

**Exercise and physical activity in people with multiple  
sclerosis: an exploration of priorities, meanings and  
implications for clinical practice**

**A thesis submitted for the degree of Doctor of Philosophy**

**By**

**Andrea M. Stennett**

**Department of Clinical Sciences**

**Brunel University London**

**July 2015**

## Abstract

### Aims

Exercise and physical activity have been found to be beneficial in managing disabilities caused by multiple sclerosis (MS). Despite the known benefits, people with MS (pwMS) are inactive. Research has focused on structured exercise programmes, rarely considering a broader range of activities, which pwMS integrate into everyday life. The aims of this study were to gain in-depth understanding of the priorities and meanings of exercise and physical activity from the perspective of pwMS and to explore how these might inform clinical practice.

**Methods:** a mixed methods approach using three interconnected studies was adopted:

**Study 1:** A four-round Delphi questionnaire scoped and determined consensus of priorities for exercise and physical activity and the reasons why pwMS (n=101) engaged in these activities. Content and statistical analyses were utilised.

**Study 2:** Sixteen face-to-face, semi-structured interviews were conducted with pwMS to explore the meanings ascribed to exercise and physical activity in relation to the Delphi study.

**Study 3:** Three focus groups involving 14 physiotherapists explored perceptions about exercise and physical activity.

Data were analysed for studies 2 and 3 using Framework Analysis and themes developed.

### Results: outcome from each phase

1. Study 1 revealed that the prioritised exercise and physical activity practices and the reasons why pwMS (n=70) undertook these activities were diverse. Consensus was found for the exercise and physical activity practices ( $W=0.744$ ,  $p<0.0001$ ) and the reasons why pwMS engaged in these activities ( $W=0.723$ ,  $p<0.0001$ ).
2. Study 2 demonstrated that the meanings pwMS ascribed to exercise and physical activity was beyond 'movement' reflecting how they lived with a variable and progressive condition. Contextual factors, specifically personal factors were dominant influences.
3. Study 3 highlighted that physiotherapists shared similar views in some aspects to pwMS, however physiotherapists perceptions of exercise and physical activity were predominately influenced by their theoretical knowledge.

### Conclusion

The priorities and meanings ascribed to exercise and physical activity were 'a matter of perspective' and context driven. Understanding the strategies used by pwMS for prioritisation might help clinicians support pwMS more effectively in their decision making about exercise and physical activity. Taking this approach creates the opportunity to deliver a more focused patient-centred approach in the management of MS. Recommendations for clinical practice and further research were identified.

## Acknowledgements

A dream will remain a dream until you turn it into a reality. My dream was to become a researcher and when I saw the opportunity that would lead me in that direction I took hold of it. Thanks Brunel! Growing up I have always been told by my family that you have to dream big! So I did! I can still hear the words of my mother and grandmother ringing out in my ear "*you can do whatever you choose to do and do not let anyone tell you otherwise*". However, I realised early on in life that the bigger your dream, the more people you need around you to help make the dream a reality. Likewise over the course of the PhD, I have had many people who ran along side me at different stages of the process. I thank you all.

I wish to express my sincere thanks to my supervisors Professor Lorraine De Souza and Dr. Meriel Norris for their continued, unwavering support and guidance throughout this entire process. I have been intellectually stretched in every way humanly possible, even beyond what I thought I was capable of. Special thanks to my mentor Dr. Elizabeth Cassidy who adopted me from early on in the PhD process and who kept me on track. I will never forget your words, "*you are a finisher*". Those few words have kept me going in times when I could not see the light at the end of the tunnel. Also special thanks to my Brunel colleagues, Professor Kenneth Gilhooly for helping to navigate my way through the statistics, the Physiotherapy Team, Administrative team (Andrea Davis, Debbie Hirst and Joao Malieque), Dr. Jean Clarke, Mrs. Carol-Ann Howson, Simone Coetzee, Ingrid Bacon, Dr. Carole Pound and Dr. Tina Ramkalawan (Graduate School) you have in your own way been a great help and an inspiration to me.

Thanks to all the people with MS who participated in the research. Thanks for inviting me into your homes to share your stories. Also, thanks to the physiotherapists who participated in the focus groups. Your views have helped us see the other side of the coin which is often unseen.

Special thanks to the Association of Charted Physiotherapists interested in neurology (ACPIN) for funding aspects of the study and to the MS Therapy Centres for advertising and supporting this research.

Thanks to my church family and friends outside of Brunel, Pastors Phil and Caroline Whitehead, The Worship Team, Desmond and Patricia Egharevba, Alastair and Sharon Webber, Gillian, Lyndon and Jordan Goodluck, Dave and Pintusorn Anstey, Karlene Fraser, Renata Joseph, Toyin Tanimowo, Dele Olaleye, Dr. Funke Adetona, Florence Acquah, Emily and George Woodrooffe, Eileen Kyerematen, Zoe Jones, Dr. Dave D. Muir, Arnie Lloyd, Gail Golding, Trudy-Ann Sinclair McDonald, Dorothyya and Allan Stennett, Mrs. Beverly Johnson, Christine Maitland-Francis, Herb and Beverley Newsome, who have supported me in practical ways and for keeping me anchored and grounded.

Overall, I must say thanks to God for giving me the strength, wisdom and courage to run this race that was set before me. Last but certainly not least, my family, Gloria Thorpe, Deleie Green, Andrene Smith and the newest addition to the family, Akeelia Benjamin. Thank you so much for your continuous love, support and understanding and for giving me the freedom to fulfil this dream. Also, in remembrance of my grandmother Linda Thorpe (Awee) who passed one month before I started the PhD. A lady who invested so much of her life into me; I will never forget you.

## Table of Contents

<b>Chapter 1 .....</b>	<b>13</b>
<b>Introduction .....</b>	<b>13</b>
<b>1.0 Introduction .....</b>	<b>13</b>
<b>1.1 Purpose of the study: .....</b>	<b>15</b>
<b>1.2 My interest in this research.....</b>	<b>15</b>
<b>1.3 Background to Multiple Sclerosis.....</b>	<b>16</b>
1.3.1 Prevalence of Multiple Sclerosis.....	16
1.3.2 Clinical Course of Multiple Sclerosis.....	17
1.3.3 Diagnosis of Multiple Sclerosis.....	19
1.3.4 Clinical features and symptoms.....	19
1.3.5 Prognosis and Disability .....	20
1.3.6 Management of Multiple Sclerosis.....	24
1.3.7 Rehabilitation and Multiple Sclerosis.....	24
1.3.8 Physiotherapy Management of Multiple Sclerosis.....	26
1.3.9 Management of MS by pwMS: the lay perspectives.....	29
<b>1.4 Outline of the Thesis .....</b>	<b>31</b>
<b>1.5 Conclusion .....</b>	<b>34</b>
<b>Chapter 2 .....</b>	<b>35</b>
<b>Literature Review .....</b>	<b>35</b>
<b>2.0 Introduction .....</b>	<b>35</b>
<b>2.1 Methods for searching the literature .....</b>	<b>36</b>
Search Strategy .....	36
Inclusion criteria for studies:.....	37
Exclusion Criteria: .....	37
Data Collection and Analysis .....	37
Literature Search Results:.....	39
2.1.1 The effectiveness and safety of exercise and physical activity in people with MS .....	39
2.1.2 Content and frequency of exercise and physical activity in pwMS .....	47
<b>2.2 Exercise and physical activity: the perspective of pwMS.....</b>	<b>58</b>
2.2.1 The experience and meaning of exercise and physical activity for pwMS.....	59
<b>2.3 Conclusion .....</b>	<b>66</b>
<b>Chapter 3 .....</b>	<b>68</b>
<b>Methodology .....</b>	<b>68</b>
<b>3.0 Introduction .....</b>	<b>68</b>
<b>3.1 Philosophical position .....</b>	<b>70</b>
3.1.1 Pragmatism .....	71
<b>3.2 Operationalising pragmatism in mixed methods approach.....</b>	<b>72</b>
<b>3.3 Conclusion .....</b>	<b>74</b>
<b>Chapter 4 .....</b>	<b>75</b>
<b>Study 1 Method: A day in the life of people with Multiple Sclerosis .....</b>	<b>75</b>
<b>4.0 Introduction .....</b>	<b>75</b>
<b>4.1 Delphi method.....</b>	<b>78</b>
4.1.1 Types of Delphi methods .....	79
4.1.2 Application of the Delphi method .....	80

4.1.3 Advantages and disadvantages of using the Delphi Method .....	82
4.1.4 Delphi method and the use of experts .....	83
4.1.5 Validity and Reliability of the Delphi method.....	85
<b>4.2 Study 1 Method .....</b>	<b>87</b>
4.2.1 Study Aim.....	87
4.2.2 Study Design .....	87
4.2.3 Ethical considerations .....	94
4.2.4 Recruitment and sample.....	94
4.2.5 Inclusion Criteria .....	95
4.2.6 Procedure and data analysis.....	95
<b>4.3 Conclusion .....</b>	<b>101</b>
<b>Chapter 5 .....</b>	<b>102</b>
<b>Study 1: Delphi Findings .....</b>	<b>102</b>
<b>5.0 Introduction.....</b>	<b>102</b>
<b>5.1 Section 1: Demographic profile of research respondents .....</b>	<b>102</b>
<b>5. 2 Section 2: Results of the Delphi Study.....</b>	<b>106</b>
5.2.1 Round 1: Open Round .....	106
5.2.2 Round 2: Selecting and limiting Round .....	109
5.2.3 Round 3: Ranking Round.....	112
5.2.4 Round 4: Consensus Round .....	116
<b>5.3 Discussion .....</b>	<b>119</b>
5.3.1 Entrance into the world of pwMS in relation to exercise and physical activity	121
5.3.2 Insights into the reasons why pwMS engage in exercise and physical activity	123
<b>5.4 Strengths and Limitations.....</b>	<b>125</b>
<b>5.5 Conclusion .....</b>	<b>127</b>
<b>Chapter 6 .....</b>	<b>129</b>
<b>Study 2 Method: A qualitative exploration of exercise and physical activity in people with Multiple Sclerosis .....</b>	<b>129</b>
<b>6.0 Introduction.....</b>	<b>129</b>
<b>6.1 Study Design.....</b>	<b>130</b>
<b>6.2 Ethical consideration.....</b>	<b>131</b>
<b>6.3 Recruitment .....</b>	<b>132</b>
<b>6.4 Participants .....</b>	<b>132</b>
<b>6.5 Setting.....</b>	<b>133</b>
<b>6.6 Topic guide and interview Process.....</b>	<b>133</b>
<b>6.7 Pilot Interview.....</b>	<b>135</b>
<b>6.8 Data management .....</b>	<b>135</b>
<b>6.9 Analysis.....</b>	<b>136</b>
6.9.1 Stage 1- The Familiarisation Phase .....	138
6.9.2 Stage 2- Identifying a thematic conceptual framework.....	140
6.9.3 Stage 3- Labelling.....	142
6.9.4 Stage 4- Charting Phase.....	143
6.9.5 Stage 5- Mapping and Interpretation Phase .....	144
<b>6.10 Enhancing Rigor in Qualitative Research .....</b>	<b>145</b>
<b>6.11 Conclusion.....</b>	<b>147</b>
<b>Chapter 7 .....</b>	<b>148</b>
<b>Study 2: Interview Findings.....</b>	<b>148</b>
<b>7.0 Introduction.....</b>	<b>148</b>
<b>7.1 Demographic profile of study participants.....</b>	<b>148</b>
<b>7.2 A type of movement.....</b>	<b>150</b>

<b>7.3 The impact of exercise and physical activity.....</b>	<b>156</b>
<b>7.4 "It Changes" .....</b>	<b>166</b>
<b>7.5 Sense of Loss .....</b>	<b>173</b>
<b>7.6 Coping with MS.....</b>	<b>178</b>
<b>7.7 Discussion .....</b>	<b>186</b>
7.7.1 Ascribing meaning to exercise and physical activity: the perspective of pwMS .....	186
7.7.2. A multidimensional view of exercise and physical activity.....	191
7.7.3 Exercise and physical activity: a way of coping with MS.....	194
7.7.4 The complexity of exercise and physical activity: the experiential perspective .....	196
<b>7.8 Strengths and Limitations of the Study .....</b>	<b>198</b>
<b>7.9 Conclusion .....</b>	<b>199</b>
<b>Chapter 8 .....</b>	<b>200</b>
<b>Study 3 Methods: A qualitative exploration of physiotherapists' perceptions about exercise and physical activity .....</b>	<b>200</b>
<b>8.0 Introduction .....</b>	<b>200</b>
<b>8.1 Purpose and study aims.....</b>	<b>200</b>
<b>8.2 Focus groups .....</b>	<b>201</b>
8.2.1 Advantages and Disadvantages of using focus groups.....	202
<b>8.3 Study Design.....</b>	<b>203</b>
<b>8.4 Ethical Considerations .....</b>	<b>204</b>
<b>8.5 Sample .....</b>	<b>204</b>
<b>8.6 Recruitment Strategies .....</b>	<b>204</b>
<b>8.7 Participants.....</b>	<b>206</b>
<b>8.8 Development of the topic guide .....</b>	<b>206</b>
<b>8.9 Conducting the three focus groups .....</b>	<b>207</b>
<b>8.10 Data Collection and Analysis .....</b>	<b>208</b>
<b>8.11 Enhancing rigor in focus groups .....</b>	<b>210</b>
8.12 Conclusion.....	211
<b>Chapter 9 .....</b>	<b>212</b>
<b>Study 3: Focus Group Findings .....</b>	<b>212</b>
<b>9.0 Introduction .....</b>	<b>212</b>
<b>9.1 Blurred terminologies.....</b>	<b>214</b>
<b>9.2 Influencing factors for the meaning of exercise and physical activity.....</b>	<b>219</b>
<b>9.3 When professional expertise meets experiential expertise.....</b>	<b>224</b>
<b>9.4 The Resolve .....</b>	<b>233</b>
<b>9.5 Discussion.....</b>	<b>238</b>
<b>9.6 Strengths and Limitations.....</b>	<b>246</b>
<b>9.7 Conclusion .....</b>	<b>248</b>
<b>Chapter 10 .....</b>	<b>249</b>
<b>Main Discussion .....</b>	<b>249</b>
<b>10.0 Introduction .....</b>	<b>249</b>
<b>10.1 The meaning of exercise and physical activity: a matter of perspectives .....</b>	<b>249</b>
10.1.1 Shared Perspective .....	251
<b>10.2 Significance of the findings .....</b>	<b>255</b>
10.2.1 Clinical implications of the findings .....	263
<b>10.3 Strengths and limitations .....</b>	<b>270</b>
<b>10.4 Conclusion.....</b>	<b>271</b>

<b>Chapter 11 .....</b>	<b>272</b>
<b>Conclusions and Recommendations.....</b>	<b>272</b>
<b>11.0 Introduction .....</b>	<b>272</b>
<b>11.1 Overview of the Research.....</b>	<b>272</b>
<b>11.2 Findings overall.....</b>	<b>273</b>
<b>11.3 Recommendations and future research.....</b>	<b>275</b>
<b>References: .....</b>	<b>279</b>

<b>List of Tables</b>		<b>Page</b>
Table 1.1	Clinical course of Multiple Sclerosis	18
Table 1.2	Kurtzke Expanded Disability Status Scale (EDSS)	22
Table 2.1	Electronic database search results	36
Table 4.1	Types of Delphi methods and their main characteristics	80
Table 4.2	Study Protocol	88
Table 5.1	Demographic profile of the respondents at the start and the end of the Delphi	103
Table 5.2	Frequency of responses of the exercise and physical activity practices of pwMS grouped into 18 categories	107
Table 5.3	Frequency of responses of the reasons why pwMS engage in exercise and physical activity grouped into 15 categories	108
Table 5.4	Selecting categories for exercise and physical activity in Round 2	110
Table 5.5	Selecting the reasons why pwMS engaged in exercise and physical activity	112
Table 5.6	Ranking for the exercise and physical activity practices	113
Table 5.7	Ranking for the reasons why pwMS engage in exercise and physical activity	115
Table 5.8	The prioritised exercise and physical activity practices of pwMS	117
Table 5.9	The prioritised reasons why pwMS engage in exercise and physical activity	118
Table 6.1	Worked example of charting phase	143
Table 6.2	Worked example of mapping and interpretation phase	145
Table 7.1	Demographic profile of sixteen interview participants with multiple sclerosis	149
Table 7.2	Major themes and sub-themes of the meaning of exercise and physical activity	150
Table 9.1	Demographic profile of study 3 participants	212
Table 9.2	Major themes and subthemes for physiotherapists' perceptions of exercise and physical activity	213

<b>List of Figures</b>		<b>Page</b>
Figure 1.1	International Classification of function disability and health (ICF)	28
Figure 1.2	Plan and design of the programme of research	32
Figure 2.1	Flow chart of literature search process	38
Figure 4.1	Flow chart showing Rounds of Delphi process	95
Figure 6.1	Participant using cue cards during interview	134
Figure 6.2	The Analytical hierarchy	137
Figure 6.3	Stages in framework analysis	139
Figure 6.4	Conceptual Framework Study 2 (Final)	140
Figure 6.5	Worked example of interview transcript and labelling	142
Figure 10.1	The meaning of exercise and physical activity from the perspective of pwMS and physiotherapists	250
Figure 10.2	Representation of the experiential (pwMS) perspectives in relation to the ICF	257
Figure 10.3	Representation of the professional (physiotherapists) perspective in relation to the ICF	258
Figure 10.4	Representation of the experiential and professional perspective in relation to the ICF	259
Figure 10.5	Reorientation of the ICF based on the experiential and professionals perspective of exercise and physical activity	262

<b>List of Appendices</b>		<b>Page</b>
Appendix 1	The 2010 McDonald Criteria for diagnosis of MS	321
Appendix 2a	Example of search terms and studies identified from Academic Search Complete	323
Appendix 2b	Key studies related to the thesis	324
Appendix 3a	Ethics approval Study 1	339
Appendix 3b	Approval of Amendment to study protocol	340
Appendix 4	Recruitment letter Study 1	341
Appendix 5	Questions for pilot study Performa	343
Appendix 6a	Cover letter Round 1	344
6b	Participant Information Sheet Study 1	345
6c	Research Booklet Round 1	350
6d	Reminder letter Round 1	369
Appendix 7	Development of categories for exercise and physical activity in pwMS	370
Appendix 8a	Development of categories for the reasons why pwMS engage in exercise and physical activity Round 1	373
8b	Extract from responses for the reasons why and list of MS symptoms	376
Appendix 9a	Cover letter Round 2	378
9b	Round 2 Research booklet	379
Appendix 10a	Cover letter Round 3	384
10b	Round 3 Research booklet	385
Appendix 11a	Cover letter Round 4	389
11b	Round 4 Research booklet	390
Appendix 12a	The frequency of MS symptoms reported by study participants	394
12b	MS symptoms in grouped categories	395

Appendix 13	Example of adjusting for ties	397
Appendix 14	Ethics approval Study 2	398
Appendix 15a	Cover letter Study 2	399
15b	Participant Information Sheet Study 2	400
15c	Consent Form Study 2	405
15d	Risk Assessment Study 2	406
15e	Topic Guide Study 2	408
15f	Cue cards	411
15g	Reflexivity Study 2	415
15h	Developing a conceptual framework Study 2 (Draft)	419
15i	Example of an interview extract and labelling stage Study 2	424
15j	Example of charting stage	427
15k	Examples of Mapping and interpretation stage	430
15l	Development of themes in the analytic process- Study 2	436
Appendix 16a	Ethics approval Brunel University Study 3	437
16b	Research and development approval-NHS	438
Appendix 17a	Consent Form	439
17b	Participant Information Sheet	440
17c	Topic guide Study 3	445
17d	Developing a conceptual framework Study 3	449
17e	Examples of focus groups extract showing labelling stage- Study 3	451
17f	Example of charting stage- Study 3	456
17g	Examples of mapping and interpretation stage- Study 3	459
17h	Development of themes Study 3	465
17i	Reflexivity Study 3	466

# **Chapter 1**

## **Introduction**

### **1.0 Introduction**

Multiple Sclerosis (MS) is a chronic disabling neurological condition of the central nervous system for which there is no cure (Compston and Coles, 2008). A damaged central nervous system presents with a wide range of symptoms, which may affect the motor, sensory and autonomic systems in individuals affected by the disease (Compston and Coles, 2008). Rehabilitation interventions such as exercise and physical activity have been shown to be beneficial in the management of symptoms and associated disability in people affected by MS (National Institute for Clinical Excellence (NICE), 2014, Khan *et al.*, 2011; Rietberg *et al.*, 2004).

The benefits of exercise and physical activity for people with MS (pwMS) have been reported widely and include improvements in mobility, strength, quality of life, cardiovascular fitness and endurance (Latimer-Cheung *et al.*, 2013; Snook and Motl, 2009; Motl *et al.*, 2008b; Rietberg *et al.*, 2004; Petajan *et al.*, 1996). However, despite the known benefits associated with exercise and physical activity, pwMS are considered to be inactive (Sandroff *et al.*, 2012; Motl, McAuley and Snook, 2005), which might place them at a higher risk of developing the secondary health complications associated with inactivity (Motl and Goldman, 2011) in particular stroke, type 2 diabetes and cardiovascular disease (Lee *et al.*, 2012; Motl, McAuley and Snook, 2005; Stuifbergen and Roberts, 1997).

Inactivity is not specific to pwMS; it is also a reflection of the general population worldwide (Lee *et al.*, 2012). In the United Kingdom, the Government has instigated a range of initiatives to address the issues of inactivity including the 'Exercise Referral Scheme', 'Start Active' and 'Stay Active' (Department of Health (DOH), 2001; DOH, 2011). However these initiatives target the healthy population and lack clear evidence about the effectiveness of exercise and physical activity for people with chronic disabling conditions.

A number of different approaches suggested to promote exercise and physical activity in pwMS include the “Blue Prescription” (a physiotherapy approach designed to enhance adherence with physical activity in pwMS) (Mulligan *et al.*, 2013; Smith *et al.*, 2013a; Hale *et al.*, 2012), behavioural approaches (Plow *et al.*, 2009; McAuley *et al.*, 2007) and self-management programmes (Barlow *et al.*, 2009b). All of the above studies reported limited effect on increasing physical activity in pwMS. Similarly, other studies have explored the barriers and facilitators of exercise and physical activity in pwMS (Asano *et al.*, 2013; Kayes *et al.*, 2011a) but there is still a lack of in-depth understanding about how these translate into increased physical activity.

Physical activity has been defined as “any bodily movement produced by skeletal muscles that results in energy expenditure” (Caspersen, Powell and Christenson, 1985 p.126) and would include domestic, occupational and sports related activities. Exercise on the other hand is defined as “a subset of physical activity that is planned, structured and repetitive” (Caspersen, Powell and Christenson, 1985, p. 126) and aims to either improve or maintain physical fitness. Every health professional has a role in promoting exercise and physical activity.

Physiotherapists are essential and play a crucial role in establishing ways this might be facilitated or encouraged (World Confederation for Physical Therapy (WCPT), 2014; Chartered Society of Physiotherapy (CSP), 2011). However, there is limited understanding and guidance for physiotherapists in the management of MS in relation to exercise and physical activity in the community. The recent MS guidance from the National Institute for Health and Care Excellence (NICE, 2014) supports and recommends exercise in the management of MS. However, its focus on exercise, which is only one form of activity, is narrow. There is therefore a need to reconsider physical activity, which is much broader in scope and incorporates exercise, as also important in managing symptoms of MS in the community.

Bearing these definitions in mind, it appears that research to date has focused more specifically on formalised, structured exercise programmes, and has rarely considered the potential utility of other physical activities which are unplanned and which could be both motivating and easy to integrate into everyday life for pwMS. In addition, due to the complex, progressive and variable nature of MS a

more comprehensive view is needed to understand exercise and physical activity from the ‘first hand’ perspective of people who experience MS and live with its multiple impacts across the life course. Gaining an understanding from the perspectives of pwMS living in the community might help shape the design of interventions programmes geared towards decreasing inactivity in this population.

## **1.1 Purpose of the study:**

The purpose of this research is to gain an in-depth understanding of the priorities and meanings of exercise and physical activity from the perspectives of pwMS. Community dwelling pwMS were chosen because the focus of the study was around exercise and physical activity in their daily lives. A secondary purpose was to obtain the views of physiotherapists whose role is to encourage exercise and physical activity in this population and ultimately compare these different perspectives to provide insights which have the capacity to inform clinical practice.

## **1.2 My interest in this research**

This section relates to my interest in the research and will be written in the language of the first person. As a physiotherapist, I acknowledge that I have a keen interest in the management of long-term conditions, especially in the area of MS. My interest in MS has been shaped by some clinical challenges as well as opportunities whilst working with people affected by MS over the years. This interest led to previous engagement in research (MSc neuro-rehabilitation) which involved examining the age and gender differences in pwMS.

Following this period, I returned to clinical practice working mainly in different community based settings where I developed an interest in exercise and physical activity based on the interactions with pwMS. Having worked within a particular community based rehabilitation team for approximately six (6) years I realised a recurring pattern with certain pwMS because of their numerous attendance at the MS clinics or re-admission for community based rehabilitation programs. I realised

over the years a general lack of adherence with exercise programs following discharge from physiotherapy. Other healthcare professionals also observed this trend. This was particularly frustrating for physiotherapists and equally frustrating for pwMS as they too felt guilty that they were not doing the prescribed exercises.

