will be made available to the MS Society, MS nurses and the wider community. However, no individuals will be identifiable from this summary.

What will happen with the results?
We hope that the results of this study will be publishable in a neuro-rehabilitation journal. The results of this study will also inform further refinements to the programme which we aim to test in a full definitive trial in the future.

Will I be able to have a copy of the results?
If you would like a summary of the results they will be sent to you at the end of the study (about 6 months after completion of the study). Usually there is a delay between collecting information and letting people know about the results.

Compensation
No harm is likely to happen to you from taking part in this study. However, in the unlikely event of a physical injury as a result of your participation in this study, you may be covered by ACC under the Injury Prevention, Rehabilitation and Compensation Act. ACC cover is not automatic and your case will need to be assessed by ACC according to the provisions of the 2002 Injury Prevention, Rehabilitation and Compensation Act. If your claim is accepted by ACC, you still might not get any compensation. This depends on a number of factors such as whether you are an earner or non-earner. ACC usually provides only partial reimbursement of costs and expenses and there may be no lump sum compensation payable. There is no cover for mental injury unless it is a result of physical injury. If you have ACC cover, generally this will affect your right to sue the investigators. If you have any questions about ACC, contact your nearest ACC office.

If I have any concerns or questions?
If you have any questions please feel free to contact one of the researchers:

Study freephone number **0508 ACTIVITY (0508 22848489)**

Nicola Kayes	Phone: (09) 9219999 ext 7309 Email: nkayes@aut.ac.nz
Marta Leete	Phone: (09) 921 9154 Email: mleete@aut.ac.nz
Kathryn McPherson	Phone: (09) 9219999 ext 7110 Email: katmcphe@aut.ac.nz

If you have any queries or concerns regarding your rights as a participant in this study, you can contact an independent Health and Disability Advocate. This is a free service provided under the Health and Disability Commissioner Act:

Telephone (NZ wide): 0800 555 050
Free Fax (NZ wide): 0800 2787 7678 (0800 2 SUPPORT)
Email: advocacy@hdc.org.nz

Other local services:	MS Society of Auckland	Phone (09) 845 5921
	North Shore MS Society	Phone (09) 4431153

Statement of Approval
This study has received ethical approval from the Northern X Regional Ethics Committee.

APPENDIX DD

Eligibility screening questionnaire – Study Six

Eligibility Screening Questionnaire

This screening questionnaire is to be completed over the telephone with any interested participants.

'I am going to ask you a few questions to check that you are eligible to take part in this research. This should take no more than 15 minutes to complete. Firstly, I am going to ask you for your contact details and also some questions about your MS and your current level of activity. Secondly, I will tell you a little bit about what the programme involves so that you can decide if you have the time to take part. Lastly, I will ask you a few questions about your medical history as we may need to obtain medical clearance from your GP before you can take part.'

Part One – Contact details and eligibility criteria

What is your name?	
What is your address?	
What is your phone number?	

Yes	No	*Do you have a definite diagnosis of MS confirmed by a neurologist?*
Yes	No	*Have you experienced a relapse within the last month?*
Yes	No	*Have you engaged in regular or intensive physical activity in the last three months? (e.g. at least 3 times/week for 30 minutes or more at a time)*

[If the person's answers fall into the shaded area, then they are **eligible** to participate so you can continue on to part two of this questionnaire. If any of their answers fall outside of the shaded area then they are **not eligible** to participate. Explain to the person that they are not eligible and the reason why. Thank them for their interest and ask them if they would like to be contacted for future research in this area. For example, in the New Year we will be trialling a Tai Chi programme in people with MS.]

Part Two – Time commitments involved in the programme

'If you wish to take part in this programme you will need to be available to:

- *Take part in a face to face session once a week for eight weeks in your home (or at an alternative location if you prefer) – approximately one to two hours per session.*
- *Complete a diary of your daily activities every day during the course of the eight week programme – approximately 30 minutes per day.*
- *Practice any strategies you might have discussed in your weekly session to help you overcome some of the difficulties you face when taking part in physical activity. You will usually be able to incorporate these strategies into your normal daily routine.*
- *Do some preparation for the following weekly session – this will vary depending on the content of your next scheduled session. For the majority of sessions, no preparation will be required. At the most, it will take you approximately 1 hour during the course of the week.*
- *Take part in two interviews (one part way through the programme and one on completion of the programme) to get your feedback on the programme – approximately 30 minutes per interview.*
- *Complete a short questionnaire on completion of the programme – approximately 15 minutes.'*

Yes	No	*With this in mind, are you available to take part in this programme over the next eight weeks?*

[If the person has answered 'yes' to this question, then continue on to part three of this questionnaire. If not, then thank them for their interest and ask them if they would like to be contacted for future research in this area. For example, in the New Year we will be trialling a Tai Chi programme in people with MS.]

Part Three – Physical activity readiness questionnaire (PAR-Q)

'Physical activity is important for physical and mental health. Typically all individuals are encouraged to participate in physical activity. There are however certain circumstances in which it is suggested a medical doctor gives you permission to take part. Please answer the following questions below honestly. It is important for us to know if you have any health conditions that can be affected by physical activity. ***All information is confidential.***

Please answer 'yes' or 'no' for each of the following questions.'