In my quest to delve deeper into understanding exercise and physical activity in pwMS I embarked on this PhD journey. As part of this journey I had to switch my 'clinical hat' for the 'hat of a researcher'. A task that proved challenging at times, especially during the early stages of the research.

### **1.3 Background to Multiple Sclerosis**

Multiple Sclerosis (MS) is defined as a demyelinating condition of the central nervous system (CNS) (Steadman, 2012; Compston and Coles, 2008). It is thought that MS is characterised by an inflammatory process, which leads to gradual deterioration of the myelin sheath (demyelination) surrounding the axons in the CNS thereby ultimately leading to loss of axons (Compston and Coles, 2008). This process may occur over a period of time and is evidenced by the presence of sclerotic plaques or scars along the myelin sheath thus causing disruption to the conductivity of electrical impulses along the fibres used to convey messages between the brain and spinal cord (Steadman, 2012; Compston and Coles, 2008). This disruption resulting from the inflammatory process and axonal degeneration is responsible for the widespread clinical features seen in individuals affected with the disease (Compston and Coles, 2008).

#### **1.3.1 Prevalence of Multiple Sclerosis**

Multiple Sclerosis is not a rare disease. It is estimated that there are approximately 2.5 million people living with the disease worldwide (Flachenecker and Stuke, 2008). A population based study using general practice databases revealed that there are approximately 126,669 (203.4/100,000 population) pwMS living in the UK (Mackenzie *et al.*, 2014).

The cause of MS is unknown, however it is thought that both environmental factors and a genetic predisposition might be implicated (Melcon, Correale and Melcon, 2014; Koch-Henriksen and Sørensen, 2010; Compston and Coles, 2008).

Environmentally, MS is more prevalent in northern Europeans who live in a more temperate climate compared with people living within the tropics (Melcon, Correale and Melcon, 2014; Compston and Coles, 2008). Also, there is an increase familial risk of occurrence of up to 20% in pwMS with the observed age adjusted higher risk in first degree relatives (siblings, 5%, parents 2%, children 2%) compared to second and third degree relatives (Compston and Coles, 2008).

The general pattern of MS within the population is one of gender and age bias. That is, it affects women more than men with a ratio of 2:1(Koch-Henriksen and Sørensen, 2010; Compston and Coles, 2002). Additionally, people are usually affected between 15-75 years, with young adults being most frequently affected between 20 -40 years (Compston *et al.*, 1998). A five-year difference in the peak incidence rate of MS is observed between men (45 years) and women (40 years)(Mackenzie *et al.*, 2014). Furthermore, men tend to be diagnosed later in years and are thought to have a more aggressive pattern of the disease (Koch-Henriksen and Sørensen, 2010; Compston and Coles, 2002).

While it has been reported that the average life span of pwMS is similar to the general population (Perry, 1994), a recent study suggested that pwMS might have a reduced life span of approximately 5-10 years (Hurwitz, 2011). With the disease being diagnosed in the prime of the individuals' life the physical, social and economic implications are great (McCrone *et al.*, 2008; Patwardhan *et al.*, 2005).

### **1.3.2 Clinical Course of Multiple Sclerosis**

The clinical course of MS fits largely into four categories namely, benign, relapsing remitting, secondary progressive and primary progressive (Compston *et al.*, 1998). Table 1.1 details the clinical course and definitions of the different types of MS.

**Table 1.1: Clinical course of Multiple Sclerosis**

Clinical course	Definition
Benign MS	One or two relapses, separated by some considerable time, allowing full recovery and not resulting in any disability
Relapsing remitting MS	Characterized by a course of recurrent discrete relapses, interspersed by period of remission when recovery is either complete or partial
Secondary progressive MS	Having begun with relapses and remissions, the disease enters a phase of progressive deterioration with or without identifiable relapses, where disability increases even when no relapse is apparent
Primary progressive MS	Typified by progressive and cumulative neurological deficit without remission or evident exacerbation

Adapted: De Souza and Bates, 2012,p.92

Relapsing remitting is the most common type of MS. Approximately 80% of people living with MS are diagnosed initially with relapsing remitting MS (Compston and Coles, 2008). This type of MS is characterised by periods of relapses and remissions where neurological decline experienced during a relapse might completely or partially resolve. Over time, the disease might transition from relapsing remitting to enter a secondary progressive phase. However some pwMS continue to experience relapses and remissions and never enter a secondary progressive phase (Compston and Coles, 2008).

Secondary progressive MS is characterised by fewer periods of remissions. People with this type of MS experience a gradual deterioration resulting in disability over time. The least common form of the disease is the more aggressive type known as primary progressive MS, with approximately 10% of pwMS diagnosed with this form of the disease. Symptoms tend to develop from onset and gradually worsen over time without remission (Compston and Coles, 2008). People with the benign type of MS experience little or no symptoms associated with the disease. A rare type of MS not represented in Table 1.1 known as the progressive-relapsing MS has also been reported. It affects approximately 5% of pwMS and is characterised by a steady decline in disability with superimposed relapses (Lublin and Reingold, 1996).

### **1.3.3 Diagnosis of Multiple Sclerosis**

Due to the variability of the symptoms and the clinical presentations, which differ from individual to individual establishing the diagnosis of MS is challenging. This has led to the use of different diagnostic criteria over the years as no one test identifies the disease with absolute certainty (McDonald *et al.*, 2001; Compston *et al.*, 1998; Poser *et al.*, 1983). The current method used for diagnosis is the McDonald criteria (see Appendix 1), which was recently updated in 2010 and recommended for use as a simple and standardise guide in research and clinical practice (Polman *et al.*, 2011). These updated criteria utilise a combination of clinical examination (e.g. motor, sensory, visual and autonomic systems), clinical history and the use of laboratory investigations (magnetic resonance imaging, cerebrospinal fluids, visual evoked potentials) to support or confirm diagnosis of MS. Diagnosis therefore is based on the existence of two or more clinical attacks in time and objective evidence in two or more regions of the CNS with no other explanation. In some cases where the evidence remains inconclusive, diagnosis is made by the exclusion of other conditions that are similar in presentation to MS (Polman *et al.*, 2011). Researchers and clinicians have been advised against making the diagnosis of MS by laboratory investigations alone (NICE, 2014).

### **1.3.4 Clinical features and symptoms**

The clinical features and symptoms of MS are diverse and are mostly responsible for the disability experienced by pwMS. They vary from individual to individual and within the same person due to the involvement of the cerebrum, optic nerve, cerebellum, brainstem and spinal cord (Compston and Coles, 2008). The three most commonly reported symptoms affecting over 80% of pwMS are weakness, sensory symptoms, and ataxia (Matthews, 1998). The impact of weakness, just one of these reported symptoms, reaches beyond physical impairments and is commonly associated with the inability to engage in exercise and physical activity (White and Dressendorfer, 2004). Several reports suggest that weakness could lead to difficulties with transfers, mobility and stair climbing which could have an

impact on pwMS' lifestyle and employment (Einarsson *et al.*, 2006; Freeman, 2001; Noseworthy *et al.*, 2000; Ng and Kent-Braun, 1997; Stuifbergen, 1997; Rodriguez *et al.*, 1994).

Comparatively, other symptoms albeit less reported can also have a significant impact on pwMS. Examples of these include, pain (65%) (Ben-Zacharia, 2011), fatigue (57%) (Matthews, 1998), and depression (>50%) (Patten *et al.*, 2003). From this list fatigue has been reported to be the most disabling symptom experienced by pwMS (Lerdal *et al.*, 2007; Krupp, 2003). However, collectively these symptoms have been associated with barriers in engaging in exercise and physical activity within the home and community (Asano *et al.*, 2013; Kayes *et al.*, 2011b).

Although many of the initial symptoms may resolve, repeated attacks to the central nervous system often result in a gradual decline in physical functioning, thereby affecting ability to engage in daily life activities as well as exercise and physical activity (Compston and Coles, 2008; Finlayson, Van Denend and Hudson, 2004). This variation of clinical features and symptoms highlights some of the complexities in managing the disease and the importance of understanding how MS impacts the individual.

### **1.3.5 Prognosis and Disability**

Although MS is a progressive condition, individuals may live a full life with the disease (Hurwitz, 2011). This has been attributed to improvement in rehabilitation as well as effectively treating complications associated with the disease in a timely manner (Brønnum-Hansen, Koch-Henriksen and Stenager, 2004). Death as a result of MS is possible and there is an increased risk in the presence of other conditions such as cardiovascular disease (Brønnum-Hansen, Koch-Henriksen and Stenager, 2004), which may occur as a consequence of inactivity in pwMS (Motl *et al.*, 2011a). Nevertheless, the majority of pwMS experience disease progression, which might be dependent on their gender, age, the type of symptoms (motor or sensory) present at onset (Motl *et al.*, 2012a;

Richards *et al.*, 2002; Compton *et al.*, 1998), and or underlying co-morbidity (Marrie and Horwitz, 2010).

Prognostic factors are also associated with disability. For example, the presence of cardiovascular disease has been correlated with disability progression in pwMS (Marrie and Horwitz, 2010). Disability may be measured using a range of scales, for example, the Guys Neurological Disability Scale (Sharrack and Hughes, 1999) and the Expanded Disability Status Scale (EDSS) (Kurtzke, 1983). Table 1.2 details the EDSS along with descriptors for each score. The EDSS is more widely used and scoring on this scale is based on the neurological assessment in 8 Functional systems (FS), namely, pyramidal, cerebellar, brainstem, sensory, bowel and bladder, visual, mental and other functions (Kurtzke, 1983). This scale has a range from 0 (no neurological impairment) to 10 (death due to MS). The EDSS is often used to measure the levels of severity of the disease. For example, an EDSS score of 3 suggests minimal disability, a score of 6 represents moderate disability where a mobility aid is required and severe disability is reserved for scores of 7 and above where people are mainly wheelchair users or bed bound.

**Table 1.2: Kurtzke Expanded Disability Status Scale (EDSS)**

0	Normal neurological exam (all grade 0 in all Functional System (FS) scores*)
1.0	No disability, minimal signs in one FS* (e.g. grade 1)
1.5	No disability, minimal signs in more than one FS* (more than 1 FS grade 1)
2.0	Minimal disability in one FS (one FS grade 2, others 0 or 1)
2.5	Minimal disability in two FS (one FS grade 2, others 0 or 1)
3.0	Moderate disability in one FS (one FS grade 3, others 0 or 1) or mild disability in three or four FS (three or four FS grade 2, others 0 or 1), though fully ambulatory
3.5	Fully ambulatory but with moderate disability in one FS (one grade 3) and one or two FS grade 2; or two FS grade 3 (others 0 or 1) or five grade 2 (others 0 or 1).
4.0	Fully ambulatory without aid, self-sufficient, up and about some 12 h/day despite relatively severe disability consisting of one FG grade 4 (others 0 or 1), or combination of lesser grades exceeding limits of previous steps; able to walk without aid or rest for about 500m
4.5	Fully ambulatory without aid; up and about much of the day; able to work a full day, may otherwise have some limitation of full activity or require minimal assistance; characterized by relatively severe disability usually consisting of one FS grade 4 (others 0 or 1) or combination of lesser grades exceeding limits of previous steps; able to walk without aid or rest for about 300m
5.0	Ambulatory without aid or rest for about 200m; disability severe enough to impair full daily activities (e.g. to work a full day without special provisions); (Usual FS equivalents are one grade 5 alone, others 0 or 1; or combinations of lesser grades usually exceeding specifications for step 4.0.
5.5	Ambulatory without aid or rest for about 100m; disability severe enough to preclude full daily activities; (Usual FS equivalents are one grade 5 alone, others 0 or 1; or combination of lesser grades usually exceeding those for step 4.0
6.0	Intermittent or unilateral constant assistance (cane, crutch, brace) required to walk about 100m with or without resting; (Usual FS equivalents are combinations with more than two FS grade 3+)
6.5	Constant bilateral assistance (canes, crutches, braces) required to walk about 20m without resting; (Usual FS equivalents are combinations with more than two FS grade 3+)
7.0	Unable to walk beyond approximately 5m even with aid; essentially restricted to wheelchair; wheels self in standard wheelchair and transfers alone; up and about in wheelchair some 12 h/day; (Usual FS equivalents are combinations with more than one FS grade 4+; very rarely pyramidal grade 5 alone.
7.5	Unable to take more than a few steps; restricted to wheelchair; may need aid in transfer; wheels self but cannot carry on in standard wheelchair a full day; may require motorized wheelchair;(Usual FS equivalents are combinations with more than one FS grade 4+).
8.0	Essentially restricted to bed or chair or perambulated in wheelchair, but may be out of bed itself most of the day; retains many self-care functions; generally has effective use of arms;(Usual FS equivalents are combinations, generally 4+ in several systems).
8.5	Essentially restricted to bed much of day; has some effective use of arms and retains some self-care functions; (Usual FS equivalents are combinations, generally 4+ in several systems).
9.0	Helpless bed patient; can communicate and eat; (Usual equivalents are combinations , mostly 4+ in several systems )
9.5	Totally helpless bed patient; unable to communicate effectively/or eat/swallow; (Usual FS equivalents are combinations, almost all grade 4+).
10	Death due to MS

Adapted: Kurtzke, 1983; Haber (1985); Abbreviation: FS: functional system Note 1: EDSS steps 1.0 to 4.5 refer to patients who are fully ambulatory and the precise step number is defined by the FS score(s). EDSS 5.0 to 9.5 are defined by the impairment to ambulation and usual equivalents in FS scores are provided. Note 2: EDSS should not change by 1.0 step unless there is a change in the same direction of at least one step in at least one FS.

Mobility remains one of the key factors used as a measure of disease severity in pwMS. It is thought that approximately 50% of individuals with MS will remain ambulant but moderately disabled after 15 years (Compston *et al.*, 1998). In fact, Confavreux and colleagues' (2000) study involving 1844 pwMS revealed that from the time of onset of the disease, people with the relapsing remitting form of MS (N=1562) took approximately 11.4 years, 23.1 years and 33.1 years to progress to EDSS scores of 4, 6, and 7 respectively. This was much longer compared to people with the progressive forms of the disease (N=282), where they took 0 years, 7.1 years and 13.4 years to deteriorate to EDSS scores of 4, 6, and 7 respectively. This highlights the differences in progression between both forms of the disease (Confavreux *et al.*, 2000).

The EDSS is widely used in both research and clinical practice to measure disease severity (Patti *et al.*, 2003; Solari *et al.*, 1999; Petajan *et al.*, 1996). An example of this is seen in therapy intervention studies where the scale is used to offer comparison between treatment groups as well as denote changes or effectiveness of treatment strategies (DeBolt and McCubbin, 2004, Petajan *et al.*, 1996; van Den Berg *et al.*, 2006, Freeman *et al.*, 2010).

Despite the widespread use of the EDSS in clinical practice and research, it remains widely criticised (Rabadi and Vincent, 2013; Rossier and Wade, 2002; Willoughby and Paty, 1988). Some criticisms of the scale include a lack of reliability due to inconsistencies with reporting ambulatory distance as well as the inclusion of subjective information both of which are necessary to decide the level of disability on the scale (Rossier and Wade, 2002; Willoughby and Patty, 1988). Other researchers argue that the scale neither reflects wider aspects of disability such as work, leisure and activities of daily living nor the changes in cognitive or visual systems (Rrossier and Wade, 2002; Cohen, Kessler and Fischer, 1993). However, the EDSS was originally developed as a neurological tool to assess the consequences of the neurological impairment of MS and was not intended to measure these broader aspects of life in pwMS (Kurtzke, 1983).

### **1.3.6 Management of Multiple Sclerosis**

Management of the condition is challenging due to the various uncertainties relating to the cause of MS, establishing a diagnosis, and the diverse symptoms. Despite this, significant advancements have been made in the management of the disease. The main stay of treatment involves the use of drug therapy and rehabilitation (NICE, 2014; Ben-Zacharia, 2011; Compston and Coles, 2008; Polman *et al.*, 2006; Freeman *et al.*, 1997).

Drugs may be used to treat the acute exacerbation of symptoms associated with the disease, for example, the use of corticosteroids (NICE, 2014). Additionally, disease-modifying drugs may be used to prevent or reduce the number of relapses and prevent disease progression (NICE, 2014; Polman *et al.*, 2006). The role of these drugs is to act at the level of the immune system with a view to reduce the de-myelinating nature of the disease (Compston and Coles, 2008; Polman *et al.*, 2006). Although disease-modifying drugs are widely used their effects in reducing disability remain inconclusive (Compston and Coles, 2008). In addition, drug therapy is widely used in symptom management, for example, in the management of spasticity and bladder dysfunction (De Souza and Bates, 2012). The majority of pwMS are likely to be taking some form of medication (NICE, 2014).

### **1.3.7 Rehabilitation and Multiple Sclerosis**

Rehabilitation is defined as "*an active process of education and enablement, which focused on the appropriate management of disability and minimising limitation of handicap, with the goal of achieving full recovery*" (Kesselring and Beer, 2005, p. 643). In managing pwMS the aim of rehabilitation is to reduce the impact of the disease and to improve independence and participation in wider society (Gaber *et al.*, 2012; Khan *et al.*, 2011; Freeman *et al.*, 1997; NICE, 2003; Kesselring and Beer, 2005). There is no established guidance for rehabilitation in pwMS relating to frequency, duration and intensity of rehabilitation (Khan *et al.*, 2011). However, general principles include regular assessments, use of goal setting/planning which guides interventions that reflect the nature of the disease and the needs of the individual at different stages of the disease (NICE, 2014; Beer, Khan and

Kesselring, 2012; De Souza, 1990). These may include improving general health, symptom management (physical, psychological, cognitive), provision of equipment to enhance function, vocational rehabilitation and education (Beer, Khan and Kesselring, 2012; Khan *et al.*, 2011; Schapiro, 2002; O'Hara, De Souza and Ide, 2000; Petajan *et al.*, 1996; De Souza, 1990).

Due to the complex nature of the disease a multidisciplinary team approach is recommended (Khan *et al.*, 2011) which draws on the experience of a range of health care professionals (NICE, 2014; Khan *et al.*, 2011; De Souza, 1990). These include physiotherapists, occupational therapists, social workers, doctors, psychologists and dieticians all of whom may be necessary to provide a coordinated and holistic approach to managing the disease (Khan *et al.*, 2011; NICE, 2003; Freeman *et al.*, 1997; De Souza, 1990). This approach to management is one of the key recommendations of guidelines and framework surrounding the care of people with MS (NICE, 2014; European Multiple Sclerosis Platform (EMSP), 2012; DOH, 2005).

Current understandings about the impact of multidisciplinary rehabilitation have been highlighted in the literature. There is more awareness that early intervention is important for people newly diagnosed with the disease (NICE, 2014). Decisions around timing of treatment and where rehabilitation occurs are dependent on the stage of the disease, level of function and also the goals of the individual (Khan *et al.*, 2011; Stuifbergen *et al.*, 2006). Rehabilitation interventions may vary depending on the needs of the individual (NICE, 2003). Nonetheless, the strength of the evidence to support multidisciplinary rehabilitation varies between settings (Khan *et al.*, 2011). A Cochrane review (Khan *et al.*, 2011) revealed strong evidence that multidisciplinary rehabilitation conducted in inpatient and outpatient settings improves disability and participation in the wider society in pwMS but does not necessarily lead to a change in symptoms. The same review showed that there was limited evidence for short-term improvement in symptoms, disability, participation and quality of life with high intensity outpatient and home base rehabilitation programs. Nevertheless, despite the limited evidence in the home based setting, the review provided strong evidence that lower intensity

multidisciplinary rehabilitation delivered over a longer period of time was more tolerated in pwMS.

Despite these advances in knowledge, there is scope for improvement in the existing evidence in relation to multidisciplinary rehabilitation. Khan and colleagues highlighted the scant evidence available for community based rehabilitation programs (Khan *et al.*, 2011). In addition, researchers have expressed concerns that the majority of existing studies based on multidisciplinary rehabilitation programs focus on physical impairments and function (Beer, Khan and Kesselring, 2012). Consideration should also be made as part of the rehabilitation program to include the use of leisure and social participation and are recommended for pwMS to either regain participation in previously enjoyed leisure actives or discover new activities (National Collaborating Centre for Chronic Conditions, 2004; NICE, 2014). These aspects are not often assessed in rehabilitation but should be considered as part of the holistic management especially of individuals living with a progressive condition. Assessing the ability of pwMS to engage in such activities falls within the remit of physiotherapy practice.

### **1.3.8 Physiotherapy Management of Multiple Sclerosis**

Physiotherapists play a critical role as part of the MDT (Patti *et al.*, 2003; Freeman *et al.*, 1997). This role is enhanced through collaboration with the person with MS to promote the physical and psychosocial wellbeing of the individual with MS (CSP, 2012). A cross sectional survey conducted with pwMS in the community revealed that physiotherapy was the third most contacted healthcare profession (Somerset *et al.*, 2001). In another UK based survey the number of respondents who utilised physiotherapy services based on the severity of their disability classified as mild, moderate and severe was 21%, 34% and 44% respectively (Vazirinejad, Lilley and Ward, 2008).

Exercise and physical activity remain one of the main strategies used by physiotherapists to manage the symptoms of MS. Positive effects reported include improved mobility, functional abilities and quality of life (Petajan and White, 1999; Solari *et al.*, 1999; Dalgas *et al.*, 2009; van der Linden *et al.*, 2014; Learmonth *et al.*,

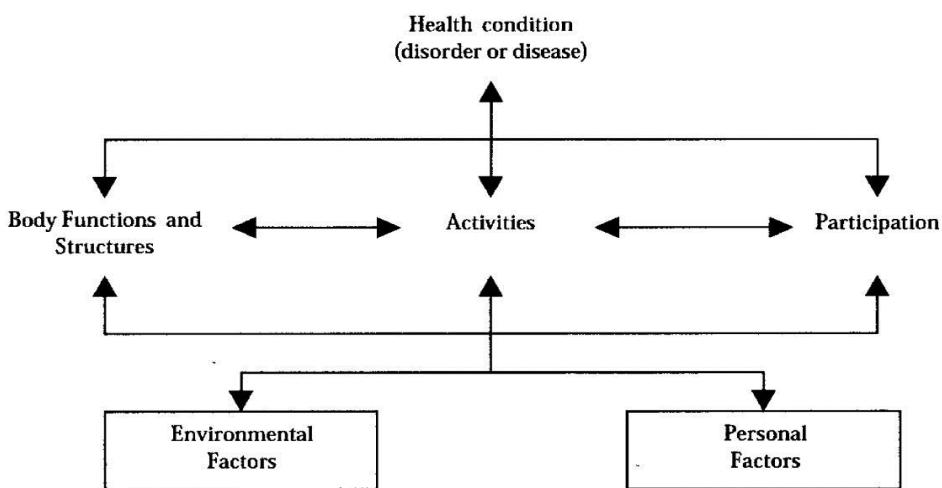
2013; McAuley *et al.*, 2007; Freeman and Allison, 2004; Lord, Wade and Halligan, 1998). However there is no standardised agreement for the recommended dose for exercise and physical activity in pwMS. For example, Dalgas *et al.*, 2009 recommend 10 to 40 minutes of moderate intensity aerobic activity (2-3 days per week) and moderate intensity (1-4 sets of 8-15 repetition) resistance training (2-3) days per week. The American College of Sports Medicine (ACSM) recommends 30mins of moderate intensity aerobic activity (3 days per week) (ACSM, 2010). Latimer-Cheung *et al.*, 2013 recommend 30 mins of moderate intensity aerobic exercise (2 days per week) and strength training for major muscle groups (2 days per week). These guidelines are aimed at pwMS who are mildly or moderately affected by the condition; and the activities used in the guidance are structured forms of exercise. To the researcher's knowledge there is no specific MS guidance that considers physical activity using a wide range of activities. Additionally, recent clinical guidance with the UK recommends the use of exercise as one strategy in the management of pwMS (NICE, 2014). These exercise practices again include, moderate progressive resistance training, aerobic, balance and stretching exercises to improve mobility and or fatigue (NICE, 2014).

While it has been argued that exercise and physical activity is beneficial for pwMS the evidence suggests that pwMS are inactive (Sandroff *et al.*, 2012; Motl, McAuley and Snook, 2005). In fact, Klaren and colleagues found that only 20% of pwMS met public health guidance for physical activity (moderate to vigorous physical activity ≥ 5 days per week or 20 minutes of vigorous activity 3 days per week) compared to 47% of the average population (Klaren *et al.*, 2013). The consequence of inactivity might result in associated secondary complications, for example, cardiovascular disease, type 2 diabetes, depression and fatigue(Motl *et al.*, 2008a; Marrie *et al.*, 2008; Brønnum-Hansen, Koch-Henriksen and Stenager, 2004). Physiotherapists play an important role in improving health and wellbeing through the promotion of exercise and physical activity in pwMS.

The role of the physiotherapist in managing MS might be influenced by the setting (in-patient, out-patient, community), the National Service Frameworks (NSF) (DOH, 2005) and the National Institute for Health and Care Excellence guidelines (NICE) (NICE, 2003). Central to all these frameworks and guidelines is the

physiotherapist using their expertise and the best available evidence to inform clinical practice (Sackett *et al.*, 1996) as well as the use of different theoretical models that underpin practice (Roberts, 1994; Nicholls and Gibson, 2010). One such model is the International Classification of Functioning, Disability and Health (ICF) (World Health Organisation, 2001).

**Figure 1.1: Showing the representation of the International Classification of Functioning, Disability and Health (World Health Organisation, 2001)**



The ICF is a global measure that is used to classify the health and health related status of an individual (see Figure 1.1) (WHO, 2001). It is made up of two key areas namely, functioning and disability and contextual factors. Functioning and disability includes three domains, the first, body functions and structures, is associated with the impact the health condition has on the physiological and psychological systems. The second domain, activity, considers the individual as a whole and is associated with execution or limitations of activities of daily living. Examples of these include, domestic and personal care activities. The third domain, participation, considers the individual within the wider spheres of life. It is associated with the engagement or restrictions in life situations, for example within the context of work or access to local clubs (WHO, 2001). The contextual

factors include, environmental and personal factors. These factors are described as being external to the individual but influence the functioning and disability domains of the ICF. Examples of environmental factors include technology, support and social attitudes. Personal Factors refers to the personal characteristics of the individual, for example, age, gender and coping mechanisms (WHO, 2001). The ICF model recognises the dynamic interactions that exist between the different domains, for example, the influence the contextual factors (environmental and personal) might have on the outcomes of an intervention (Kayes *et al.*, 2011b; Rimmer, 2006; Van Der Ploeg *et al.*, 2004).

The ICF is underpinned by the principles of the bio-psychosocial approach to understanding disability. Within this context, the ICF views disability as an interaction between the biological and social aspects of life (WHO, 2001). It is widely used to provide a common language amongst clinicians, researchers, and people with disability, including pwMS, to describe disability and contextual factors that might have an impact on their lives(Karhula *et al.*, 2013; Hamed, Tariah and Hawamdeh, 2012; Coenen *et al.*, 2011; Khan and Pallant, 2007; Rimmer, 2006).

The ICF informs physiotherapy practice which shares the alignment of the bio-psychosocial approach to understanding disability. It allows physiotherapists, whose traditions of practice had been embedded and aligned to the medical model (Nicholls and Gibson, 2010; Roberts, 1994), the tools to think holistically about the impact of the disease on the person with MS as well as the individual's role within the wider society (Khan and Pallant, 2007; Rimmer, 2006). In addition the ICF is used to underpin physiotherapy planning and interventions (Jette, 2006; Steiner *et al.*, 2002) and therefore its clinical applicability to pwMS is important to consider as part of this thesis.

### **1.3.9 Management of MS by pwMS: the lay perspectives**

Although the benefits of rehabilitation are well known and recommended (NICE, 2014), accessing services in the UK remains an issue and does not meet the needs of community dwelling pwMS (Vazirinejad, Lilley and Ward, 2008; Freeman and

Thompson, 2000). However, research suggests that pwMS, through their lived experience, have developed ways to cope and manage their symptoms (Rae-Grant *et al.*, 2011; Knaster *et al.*, 2011; Malcomson, Lowe-Strong and Dunwoody, 2008; Barlow *et al.*, 2009a; O'Hara, De Souza and Ide, 2000). That is, they have developed skills in self-management. Self- management is defined as "*the ability to manage the symptoms, treatment, physical and psychosocial consequences and life style changes inherent in living with a chronic condition*" (Barlow *et al.*, 2002,p.178).

One common method used in self-management is through formal established programmes endorsed by government led initiatives such as the chronic disease management program developed in the United States of America by Lorig and colleagues (Lorig *et al.*, 1999; Lorig, Ritter and Plant, 2005). The existing version within the United Kingdom is known as the 'Expert Patient Program' (DOH, 2001). This lay-led program was developed for people living with chronic illnesses including MS (Lorig, Ritter and Plant, 2005) and is underpinned by the self-efficacy theory (Bandura, 1977). The course is delivered over a six-week period and covers a range of topics such as, self-management principles, relaxation, pain management, and exercise. The evidence for the efficacy of the expert patient program is sparse. Barlow and colleagues (2009a) explored the views of community dwelling pwMS (N=10, Age, 35-60) using interviews and found that some participants developed additional skills in self-management such as energy conservation, fatigue and goal setting. However others felt that the program confirmed what they already knew, from their experience of living with MS.

There is a growing body of evidence that supports the view that pwMS develop methods of self-management without necessarily engaging in formal programmes (Salminen, Kanelisto and Karhula, 2014; Knaster *et al.*, 2011; O'Hara, De Souza and Ide, 2000; McLaughlin and Zeeberg, 1993). Knaster and colleagues (2011) gathered information using focus groups to highlight some of these self-management practices amongst community dwelling pwMS. They found that pwMS learnt how to manage their symptoms (e.g. pain, fatigue), adjust their life situations and develop methods of coping and taking control over their life with support from family, friends and health professionals. This study demonstrated that pwMS developed diverse ways of managing their disease through their lived

experience (Knaster *et al.*, 2011). Other studies have shown the positive effects of self- management in health promotion, including strategies for keeping active despite the variability of the condition (Malcomson, Lowe-Strong and Dunwoody, 2008; Bombardier *et al.*, 2008; Stuifbergen *et al.*, 2003) and the impact of such strategies on quality of life (O'Hara *et al.*, 2002).

Despite the formal and informal means of employing self-management strategies, this method of managing MS is attractive as it offers tools for pwMS to feel empowered and develop ways of coping and living with MS. Empowering people is endorsed by the Department of Health and various clinical guidance such as the NSF and NICE (NICE, 2014; DOH, 2005) and highlights the importance of incorporating the views and experiences of pwMS. These views have been used to shape key guidance (NICE, 2014), influential in the development of ICF core sets (Kahrula *et al.*, 2013; Coenen *et al.*, 2011; Khan and Pallant, 2007), and highlights the needs of pwMS not only in relation to the physical but also the psychosocial aspects of their lives (EMSP, 2012; Knaster *et al*, 2011; Malcomson, Lowe-Strong and Dunwoody, 2008; Barlow *et al.*, 2009a; O'Hara, De Souza and Ide, 2000).

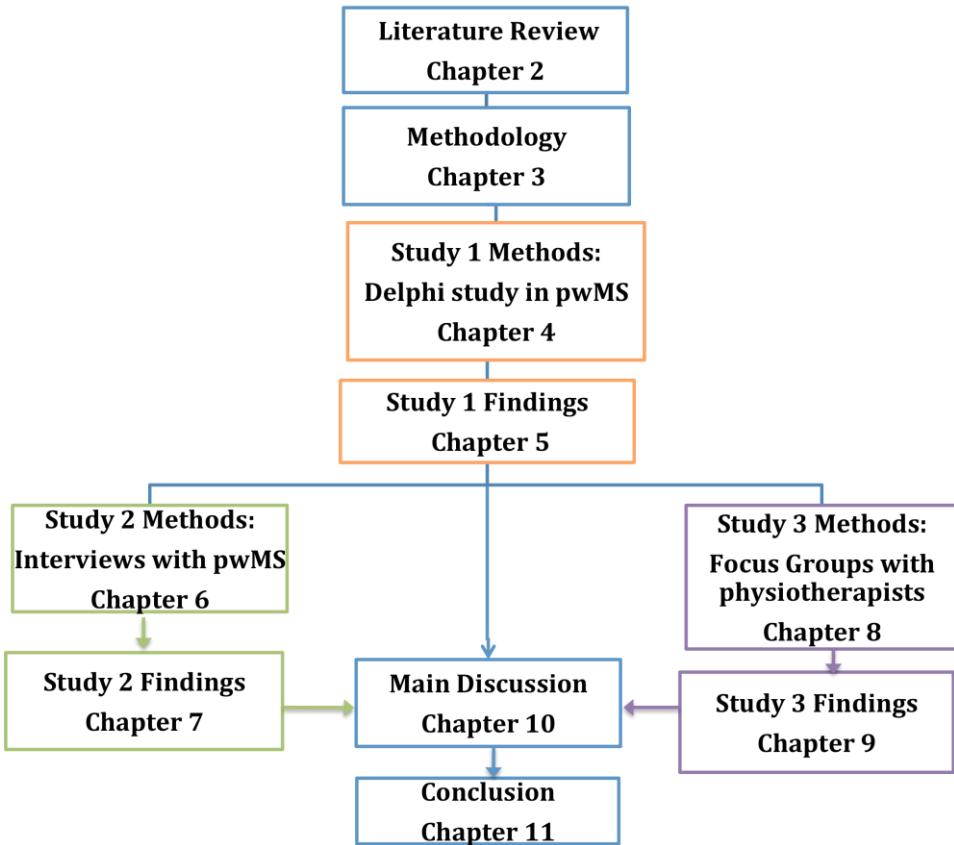
## **1.4 Outline of the Thesis**

The outline of the thesis briefly describes the chapters to follow in order to guide the reader through the different stages of the thesis. Figure 1.2 provides a visual representation of the plan and design of the programme of research.

### **Chapter 2: Literature Review**

Research focussed on the use of exercise and physical activity in managing the symptoms of MS are explored through a review of the literature. Through critical analysis of studies investigating exercise and physical activity as interventions and treatments for MS the current profile of the evidence is identified and gaps where future research would further inform practice are ascertained.

**Figure 1.2: Plan and design of the programme of research**



### **Chapter 3: Methodology**

This chapter presents the epistemological and ontological assumptions that guided the thesis. The use of pragmatism and how this philosophical stance was operationalised are discussed.

### **Chapters 4 and 5: Delphi Method and Findings**

These chapters are related to study 1 method and findings. Chapter 4 describes and justifies the use of the Delphi method as the most appropriate consensus building communication method to identify and prioritise the exercise and

physical activity practices of pwMS and the reasons why they engaged in their chosen activities. Chapter 5 presents the results of the Delphi study and discussion. The findings from the Delphi study were used to facilitate discussions around exercise and physical activity in pwMS and physiotherapists.

### **Chapters 6 and 7: Interview method and Findings**

In-depth semi-structured, face-to-face, interviews were used to explore the meanings of exercise and physical activity in pwMS. The results from the Delphi study (study 1) were used as the research tool to elicit the meanings of exercise and physical activity in pwMS living in the community. Following the description of the methods related to the semi-structured interviews (chapter 6), chapter 7 presents the findings and a brief discussion highlighting the experiential perspectives of exercise and physical activity from pwMS.

### **Chapters 8 and 9: Focus Groups method and Findings**

Focus Groups were used to explore physiotherapists' understandings about exercise and physical activity in light of the Delphi results and its relevance to clinical practice. Chapter 8 describes the use of Focus Group as the most appropriate data collection method to elicit the views and opinions of exercise and physical activity from the physiotherapists' perspective. Chapter 9 presents the findings and a brief discussion highlighting the professionals' perspective of exercise and physical activity.

### **Chapter 10: Main Discussion**

This chapter discusses the findings from all three studies in the thesis. It draws together the key findings from the different studies and highlights how each study informed the other to gain deeper insights into the meaning of exercise and physical activity in community dwelling pwMS. Clinical implications of the findings are discussed and the strengths and limitations of the overall research are explored.

## **Chapter 11: Conclusion**

Chapter 11 concludes the thesis by summarising the key findings of the research and considers how these studies make a unique contribution to knowledge in this field. In light of the key findings recommendations are made for health professionals, rehabilitation and for future research.

### **1.5 Conclusion**

This introductory chapter sought to set the scene for a variety of elements within the thesis. It has briefly outlined the chapter structure with the intention to aid the readers' journey. The next section will explore the literature on exercise and physical activity and highlight how current understandings of the management of MS have been shaped predominately through intervention studies. It also presents the growing body of evidence, albeit limited, which considers the views and opinions of exercise and physical activity from the perspective of people with MS.

# **Chapter 2**

## **Literature Review**

### **2.0 Introduction**

This chapter presents a critical review of the literature relating to exercise and physical activity in people with Multiple Sclerosis (pwMS). The evidence base pertaining to exercise and physical activity is broad and a number of systematic reviews have been completed. Therefore, in order to provide a comprehensive overview of the existing body of literature, to identify the current gaps and to position this thesis, a critical narrative review was employed (Pope, Mays and Popay, 2007; Cook *et al.*, 1997). This type of review provided the scope to draw on a range of studies using different methodologies, moving beyond systematic reviews which utilise data mainly obtained from randomised controlled trials (RCTs). The intention was to demonstrate how this area of research has been developed and used to shape current understandings about exercise and physical activity in pwMS.

In order to summarise and critically appraise the existing evidence in relation to exercise and physical activity in pwMS, the key literature review questions were:

1. Is exercise and physical activity effective and safe in pwMS?
2. What is the content and frequency of exercise and physical activity undertaken by pwMS?
3. What is the experience and meaning of exercise and physical activity for pwMS?

## **2.1 Methods for searching the literature**

The methods used to search the literature included electronic database searches (the main source) and scanning reference lists of relevant studies. A range of strategies which include, a process of searching, collecting, organising and retrieving information related to the specific search over a period of time was used (Bates, 1989). An extensive search of the electronic databases was initially carried out in 2011 and at various points over the course of the PhD. A final and thorough search was conducted in June 2014 with a specific focus on ensuring that studies relevant to the research questions were captured and new publications included. From this final search three studies were identified and included (Pilutti *et al.*, 2014; Ensari, Motl and Pilutti, 2014; Rietberg *et al.*, 2014). No other studies relevant to the meanings pwMS ascribe to exercise and physical activity were identified.

### **Search Strategy**

The electronic databases searched were, Academic Search Complete, PubMed, CINAHL Plus, Cochrane Database of Systematic Reviews, PsycINFO, SCOPUS and Web of Knowledge. The search dates for each database ranged from its inception to 2014 (See Table 2.1).

**Table 2.1: Electronic database search results**

<b>Database</b>	<b>Year of Inception-search year</b>	<b>Number of studies identified from database</b>
Academic Search Complete	1949-June 2014	39
PubMed	1969-June 2014	61
CINHAL Plus	1976-June 2014	22
Cochrane Database of Systematic Reviews	1993-June 2014	1
PsycINFO	1970-June 2014	70
SCOPUS	1995- June 2014	155
Web of Knowledge	From inception- June 2014	22
<b>Total studies identified from database search</b>		<b>370</b>

The key search terms used were: Multiple Sclerosis, Exercise, Exercise Therapy, Physical Activity, Community, Qualitative, Lived Experience, Interview, Meaningful Activities, Patient Perspective, Patient Voice, Mixed Methods, Delphi Method. The key search terms were combined using Boolean operators (AND/OR) in order to identify the studies relevant to achieving the aims of the literature review. All databases listed were searched using the same search terms. An example of the search terms and corresponding database is shown in appendix 2a.

### **Inclusion criteria for studies:**

Studies were included for review if they:

1. Included adults with MS
2. Were related to exercise and physical activity in pwMS living in the community
3. Covered subject areas of medicine, nursing, health, psychology and therapy
4. Were published in the English Language
5. Had been published as peer reviewed studies or reviews

### **Exclusion Criteria:**

1. Studies examining exercise and physical activity in pwMS in inpatient settings
2. Intervention based studies not exploring exercise and physical activity
3. All drug and animal related studies
4. Case reports
5. Other publications such as letters, editorials and opinion pieces.

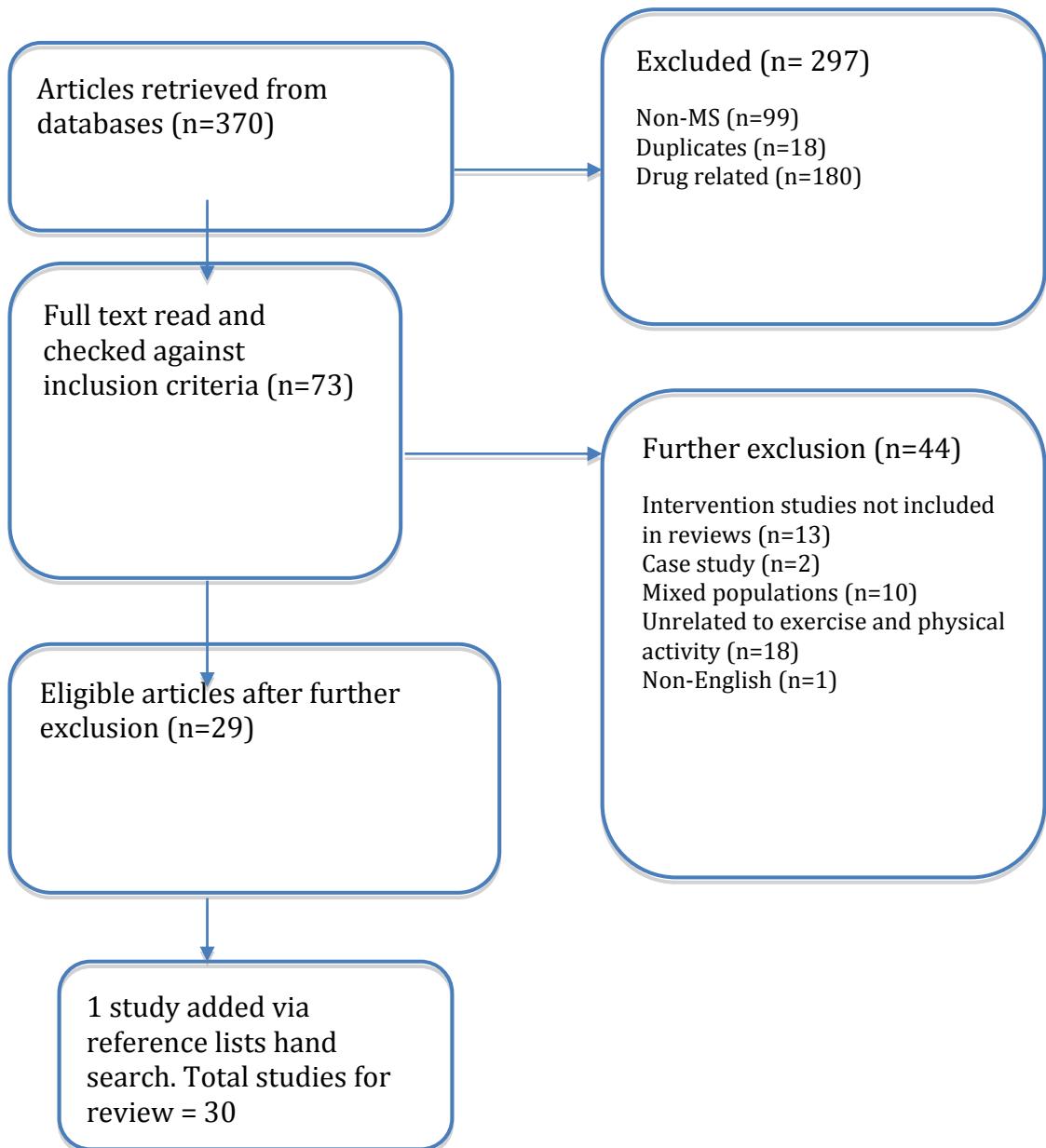
### **Data Collection and Analysis**

Studies identified from the search were scrutinised based on their title and abstract to identify whether or not they were eligible for inclusion and duplicates were identified and removed. Full text articles were then obtained of all studies deemed relevant to the review. Following this process, articles were again perused for relevance against the inclusion criteria and chosen based on the latest and most robust evidence in the area of exercise and physical activity (see Figure 2.1). A table of all the relevant studies was created and included the different

reviews in the area of exercise and physical activity, as well as studies using other methods (qualitative, mixed methods and Delphi Methodology), representing the participants' perception of exercise and physical activity (Appendix 2b).

A final assessment excluded further studies that were initially thought to be relevant but did not meet the inclusion criteria after detailed reading. The reference lists of studies were examined to identify any further articles that met the inclusion criteria.

**Figure 2.1: Flow chart of literature search process**



Guidance from various critical appraisal tools was used to assess the quality of the studies included in the review. The choice of tools was dependent on the methodological design of the study to be reviewed. For example, the Critical Appraisal Skills Program (CASP) (<http://www.casp-uk.net>) was used to assess the quality of systematic reviews, randomised controlled trials (RCTs), and qualitative studies. However, where the CASP tool was limited, other guidance such as, the quality of mixed methods in health services research for mixed methods studies (O'Cathain, Murphy and Nicholl, 2008) and guidance for using and reporting Delphi procedures (Boulkedid *et al.*, 2011) were used.

### **Literature Search Results:**

A total of 370 studies were retrieved from the database search. Figure 2.1 details the screening process. In total, 341 did not meet the inclusion criteria and were removed leaving twenty-nine (n=29). One study (Borkoles *et al.*, 2008) was found through searching the reference lists and was later added to the total number of included studies (n=30). The studies used in the literature review were summarised, grouped according to themes and are discussed in three main sections. The first section summarises the current evidence relating to the benefits and safety of exercise and physical activity based on systematic reviews and meta-analyses (n=9). These reviews helped to summarise the evidence base for existing intervention studies. Other studies (n=11) that have influenced current understandings about the content and frequency of exercise and physical activity undertaken by pwMS were examined in the second section. The third section presented the studies (n=10) exploring the experience and meaning of exercise and physical activity in pwMS living in the community.

#### **2.1.1 The effectiveness and safety of exercise and physical activity in people with MS**

Systematic reviews and meta-analyses (n=9) completed over a period of 10 years have provided information about the effects and safety of exercise in pwMS (Rietberg *et al.*, 2004; Sa, 2013, Snook and Motl, 2009; Toomey and Coote, 2012; Motl and Gosney, 2008; Anthony and Gidugu, 2012; Andreasen *et al.*, 2011; Ensari,

Motl and Pillutti, 2014; Pillutti *et al.*, 2014). These reviews have shaped current understandings about the benefits and safety of exercise and physical activity in pwMS living in the community, as historically people with MS were advised against exercise. That is, exercise was thought to be detrimental to their health (Sutherland and Andersen, 2001). The reviews presented in this section emphasise the benefits of exercise and physical activity on the physical and psychosocial aspects of life. Appendix 2b summarises the key findings from the systematic reviews and meta-analyses.

Two systematic reviews (Rietberg *et al.*, 2004; Sa, 2013) provided evidence about the efficacy of exercise therapy for pwMS in relation to activities of daily living. One, a Cochrane review examined the evidence relating to a wide range of exercise interventions, for example, physical therapy, rehabilitation, functional training and home based exercises and their effects on pwMS (Rietberg *et al.*, 2004). The other included various types of exercise therapy such as balance rehabilitation, endurance and resistance training (Sa, 2013). Included studies in both reviews were considered to be of high (>6) methodological quality using the Physiotherapy Evidence Database (PEDro) scale (Maher *et al.*, 2003; Verhagen *et al.*, 1998). The authors concluded that exercise improved muscle strength (Rietberg *et al.*, 2004; Sa, 2013), mood (Rietberg *et al.*, 2004), balance and quality of life (Rietberg *et al.*, 2004; Sa, 2013). However, the findings for the effect of exercise therapy on fatigue were mixed. For example Rietberg and colleagues (2004) found that exercise therapy had no effect on fatigue whilst Sa (2013) reported reduction in fatigue. One reason for this could be the wide range of outcome measures (e.g. Fatigue index, Fatigue severity scale, general fatigue of the multidimensional fatigue inventory) used to measure fatigue in the studies included in Sa's review which was not noticeable in that of Rietberg and colleagues' (2014). Importantly one review highlighted that exercise was considered safe for pwMS (Rietberg *et al.*, 2004).

Whilst both reviews (Rietberg *et al.*, 2004; Sa, 2013) confirm the benefits of exercise therapy for pwMS, how improvements benefit individuals in their daily lives remains unclear. For example, the authors were interested in the effects of exercise on activities of daily living (ADL) yet the reviewed studies only focused on

activities limited to restrictions in walking, maintaining body posture and fatigue, which, might be a reflection of the current available evidence. However, it highlights the need for the use of measures of activities of daily living in a wider context, for example, more functional outcome measures that also would consider the impact of exercise therapy on day-to-day activities such as personal care, domestic activities, shopping and leisure activities.

Using the CASP tool, strengths and weaknesses of the reviews were identified. The Cochrane review (Rietberg *et al.*, 2004) was comprehensive and reasonable conclusions were drawn which offered clinicians and researchers reassurance about the safety of exercise for this population. However, Sa's (2013) review was not comprehensive as the search strategy was limited to only one database (PubMed), which questions whether or not key studies might have been missed. Furthermore, it was not explicit how effectiveness of exercise therapy was determined. The author appeared to have used the PEDro scale. However, whilst the PEDro scale is used to determine the methodological quality of studies, users have been advised against using the scale as a way to determine effectiveness of interventions (Maher *et al.*, 2003; Verhagen *et al.*, 1998).

Despite Sa's (2013) claim to build on Rietberg and colleagues' (2004) Cochrane review, it has identified some of the same methodological limitations of RCT's as well as the population studied in this field of research. That is, some of the same weaknesses in the methods and design of individual studies still exist, for example, studies are limited by small sample size, people mildly to moderately affected by MS, limited use of power calculations to determine sample size, variations of dose (amount) of exercise and stratification of the type of MS, all which limit the generalisability of these therapies for research and clinical practice. This highlights that over a period of almost 10 years little has changed to improve the evidence-base relating to exercise and physical activity.

Exercise therapy has been found to be an effective strategy to enhance mobility in people with either the relapsing or progressive form of MS. Snook and Motl (2009) examined the evidence to determine the effects of exercise training on walking mobility in pwMS using meta-analytic procedures. Twenty-two RCTs with a total of

600 participants mildly to moderately affected by MS based on the EDSS were examined. The range of effect size of all the included studies was diverse.