Yes	No	*Has a doctor ever told you that you have asthma?*
Yes	No	*Has a doctor ever told you that you have diabetes?*
Yes	No	*Has a doctor ever told you that you have a heart problem?*
Yes	No	*Do you ever have pains in your chest when engaging in physical activity?*
Yes	No	*Do you currently take prescription drugs for blood pressure or heart condition?*
Yes	No	*Do you have a bone or joint problem that may be made worse with exercise?*
Yes	No	*Do you ever get light headed or dizzy while exercising?*
If so, please explain:		
Yes	No	*Do you know of ANY other reason why you should not engage in physical activity?*
If so, please explain:		

Please inform us as soon as possible if any aspect of your health changes that would result in a change of the answers on this form.'

[If the participant answers "No" to all questions:
They are able to participate without obtaining medical clearance. Thank them for their time and let them know that one of our physiotherapists who will be delivering the programme will be in touch with them shortly to arrange a time for their first session. Explain that the physiotherapist will bring with them a consent form to complete at the beginning of the session for them to sign. Do not continue any further with this screening tool]

If one or more of the answers is "Yes":

'Because you have answered 'yes' to some of these questions we will need to obtain clearance from your GP for you to take part in this programme. You will not be able to participate in the study until we receive that clearance.

Because you need medical clearance, with your permission, we will make contact with your GP. We will give them information about the programme and about the kinds of activities you may participate in if you choose to take part.

- *Your GP may be able to give medical clearance after consulting your medical notes. If this is the case, we will ask them to fax the medical clearance to us for our records;*

OR

- *Your GP may wish to see you in person before giving medical clearance. If this is the case, we will notify you as soon as possible and ask that you make an appointment to see your GP to obtain this clearance. If you do need to see your GP in person, we will cover any costs that may be incurred.'*

'What are your GP details?'

GP Name		Phone	
Surgery Name			

'We will let you know as soon as we have medical clearance, or if your GP wishes to see you in person. Do you have any questions?'

[Answer any questions the participant has and thank them for their time, saying you will be in touch soon]

APPENDIX EE

Consent form – Study Six

Consent Form

Facilitating Activity for well-Being (FAB): A Pilot Study in people with Multiple Sclerosis (MS)

Principal Investigator	Nicola Kayes	Phone: 921 9999 ext. 7309

- I have read or had read to me, and I understand, the information sheet dated 25/07/07 for volunteers taking part in the pilot study exploring the Facilitating Activity for well-Being (FAB) programme. I have had the opportunity to ask questions and I am satisfied with the answers I have been given.

- I have had the opportunity to use family/whanau support or a friend to help me ask questions and understand the study.

- I understand that taking part is entirely voluntary (my choice) and that I may withdraw from the study at any time and this will in no way affect my future health care.

- If I choose to withdraw from the study, I understand that I may request that any data collected from me is also withdrawn.

- I understand that my participation in this study is confidential and that no material which could identify me will be used in any reports on this study.

- I understand that the study will be stopped if it should appear harmful to me.

- I understand the compensation provisions for this study.

- I have had time to consider whether to take part and I know who to contact if I have any questions about the study.

Please complete the following:

I consent to taking part in this pilot study	Yes ○ No ○ *Please tick*
If I require medical clearance to take part, I agree to my GP or other current health provider being informed of my participation in this study	Yes ○ No ○ *Please tick*
I wish to receive a summary of the results	Yes ○ No ○ *Please tick*
I consent to a copy of my activity diary being taken on completion of the programme	Yes ○ No ○ *Please tick*
I consent to my interviews being audio-taped and transcribed	Yes ○ No ○ *Please tick*
I wish to have a copy of the audio-tape returned to me on completion of the study	Yes ○ No ○ *Please tick*
I wish to have a copy of the transcript of my interviews returned to me on completion of the study	Yes ○ No ○ *Please tick*
I agree to being contacted regarding future related studies	Yes ○ No ○ *Please tick*

Full Name			
Address			
Phone	(Home)	(Mobile)	
Signature		Date	

APPENDIX FF

FAB programme weekly report – Study Six

Weekly Report	**Week 1 2 3 4 5 6 7 8 12** *(please circle)*

Date		**Participant ID**			
Module Title					
Clinician Name					
How long did this session last for?					

What did you like about this session?
What did you not like about this session?
How well did the participant engage in this session? (please explain your answer) Not at all engaged 1 2 3 4 5 Extremely engaged *(please circle)*

Were the resources for this session adequate? (please explain your answer) Yes / In Part / No *(please circle)*
How could this session be improved?

Please add any additional comments on the back of this sheet

APPENDIX GG

FAB programme final report – Study Six

Final Report

Date		**Participant ID**			
Clinician Name					

Activity Diary and Home-based Tasks

1. Did the participant complete the activity diary? All the time / Some of the time / Not at all *(please circle)*
2. Did the participant complete the home-based tasks? All the time / Some of the time / Not at all *(please circle)*
3. Is there anything you think we could do to encourage participants to complete their activity diary or home-based tasks more consistently?

Length of the Sessions

4. The sessions were supposed to last between one to two hours. **Were you able to fit the content of the modules into this time adequately?** Yes / No (please circle)
5. Do you feel the sessions were…? Too short / Just the right length of time / Too long (please circle)
6. Do you have any comments about the length of the sessions?

Length of the Programme

7. The programme lasted for twelve weeks. Was this…? Too short / Just the right length of time / Too long (please circle)
8. Do you have any comments about the length of the programme?

General

Overall, what did you like about the FAB™ programme?
Overall, what did you NOT like about the FAB™ programme?

How do you think the FAB™ programme could be improved?

Any other comments?