Calculations of the combined mean effect size provided evidence to support the use of exercise training to improve mobility in pwMS, albeit a small improvement (Mean effect size of  $g=0.19$  (95% confidence interval (CI), 0.09-0.28). This finding is clinically relevant as difficulties with mobility are one of the most cited detrimental effects of MS (vanAsch, 2011; Sutliff, 2010; Coote *et al.*, 2009; Zwibel, 2009).

All the systematic reviews cited above pre-dominantly included participants who were mildly to moderately affected by MS. However, Toomey and Coote (2012) attempted to address this gap by examining the evidence for the efficacy of physical rehabilitation interventions in participants who were non-ambulant ( $EDSS \geq 7$ ) and severely affected by MS. Due to the limited RCTs available in the non-ambulant population, the authors drew on a wide range of study designs (e.g. case studies, cross sectional designs) and included studies that focused on physical function as an outcome (e.g. Barthel Index, Functional Independence Measure). The authors assessed the internal validity of each study based on the Cochrane risk of bias assessment tool (Higgins and Green, 2011) and the methodological quality was judged using the GRADE approach (Higgins and Green, 2011). Sixteen studies were reviewed (see Appendix 2b). All the studies were judged as being of low methodological quality. Based on the limited evidence and low quality of studies, the authors concluded that the evidence for the effectiveness of physical intervention in non-ambulatory pwMS was inconclusive. This review highlighted the dearth of evidence and the limited guidance for therapy interventions in people with the severe form of the condition (Toomey and Coote, 2012).

The reviews presented thus far focused on the effects of exercise and physical activity on the physical body. However some researchers are interested in exercise and physical activity more broadly; that is, beyond its effect on the physical body. Two reviews, one using meta-analytic procedures (Motl and Gosney, 2008) and the other a systematic review of the literature (Anthony and Gidugu, 2012) examined the effects of exercise and physical activity on quality of life in pwMS. Motl and Gosney (2008) were interested in studies that measured quality of life before and

after exercise (aerobic, non-aerobic or combined) and concluded that exercise training had a small positive effect on quality of life in pwMS (Hedges adjusted  $g=0.23$  (95% CI= 0.15, 0.31). In contrast, studies included in Anthony and Gidugu (2012) review used a range of activities such as, aerobic exercise, resistance training and yoga. The authors concluded that exercise and physical activity had a positive impact on self-reported quality of life in people mildly or moderately affected by MS. In addition, they found that increased physical activity led to an increase in quality of life, self-esteem and reduced depression, fatigue and pain.

Although the aims of both reviews were similar, the authors were interested in different aspects of quality of life. For example, Motl and Gosney (2008) focused on health related quality of life whilst Anthony and Gidugu (2012) focused on the psychosocial aspects of quality of life. Both reviews included studies that used either disease-specific and or general quality of life measures, for example, The Multiple Sclerosis Quality of life-54 (MS Qol-54) and The Medical Outcomes Study Short Form- 36 (SF-36). Of note, Motl and Gosney (2008) included studies in their review that used fatigue (e.g. Fatigue Severity Scale) as a measure of quality of life, which highlights the wide range of outcome measures used across studies. Nevertheless, the findings from both reviews support and encourage the use of exercise and physical activity as a mean to improve quality of life in pwMS.

However, the findings from both reviews were somewhat conflicting when the authors examined the effects of different exercise and physical activity interventions on quality of life. Motl and Gosney (2008) found that interventions that included aerobic exercise had a significant effect on quality of life compared to non-aerobic type interventions (e.g. yoga and resistance training) whereas Anthony and Gidugu (2012) concluded that the type of intervention (aerobic or non-aerobic) did not influence quality of life in pwMS. Nonetheless, the meta-analysis (Motl and Gosney, 2008) provided more robust evidence than the narrative synthesis (Anthony and Gidugu, 2012) in that it provides information about the precise estimate of the treatment effect as well as enables researchers to make valued judgements about the clinical effectiveness of an intervention.

The strength of both reviews lies in the comprehensive search strategy used to identify the relevant studies. However, only one review addressed the methodological quality of the studies included (Anthony and Gidugu, 2012). Another critique of both reviews was that the authors did not report the demographic profile of study participants such as, gender, the different MS subtypes, and or the age range, as such, it remains unclear which groups of pwMS these findings are relevant for.

The evidence for the effect of exercise on fatigue is uncertain. As mentioned in chapter one, fatigue is one of the most disabling symptoms experienced by pwMS (Lerdal *et al.*, 2007; Krupp, 2003). A recent systematic review examined the effects of exercise therapy on fatigue in pwMS (Andreasen, Stenager and Dalgas, 2011). The exercise interventions included, endurance training, resistance training and combinations of the two and a category for other types of exercise that did not fit these criteria. The authors did not state explicitly how they analysed the studies but concluded that exercise therapy had the potential to cause a positive effect in MS fatigue. Based on the studies included in the review, it was apparent that in the majority of studies fatigue was not used as the primary outcome measure. Hence the authors highlighted the need for researchers to address this imbalance in order to draw stronger conclusions in the future about the effects of exercise on fatigue.

Results from a meta -analysis by Ensari and colleagues (2014) revealed that exercise training was effective in reducing depression in pwMS (Ensari, Motl and Pilutti, 2014). The included studies evaluated a range of exercise interventions (e.g. aerobic exercise, stretches, balance, resistance and mobility training) with varied frequency (range 1 to 6 times per week) and duration (range from 4-26 weeks). Depression was measured using a range of outcome measures, for example, the Hospital Anxiety and Depression Scale (HADS) and The Centre for Epidemiologic Studies Depression Scale (CES-D). Participants were predominately women with diverse EDSS scores ( $\leq 6$ ) except for 1 study where EDSS scores ranged from greater than 6 to 8. The studies scored 6 or higher on the PEDro scale suggesting that they were of good methodological quality. The authors concluded that exercise reduced depression based on the mean effect size (Hedge's  $g=0.36$ ,

$SE=0.09$ ,  $95\% CI=0.18-0.54$ ,  $z=3.92$ ,  $p<0.001$ ). The effect size was small but statistically significant.

Assessment with the CASP tool demonstrated that the review was of good quality. The authors were explicit in their methodological approach and data analysis of studies reviewed. The findings provided evidence for the benefits of exercise and physical activity to the psychological health of pwMS. However, the review, which might be a reflection of the studies included, did not report on the clinical course of MS (e.g. relapsing remitting, primary progressive, secondary progressive). Also, similar to other reviews, the findings are limited to pwMS who are ambulant thereby limiting the generalisation of the findings to those who are mildly or moderately affected by MS.

### **Safety of exercise and Physical activity in people with MS**

The Cochrane review by Rietberg and colleagues provided evidence that exercise was safe in pwMS (Rietberg *et al.*, 2004). However several studies have reported adverse events as a result of their participation in exercise interventions (Sosnoff *et al.*, 2014; Bjarnadottir *et al.*, 2007; Oken *et al.*, 2004; Romberg *et al.*, 2004). Pilutti and colleagues (2014) conducted a systematic review to examine not only the adverse events reported in studies of exercise and physical activity for pwMS but also the effect of exercise on rate of relapse. Twenty-six RCTs with a total of 1295 participants met their inclusion criteria and included those reporting adverse events. This review was strictly confined to exercise training in pwMS. The exercise intervention varied (dose and type of intervention) across the studies, and included primarily aerobic exercises and resistance training (individually and combined training). The rate of relapses and adverse events were calculated for each study and expressed as a percentage (e.g. the number of events reported in the control or exercise group divided by the number of participants per control or exercise group). The majority of the studies reviewed ( $n=24$ ) were judged to be of high methodological quality with a PEDro score of six and above.

Of the total participants across all the studies in the intervention groups (n=626) 4.6% (n=29) reported relapses. Of the participants in the control groups (n=412) 6.3% (n=26) reported relapses. The authors were interested mainly in relapses that occurred during the intervention as oppose to the follow up periods in order to make judgements about relapses and exercise training. They concluded that exercise training reduced the risk of relapse in pwMS compared with controls. In relation to adverse events, there were similarities across both the intervention and control group. These include illness, back and joint pain. These adverse events were reported by 1.2% of participants (n=5) in the control groups and 2% (n=13) in the intervention groups. The authors concluded that the risk of adverse events were higher compared to controls but comparable to studies (1.4%-2.4%) on healthy populations (Powell *et al.*, 1998).

The review had clearly stated aims and explicit search criteria which would suggest that appropriate studies were selected for inclusion. However the findings should be treated with caution as relapse was self-reported and there was no mention whether this was clinically verified. Also, the findings are limited to people who are mildly or moderately affected by MS. Accumulating evidence suggest that other people with the same severity of MS, exercising under the same conditions as those included in the original trials, are at no more risks of adverse events than the general population (Powell *et al.*, 1998).

## **Summary of the reviews**

In summary, the key findings from the reviews (systematic and meta-analysis) have demonstrated that exercise and physical activity is effective and safe for pwMS. Improvement in muscle strength and fitness (Rietberg *et al.*, 2004), quality of life and depression (Ensari, Motl and Pilutti, 2014) were reported. The effects of exercise as a strategy to reduce fatigue were mixed (Sa, 2013; Andreasen *et al.*, 2011; Motl and Gosney, 2008). In addition, there is evidence to suggest that exercise is safe for pwMS (Rietberg *et al.*, 2004; Pilutti *et al.*, 2014) and does not pose any additional risks to that seen in the average population. However, these findings are limited mainly to pwMS with mild to moderate disability. The effects

of exercise interventions in pwMS with severe disability remain uncertain (Toomey and Coote, 2012).

The existing evidence base centred on the effects of exercise and physical activity has several limitations. The studies included are predominantly randomised controlled trials, which utilise mainly structured, supervised and professionally driven interventions (Broekmans *et al.*, 2011; Bjarnadottir *et al.*, 2007; Mostert and Kesselring, 2002). Little is known about the types of unsupervised exercises and activities undertaken by pwMS within the home environment and wider community. More studies need to reflect physical activity, which includes both structured and unstructured forms of activities. This will provide and or create the opportunity to offer choice to pwMS especially because of the variability of the condition. Equally, there is a call for clinicians and researchers to improve the methodological quality of studies (Rietberg *et al.*, 2004) as well as to conduct more studies in relation to exercise and physical activity in pwMS with moderate to severe disability (Toomey and Coote, 2012). The next section will examine the literature relating to the content and frequency of exercise and physical activity undertaken by pwMS living in the community.

### **2.1.2 Content and frequency of exercise and physical activity in pwMS**

Four studies were found that highlighted the content of exercise and physical activity in pwMS living in the community. Of these, one study (O'Hara, De Souza and Ide, 2000) used a Delphi Methodology and three used a quantitative cross sectional questionnaire design to ascertain the types of activities people with MS were involved with in the community (Weikert *et al.*, 2011; Currie *et al.*, 2009; Einarsson *et al.*, 2006).

Each study had a different focus and emphasis. O' Hara and colleagues (2000) examined self-care practices of pwMS in the community. The authors defined self-care as things people personally do to manage their MS. They conducted a 3 round postal Delphi questionnaire to find out the views of 136 pwMS living in the community. Participants were asked to prioritise their 10 most important self-care practices out of a total of 17. The authors found that of the top 10 strategies

reported, coping (described as cognitive or behavioural strategies to deal with stress) was viewed by participants as the most important to manage MS, followed by independence in activities of daily living (ADL). Exercise, which included activities such as walking, stretching and swimming, was ranked eighth. They found no consensus among the group regarding the self-care practices tested by using Kendall's coefficient of concordance to determine overall agreement between groups' responses.

This study (O'Hara, De Souza and Ide, 2000) highlighted three key ideas. Firstly, that pwMS prioritise their activities as a way of managing their MS. Secondly, that exercise and physical activity whether structured or unstructured played an important role in the lives of pwMS; most of the categories of the top 10 included some form of exercise and physical activity (ADL- ranked 2, social life- ranked 3, mobility- ranked 5, exercise- ranked 8 and leisure activities- ranked 9). Thirdly, pwMS living in the community viewed unstructured activities as important in contrast to other existing interventions, which have been found to focus on structured forms of exercise in their treatment designs (Sosnoff *et al.*, 2014; Sabapathy *et al.*, 2011; Collett *et al.*, 2011; O'Connell *et al.*, 2003; Lord, Wade and Halligan, 1998; Petajan *et al.*, 1996).

Three studies provided a sense of the types of exercise and physical activity pwMS engage with in the community (Weikert *et al.*, 2011; Currie *et al.*, 2009; Einarsson *et al.*, 2006). One that focused on describing the personal and instrumental activities of daily living of pwMS living in the community (Einarsson *et al.*, 2006) aimed to ascertain the levels of independence in daily activities. This was a cross sectional study design using a standard questionnaire as the data collection tool. One hundred and sixty-six participants were divided into four categories based on the EDSS score of mild (0-3.0), moderate (3.5-5.5), severe (6.0-6.5) and very severely disabled ( $\geq 7$ ). The key findings were that 52% (n=85) were independent in personal ADLs, 30% (n=50) in instrumental ADLs, and 35% (n=57) were involved in social/lifestyle activities. The items participants reported difficulty with were stairs, mobility and dressing. This led to the conclusion that exercise interventions should target activities of daily living in pwMS in order to improve their independence in these tasks.

Similarly, Currie and colleagues (2009) also used a cross sectional survey to find out the types of physical activities (e.g. structured, unstructured and activities of daily living) pwMS were involved in and the relationship between these activities and disability. Participants were asked to record their physical activities over the week noting the type of activity and frequency of the activity. Participants (n=108) were divided into groups based on their EDSS scores and classified into three categories representing mild (0-3.5), moderate (4-6) and severe (6.5-9) forms of the disease. Results from the study demonstrated that 93.5% of all responders were involved in moderate intensity activity during the week. These included group classes (15.7%), self-directed continuous activity (63.9%) and short bursts of moderate physical activity (88%). No statistical significance was found between physical activity levels, age and gender. The authors concluded and highlighted the importance of considering a wide range of activities when examining physical activity levels in pwMS. Interestingly, all participants reported that self-care activities required moderate effort across all disability levels. This is an unexpected finding as one would have thought that people who are considered to be mildly affected by MS would not report lower level activities such as personal care as challenging. Such a finding points to the importance of keeping an open mind when assessing pwMS irrespective of disability status.

Both studies provided some insight into the activities pwMS are engaged in within the community. However, the findings from both studies were limited due to the different ways in which the data were gathered and analysed. For example, Einarsson and colleagues (2006) used structured interviews. This meant that the authors followed a strict (structured) way of gathering the information thereby limiting participants' response; such responses might be restricted to pre-determined answers. On the other hand, Currie and colleagues (2009) used a modified physical activity postal questionnaire (Godin and Shephard, 1985) which focused more on intensity of activities rather than providing a comprehensive view of the types of activities participants were engaged in. As such, direct comparisons of these two studies were limited as only one study provided information about the types of activities people were involved in (Einarsson *et al.*, 2006). In addition, both studies used cross sectional surveys; as such the authors

were unable to draw conclusions about cause and effect. Furthermore, this type of method might introduce bias due to the selectivity of participants. Only one author acknowledged these limitations (*Currie et al., 2009*).

The third, a longitudinal study, conducted in the United States of America (USA) provided some insight into the most frequently used physical activities in pwMS living in the community (*Weikert et al., 2011*). This survey aimed to examine the most common types of self-directed physical activity pwMS engaged in. Two hundred and seventy two participants responded to the survey. Ranking of the most important activity based on frequency scores revealed the 5 most frequently reported activity. These include walking (79%), gardening (44%), weight training (34%), bicycling (30%) and calisthenics (20%). This study, provided evidence for the most common activities people with MS engaged in over the period of a year. The limitations of the study were that all the participants had RRMS and the authors were only interested in frequency and not the importance of these activities to pwMS.

These four studies cited above added some insights into the activities people with MS are involved with in the community (*Weikert et al., 2011; Currie et al., 2009; Einarsson et al., 2006; O'Hara, De Souza and Ide, 2000*). They add to a growing body of evidence using different methodologies and participants, which suggests that pwMS participate in a wide range of activities. Whilst they highlighted the diversity of different forms of exercise and physical activity used, none addressed the reasons why these activities are preferred by pwMS (*Weikert et al., 2011; Currie et al., 2009; Einarsson et al., 2006; O'Hara, De Souza and Ide, 2000*). Activities were predominantly self-selected by pwMS and suggest firstly that pwMS may conceptualise exercise and physical activity in ways that may not be fully appreciated or understood by health professionals. Secondly, if this is the case, it widens the scope to utilise and integrate activities that are widely used by pwMS in the community as a way to promote and sustain exercise and physical activity in this population.

This literature review highlights the complexities that exist when comparing studies in relation to exercise and physical activity in pwMS. All the studies

reviewed in this section used different scales to rate the disease severity of MS, for example, self-reported impact of MS Likert Rating Scale (O'Hara, De Souza and Ide, 2000), EDSS (Currie *et al.*, 2009), and the PDDS (Weikert *et al.*, 2011). Of the two studies that used the EDSS, the authors used different interpretations to determine disability status of the participants in their sample. For example, Einarsson *et al* (2006) used 4 categories for the EDSS (mild, moderate, severe and severely disabled) whilst Currie *et al* (2009) used 3 categories (mild, moderate and severe).

Additionally, of the four studies only three (Weikert *et al.*, 2011; Einarsson *et al.*, 2006; O'Hara, De Souza and Ide, 2000) reported the types of MS of the participants. Three used physical activity outcome measures but all these measures were different and measured different aspects of activity. This identifies a lack of consistency in the use of measurement scales in studies of pwMS. This was also noted in the previous sections.

Despite evidence that illustrates that pwMS participate in some types of exercise and physical activity they are still considered inactive. A review completed by Motl and colleagues compared physical activity levels in pwMS, healthy and non-healthy individuals using meta-analytic procedures (Motl, McAuley and Snook, 2005). Thirteen studies with a total of 2369 pwMS fulfilled the eligibility criteria. Using quantitative synthesis of effects the authors concluded that pwMS were more inactive ( $ES = -0.60$  (95% CI=-0.44, -0.77) compared to sedentary healthy individuals but not other individuals with chronic conditions (e.g. Chronic Fatigue Syndrome, Chronic Obstructive Pulmonary Disease and Cerebral Palsy).

The meta-analysis also highlighted a difference in activity levels based on the type of MS. For example, participants with primary progressive MS were less active compared with those with relapsing remitting. Again examining the studies included in this meta-analysis pointed to the dearth of information related to physical activity in the broader sense, as the majority of the studies focused mainly on structured forms of exercise (resistance training, aerobic exercises). This signals that little is known or understood about the activities or how much pwMS participate in unstructured activities. There is a need to develop more programs geared towards improving physical activity using a holistic approach that would

include activities across all the levels of the ICF (impairment, activity and participation).

While the research reviewed above has focussed on activity, little work has been carried out on levels of inactivity.

A study conducted by Sandroff and colleagues (2012) investigated whether or not pwMS living in the community ( $n= 77$ ) with minimal disability were inactive compared to their healthier peers matched for age, gender, weight and height.

Physical activity levels were measured subjectively using questionnaires (Godin Leisure-Time Exercise Questionnaire (GLTQ) and International Physical Activity questionnaire (IPAQ) and objectively using accelerometers over the period of a week. The study found statistically significant differences between groups based on accelerometer readings ( $t=-3.87$ ,  $p=0.0001$ ), GLTQ questionnaires ( $t=-3.83$ ,  $p=0.0001$ ) and the IPAQ ( $t=-3.42$ ,  $p=0.001$ ). These findings suggest that pwMS were moderately less physically active compared to their healthier peers (ES,  $d=-0.59$ , range  $-0.40$  and  $-0.71$ ). The results from this study quantify what has been known about physical activity levels in pwMS (Motl, McAuley and Snook, 2005). However, the strength of this study lies in the fact that they have captured activity levels in peoples' daily routines and have done so using both subjective and objective measurements. The authors concluded by recommending that researchers should develop ways of increasing physical activity levels in this population using both structured and unstructured forms of activity.

Despite the noted strengths of this study, there were some limitations which the authors have acknowledged. Firstly, all the pwMS in this study were ambulant with or without mobility aids. This highlights again that the majority of the current evidence is related to people mildly to moderately affected by the condition. Also, participants were recruited specifically from the MS Society, which might bias these findings, as the views, opinions and behaviours of pwMS affiliated with these societies might not represent the wider population of pwMS.

Rietberg and colleagues (2014) presented similar findings, which also purport that pwMS are inactive. However the key focus of this study was to examine whether or not within a 24- hour period physical activity levels were different between pwMS

and their healthier peers. Forty-three ambulant pwMS and 26 people without MS matched for age and gender were recruited. Physical activity levels were measured using accelerometers, which provided readings for both posture (sitting, lying and standing) and movements. Data were analysed using descriptive statistics and multilevel modelling to determine the association between physical activity levels between the groups. The authors found that over a 24 hour period, pwMS spent less time walking ( $p<0.001$ ), more time in static activities ( $p=0.003$ ) and less time standing ( $p=0.011$ ) when compared to their healthier peers. One interesting finding was the patterns of movement over the course of the day, where pwMS spent more time on static activities in the afternoon ( $p=0.03$ ). This was statistically significant which would suggest that pwMS adjusted their activities as a way to manage their energy demands. However, the authors did not examine the mean effect size so although this is statistically significant the magnitude of this finding compared to their healthier peers remains unknown.

The strength of this study is that the authors objectively measured activities within daily routines; however this only provided a snapshot view as activities were confined to the home environment. Therefore it does not provide a comprehensive picture of physical activity including leisure and other social commitments and whilst the study provided information about posture and movement, it did not state what these activities included. As this study only reflected physical activities within a day one could argue that since MS is a fluctuating disease, if participants had an “off day” this could influence the findings. A larger sample size could have helped to account for MS participant variation. The main limitation of this study is that it mainly involved pwMS who were mildly affected (EDSS mean 3.5).

Key insights into factors that might influence engagement in physical activity in pwMS were reported in a cross sectional study that aimed to explore the health beliefs and illness behaviours of pwMS ( $n=282$ ) using questionnaires (Kayes *et al.*, 2011a). The study revealed that participants were more likely to engage in lower intensity activities, such as household activities. Barriers that limited engagement in physical activity were being tired (reported by 86%), impairment (59%), lack of time (53%), and bad weather (51%). These findings are of clinical importance as it highlights the need for clinicians to engage with pwMS to address these factors.

Within the framework of the ICF, identifying these barriers, which are recognised as contextual factors, might influence whether or not pwMS engage in exercise and physical activity.

A similar study investigated the levels of physical activity in pwMS to identify factors that influenced participation in physical activity using questionnaires as the data collection method (Beckerman *et al.*, 2010). One hundred and six pwMS with mean age of 42.7 years ( $SD=9.6$ ) participated in the study. Similar to the findings reported by Kayes and colleagues (Kayes *et al.*, 2011a), Beckerman and colleagues (2010) found that the majority of pwMS were engaged in on average 30 hours per week lower level activities of “light intensity” (Metabolic Equivalent of Task (MET), 2-4) such as, household activities, walking and gardening. The barriers to exercise identified were fatigue, low energy, social obligations and poor health. Participants reported that physical activity improved physical fitness and muscle strength. These findings are consistent with other intervention studies (Rietberg *et al.*, 2004, see above).

Despite similar findings, comparing both studies (Kayes *et al.*, 2011a; Beckerman *et al.*, 2010) was difficult because of the different physical activity and disability outcome measures used. For example, one study used the Guys Neurological Disability Scale (GNDS) as their measure of disability and the Physical Activity Disability Survey-Revised (PADS-R) as their measure of physical activity (Kayes *et al.*, 2011a). Conversely, Beckerman and colleagues used EDSS as their measure of disability and the Short Questionnaire to assess Health-Enhancing Physical Activity (SQUASH) (Beckerman *et al.*, 2010). The SQUASH is more suited for use in the average population and is dependent on memory recall as far back as the previous month (Beckerman *et al.*, 2010) which might be a difficulty for some pwMS as memory impairment is a known symptom (Matthews, 1998).

Both studies had limitations. For example, Kayes and colleagues’ (2011a) study was limited by low response rate (38%) and therefore might not represent the views of the wider MS population. In Beckerman and colleagues’ study (Beckerman *et al.*, 2010), the majority of participants were mildly affected by MS (53.3%) with only 9 % severely affected based on the EDSS. Also, the majority of

participants (83%) had relapsing remitting MS which is representative of the MS population however all the other classifications of MS were placed in the category of non-relapsing remitting MS. Therefore it is unclear which other subtypes of MS were represented in the sample (Beckerman *et al.*, 2010). This is important, as although the other group was labelled as having the progressive form of MS, one is known to progress rapidly (PP) and the other is known to progress slowly (SP) (Compston *et al.*, 1998), hence views about how these impact physical activity may differ. In addition, Kayes and colleagues (2011a) highlighted that pwMS classified with primary and secondary MS were less likely to engage in physical activity. However, these results should be viewed with caution as both studies are cross sectional in design and therefore cannot address causal relationships (Kayes *et al.*, 2011a). Nevertheless, both studies provided some insight into the barriers and facilitators experienced by pwMS living in the community. These findings highlight the importance of health professionals' working jointly with pwMS to identify and address the impact of these facilitators and barriers on physical activity in relation to the functioning, disability and contextual domains of the ICF. The aim then should be to increase the facilitating factors and reduce the perceived barriers.

The studies presented above (Kayes *et al.*, 2011a; Beckerman *et al.*, 2010) have helped to shape our understanding about the factors that might have an effect on participation in exercise and physical activity, however, their aims did not extend to investigating how these factors might sustain and promote physical activity levels in pwMS. Two studies that highlighted the benefits of sustaining and promoting exercise and physical activity participation in pwMS will be discussed (Motl *et al.*, 2011b; McAuley *et al.*, 2007).

McAuley and colleagues (2007) conducted a 3-month RCT to determine the effects of a self-efficacy enhancement programme on exercise adherence and wellbeing. Twenty-six participants were eligible for inclusion, based on a diagnosis of MS, ability to ambulate with minimal assistance and described as sedentary (defined by the authors as being physically active less than three times per week). The intervention was an efficacy enhancement exercise programme (workshop focused on efficacy information in relation to participation in physical activity, e.g. goal setting, strategies to overcome barriers of exercise and exercise class) and the

control was standard care (workshops discussing general health related information, benefits of physical activity and nutrition, exercise class). Both groups participated in a physical activity program lasting one hour, three times per week over a period of three months. The physical activity program consisted of structured activities such as stretches and aerobic type activities. The participants were randomised into either standard care or the efficacy enhancement group. The outcome measures used were self-reported measures for exercise self-efficacy (EXSE), wellbeing (Satisfaction with Life Scale (SWLS), 12-item Short Form Survey (SF-12), and adherence measured as the number of classes attended. Data were analysed using one-way or two way analysis of variance, Pearson's correlation coefficients and effect size using Cohen's d.

The authors found no statistical significance between standard care and the intervention group in relation to exercise adherence. However the group that received the efficacy enhancement program guided by the principles of social cognitive therapy engaged in more exercise and physical activity ( $d=0.47$ ), for longer durations ( $d=0.45$ ), reported greater levels of enjoyment ( $d=0.15$ ) and other effects ( $d=0.57$ ). The findings from this study suggest that a self-efficacy based physical activity program had a positive effect on engagement and participation in physical activity. These findings reflect an innovative approach to promote physical activity in pwMS but should be viewed with caution due to some methodological flaws which questions the internal validity of the RCT. The main issues were a lack of detail on the methods of randomisation, no reporting of allocation concealment or of subject blinding and lack of information about what, if any, efforts were made to manage these potential biases.

Another innovative approach for promoting physical activity was reported by Motl and colleagues (Motl *et al.*, 2011b). They examined the effect of an internet intervention program based on the social cognitive theory (SCT) principle and incorporated information on self-efficacy, outcome expectations, impediments and goal setting. The aim of the study was to ascertain whether or not this approach increased physical activity levels in pwMS. Fifty-four (54) people with relapsing remitting MS were randomised into either an Internet programme or waitlist control group. Treatment lasted for three months.

The outcome measures were self-reports of physical activity (Godin Leisure-Time Exercise Questionnaire –GLTEQ), self-efficacy (Self-Efficacy Scale (EXSE), disease severity (Patient Determined Disease Steps Scale-PDDS) outcome expectation and goal setting using the exercise goal setting scale (EGS) before and after 3 months. Analysis used descriptive statistics, two way ANOVA and effect size (Cohen's d).

The key findings demonstrated that both groups showed an improvement in physical activity over the 3 month period with a statistically significant result for the intervention group ( $d=0.72$ ,  $p=0.01$ ). The control group had a smaller non-significant change ( $d=0.04$ ,  $p=0.71$ ). Also, participants who engaged in goal setting showed greater levels of physical activity ( $p=0.001$ ,  $d=0.97$ ). This is an interesting finding as it highlights the importance of goal setting as a means of increasing physical activity levels in pwMS who are considered to be sedentary. Goal setting is widely used within the clinical setting by physiotherapists, but evidence about whether or not this is utilised in practice to detect changes in physical activity levels in pwMS are unknown.

Although the authors utilised an innovative approach there were limitations most of which the authors have acknowledged. Examples include the demographic profile of the participants who all had relapsing remitting MS and minimal levels of disability. Also, the outcome measures used were all self-reports of physical activity, which could have resulted in participants either over or understating changes in physical activity levels. Having more objective measures, for example, through the use of accelerometers would have provided more convincing results (Gosney *et al.*, 2007).

### **Summary of content and frequency of exercise and physical activity**

In the above sections, the literature centred on exercise and physical activity in pwMS was summarised. The findings presented thus far, have demonstrated that exercise and physical activity is effective and safe in pwMS yet despite this knowledge pwMS have low levels of activity. The key findings also highlight that pwMS engage in a wide range of exercise and physical activity some of which might not be appreciated by clinicians. Yet for pwMS accomplishing a practical task

(e.g. personal care) contributes not only to achieving that task but the physical effort involved also contributes to participation in exercise, a bonus, and it is this that is perhaps under appreciated by clinicians. Initiatives taken to increase the frequency of participation in exercise and physical activity using the principles of social cognitive theory prove promising. However, researchers need to be more explicit about the content of these programmes in order to enhance the repeatability of these studies.

Although the studies presented thus far provided insight into exercise and physical activity, none explored the reasons why these self-selected activities were chosen or the meanings these activities have to the individual, as this was not their central focus. The following section will analyse and critique the qualitative studies related to exercise and physical activity from the perspectives of pwMS living in the community. Due to the limited research associated with perspectives of pwMS in relation to exercise and physical activity, mixed methods studies were included if there was a qualitative component. Qualitative studies are designed to offer in-depth exploration into meanings and peoples' world (Ritchie and Lewis, 2009). They provide information about the views and opinions of individuals and may enhance the understanding and appreciation of the goals and objectives of pwMS in their own management of the condition.

## **2.2 Exercise and physical activity: the perspective of pwMS**

Gaining the views of individuals about a particular topic relevant to them is not a new concept. This method has been used in the development of different policy guidelines and government initiatives, which have patients being the centre of care at its core (CSP, 2012; DOH, 2005; NICE, 2014). To this end, patients' perspectives have been sought to inform the content of concepts such as functioning and disability based on the International Classification of Function (ICF) (Coenen *et al.*, 2011), to determine self-care practices of pwMS in the community (O'Hara *et al.*, 2002; O'Hara, De Souza and Ide, 2000), the development of different exercise intervention programs such as the Blue Prescription Program (Hale *et al.*, 2012) and the development of exercise and physical activity recommendations for pwMS (Latimer-Cheung *et al.*, 2013).

### **2.2.1 The experience and meaning of exercise and physical activity for pwMS**

A total of seven studies were found addressing the experience of exercise and physical activity in people with MS living in the community. Of these studies, five (Kayes *et al.*, 2011b; Smith *et al.*, 2011; Plow, Resnik and Allen, 2009; Smith *et al.*, 2009; Dodd *et al.*, 2006) used a qualitative methodological approach whilst two studies (Van Der Linden *et al.*, 2014; Learmonth *et al.*, 2013) used a mixed methods approach.

The aims of van der Linden et al (2014) were to ascertain the feasibility, efficacy and experiences of a Pilates programme for pwMS who were wheelchair users. Participants engaged in a 12-week group based Pilates exercise class. The study included 15 people diagnosed with secondary progressive MS between the age ranges of 31-65 years and severely affected by MS (EDSS 7-8). The quantitative findings revealed positive outcomes on physical measures (e.g. Visual analogue Scale, Centre of pressure) but not on the functional measure (The Canadian Occupational Performance Measure-COPM). The qualitative phase of the study used two focus groups and revealed physical, psychological and social benefits of the exercise group (e.g. improved transfers, self-care and peer support). Despite reporting no statistical differences in the functional outcome (COPM) the qualitative phase of the study highlighted that participants generally felt there were improvements in daily activities. This highlights the importance of daily activities to pwMS living in the community. Furthermore whilst participants valued peer support and expertise of professionals gained from attending a group based programme they reported that the exercises were not transferable to the home environment. This would suggest that whilst these approaches were somewhat beneficial, sustaining these activities within the context of the community remained a challenge. The findings also highlighted aspects of participants' decision-making process around whether or not certain forms of activities can be adopted as part of daily exercise routine.

Using a similar mixed methods design Learmonth and colleagues (2013) elicited views about the general experience of involvement as well as the positive and negative outcomes associated within a group based exercise program held in a community leisure centre. Fourteen people, age range 41-68 years, moderately affected by MS participated in focus groups. A thematic content analysis revealed improvements in MS symptoms, goal achievement and social support. Lack of expertise of the health and leisure centre staff, exercising with healthy people and fatigue were some of the reported barriers to engaging in exercise.

There were some similarities between both studies. They were focused on participants' experiences based on exercise group sessions, ran for 12 weeks, used focus groups to elicit information and similar sample size of 10 (van der Linden *et al.*, 2014) and 14 (Learmonth *et al.*, 2013). Whereas, van der Linden and colleagues (2014) were interested in the views of pwMS who were wheelchair users (EDSS, 7-8), Learmonth and colleagues were interested only in participants who were moderately affected but still ambulant (EDSS, 5-6.5). Both studies used different analytical approaches. For example, van der Linden and colleagues (2014) used Framework Analysis while Learmonth and colleagues (2013) used thematic content analysis. Despite the two analytic variations the findings were similar and revealed the positive experiences of being involved in group based exercise programs (Van Der Linden *et al.*, 2014; Learmonth *et al.*, 2013). The positive experiences reported were generally improvement in physical MS symptoms (Van Der Linden *et al.*, 2014; Learmonth *et al.*, 2013), improvement in functional abilities such as transfers (Van Der Linden *et al.*, 2014) and peer support from group sessions (Van Der Linden *et al.*, 2014; Learmonth *et al.*, 2013). However, some participants in both studies expressed negative experiences of exercise such as difficulties to engage due to previous musculoskeletal injuries (Van Der Linden *et al.*, 2014) and fatigue (Learmonth *et al.*, 2013). Both studies highlighted the importance of having professional experts conducting the classes as this was cited as a motivating factor for engaging in exercise groups (Van Der Linden *et al.*, 2014; Learmonth *et al.*, 2013).

Five studies explored the perceptions of exercise and physical activity in pwMS using qualitative approaches only (Kayes *et al.*, 2011b; Smith *et al.*, 2011; Plow,

Resnik and Allen, 2009; Smith *et al.*, 2009; Dodd *et al.*, 2006). All used semi-structured interviews as their data collection method. The participants were similar in age range (Kayes *et al.*, 2011b; Plow, Resnik and Allen, 2009; Smith *et al.*, 2009; Dodd *et al.*, 2006), however, Smith and colleagues' (2011) participants were slightly older (range 28-70 years). Four studies included both men and women (Kayes *et al.*, 2011b; Plow, Resnik and Allen, 2009; Smith *et al.*, 2009; Dodd *et al.*, 2006) and one study consisted of only women (Smith *et al.*, 2011).

Each study had a different focus and emphasis. They were the experiences of pwMS based on 10 week gym based progressive resistive exercise program (Dodd *et al.*, 2006), the experiences of a home exercise program consisting of structured exercises (Plow, Resnik and Allen, 2009), understanding the facilitators and barriers of physical activity (Kayes *et al.*, 2011b), the influences of exercise on fatigue following an 8 week exercise professionally led program consisting of structured exercises within a physiotherapy gym (Smith *et al.*, 2009) and the influence of fatigue on exercise in pwMS who were active exercisers within the community and who self selected their activities (Smith *et al.*, 2011).

Three studies included participants with both relapsing remitting and secondary progressive MS (Kayes *et al.*, 2011b; Smith *et al.*, 2011; Plow, Resnik and Allen, 2009). One study only included participants with relapsing remitting MS (Smith *et al.*, 2009). Dodd and colleagues (2006) did not report on these classifications in their study or specify how the data were analysed. The analytic approach used in Smith and colleagues' study was that of Interpretive Description (Smith *et al.*, 2011; Smith *et al.*, 2009), Plow and colleagues used a Modified Analytic Induction approach (Plow, Resnik and Allen, 2009) whilst grounded theory informed Kayes and colleagues' study (Kayes *et al.*, 2011b).

The findings from four studies described a positive experience with exercise interventions in the community. These benefits were associated with improvement in physical outcomes (Smith *et al.*, 2011; Plow, Resnik and Allen, 2009; Smith *et al.*, 2009; Dodd *et al.*, 2006) and psychological outcomes (Smith *et al.*, 2011; Plow, Resnik and Allen, 2009; Smith *et al.*, 2009; Dodd *et al.*, 2006). The social benefits of exercise and physical activity were only found in two studies (Dodd *et al.*, 2006;

Plow *et al.*, 2006). Smith and colleagues' study was based on an individualised program hence the social aspect usually reported in group exercises might not have been experienced (Smith *et al.*, 2011; Smith *et al.*, 2009). However the findings from Kayes and colleagues' (2011b) study highlighted a more complex dimension of physical activity whereby pwMS held both positive and negative beliefs about exercise and physical activity. These beliefs were central to whether or not these individuals engaged in physical activity.

All five studies highlighted some interesting insights about exercise and fatigue. In one study, participants felt that fatigue was decreased by engaging in an exercise program (Dodd *et al.*, 2006). In three studies participants reported that the benefits of exercise and physical activity provided a sense of control over fatigue (Smith *et al.*, 2011; Plow, Resnik and Allen, 2009; Smith *et al.*, 2009). However, the complexities and intricacies of fatigue and exercise were highlighted in three studies (Kayes *et al.*, 2011b; Smith *et al.*, 2011; Smith *et al.*, 2009). Of these, one study, (Kayes *et al.*, 2011b) found that fatigue played a major role in influencing physical activity; where activities were carefully designed and scheduled into daily life as a way of managing fatigue. Smith and colleagues (2009) found that the perception of being in control over fatigue led to positive outcomes with exercise, such as, healthy tiredness, increased strength and sense of achievement. Similarly, lack of perceived control over fatigue led to negative outcomes, such as physical deterioration (Smith *et al.*, 2009), whilst perceived control over fatigue influenced wellness philosophy, goal attainment and an improved sense of self (Smith *et al.*, 2011). This highlights the range of perspectives that exists in pwMS relating to fatigue. Whereas some participants felt fatigue was a barrier to exercise, others used exercise and physical activity to control symptoms of fatigue. It could also be argued that participants prioritised their activities in order to manage fatigue (Kayes *et al.*, 2011b).

These five studies have some limitations in terms of their transferability to the wider population with MS. All except one (Kayes *et al.*, 2011b) included participants with MS who were all mobile with or without aid therefore extending these findings to other pwMS would be limited. One study only elicited the views of women with MS (Smith *et al.*, 2011) and another did not state the type of MS

included in their sample or how their data were analysed thereby limiting the interpretations and methodological rigor of the study (Dodd *et al.*, 2006).

In summary, despite all these studies exploring the perceptions of pwMS they were all based on experiences of being involved in an exercise and physical activity program. There is a dearth of information relating to the general views of pwMS regarding unsupervised exercise and physical activity in the community and the meanings pwMS ascribe to these activities.

The literature search revealed three studies that reported the perceptions of pwMS living in the community in relation to the meaning of exercise and physical activity. All used semi-structured interviews as their data collection methods (Dlugonski, Joyce and Motl, 2012; Kasser, 2009; Borkoles *et al.*, 2008). Whilst the aims of two studies were focused on exploring the meanings and motivations of engaging in exercise and physical activity (Dlugonski, Joyce and Motl, 2012; Kasser, 2009), the third study was focused on the lived experience of pwMS in relation to exercise (Borkoles *et al.*, 2008).

Borkoles and colleagues (2008) examined the lived experiences of pwMS who were physically active using an Interpretative Phenomenological Analysis (IPA) approach (Smith and Osborn, 2003). The authors concluded that loss of functional ability, loss of spontaneous opportunities to exercise, psychological and environmental factors had an impact on whether or not pwMS engaged in exercise and called for the need for health services to reconsider how opportunities are provided for pwMS to engage in exercise. These findings are important as they demonstrate the need for professionals (e.g. researchers and clinicians) to offer pwMS greater choice in the exercise and physical activities pwMS can engage in. That is, choices shaped by the activities pwMS regard as important thereby creating space for activities to be more spontaneous.

Using a similar phenomenological approach, Kasser (2009) explored the meaning of exercise and motivations for engaging in exercise in pwMS who attended a gym based exercise program 2-3 times per week. The intervention consisted of mainly structured exercises (strength, flexibility, endurance and balance), which included both 1:1 sessions as well as group interventions. A thematic analysis highlighted

three key themes developed from the data. These were, exercising to maintain function and health, enhanced exercise self-efficacy and feelings of hope and optimism. Again this study demonstrates the physical and psychological benefits associated with structured forms of exercise within the context of the gym environment. There is a need for more studies to explore self-selected activities which extends beyond structured forms of activities performed by pwMS within the community in order to understand the activities performed within this context.

The two studies reported above provided views of pwMS who are already motivated and considered to be physically active (Kasser, 2009; Borkoles *et al.*, 2008). However, Dlugonski and colleagues (2012) included people who were described as active, moderately active or inactive. Inactivity was rated as being involved in physical activity for 30 mins or more on less than or equal to 2 days per week. Being active was described as being involved in physical activity on more than or equal to 5 days. Also regular activity was defined as engaging in physical activity on 3-4 days per week. Using an inductive approach to analyse their data several themes were identified (Dlugonski, Joyce and Motl, 2012). The authors found that engaging in physical activity was a means of maintaining current health, physical functioning, sense of enjoyment and a sense of normality. This study highlighted the importance participants placed on activities of daily living as participants considered these activities to be part of their physical activity routine irrespective of the levels of intensity. Based on their findings the authors recommended that future researchers further explore the personal meanings of physical activity in pwMS and use this as a way to inform or promote physical activities in this population (Dlugonski, Joyce and Motl, 2012).

The strengths of the studies include good rationale and justification of the chosen approach (Dlugonski, Joyce and Motl, 2012; Kasser, 2009; Borkoles *et al.*, 2008). The key findings provided some insight and depth to the understanding of the positive and negative impact of exercise and physical activity on the physical and psychosocial aspects of pwMS living in the community. However transferability of the key findings albeit from three studies are limited to the experiences of people mildly or moderately affected by MS (Dlugonski, Joyce and Motl, 2012; Kasser, 2009; Borkoles *et al.*, 2008), pwMS who were already physically active (Borkoles

*et al.*, 2008), pwMS already motivated to engage in exercise (Kasser, 2009) and women diagnosed with RRMS (Dlugonski, Joyce and Motl, 2012). Also, considering the cultural context of these studies (Dlugonski, Joyce and Motl, 2012; Kasser, 2009; Borkoles *et al.*, 2008) only one (Borkoles *et al.*, 2008) was based on the experiences of exercise and physical activity in pwMS living in UK, the others (Dlugonski, Joyce and Motl, 2012; Kasser, 2009) were undertaken in the United States of America; thereby highlighting the need to for more studies to explore and expand current understandings of the meaning of exercise and physical activity to pwMS in the community.

In addition, one of the challenges which was identified in the quantitative studies and now highlighted here is the diverse measures used by researchers to measure levels of disability in pwMS. For example, Borkoles and colleagues (2008) used the EDSS while Dlugonski and colleagues (2012) used the PDDS score which is a patient reported outcome measure. Kasser (2009) did not report on any disability measures in their study. However, all the studies provided some descriptors of disability. Nevertheless, the use of a wide range of measures limits the comparability and transferability of the findings from each study.

### **Summary of exercise and physical activity: the perspectives of pwMS**

In summary, the qualitative findings from all three studies exploring the meaning of exercise and physical activity highlighted that pwMS value exercise and physical activity and use these activities as a way to maintain psychological well being and physical functioning (Dlugonski, Joyce and Motl, 2012; Kasser, 2009; Borkoles *et al.*, 2008). The findings also suggest that the value placed on exercise and physical activity was irrespective of the intensity of the activity (Dlugonski, Joyce and Motl, 2012). As far as the researcher is aware no study has identified the types of exercise and physical activity pwMS value or prioritise in the community and the meanings they ascribe to these prioritised activities. Having an intentional focus on the activities pwMS value might be one way to engage and sustain exercise and physical activity participation in these individuals. In addition, as mentioned earlier the majority of the studies are limited to pwMS who are mildly or

moderately affected by MS, hence more studies are needed to highlight the meaning of exercise and physical activity across the whole disability spectrum.

## 2.3 Conclusion

A review of existing research has identified that there are few high quality publications relating to exercise and physical activity in pwMS. Systematic reviews and meta-analyses of interventions have indicated evidence for the physical and psychosocial benefits of exercise and physical activity. However, the majority have focused on formal, supervised structured exercise and demonstrated improvements for people mildly or moderately affected by MS. Unfortunately, a similar body of research investigating the efficacy of exercise and physical activity for those more severely affected by the condition is lacking.

Qualitative studies, although few in number, have provided some in-depth understanding of exercise and physical activity in pwMS. Although they are limited, reporting mainly the views and experiences of pwMS who are predominantly ambulant and with the relapsing remitting form of MS, they provide a better understanding of the meanings of exercise and physical activity of pwMS living in the community. Once again the focus has been on participants' experiences of supervised and structured exercise programs. Only one qualitative study explored the meaning of exercise in the daily lives of pwMS (Borkoles *et al.*, 2008) and this emphasised the importance of creating spontaneous opportunities for exercise. However this study was limited to questions about participation in exercise and not expansive of other forms of activities. Also the interview questions were based on experience of previous engagement not on self-selected exercise and physical activities.

There appears to be a paucity of research on exercise and physical activity in pwMS who are severely disabled. Similarly, there is little published work on exercise and physical activity outside of structured, supervised programmes. The type of exercise and or physical activities pwMS carry out in their daily lives and why they choose to engage with them remains under researched. Likewise, the

meaning of exercise and physical activity in the lives of pwMS has not been well studied. Gaining a better understanding of the meaning of exercise and physical activity for pwMS will add to the knowledge base and offer clinicians deeper insight into the priorities and experiences of those living with the condition. These insights will aid the design of treatment programs that are meaningful and relevant to pwMS living in the community.

This thesis will build on the findings from previous studies to gain a deeper understanding of exercise and physical activity for pwMS and to bridge some of the gaps previously mentioned. The primary aim of this thesis is to explore the priorities and meanings of exercise and physical activity in pwMS living in the community. The views and opinions will be sought from pwMS living in the community with varied MS classifications as well as different severities of the condition. The secondary aim is to explore physiotherapists' views and professional reflections about the meanings ascribed by pwMS to exercise and physical activity.

The overarching research questions for this study are:

- What are the priorities and meanings of exercise and physical activity in pwMS living in the community?
- How might the meanings pwMS ascribe to exercise and physical activity inform clinical practice?

# **Chapter 3**

## **Methodology**

### **3.0 Introduction**

This chapter details the methodological overview of the thesis. It presents an integrated methodology that underpins each of the methods that constitute the three studies in the thesis. Each method was chosen to provide insights into understanding the priorities and meanings of exercise and physical activity from the perspectives of pwMS; an area underexplored within the existing evidence. This thesis argues that insights into how pwMS ascribe meaning to exercise and physical activity might enhance more effective collaboration between pwMS and physiotherapists, which might be necessary to address the issues associated with inactivity in this population.

The overarching research questions for this study are:

- What are the priorities and meanings of exercise and physical activity in pwMS living in the community?
- How might the meanings pwMS ascribe to exercise and physical activity inform clinical practice?

In order to address the research questions, the study was divided into three phases:

1. Phase 1- The Delphi method was used as a consensus building communication method to identify and prioritise the exercise and physical activities pwMS engaged in and the reasons why they engaged in their chosen activities. This phase informed later discussions around the exercise and physical activity practices in pwMS. Chapter 4 details the Delphi Method.

2. Phase 2: Further exploration of the meaning of exercise and physical activity was carried out using in-depth semi-structured, face-to-face, interviews. This phase used the results from the Delphi study as the research tool to elicit the meanings of exercise and physical activity in pwMS living in the community. Chapter 6 details the methods used in this phase of the study.
3. Phase 3: Focus Groups were used to explore physiotherapists' understandings about exercise and physical activity in light of the Delphi results and its relevance to clinical practice. Chapter 8 details the methods used in this phase of the study.

Overall this thesis was guided by the principles of a mixed methods approach. This methodological approach is defined as "*research in which the investigator collects and analyses data, integrates the findings, and draws inferences using both qualitative and quantitative research techniques, methods, approaches, concepts or language into a single study or programme of inquiry*" (Tashakkori and Creswell, 2010,p.4). Whilst this definition only highlights integrating qualitative and quantitative studies, this concept also extends to a wide range of methodological approaches (Greene, 2006). For example, Greene (2006) highlights that the nature of mixing within the context of mixed methods can occur at different levels, these include, the tools used to collect the data (e.g. questionnaires, interviews, focus groups), the methodological approach (e.g. experimental and or qualitative designs) and theoretical assumptions (e.g. ontology, epistemology).

There are several reasons for the use of mixed methods in research. These include, the ability to understand and solve complex problems (Hanson *et al.*, 2005; Creswell *et al.*, 2011;Rauscher and Greenfield, 2009); to add deeper insights and understandings to the research topic under investigation (Sandelowski, 2000) and also to draw from the strengths gained through using a range of methodological approaches (Creswell *et al.*, 2011). The meaning of exercise and physical activity is a complex issue which lends itself to an examination from different perspectives. Multiple perspectives deepen understandings and facilitate comparisons between studies, and the elaboration of findings derived from single study methods. The

flexibility of this methodological approach made mixed methods an appropriate option to explore exercise and physical activity from different perspectives using different data collection methods.

Specifically related to this thesis, intentional mixing occurred at multiple levels. That is, at the design level the results of the Delphi Study (Chapter 5) were used to inform the development of the topic guides for the interviews (Chapter 6) and focus groups (Chapter 8). Data collection tools differed in each of the three methods (survey, semi-structured interviews, focus groups). The theoretical assumptions were underpinned by a pragmatic approach which supported diverse means of achieving research goals. Further discussions on this follow in the next section (section 3.1.1). In addition, mixing occurred during the discussion (Chapter 10), which highlights the diverse perspectives about exercise and physical activity and implications for clinical practice.

### **3.1 Philosophical position**

Scholars advise that researchers undertaking research should be open about the philosophical positions, assumptions and beliefs used to guide their research (Snape and Spencer, 2010; Biesta, 2010; Shannon-Baker, 2015). It is argued that philosophical positions are driven by the researchers' beliefs about the nature of knowledge and how knowledge can be acquired (Biesta, 2010). That is, their ontological and epistemological perspectives.

Ontology relates to the beliefs and assumptions one holds about the nature of reality (Guba, 1990). The researcher's approach to this thesis is one that assumes that multiple versions of realities (ontology) exist, which are diverse, complex and extend beyond simply identifying the cause and effect of a phenomenon (Biesta, 2010; Snape and Spencer, 2009). That is, the researcher recognises and understands that MS is a complex condition and each person with MS might be affected by the condition in different ways. In addition, pwMS might have different experiences of living with the condition and there might be multiple factors (e.g. physical, psychosocial, and environmental) that may influence their exercise and

physical activity practices and the meanings pwMS ascribe to exercise and physical activity.

Epistemology relates to the belief one holds about how knowledge is generated (Biesta, 2010; Snape and Spencer, 2009). In this thesis the researcher holds the view that knowledge can be acquired and generated in a number of ways, for example, objectively through statistical testing as well as through subjective interpretation of textual data. Mixed methods research provides the possibility to combine both empirical and textual data within the same study (Biesta, 2010). This combination has been encompassed with the approach of pragmatism.

### **3.1.1 Pragmatism**

Pragmatism as a philosophical position has been developed and critically appraised through the earlier works of philosophers John Dewey, Charles Pierce and William James (Johnson and Onwuegbuzie, 2004). Pragmatism offers a credible alternative to the two predominantly existing traditions of the positivist and interpretative approach to research (Biesta, 2010; Johnson and Onwuegbuzie, 2004). The positivist ontological and epistemological position assumes that there is one reality that can be measured objectively, one truth which can be obtained, the knower and that which is to be known or observed can and should be independent, biases can be eliminated and claims made towards generalisation (Lincoln and Guba, 1985). In contrast, the interpretivists dismiss the positivist philosophy and uphold the assumptions that multiple versions of reality exist, which are subjective and peoples' experiences of these realities are diverse (Lincoln and Guba, 1985). Furthermore the interpretivist believes that it is impossible to separate the knower from what is known and or observed (Lincoln and Guba, 1985). Considering both traditional perspectives about the nature of reality and how knowledge is acquired, pragmatism bridges the gap between these two distinct perspectives to offer an alternative that claims that knowledge can be acquired through both objective and subjective means in the same study (Biesta, 2010; Johnson and Onwuegbuzie, 2004).

Pragmatism was adopted as the philosophical underpinning of this thesis (Creswell et al., 2011; Biesta, 2010; Johnson, Onwuegbuzie and Turner, 2007; Johnson and Onwuegbuzie, 2004; Cherryholmes, 1992) due to its key characteristics. Pragmatism asserts that there are multiple ways of knowing or seeking knowledge (Tashakkori and Teddlie, 2010). Knowledge obtained therefore might be co-constructed as well as shaped by the experience of the world and interactions with the world in which one exists (Johnson and Onwuegbuzie, 2004; Biesta, 2010). Pragmatism focuses on using the most appropriate tools to answer the research questions (Tashakkori and Teddlie, 2010); it is practically based and outcome directed and methods utilised by the researcher are used to complement each other (Johnson and Onwuegbuzie, 2004).

Specifically relating to this study, a pragmatic position provided the opportunity for the researcher to understand the meanings of exercise and physical activity from different perspectives. That is, the perspectives of pwMS living in the community who experience life with a chronic progressive neurological condition as well as the perspectives of physiotherapists who were involved in working with pwMS. Combining the insights of the different perspectives that exist and the knowledge gained through exploring this topic from different viewpoints might help to shape treatment ideas about exercise and physical activity in pwMS living in the community.

### **3.2 Operationalising pragmatism in mixed methods approach**

This thesis explored the priorities and meanings of exercise and physical activity in people with MS. The central focus of the thesis is the views about exercise and physical activity from the perspectives of pwMS living in the community, and to identify the clinical implications of these views.

A mixed methods approach was chosen as the most appropriate method to answer the research questions specific to this thesis. As highlighted above, intentional mixing of different methodological approaches can be done at different levels within a single study (Shannon-Baker, 2015; Biesta, 2010).

Whilst pragmatism was utilised and deemed the most appropriate philosophical position that suited the researcher's ontological and epistemological approach to this research, it should be noted that there were underlying tensions, which should be acknowledged. As highlighted above, the pragmatic approach in mixed methods research supports both subjectivity and objectivity in a complementary manner towards the development of knowledge (Biesta, 2010; Johnson and Onwuegbuzie, 2004). The pragmatic approach is therefore fundamentally pluralist and primarily driven by using the best-suited approach to answering the research questions (Johnson and Onwuegbuzie, 2004). As such, the focus and decisions made by the researcher in this thesis were not driven specifically by which philosophical position should be taken but by determining the best approach needed to address the research questions. Therefore, the results and consequences of the research were judged by whether the methods chosen were appropriate in eliciting the complexities associated with how pwMS living in the community ascribe meaning to exercise and physical activity and to determine the clinical implications of these meanings from the perspectives of health professionals.

In addition, philosophically the Delphi method (Chapter 4), interviews (Chapter 6) and focus groups (Chapter 8) have the potential to be viewed as being in epistemological dispute. On the one hand the Delphi seeks order and consensus thereby resting on the idea that there is a single truth about the meaning of exercise and physical activity to which all pwMS living in the community would agree objectivity. On the other hand, researchers using interviews seek subjective views and are aligned to the belief that a single phenomenon can have multiple meanings depending on personal perspectives, context and experiences (Holloway and Wheeler, 2010; Kvale and Brinkmann, 2009; Lewis, 2009). Furthermore focus groups tend to look for consensus but can be utilised to look for convergent and divergent views (Finch and Lewis, 2009). However, the pragmatist position was helpful in that it offers a resolution to this potential conflict by looking at what is the best way to answer the research question first and by embracing a pluralist position (Biesta, 2010; Johnson and Onwuegbuzie, 2004).

It should also be acknowledged that pragmatic decisions were made about the order of the studies (Studies 1-3), which had the potential to pose tensions within the thesis. Therefore decisions were made about the practicalities of navigating through the process of answering the research questions for each study. For example, one of the commonalities amongst study participants (Studies 1 and 2) is that they all had MS. As such, starting the study by identifying the commonalities of the exercise and physical activity practices of pwMS through an objective consensus building technique was thought to be appropriate in highlighting the prioritised exercise and physical activity practices and the reasons why pwMS as a group engaged in exercise and physical activity. Findings from the Delphi study (Study 1) then facilitated the move beyond a group-based discussion to initiating one to one discussion through the use of interviews (Study 2). As highlighted in chapter 2, MS is a diverse condition and pwMS have a wide range of disabilities and experiences of living with the condition. Therefore the methodological approach provided the opportunity for the researcher to give space for the multiple versions of reality that exist for pwMS in order to make judgements at the end about the meanings pwMS ascribe to exercise and physical activity.

Overall a pragmatic view was helpful in that it provided the opportunity to combine different methods. The aim of the researcher was to elicit the multiple variations of reality that exists and unearth these experiences through the different methodological approach; that is, through the use of surveys, interviews and focus groups. However the researcher acknowledges that strengths and weaknesses exist. Pragmatism was used to balance these in part. Specifics will be discussed in individual chapters (Chapters 5, 7 and 9).

### **3.3 Conclusion**

This chapter presented the methodological overview of this thesis. It described the rationale for using mixed methods as the most appropriate method to answer the research questions. Details were provided about the researcher's ontological and epistemological position as well as how each method interacted in a complementary way to inform the different stages of the study.

## **Chapter 4**

### **Study 1 Method: A day in the life of people with Multiple Sclerosis**

#### **4.0 Introduction**

This chapter details the methods used in the Delphi study to gain entrance into the world of pwMS. A study entitled "***A day in the life of people with Multiple Sclerosis: an exercise and physical activity study***" was designed to explore the exercise and physical activity practices and priorities of pwMS living in the community. The researcher was interested in identifying the prioritised exercise and physical activities as a way to understand the activities pwMS considered important. In addition, the researcher was interested in determining whether or not there was consensus about the prioritised exercise and physical activity practices in pwMS. The purpose for determining consensus was to gather the groups' opinions about the exercise and physical activity practices that are likely to be meaningful to pwMS which might assist to initiate discussions about exercise and physical activity at an individual level. Therefore, the research questions to be addressed in this study were:

- What are the prioritised exercise and physical activity practices of pwMS living in the community?
- Why do pwMS living in the community undertake exercise and physical activity?
- Is there consensus about their prioritised exercise and physical activity?
- Is there consensus about the reasons why they engage in these activities?

The research questions focused on the viewpoints of pwMS therefore methods that could be considered include, interviews, focus groups and traditional questionnaires (Hicks, 2004; Holloway and Wheeler, 2010; Kvale and Brinkman, 2009). However, these methods have specific advantages but more importantly

disadvantages which result in the fact that they cannot address the specific research questions. For example, interviews are mainly used in the literature to explore in-depth meaning of a phenomenon (Tod, 2010; Kvale and Brinkmann, 2009). Whilst interviews could be used to explore the research questions in-depth within the context of the individuals' experience, this study aimed to identify the common exercise and physical activity practices pwMS carried out in the community and to examine whether or not there was consensus about which exercises and physical activities were their priorities.

In addition, focus groups are known to provide insightful information about a particular topic or issue of interest and are best suited to arriving at a consensus through active discussion (Goodman and Evans, 2010). However, the use of focus groups presents its own challenges due to the structure of the technique, such as group dynamics, which has the potential to influence participants' decision-making process especially by other participants with dominant personalities (Holloway and Wheeler, 2010). As such, considering the research aims where participants would be asked about their physical activity practices, the answers provided could be viewed as socially desirable. Also, bearing in mind that some pwMS have speech impairment, such individuals may not have the time or space to express themselves in a focus group discussion.

Another limitation, similar in both interview and focus group approaches in research, is the sample size. The number of participants involved in either approach is usually small and, as such the results are not generalisable, although they may provide in-depth information (Goodman and Evans, 2010; Tod, 2010). In this study, the sample size was important, in order to gain information that is representative of pwMS of varying disability, lifestyles and experiences of the disease.

Another methodological approach that is widely used in research is traditional questionnaires, which are an inexpensive way of collecting information from a large sample size about a topic of interest (Jones and Rattray, 2010). However, traditional questionnaires, would only answer part of the research questions

posed. That is, the types of activities people undertake and reasons why they engage in these activities. Therefore, this method would not be able to capture the iterative process of consensus building, which is necessary to determine whether or not there is agreement with the prioritised activities and reasons why pwMS engaged in their chosen activities. One major drawback of traditional questionnaires is that respondents answer the questions set by the researcher so other areas of interest to the research may not be identified (Denscombe, 2003). By using a more open approach, such as in the initial stages of a Delphi, the information generated and findings can be constructed by the respondents and not by the researcher.

In summary, the traditional methodological approaches stated above used in research were limited in answering the posed research questions for this study (Study 1). Whilst the study could have used any of the above approaches, staying true to one of the research aims, the researcher needed another method that would provide evidence of group consensus for the activities prioritised by pwMS living in the community.

The following sections will explore an alternative method used to elicit views from pwMS that would provide a way for prioritisation and consensus building to occur through a democratic process where all participants have an equal voice. This method is known as the Delphi method and is defined as “a method for the systematic solicitation and collation of judgements on a particular topic, through a set of carefully designed sequential questionnaires, interspersed with summarised information and feedback of opinions derived from earlier responses” (Delbecq et al., 1975,p.10). This approach is becoming more widely used in healthcare research and was considered to be the most appropriate methodological approach to be used in this study.

## **4.1 Delphi method**

The Delphi method is an alternative approach that may be used to elicit views from respondents about a particular topic of interest as well as a means of prioritisation and or consensus building, (Keeney, Hasson and McKenna, 2011). Consensus strengthens the outcome of the study. It is based on the assumption that the opinion of all the participants collectively as a group is more valid as opposed to an individual (Keeney, Hasson and McKenna, 2011). The group-based consensus epitomises the acceptability or resolution of participants to support decisions made by the group even if the decision was not their choice as an individual.

The Delphi method has been used to good effect for setting research priorities (Chang *et al.*, 2003; Daly, Chang and Bell, 1996), development of methodological tools (Mokkink *et al.*, 2010) and shaping practice such as guiding health professionals in the management of specific conditions (Prodinger *et al.*, 2010; Khan and Pallant, 2007; O'Hara, De Souza and Ide, 2000). However, there is a dearth of evidence using patients or laypersons as experts; some studies have shown the valuable contribution their perspective can have on healthcare research (Prodinger *et al.*, 2010; O'Hara, De Souza and Ide, 2000)

Focusing on the area of MS research, the Delphi method has contributed in ways that benefited people living with the disease. One of the key contributions has been highlighted in a study used to identify the self-care strategies in people with MS living in the community (O'Hara, De Souza and Ide, 2000). The findings from this study influenced the development of a professionally guided self-care program for community dwelling people with MS (O'Hara *et al.*, 2002). Similarly, Prodinger and colleagues (2010) used a 3 Round Delphi study to identify the environmental factors that impact the work and social life of pwMS (Prodinger *et al.*, 2010). Both studies used pwMS as the experts because the topics being researched were focused on issues of living with MS.

#### **4.1.1 Types of Delphi methods**

There are many different types of Delphi methods (Linstone and Turoff, 1975; Ziglio, 1996; Keeney, Hasson and McKenna, 2011). Table 4.1, details the common types widely used in research and their characteristics.

The three most common methods are the Classic, Policy and Decision Delphi. The Classic Delphi is the original Delphi, which is characterised by four main features, namely anonymity, iteration, controlled feedback and statistical group response (Dalkey and Helmer, 1963). The main aim is to determine consensus through statistical testing and or to determine if there is stability across the responses given by research participants. The Classic Delphi is used with people who are considered to be experts in the topic being discussed and is the approach most appropriate for this study.

There are two different administrative modes of delivery of the Classic Delphi (Linstone and Turoff, 1975). The first involves the use of the paper-pencil version (Linstone and Turoff, 1975), which requires a monitor team responsible for designing the questionnaires and summarising the results in order to develop the other questionnaires for each Round. This mode of delivery is advantageous as it allows participants to respond to the questionnaires at their own pace. For these reasons it was the administrative mode of choice for this study. The other mode of administration is known as the Real-Time Delphi or Delphi Conference (Ziglio, 1996; Linstone and Turoff, 1975). In this version a computerised program is used instead of having a monitor team. This programme is designed to collate the groups' response and unlike the paper and pencil version requires immediate response.

**Table 4.1: Types of Delphi methods and their main characteristics**

Classic Delphi	Uses an open first Round to facilitate idea generation to elicit opinion and gain consensus. Uses three or more postal Rounds Can be administered by email
Modified Delphi	Modification usually takes the form of replacing the first postal Round with face-to-face interviews or focus group. May use fewer than three postal or email rounds.
Decision Delphi	Same process usually adopted as a classical Delphi Focuses on making decision rather than coming to consensus
Policy Delphi	Uses the opinions of experts to come to consensus and agree future policy on a given topic.
Real Time Delphi	Similar process to classical Delphi except that experts may be in the same room. Consensus reached in real time rather than post. Sometimes referred to as a consensus conference.
E-Delphi	Similar process to the classical Delphi but administered by email or online web survey.
Technological Delphi	Similar to the real time Delphi but using technology, such as hand held keypads allowing experts to respond to questions immediately while the technology works out the mean/,median and allows instant feedback allowing experts the chance to re-vote moving towards consensus in the lift of group opinion.
Online Delphi	Same process as classical Delphi but questionnaires are completed and submitted online
Argument Delphi	Focused on the production of relevant factual arguments Derivative of the Policy Delphi Non-consensus Delphi
Disaggregative Delphi	Goal of consensus not adopted Conducts various scenarios of the future for discussion Uses cluster analysis

Adapted from: Keeney, Hasson and McKenna, 2011, p.7

#### **4.1.2 Application of the Delphi method**

There is no clear guidance about the application of the Delphi method (Hasson and Keeney, 2011; Ziglio, 1996; Linstone and Turoff, 1975; Dalkey and Helmer, 1963). This lack of clarity about the application makes it susceptible to various interpretations, which have been a source of widespread criticisms of the method (Walker and Selfe, 1996; Rowe, Wright and Bolger, 1991; Woudenberg, 1991; Sackman, 1975). Nevertheless, despite no agreed guidance there are some common features for which the method is known. These include the use of questionnaires, feedback process and consensus testing.

The Delphi method uses questionnaires as the data collection tools to find out the views and opinions about a particular subject of interest (Adler and Ziglio, 1996; Linstone and Turoff, 1975). The questionnaires are designed and used throughout the study using an iterative process known as Rounds. Each Round is built on the responses gained from previous Rounds (Rowe and Wright, 1999; Adler and Ziglio, 1996). The first Round is often considered as the information-generating Round, where the aim is to generate as many responses to the questions asked. For subsequent Rounds, the questionnaires are then designed based on the responses to the previous Round, grouped into categories and fed back to the group (Adler and Ziglio, 1996).

Another common feature observed in many Delphi studies is the use of feedback throughout the Rounds (Ziglio, 1996; Linstone and Turoff, 1975). At each stage of the process research participants are presented with the groups' opinion about the topic under discussion. They are then required to make a decision about whether to change their views in light of the information presented or stay with their original decision (Rowe and Wright, 1999). In other words, each Round provides the opportunity for participants to reflect and change their responses if they so choose (Rowe and Wright, 1999).

Another common feature of Delphi studies is related to achieving consensus. This is the main purpose of the classic Delphi. The process of defining and achieving consensus has been cited in the literature in different ways (Hasson, Keeney and McKenna, 2000; Williams and Webb, 1994). These include, taking into account the entire judgement of the participants (Delbecq et al., 1975), pre-setting the level of consensus (William and Webb, 1994), looking for central tendency (Dajani, Sincoff and Talley, 1979) and observing the data for stability between two Rounds (Dajani, Sincoff and Talley, 1979).

#### **4.1.3 Advantages and disadvantages of using the Delphi Method**

The Delphi method like any other methods used in research has both advantages and disadvantages (Creswell, 2009; Crotty, 1998; Linstone and Turoff, 1975). One of the key advantages is the ability to gain expert views on a topic of interest (Linstone and Turoff, 1975). For example, as illustrated in the literature review, there is a large evidence base for exercise and physical activity in pwMS but little information about the prioritised physical activities of pwMS living in the community.

Another advantage is the flexibility of this approach to recruit a large number of research participants not bound by a specific geographic area (Ziglio, 1996). However, this would be dependent on the availability of resources to ensure feasibility of the study.

Anonymity, another key advantage, allows participants to express and or change their views as the study progresses without influence or pressure of other participants (Dalkey and Helmer, 1963; Rowe and Wright, 1999; Goodman, 1987). This is one of the known strengths of the Delphi method, which is in contrast to other face-to-face methods such as interviews and focus groups (Tod, 2010; Goodman and Evans, 2010).

Despite these key advantages the Delphi method has known disadvantages, which can be considered as primary and secondary to the use of the method. The primary disadvantages associated with the Delphi method are that the approach may be time consuming (Keeney, Hasson and McKenna, 2011; Duffield, 1993), requires adequate resources depending on the number of Rounds involved (Ziglio, 1996), and due to the underlying use of questionnaires, the risks associated with attrition rates throughout the Rounds are high (Linstone and Turoff, 1975; Keeney, Hasson and McKenna, 2011; Clibbens, Walters and Baird, 2012).

The secondary disadvantages are those for which the method has been heavily criticised. One is associated with scientific rigor due to lack of random sampling as a technique (Sackman, 1975; Gupta and Clarke, 1996; Paliwoda, 1983). Other criticisms are associated with poor questionnaire design and procedural deficiencies (Gupta and Clarke, 1996), validity (Goodman, 1987), reliability

(Walker and Selfe, 1996) and credibility (Sackman, 1975). These criticisms are not only reflective of the Delphi method but can also apply to other methods previously discussed (Gerrish and Lacey, 2010).

#### **4.1.4 Delphi method and the use of experts**

One of the key characteristics of the Delphi method is the use of ‘experts’ as people who voice their views and opinions about a particular topic of interest based on their expertise of that area (Keeney, Hasson and McKenna, 2011; Adler and Ziglio, 1996; McKenna, 1994). However, the use of experts in Delphi studies has been controversial. Lying at the heart of this controversy is the definition of an expert (Sackman, 1975; Linstone and Turoff, 1975; McKenna; 1994; Green *et al.*, 1999; Rowe, Wright and Bolger, 1991). These arguments have been the centre of debate in Delphi studies for decades (Green *et al.*, 1999; Rowe, Wright and Bolger, 1991).

When the Delphi method was first developed, the term ‘expert’ was limited to professionals with specific knowledge and expertise in a particular field (Ziglio, 1996; Linstone and Turoff, 1975). Since then, the use of the term ‘expert’ has been expanded to include non-professionals (McKenna, 1994; Powell, 2003). With this broadening of the term, the literature has also shifted albeit not in meaning, but in the use of the word, where experts are now at times being referred to as “informed advocates” (Goodman, 1987, p.730), “informed individuals” (McKenna 1994;p.1221), and or anyone with sufficient knowledge about a particular topic (Keeney *et al.*, 2001).

In considering who should be called experts, Ziglio (Ziglio, 1996) offers some guidance for both the researcher and the participants suggesting that experts should have:

- *Knowledge about the topic and willingness to engage in the topic*
- *Capacity and willingness to contribute to the exploration of a particular problem.*
- *Sufficient time to dedicate to the Delphi exercise*
- *Skill in written communication and in expressing priorities through voting procedures*  
(Ziglio, 1996,p.14)

The choice of appropriate experts is guided by the research questions (Adler and Ziglio, 1996; Linstone and Turoff, 1975). In Delphi studies, the primary researcher has the responsibility to choose the experts and clearly state how experts were chosen. Some studies have tried to resolve this issue by having clear criterion of whom they consider experts. For example, Campbell and colleagues (2000) in their study examining the prescribing indicators for UK general practice used as their experts all pharmaceutical and medical advisors in the UK. In other studies, Georgiou and colleagues (2012) used disabled students as their experts when exploring the experience of disabled students on work placements, whilst Ferguson and colleagues (2008) used physiotherapists as their experts to determine consensus in the management of low back pain. These studies used the research question and context of the study as the guide to decide on the expertise needed to provide answers to the research questions.

Similarly, in this study, the researcher was guided by the research questions which has a focus within the context of the community. As such, pwMS who are living in the community would be appropriate experts. This decision was made because community dwelling pwMS have a more established routine and are likely to be more stable with the disease progression, unlike pwMS who are in the hospital setting undergoing various interventions.

Therefore, in order to answer the research questions regarding what activities pwMS living in the community were engaging with and the reasons why they were undertaking these activities, community dwelling pwMS were chosen as the experts. It is not unusual in Delphi studies to use lay people as experts although this study is deemed to be health related. In fact, Powell (2003) reiterates that experts used in healthcare studies can range from clinicians, patients or lay people who have a particular disease or disability or who have had some form of intervention. Similarly, studies have shown the value of having patients' or carers' views on a wide range of issues relating to them (O'Hara, De Souza and Ide, 2000). This has been demonstrated in studies looking at lifestyle needs of people with disability; or the inclusion of patients in Delphi studies as experts (O'Hara, De Souza and Ide, 2000).

In this study, pwMS were considered appropriate experts on the basis that they had the knowledge and experience of living with the disease and had expertise in managing their MS in their daily lives. Using pwMS as experts have some advantages but also disadvantages that should be considered. The main advantage is that this information will add to the existing body of evidence around exercise and physical activity as well as provide some insight about the prioritisation of activities in people with MS, irrespective of their disability. Engaging people with significant disability in physical activity based research offers participants a way of expressing their views about their priorities as their views and opinions might not otherwise be heard due to the strict inclusion criteria of some physical activity based studies.

In summary, the researcher has the responsibility to clearly define who the experts are and whether they are capable of answering the research question in a Delphi study. The key consideration is whether the experts have knowledge, experience and a willingness to participate in the Delphi process.

#### **4.1.5 Validity and Reliability of the Delphi method**

The robustness of a tool is judged against certain standards such as its reliability and validity. Reliability is defined as “the extent to which a measuring procedure yields the same results on repeated trials” (Neuendorf, 2002, p.112). This definition of reliability is widely used by quantitative researchers. As such, researchers with a quantitative stance may look for repeatability as the hallmark in any given study. However, Delphi studies are not predominantly based on quantitative markers and using this definition for reliability leaves the method open to critics who claim that Delphi studies are not repeatable (Woudenberg, 1991; Rowe, Wright and Bolger, 1991). The repeatability is challenged by the very nature that Delphi studies collect a mixture of quantitative and qualitative information. Additionally, by generating qualitative data in Delphi studies repeatability is near impossible as peoples’ views and opinions might change based on the context and over a period of time.

In response to the critics regarding the lack of reliability in Delphi studies, some researchers assert that it is pointless to examine reliability through the lens of a

quantitative view of the world (Blass, 2003; Hasson, Keeney and McKenna, 2000). Instead, they argue that reliability in Delphi studies should be determined by utilising more of a qualitative view of the world (Hasson, Keeney and McKenna, 2000), which includes evaluation of credibility (truthfulness), fittingness (applicability), consistency and confirmability (Lincoln and Guba, 1985).

In this study, the researcher's interpretation of reliability was based on taking a pragmatic stance and being guided by the research questions. That is, to ensure that as far as possible the study's processes could be repeated, whilst accepting that views and opinions may change due to the progressive and variable nature of MS, which might have implications for credibility and applicability of the study. As such, it was the researcher's responsibility to provide participants with clear instructions about what should be done at each stage of the Delphi as well as providing adequate information about how data were collected and managed. These steps were central to this study and have been shown to have a positive impact as well as improve reliability (Scheibe, Skutsch and Schofer, 1975; Ziglio, 1996).

Validity is defined as "the extent to which a measuring procedure represents the intended and only intended concept" (Neuendorf, 2002, p.112). That is, with reference to this study, gaining the views about the prioritised exercise and physical activity practices from pwMS who have knowledge and experience of living with the condition in the community. Validity is one of the strengths of the Delphi Method (Goodman, 1987; Walker and Self, 1996) and is based on the assumption that there is strength in numbers. In other words group opinion is more representative of the general experience than individual opinion (Dalkey, 1969; Keeney, Hasson and McKenna, 2011). In Delphi studies, validity is enhanced by the feedback mechanisms innate to the procedures (Linstone and Turoff, 1975; Ziglio, 1996). Validity can be further enhanced through piloting the questionnaire prior to the start of the study and is recommended as a way to check for face validity and feasibility of the intended study (Jairath and Weinsten, 1994).

#### **4.1.6 Summary**

Based on the information highlighted in the previous sections and by considering the different communication methods of eliciting views from research participants, the Delphi Method was deemed the most appropriate to answer the research questions about the prioritised exercise and physical activity and the reasons why pwMS living in the community engaged in these activities.

### **4.2 Study 1 Method**

#### **4.2.1 Study Aim**

To identify the prioritised exercise and physical activity practices of pwMS living in the community and the reasons why they engaged in these activities.

#### **4.2.2 Study Design**

A four Round classic Delphi method was used to identify, gather, prioritise and agree the exercise and physical activity practices of pwMS and the reasons why they carried out these activities in the community. The common features of the Classic Delphi adopted for this study include, the paper and pen version, anonymity, the use of questionnaires and consensus testing (Section 4.1.1).

##### **4.2.2.1 Development of protocol and materials used in the study**

###### **a) Development of study protocol**

A protocol was developed based on publications using the Delphi method in health research (Keeney, Hasson and McKenna, 2011; Adler and Ziglio, 1996). The protocol details the step-by-step procedure of the Delphi (see Table 4.2).

Participants were asked to complete the survey and return it within a 2-week time frame. A few days before the deadline, a reminder letter was sent to non-responders with an additional two weeks for responding after which, no further reminders were sent. The time interval between each Round was approximately

two months to provide enough time for participants to respond to the survey, and for analysis to be completed but not too long so participants lost interest between the Rounds of the Delphi.

**Table 4.2: Study Protocol**

Rounds	Steps	Timeframe
Round 1 (Open Round)	Step1- Researcher mails questionnaire # 1 to respondents	July- December 2012
	Step 2- Participants brainstorm individually to generate lists for exercise and physical activity and reasons why.	
	Step 3- Participants mail completed questionnaire back to researcher.	
	Step 4- Reminder letters sent to non-responders	
	Step 5- Researcher collates information based on the responses and identifies categories based on the items listed.	December 2012- January 2013
Round 2 (Selecting and limiting Round)	Step 6- Researcher mails questionnaire # 2 to participants based on the categories identified from Round 1.	January 2013
	Step 7- Participants asked to review the groups' response and choose 10 categories from the list in order of importance.	
	Step 8- Participants mailed completed Questionnaire back to researcher	February 2013
	Step 9- Reminder letters sent to non-responders	February 2013
	Step 10 – Researcher calculates the most frequently reported categories.	March 2013
Round 3 (Ranking)	Step 11- The researcher mails questionnaire #3 to the participants. Participants asked to rank their chosen 10 categories in order of importance and state whether or not they agree with categories.	March 2013
	Step 12-Participants mail response back to the researcher	April 2013
	Step 13- Reminder letters sent to non-responders	April 2013
	Step 14- Researcher use descriptive statistics to calculate the mean rank and note whether the group agreed or disagreed with the categories.	April 2013
Round 4 (Consensus)	Step 15- Researcher mail questionnaire #4 to participants. Participants asked whether they agreed with the ranked order of each category.	May 2013
	Step 16- Researcher applies statistical analysis to find out whether or not consensus was achieved.	June 2013
Study complete	Step 17 –Researcher to compile summary report post PhD for respondents.	November 2015

## **b) Development of questionnaires**

Central to the Delphi method is the developmental phase of the questionnaires. This is the mode of communication between the researcher and respondents and is crucial to the success of the study. In this study, key decisions were made about the questionnaires for each Round. These decisions were taken to inform the design of the questionnaires so as to reduce the attrition rate and to reduce the burden on participants.

### **i. Development of Round 1 questionnaire**

The aim of Round 1 was to generate information about the exercise and physical activity practices of pwMS living in the community and to ascertain the reasons why pwMS undertake these activities in a typical day. A questionnaire was needed at this stage as an open first Round to facilitate idea generation, in order to elicit views and opinions from respondents (Keeney, Hasson and McKenna, 2011). A secondary aim was to collect demographic information (e.g. age, sex, marital status, employment), ascertain information about the functional level and also to gauge the perceptions of the sample regarding respondents' general health.

The Barthel Index (BI) (Gompertz, Pound and Ebrahim, 1994) and the Short Form-36 (SF-36) (Ware and Sherbourne, 1992) were used as descriptors to provide information about the participants' functional level and perception of quality of life. The Barthel Index was developed in the sixties and is widely used in the area of research and rehabilitation as a measure of disability (Hobart *et al.*, 2001; Mahoney and Barthel, 1965). Since then it has been modified and the type used in this study was the postal version (Gompertz, Pound and Ebrahim, 1994), which allows respondents to rate themselves with regards to their functional ability and was more feasible because respondents were located in widespread regions of the UK. The Barthel Index consists of 10 questions about the functional activities individuals are able to perform on a daily basis. The potential score on the Index ranges between 0-20 where lower scores indicate increased disability. The BI is easy to use and widely used in research and clinical practice, as such the findings from this study could be compared to previous studies. The validity and reliability

for the postal version of the Barthel index has been reported (Hobart, Lamping and Thompson, 1996).

In addition, the SF-36 questionnaire was designed from the medical outcome study (MOS) in the USA (Ware and Sherbourne, 1992) and measures health related quality of life. It has eight health dimensions namely, physical functioning (10 items); role limitations due to physical problems (4 items); bodily pain (2 items); general health perception (5 items); vitality (4 items); social functioning (2 items); role limitation due to emotional problems (3 items) and mental health (5 items). Each dimension is scored based on a likert scale and summed to provide a score ranging between 0-100 where 0 is equivalent to worst health and 100 is equivalent to optimal health.

The validity and reliability of the SF-36 has been well established (Nortvedt *et al.*, 1999; Vickrey *et al.*, 1997; Brazier *et al.*, 1992) and has been used in pwMS living in the UK (O'Hara *et al.*, 2002). The SF-36 was chosen for use in this study because it is valid, reliable and can be used as a self- administered tool (Vickrey *et al.*, 1997).

One key decision made in the development of Round 1 questionnaire was to ensure clarity of the terms used in the study. For example, as mentioned in chapter 1, exercise and physical activity are used interchangeably in the literature. As such, these terms were defined based on Caspersen and colleagues (Caspersen, Powell and Christenson, 1985) and examples provided to add clarity to the terms. However, participants were encouraged to only the use the examples as a guide.

Another term that needed to be clarified was 'typical day'. Typical day was defined as any day of their choice. A 'typical day' was chosen so as to reduce the likelihood of recall bias (Matthews, 1998), which may have been a factor if activities in a specific time were asked about, and to ensure that typical and regular activities were reported.

Following the development of the Round 1 questionnaire, it was piloted on three pwMS of varying disability as defined by the Barthel Index (Mahoney and Barthel, 1965). The pilot study will be fully described later. Piloting is encouraged in

Delphi Studies (Jairath and Weinstein, 1994), however there is an ongoing debate about whether to pilot only the first Round or throughout all the different Rounds. Also, whether the piloting should occur for all the Rounds prior to the start of the study or pilot each Round separately as the study progresses.

In this study, the first Round was piloted to check for face and content validity. This is in line with the majority of other Delphi researchers (Hasson and Barnett 2002, Hung, Altschuld and Lee, 2008; Valdez, 2009). Subsequent Rounds 2-4 were not piloted. This decision was based on the number of iterations involved in the study, as such the researcher did not wish to create undue burden by subjecting respondents to more Rounds than were needed. Subjecting respondents to piloting throughout the Rounds has been shown to increase attrition rates (Clibbens, Walters and Baird, 2012).

All the paperwork relating to Round 1 was used in the piloting phase and included the participant information sheet and booklet. Considerations were made to the design of the layout of the booklet so that it was easier to turn pages. Also, all documentation was written in a 14-point font size with 1.5 line spacing with a view to make the information more readable for respondents (Alderson 2004).

Details of the pilot study will be presented below.

## **ii. Pilot Study: Round 1**

### **Aim:**

The aims of the pilot study were:

1. To assess the content of the materials and tools developed and chosen for the study to see whether or not they were appropriate to the targeted study group, that is, pwMS who were disabled.
2. To test the study protocol and procedure in order to identify any potential problems unforeseen by the researcher.

## **Method:**

**Sample and recruitment:** A sample of convenience was recruited through MS therapy centres, MS Society websites and through snowball sampling techniques. Three women diagnosed with MS with varying degrees of disability were used in the piloting phase of the study, as they were the first to contact the researcher, fulfilled the criteria for inclusion and gave informed consent.

## **Materials and tools used in piloting:**

The materials to be piloted included the participant information sheet, booklet and the study protocol. The booklet included the two key Delphi questions, the monitoring tools (SF-36 and Barthel Index) as well as a pro forma to collect the demographic information.

## **Procedure:**

The three respondents were posted the research pack which included the participant information sheet, Round 1 booklet and stamped address envelope. The study protocol (steps 1-5) was applied. Following completion of the booklet, the researcher asked respondents to provide feedback about three areas, namely, the overall content of the paperwork, the clarity of the instructions and the time taken to complete the booklet. This feedback was provided over the telephone (2 respondents) and face to face (1 respondent). Information was recorded using a pro forma designed by the researcher (see Appendix 5).

## **Findings:**

### **Content**

All three respondents judged that the information sheet along with the booklet was clear, relevant, followed a logical pattern and the font size was adequate. Therefore these aspects of the booklet did not require revisions.

All three respondents completed the section related to the participants' descriptors (e.g. Barthel Index and SF-36 Health Survey) used in the study

appropriately. However, one respondent comment on whether a question in the Barthel Index was needed but as the other two did not it was decided to leave it in.

The time taken to complete the questionnaire varied between 20 minutes to 1 hour but none of the respondents felt the completion time was problematic.

The timeframe was also checked in relation to the time taken for the researcher to mail a questionnaire using the postal system through to the time the completed questionnaire was returned. Based on the pilot study respondents took approximately two weeks to return the completed questionnaire. This was necessary to set realistic cut-off times for each Round.

## **Protocol**

As a result of the pilot, a cover letter was included in the research pack, which stated the deadline date for response of the completed questionnaire and added a level of personalisation to the study.

## **Discussion and conclusion:**

The aim of piloting was to assess the content of the materials and tools used in the study. Following piloting no change was made to the participant information sheet, as all three respondents were satisfied with the information provided and the layout of the information. The final research pack consisted of a cover letter, participant information sheet, booklet and a stamped envelope for returning the completed booklet.

### **iii. Development of Rounds 2-4 questionnaires**

All other questionnaires for Rounds 2-4 were developed using the underlying principles used in Round 1. These included, writing devoid of professional jargon, layout out of the information in an easy to read format and only providing the information that is necessary to inform respondents about what is required for the Round. The information presented to the respondents provided feedback from the results of the previous Round and asked only the necessary questions that would inform each subsequent Round.

### **4.2.3 Ethical considerations**

The Research Ethics committee at the School of Health Sciences and Social Care, Brunel University approved the study (Reference 12/4/PhD/04, see Appendix 3a). The initial ethics approval was based on 3 Rounds however due to the addition of a 4<sup>th</sup> Round which was necessary to determine consensus, amendments were made and approved by the ethics committee (see Appendix 3b). Considerations were made in relation to working with vulnerable adults, consent to participate, anonymity, and confidentiality. A participant information sheet provided all details of the study and explained fully the tasks required of respondents. Informed consent was assumed when respondents returned completed questionnaires and a note to this effect was included at the end of the questionnaires.

### **4.2.4 Recruitment and sample**

Recruitment involved a series of targeted strategies aimed at people who have been diagnosed with MS and were living in the community. The MS Society and MS Trust were contacted to advertise the study on their websites and agreed to do so on receipt of the ethics approval. A second strategy implemented aimed to target known places where pwMS have an established community, for example, through locally led MS groups and MS Therapy centres (n=29). This involved emailing and telephoning many MS therapy groups in different regions of the UK to raise awareness of the study and to pass the information on to their members through their membership emails and newsletter portals.

Awareness of the study was raised by promoting and delivering presentations at MS group meetings in and around southeast England. The research flyer along with the research pack, which contained the participant information sheet and booklet were distributed at the request of potential respondents.

Finally the snowball sampling technique (Procter, Allan and Lacey, 2010), was used by asking respondents to forward the study flyer to other people with MS.

There is no guideline about how many respondents should be included in a given Delphi study and numbers may range from fifteen (Paliwoda, 1983) to over one

hundred (O'Hara, De Souza and Ide, 2000). However, one of the key principles to consider regarding the number of respondents is that there is strength in numbers (Linstone and Turoff, 1975). Large numbers are recommended to improve the quality of a Delphi study, reduce group error and enhance validity (Ziglio, 1996; Rowe, Wright and Bolger, 1991) whilst small numbers question the validity of the study (Walker and Selfe, 1996). Therefore, the aim was to recruit a minimum of 100 respondents for this study

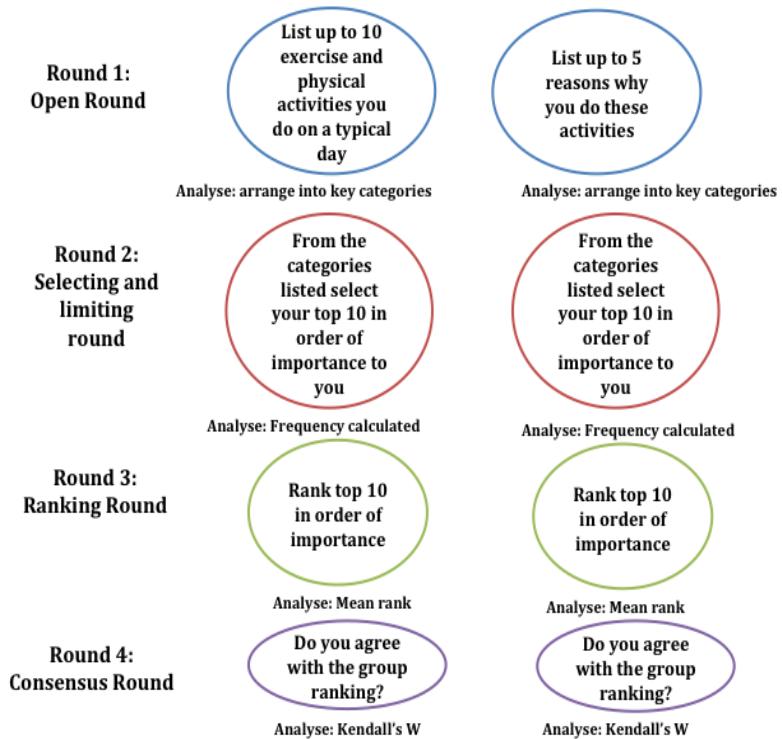
#### **4.2.5 Inclusion Criteria**

Participants were pwMS living in the community. The inclusion criteria were kept very broad to recruit as many people as possible living with the disease irrespective of disability. These included:

- Adults with a diagnosis of MS living in the community
- Ability to complete questionnaires in writing or via telephone.

#### **4.2.6 Procedure and data analysis**

**Figure 4.1 Showing Delphi Round and questions used in study**



The procedure of any given Delphi study is dependent on the type of Delphi being used. In this study, a four Round Delphi postal questionnaire was selected as an appropriate way to gather, prioritise and agree the activities pwMS participated in during a typical day and the reasons why they engaged their chosen activities.

Figure 4.1 provides a summary of the procedure used in the study. For ease of reporting, the data analysis will be described alongside the procedure, as the type of analysis varied and was dependent on the Round of the Delphi.

### **i. Round 1: Open Round**

Following recruitment, respondents were sent a research pack containing an invitation letter, participant information sheet as well as the Round 1 booklet (see Appendix 6a-c). The aim of this Round was to gather a wide range of information about the exercise and physical activity practices in pwMS living in the community. Respondents were asked to list up to ten exercise and physical activities they engaged in during a typical day and to list up to five reasons why they undertook these activities. They were also asked to provide information about their age, sex, marital status, complete the Barthel Index and the SF-36, as well as list the MS symptoms that affected their ability to undertake exercise and physical activity. Additionally, information relating to the impact of MS on physical activity and self-reported type of MS (benign, secondary progressive, primary progressive and relapsing remitting) was also collected. All the information collected was self-reported by pwMS and not confirmed by health professionals.

#### **a) Data analysis Round 1**

Two methods of analyses were used to analyse the data collected from Round 1. Firstly descriptive statistics (frequency, percentages, mean, standard deviation) were used for analysing the demographic data; frequency scores were used to identify the most and least commonly reported activities in Round 1. Secondly, thematic content analysis was used to analyse the data relating to the two main Delphi questions in order to interpret and develop categories in Round 1 (Weber, 1990; Kvale and Brinkman, 2009).

### **b) Development of the categories Round 1**

Data were entered into an Excel spreadsheet and checked for accuracy. Similar activities and the reasons why reported by respondents were grouped into categories (Appendix 7 and 8a) and a frequency count of all the activities listed and reasons why was calculated. The categories were formed intentionally using as many words or phrases used by the respondents to describe their exercise and physical activity practices. For example, activities listed as cooking, cleaning and laundry were grouped under the category domestic activities. However, some activities could fall under more than one category and in those instances the researcher used some interpretation of what respondents meant to decide which category that particular activity should be. For example, Zumba could be listed under aerobic activity and also leisure but re-examination of the raw data clarified that respondents were referring to Zumba not as an aerobic activity but as a fun leisure activity. This approach was also applied to developing the categories for the reasons why respondents engaged in these activities (Appendix 8b).

During the phase of defining the key categories in Round 1, two members of the supervisory team with expertise in neurological conditions reviewed the categories along with their descriptions to ascertain whether or not there was agreement with the key categories as identified by the researcher. The aim of this process of critical peer review was to enhance credibility of the categories used in the study. As such, categories and their descriptions that were not in agreement by the researcher and the supervisory team were rechecked and in some cases redefined by returning to the data. This iterative process continued until the research team were in agreement with the categories.

Following agreement similar categories were grouped together thereby further reducing the data. The first analysis yielded 28 categories. Further analysis reduced the categories by grouping similar activities, which led to the final 18 categories (Appendix 7).

Developing categories for the reasons why pwMS engaged in exercise and physical activity followed a similar format to that described above. Each reason given by the respondents was noted and grouped based on similarities. This yielded 26

categories in the first analysis. Further exploration of the data reduced the data to 17 categories and then to the final 15 categories. A table with the full description of all the categories along with their descriptions is presented (see Appendix 8a).

## **ii. Round 2: Selecting and limiting Round**

In Round 2, the 18 categories identified for exercise and physical activity and the 15 categories for the reasons why pwMS engaged in these activities were presented to the respondents. Respondents were asked to select their top 10 categories from each list in order of importance. Respondents were asked to assign a score of 1 to their most important category, the next most important category 2 and continue until their 10<sup>th</sup> most important category (Appendix 9b).

Respondents were given a two-week timeframe in which to return the completed questionnaires. Reminder letters were sent to non-responders just prior to the deadline to improve the response rate of the study.

### **a) Data analysis Round 2**

The main aim for this Round was to identify the top 10 exercise and physical activity practices and reasons why pwMS engaged in these practices. Descriptive statistics (frequency scores and percentages) were used to identify the top 10 chosen categories. In this Round, the frequency was calculated based on the sum total of all respondents' assigned scores, where higher scores represent the most commonly chosen category.

## **iii) Round 3: Ranking Round**

The top 10 activities chosen and the reasons why they undertook these activities were fed back to the group in Round 3. The top 10 categories were presented in random order. This was a methodological decision taken to blind respondents to the most frequently occurring category and to ascertain whether or not it affected the ranking. Respondents were asked to examine the 10 categories and rank them in order of importance, where the most important category was ranked as 1, the

next important ranked as 2, this continued until their 10<sup>th</sup> important category (Appendix 10b).

In this Round, participants were also given the opportunity to state whether or not they agreed with the 10 categories and to re-enter any category they felt should have been included in the top 10 but did not make the list.

Round 3 questionnaires were mailed giving a 3-week timeframe for people to respond. This time frame was chosen to take into account the Easter holidays. Reminder letters were sent to non-responders just prior to the study deadline.

### **a) Data analysis Round 3**

Descriptive statistics (frequency, mean ranks) were used to identify the order of the top 10 exercise and physical activity practices and the reasons why pwMS engaged in exercise and physical activity. In addition, percentage was used to calculate the number of respondents who agreed or disagreed with the categories for the exercise and physical activity practices, as well as those for the reasons why pwMS engaged in exercise and physical activity. The researcher also noted the categories that respondents re-entered that did not make the original list.

### **iv) Round 4: Consensus Round**

In Round 4, the results from Round 3 were presented in ranked order (no blinding). The aim of this Round was to determine consensus. Respondents were asked whether or not they agreed with the groups' ranking of the categories presented (Appendix 11b). Also, if they disagreed they were asked to re-rank categories in their preferred order.

A two week time frame was allocated for return of the response. A reminder letter was sent to non-responders just prior the deadline date to enhance response rate.

### **a) Data Analysis Round 4**

The first step in this Round was to determine whether consensus was reached and if there was stability in the responses between the final Rounds. The majority of the studies in this area highlight two main ways of establishing consensus, namely, stability and convergence (Dajani, Sincoff and Talley, 1979; Buck *et al.*, 1993). Stability is demonstrated by the limited variation or movement of responses between the Rounds and convergence is demonstrated by the level of agreement amongst the respondents.

Drawing on the definitions for stability and convergence, in this study, consensus was determined by:

1. The stability of the groups' rankings in Rounds 3 and 4 calculated by using descriptive statistics (mean rank), which provides an indication for the groups' opinion (Greatorex and Dexter, 2000).
2. Consensus by the group was tested statistically by using Kendall's coefficient of concordance (Schmidt, 1997). The coefficient represents the degree of variation in the mean ranks assigned by the respondents to each category. Calculations of the coefficient produces a W value which ranges between 0 and 1; where 0 represents no agreement and 1 strong agreement. In addition, a Kendall coefficient of concordance p value of  $p<0.05$  for group ranking was considered to be statistically significant.

Data were analysed using SPSS v 13.0 for windows (Pallant, 2010). Descriptive statistics was used to determine the frequency of each category and mean rank for each category. Percentage was used to calculate whether or not respondents agreed with the groups' ranking. Additionally, a non-parametric test, Kendall's coefficient of concordance (Siegel and Castellan, 1988) was used to demonstrate whether or not there was agreement amongst the group.

### **4.3 Conclusion**

This chapter provided a rationale for using the Classic Delphi as the most appropriate research method to answer the research questions. Strategies for recruitment of appropriate participants and the development of tools used in the study, the study protocol, and how the data were collected, managed and analysed were described. The Delphi method used to carry out this study, along with the analytical processes used for each stage, has been detailed.

# **Chapter 5**

## **Study 1: Delphi Findings**

### **5.0 Introduction**

This chapter presents the findings from the four Round Delphi study. It is divided into two sections. Section one presents the demographic profile as well as the disability status of study respondents at the start and completion of the Delphi study. The second section details the results of each Round for the prioritised exercise and physical activity practices of pwMS and the reasons why pwMS engage in exercise and physical activity.

### **5.1 Section 1: Demographic profile of research respondents**

One hundred and sixty eight (168) respondents registered their interest in the study. Of these, 101 (response rate- 60%) returned Round 1 questionnaires, 90 (response rate- 89%) returned Round 2, 82 (response rate- 94%) returned Round 3 and 75 (response rate- 94%) returned Round 4. The main reasons for attrition provided by some respondents were moving homes (n=2), holidays (n=3) and hospitalisation (n=2). Also, respondents were excluded if they missed the deadline and the study had progressed to the next phase (n=8). Other reasons for attrition were unknown. The demographic profiles of the respondents who started the study (n=101) and those who completed (n=70) are presented in Table 5.1. It demonstrates that at the start of the study there were 71 females and 30 males in a ratio of 2:1 in keeping with the usual sex ratio for pwMS. At the end of the study this 2:1 ratio for females and males was maintained. The mean age of the sample at the start of the study was 55.25 years (SD 10.29). However, by the completion of the study the mean age of the respondents increased slightly to 57.37 years (SD 9.22).

**Table 5.1: Showing the demographic profile of the respondents at the start and the end of the Delphi.**

<b>Demographics</b>	<b>Respondents starting the Delphi (N=101)</b>	<b>Respondents completing the Delphi (N=70)</b>
<b>Gender</b>		
Male	30	20
Female	71	50
<b>Mean age (SD)</b>	55.25 (10.29)	57.37 (9.2)
<b>Marital status (%)</b>		
Single	15 (14.9)	6 (8.6)
Married	53 (52.4)	43 (61.4)
Separated	6 (5.9)	4 (5.71)
Divorced	9 (8.9)	5 (7.1)
Widowed	6 (5.9)	6 (8.6)
Living with partner	7 (6.9)	3 (4.3)
Missing data	5 (4.9)	3 (4.3)
<b>Living arrangement (%)</b>		
By themselves	23 (22.7)	14 (20)
Husband/Wife	50 (49.5)	40 (57.1)
Partner	7 (6.9)	5 (7.1)
Adult family	14 (13.9)	6 (8.57)
Other adults	2 (1.9)	2 (2.85)
With children under 16	4 (3.96)	3 (4.3)
Missing data	1 (0.9)	0
<b>Employment status (%)</b>		
Full-time	9 (8.9)	3 (4.2)
Part-time	13 (12.8)	10 (14.2)
Retired	67 (66.3)	49 (70)
Voluntary work	10 (9.9)	7 (10)
Missing data	2 (1.9)	1 (1.4)
<b>Mean Barthel (SD)</b>	15.1 (SD 5.09)	15.83 (4.65)
<b>Mean SF-36 (SD)</b>		
Physical functioning	26.9 (26.09)	25.3 (23.35)
Role physical	33.4 (39.33)	29.6 (37.42)
Pain	67.9 (25.75)	64.8 (24.09)
General health	51.5 (21.45)	50.5 (21.79)
Vitality	44.0 (20.36)	40.1 (19.48)
Social function	62.9 (28.78)	62.3 (27.94)
Role emotion	72.9 (38.69)	74.5 (37.56)
Mental health	75.6 (16.15)	74.4 (16.83)
<b>Impact of MS on PA (%)</b>		
No effect at all	2 (1.9)	0
Slightly	12 (11.8)	10 (14.3)
Moderately	33 (32.6)	21 (30)
Severely	52 (51.4)	38 (54.3)
Missing data	2 (1.9)	1 (1.4)

<b>Demographics</b>	<b>Respondents starting the Delphi (N=101)</b>	<b>Respondents completing the Delphi (N=70)</b>
<b>Type of MS (%)</b>		
Benign	1 (0.9)	1 (1.4)
Primary progressive	18 (17.8)	15 (21.4)
Secondary progressive	34 (33.6)	22 (31.4)
Relapsing remitting	29 (28.7)	17 (24.3)
Not known	14 (13.9)	12 (17.1)
Missing data	5 (4.9)	3 (4.3)
<b>Relapse within past 6 months (%)</b>		
No	58 (57.4)	41 (58.6)
Yes	40 (39.6)	28 (40)
Missing data	3 (2.97)	1 (1.4)
<b>Time since relapse (%)</b>		
Within the last week	2 (1.9)	1 (1.4)
Within the last month	8 (7.9)	6 (8.6)
2-3 months	14 (13.9)	11 (15.7)
4-6 Months	11 (10.9)	6 (8.6)
N/A	63 (62.4)	44 (62.9)
Missing data	3 (2.9)	2 (2.9)

## Employment

At the start of the study, the majority (n=67, 66.3%) of the respondents stated that they were not currently working, 13 (12.8%) reported that were currently engaged in paid part-time work, 10 (9.9%) were involved in voluntary work and 9 (8.9%) in full time work. Of the 9 (8.9%) study respondents who were in full time employment, only 3 (4.2%) completed all the requirements of the Delphi study. The reasons why were not provided.

## Classification of MS in the Sample

Of the one hundred and one respondents in the study, 34 (33.6%) were diagnosed with secondary progressive MS. Other types of MS represented in the sample were relapsing remitting, primary progressive MS and benign MS. Some respondents were unsure of their classification (n=14, 13.9%). The majority of those completing the study were also classified as having secondary progressive MS (see Table 5.1).

## **Relapse Rate**

All respondents in the study answered this question irrespective of their type of MS. Although only 29 (28.7%) of the sample reported being classified as having relapsing remitting MS, 40 (39.6%) respondents at the start of the study reported to have experienced a relapse (see Table 5.1). However, feedback from respondents explained that despite not being classified with the relapsing remitting form of MS they felt that they had experienced a relapse during the stated timeframe. This illustrates the difference in data between medical confirmation and patient self-report.

## **The impact of MS on exercise and physical activity**

The majority of the sample at the start of the study (n= 52) and at the end of the study (n= 38) rated the impact of MS on their ability to perform exercise and physical activity as severe. Two respondents (n=2) at the start of the study stated that MS did not have any effect on their ability engage in exercise and physical activity (see Table 5.1). However, those two respondents did not complete the study for reasons that were not provided.

## **Demographic descriptors used in the Study**

The functional levels of respondents based on the Barthel score at the start (mean=15.1; SD=5.09) of the study were similar to those who completed (mean 15.83; SD=4.65). The mean quality of life score (SF-36) is demonstrated in Table 5.1. The mean score per quality of life domain were similar for respondents who completed and those that did not complete the study. The lowest mean quality of life scores for those who started (26.9) and those who completed (25.2) the study were seen for the Physical functioning domain. Also, the highest mean scores were seen for the Mental health domain for those who started (75.6) and the Role emotion domain those who completed (74.5) the study.

## **MS Symptoms**

At the start of the study respondents were asked to describe five MS symptoms, which they perceived to have an impact on their capacity to undertake exercise and physical activity. The respondents in the study described 50 symptoms which were grouped into 27 categories (Appendix 12a and 12b). Fatigue (n=63) was the most frequently described symptom followed by weakness (n=58), mobility (n=49) and poor balance (n=45). Other symptoms listed by respondents as affecting their ability to engage in exercise and physical activity included lack of confidence (n=4), sleep disturbance (n=1), difficulty carrying grocery (n=1) and requiring assistance with exercise (n=2).

## **5.2 Section 2: Results of the Delphi Study**

### **5.2.1 Round 1: Open Round**

Round 1 of the Delphi required respondents to list up to 10 activities they engaged in during a typical day. All respondents (n=101) answered this question and provided in total 81 different types of exercise and physical activity. Following thematic content analysis, (see section 4.2.6), 18 categories for exercise and physical activity were identified (Table 5.2). The number of responses provided per category was added to identify the most and least commonly reported category. The total (626) represented the frequency of responses.

**Table 5.2: Frequency of responses for the exercise and physical activity practices of 101 pwMS grouped into 18 categories.**

Categories for exercise and physical activity	Frequency of responses per category
Domestic activities (e.g. cooking, shopping, housework, laundry)	175
Everyday life activities (e.g. transferring, standing, pushing wheelchair or walking, climbing stairs)	139
Self-care activities (e.g. shaving, shower, washing and dressing, cleaning teeth)	54
Activities without the use weights (e.g. upper and lower limb exercises, bed and chair exercises)	53
Activities done with the use of equipment (e.g. treadmill, power-plate, gym-ball, stationary exercise bike)	35
Leisure activities (e.g. gardening, dancing, sport, visiting friends)	28
Stretches (e.g. activities done to stretch the upper and lower limbs)	22
Physiotherapy (e.g. activities done with or by a physiotherapist)	20
Unconventional therapies (e.g. yoga, Pilates, tai chi, massage)	18
Activities to increase or maintain strength (e.g. use of weights or using the body weight)	16
Endurance activities (e.g. swimming, running, cycling, aerobics)	13
Activities due to family roles (e.g. spending time with family, looking after or playing with children/grandchildren)	11
Transportation (e.g. using public (bus/taxi) or personal transportation)	11
Activities done with technology (e.g. computer, exercise DVD, phone, Wii)	9
Activities done in different environment (e.g. gym)	9
Activities due to being pet owners(e.g. feeding, playing with and or taking out for walks )	7
Activities done for administrative purposes (e.g. sort mails/bills)	3
Employment (e.g. activities does as part of paid/voluntary work)	3
<b>Total</b>	<b>626</b>

Round 1 highlights the wide variety of exercise and physical activity practices amongst community dwelling people with MS. The most frequently mentioned were activities necessary for daily living (e.g. domestic activities, everyday life activities and self-care activities). Activities such as stretches, physiotherapy and activities using weights; the more structured forms of exercise, were less frequently reported by participants. Also, of interest is the reporting of activities carried out for administrative purposes, activities due to pet ownership and use of

technology. These responses illustrate the diversity of activities considered as exercise and physical activity.

### **The Reasons why pwMS engage in exercise and physical activity in Round 1**

Respondents were also asked to list up to five reasons why they engage in exercise and physical activity. All 101 respondents answered this question. They provided 74 reasons why they engaged in exercise and physical activity in a typical day. Through thematic content analysis these were grouped into 15 categories. The total frequency of responses for all the categories was 390 (see Table 5.3). Examples of each item and the development of the categories are provided in Appendix 8a and 8b.

**Table 5.3: Frequency of responses for the reasons why 101 pwMS engage in exercise and physical activity grouped into 15 categories**

<b>Reasons why</b>	<b>Frequency of responses per category</b>
To improve MS symptoms (e.g. to improve or maintain strength, reduce pain, reduce spasms)	75
Because of my role within home/family (e.g. keep home tidy, role as partner or parent)	40
For emotional wellbeing (e.g. pleasure, improve mood, reduce stress)	37
Health and fitness (e.g. to be healthy and for cardiovascular fitness)	37
For self esteem (e.g. to manage weight, sense of achievement, self worth)	29
For mobility (e.g. to keep walking)	24
To keep active (e.g. to keep mind and body active, to maintain function and keep transferring)	24
Living with MS now and in the future (e.g. fear of deterioration, combat MS)	23
For self-reliance (e.g. to maintain ones' independence and choice)	21
Flexibility (e.g. to maintain or improve flexibility)	20
Out of necessity (e.g. part of daily activities, activities that must be done)	19
For social reasons (e.g. social, feel connected, be a part of community)	17
Because of the environment (e.g. due to the structure of home or work environment)	12
For employment (e.g. paid or voluntary work)	6
Because of advice given (e.g. given by physiotherapist or other healthcare professional)	6
<b>Total</b>	<b>390</b>

The reasons why people with MS living in the community engaged in certain activities were widespread and included the physical, psychological and social aspects of their lives. The most frequently occurring reason why they engaged in exercise and physical activity was to improve MS symptoms. This category included reasons associated with improving or maintaining range of movement, strength, balance, and reduction in pain levels as well as to alter muscle tone (see Appendix 8a). The role within the family was also reported as one of the primary reasons why respondents engaged in exercise and physical activity. Some respondents, albeit a small number, acknowledged participation in exercise and physical activity was based on advice given by others. The reporting of the 'reasons why' gave a sense that their engagement in exercise and physical activity was not linked to direct advice but other factors such as how they looked, felt and prepared themselves for living with MS now and in the future.

### **5.2.2 Round 2: Selecting and limiting Round**

One hundred and one questionnaires were sent out to respondents in Round 2. Of these 90 (89%) were returned. In Round 2 respondents were provided with the 18 categories for exercise and physical activity and the 15 categories for the reasons why people with MS undertake these activities in random order. Respondents were instructed to look through the list and select 10 categories according to their importance to each individual.

Of the 90 respondents, 85 answered the questionnaire appropriately. That is, they selected their top exercise and physical activities in order of importance. Five respondents assigned scores by tying some categories thereby giving them equal importance. To ensure that all respondents had their responses included, the data were sorted by adjusting for ties where the average of the tied score was given to both categories (see Appendix 13 for worked example). Using this method, only data from two of the five questionnaires could be included in the analysis. The remaining three questionnaires had to be removed from the analysis, as it was not possible to ascertain how the respondent was selecting the categories and adjusting for ties could not be used in these cases. The method used for adjusting

for ties was checked independently by a health statistician. As such, analysis in Round 2 was completed on data from 87 respondents.

### **Selecting the top 10 categories for exercise and physical activity in Round 2**

Table 5.4 reveals the exercise and physical activity practices selected by community dwelling people with MS (n=87). The higher frequency scores indicate that respondents as a group have attributed more importance to a category.

**Table 5.4: Selecting categories for exercise and physical activity in Round 2 (N=87).**

<b>Categories for exercise and physical activities</b>	<b>Frequency of responses per category</b>	<b>%</b>
Self-care activities (e.g. shaving, shower, washing and dressing, cleaning teeth)	80	91.9
Everyday life activities (e.g. transferring, standing, pushing wheelchair or walking, climbing stairs)	75	86.2
Transportation (e.g. using public (bus/taxi) or personal transportation)	70	80.5
Domestic activities (e.g. cooking, shopping, housework, laundry)	68	78.1
Leisure (e.g. gardening, dancing, sport, visiting friends)	67	77.0
Activities due to family roles (e.g. spending time with family, looking after children/grandchildren)	65	74.7
Stretches (e.g. activities done to stretch the upper and lower limbs)	65	74.7
Activities done with technology (e.g. computer, move it for MS DVD, phone etc)	61	70.1
Physiotherapy (e.g. activities done with or by a physiotherapist)	55	63.2
Activities without the use weights (e.g. upper and lower limb exercises, abdominal, bed and chair exercises)	50	57.4
Activities to increase or maintain strength (e.g. use of weights or using the body weight)	37	42.5
Activities done with the use of equipment (e.g. treadmill, power-plate, gym-ball, exercise bike)	36	41.3
Activities done for administrative purposes (e.g. sort mails/bills)	36	41.3
Employment (e.g. activities done as part of paid/voluntary work)	35	40.2
Unconventional therapies (Yoga, Pilates, tai chi, massage)	33	37.9
Activities due to being pet owners (e.g. feeding, playing with and or talking out for walks)	20	22.9
Endurance activities (e.g. swimming, running, cycling, aerobics)	20	22.9
Activities done in different environment (e.g. gym, pool)	18	20.6

In Round 2 there were notable movements with certain categories based on the selection of activities that were important to the individual (see Table 5.4). For example, activities with the use of equipment, endurance activities and activities to improve or maintain strength were in the top 10 for frequency in Round 1 (see Table 5.2). However in Round 2, where respondents were asked to select their activities based on their importance, these activities had lower frequencies. Some activities were not placed in the top 10, for example, activities to increase and maintain strength, endurance, and employment.

In contrast, the categories including activities due to family roles, technology and transportation, which were all less frequently reported in Round 1, were amongst the top 10 chosen categories for importance of exercise and physical activities. The results seem to suggest in this Round a preference for unstructured forms of activities as being important to community dwelling pwMS.

### **Selecting the reasons why people with MS engage in exercise and physical activity**

Respondents were also asked to select their top 10 categories for the reasons why they engaged in exercise and physical activity in order of importance. Table 5.5 shows the categories and the frequency scores for each category. The higher scores indicate that respondents as a group attributed more importance to a category.

The selection Round, presented some notable changes in the categories based on respondents' choice, which was linked to their levels of importance. For example, in Round 1, Living with MS now and in the future, Out of necessity, For social reasons were not frequently reported as activities respondents engaged in.

However, in Round 2, these all occupied the top 10 categories with more than 79% of respondents selecting these activities. Similar patterns were observed in other categories such as self-reliance (moved from 9<sup>th</sup> to 2<sup>nd</sup> place). This might suggest an inherent desire for independence and to maintain a level of confidence that would afford them the ability to carry out their daily tasks. Finally, two categories namely, 'Because of advice given' and 'Health and fitness' that did not make the top 10 selections were interesting to note.

**Table 5.5: Selecting the reasons why pwMS engaged in exercise and physical activity (N=87)**

Categories for reasons why	Frequency of responses per category	%
Living with MS now and in the future (e.g. to limit deterioration, to combat MS)	83	95.4
For self-reliance (e.g. to maintain ones' independence and choice)	79	90.8
To keep active (e.g. to keep mind and body active, to maintain function and keep transferring)	78	89.6
To improve MS symptoms (e.g. to improve or maintain range of movement, strength, balance, reduce pain and alter muscle tone)	77	88.5
For social reasons (e.g. to maintain a social life, provide a sense of belonging and to feel connected to community)	70	80.4
Out of necessity (e.g. need to because they are part of daily activities and everyday life)	69	79.3
For emotional wellbeing (e.g. for pleasure, improve mood, reduce stress)	69	79.3
For Self-esteem (e.g. to manage weight, feel better, sense of achievement, self-worth)	66	75.8
For mobility (e.g. to keep walking)	66	75.8
For flexibility (e.g. to maintain or improve flexibility)	57	65.5
Health and fitness (e.g. to be healthy and for cardiovascular fitness)	52	59.7
Role within the home/ family (e.g. to keep home tidy, provide food for family or part of role as a partner or parent)	51	58.6
Employment (e.g. as part of paid or voluntary work or to keep working)	29	33.3
Because of the environment (e.g. due to the structure of home or work environment)	26	29.8
Because of advice given (e.g. by health professional or personal trainer)	24	27.5

### 5.2.3 Round 3: Ranking Round

Eighty-seven (87) questionnaires were sent out to respondents in Round 3 presenting the top 10 categories for exercise and physical activity and the reasons why pwMS undertake these activities in random order. Of these 82 (94.3%) were returned however data analysis was completed on 80 responses. This was because two participants missed the study deadline and as such, the study had already progressed to the next stage. Other reasons for non-response were unknown.

In Round 3 respondents were asked to rank the 10 categories selected in order of importance, where their most important category ranked as 1, the next most important category ranked as 2, this continues until the 10<sup>th</sup> most important category. In this Round respondents were also asked to state whether they agreed or disagreed with the 10 categories selected. Additionally, respondents were given the opportunity to feedback to the researcher any categories they felt should have been included in the top 10 categories in Round 2 and was now excluded.

Table 5.6 shows the results of Round 3. Lower scores and ranks represent more importance than higher scores and ranks. The frequency is the total ranked score of each respondent per category. The ranking for this Round was calculated based on the mean ranks.

**Table 5.6: Ranking for the exercise and physical activity practices (N=80)**

Categories	Frequency per category	Mean Rank
Self- care activities	211.5	2.84
Everyday life activities	256.5	3.36
Domestic activities	389.5	5.09
Transportation	430.0	5.62
Leisure activities	436.0	5.66
Activities due to family roles	440.5	5.76
Stretches	460.0	6.07
Physiotherapy	469.0	6.16
Activities without weights	500.5	6.55
Activities with technology	604.5	7.90

In Round 3, some categories maintained their position from the previous Round. Examples of these include Self-care activities (ranked 1), Every day life activities (ranked 2) and Leisure activities (ranked 5). This indicated that between Round 2 and Round 3 five categories were stable out of 10 based on the mean ranks.

The other categories were less stable and were displaced by one rank either in the upward or downward direction. For example, Transportation the third most frequently reported category in Round 2, slipped down by one place in the ranking order to fourth place in Round 3. Similarly, the category Domestic activity the fourth most selected activity in Round 2 moved up the rank by one place based on importance to number 3 in Round 3. This would suggest that by the third Round

the group was still undecided about the ranking of the categories as priorities were now being negotiated.

### **Agree or disagreement of categories for exercise and physical activity**

Respondents were asked whether or not they agreed with the categories for exercise and physical activity used in the study. Of the 80 respondents who responded to Round 3, 78 (97.5 %) answered this question. The reasons for not responding are unknown. Of the respondents who answered this question, 67 (86%) agreed and 11 (14%) disagreed with the categories for exercise and physical activity.

### **Re-voting previously eliminated categories for exercise and physical activity**

In Round 3 respondents were given the opportunity to feedback to the researcher any category they felt strongly should have been included in the top 10. Four categories were identified which included Employment (n=4), Activities done with the use of equipment (n=1), Unconventional therapies (n=1) and Activities to increase or maintain strength (n=1). One respondent stated that mental activity should have been included in the list of activities in the first place. However, this activity was not listed originally in Round 1. These individual responses were considered by the researcher and the supervisory team and discounted, as they did not influence the results of the top 10 because the majority of the respondents were in agreement with the existing categories.

### **Ranking for the reasons why people undertake exercise and physical activity**

The results pertaining to the reasons why people with MS undertake exercise and physical activity is demonstrated in Table 5.7 below. In this Round only three categories maintained their positions across the Rounds. They were, To keep active (ranked 3), Emotional wellbeing (ranked 7) and Self-esteem (ranked 8). This suggests that only three categories were stable across Round 2 and Round 3.

The other categories were unstable in this Round. For example, 'Living with MS now and in the future', which was the most frequently selected category in Round

2 slipped down to rank number 5 in Round 3. Also, the category 'Out of necessity' that was sixth in Round 2 moved up the rank to number 2 in Round 3. Similarly, 'mobility' that was the ninth most selected activity in Round 2 moved up the rank based on the individuals' importance to rank 4 in Round 3.

**Table 5.7: Ranking for the reasons why pwMS engage in exercise and physical activity (n=80)**

Categories	Frequency per category	Mean Rank
To improve MS symptoms	347.5	4.48
Out of necessity	367.0	4.77
To keep active	372.0	4.83
For mobility	374.0	4.84
Living with MS now and in the future	389.5	5.04
For self-reliance	398.5	5.16
Emotional wellbeing	489.5	6.28
For self esteem	492.5	6.37
For flexibility	494.5	6.39
For social reasons	530.0	6.84

#### **Agreement or disagreement of categories for the reasons why people undertake exercise and physical activity**

Respondents were asked whether they agreed or disagreed with the categories for the reasons why pwMS engaged in exercise and physical activity. Seventy-five respondents answered this question. Of these, 92 % (n=69) reported that they agreed with the categories for the reasons why people were engaged in physical activity whilst 8% (n=6) of respondents disagreed. The reasons why the other respondents did not complete this question are not known.

#### **Re-voting previously eliminated categories for the reasons why people with MS undertake exercise and physical activity**

Respondents were given the opportunity to report categories they felt strongly should have been included in the top 10. Categories identified by respondents were, because of advice given (n=1) and health and fitness (n=1). One participant reported that mobility should not have been included in the top 10 in the first place as they were immobile (n=1). The individual responses were considered but

were not included, as they did not influence the results of the top 10 reasons why pwMS undertake exercise and physical activity.

### **5.2.4 Round 4: Consensus Round**

The aim of this Round was to reveal the groups' priorities for the exercise and physical activity practices and the reasons why they engaged in exercise and physical activity in order to determine whether or not there was consensus. As mentioned in chapter 4, consensus was determined by the stability of the groups' ranking across Rounds 3-4 and through statistical testing. The Kendall's coefficient of Concordance was used to ascertain levels of agreement amongst respondents. The data were analysed using SPSS version 13.0 for windows in order to calculate the mean ranks for each category and Kendall's coefficient of concordance.

Eighty questionnaires (80) were sent out to respondents. Of these, 75 (94%) questionnaires were returned, however, data were analysed on 70 as some respondents missed the deadline for the study. In this Round respondents were presented with the results from Round 3 in ranked order of importance. They were asked whether or not they agreed with the ranking. If they disagreed they were asked to re-rank, where their most important category should be ranked as 1, the next most important ranked as 2 and continue ranking until the 10<sup>th</sup> most important category.

### **Stability across the Rounds for exercise and physical activity**

Table 5.8 presents the results of Round 4. Similar to Round 3, the lower scores mean that as a group greater importance was attributed to a category compared to the higher scores and ranks. The ranks were based on the mean ranks of the items. The results reveal high levels of stability across Round 3 and Round 4. There were no displacements of any of the categories for Round 4. That is, all the categories remained stable between Rounds 3 and Round 4. Self-care activities retained the number 1 position out of the top 10. Also, interestingly two categories, '*Self-care*

*activities*' and '*Everyday life activities*', maintained their positions between Round 2 through to Round 4.

**Table 5.8: The prioritised exercise and physical activity practices of pwMS (N=70)**

Categories	Frequency per category	Mean Rank
Self-care activities	106	1.38
Everyday life activities	151	2.19
Domestic activities	252	3.62
Transportation	329	4.72
Leisure activities	374	5.40
Activities due to family roles	397	5.83
Stretches	459	6.60
Physiotherapy	508	7.35
Activities without weights	580	8.37
Activities with technology	666	9.54

### **Levels of Agreement amongst the group for exercise and physical activities people with MS undertake**

Kendall's co efficient of concordance (W) was used to ascertain overall agreement between the respondents' ranking in Round 4. The concordance was significant and the co-efficient was high indicating strong agreement amongst the group ( $W=0.744$ , chi-squared = $455.093$ , df=9,  $p=0.000$ ). This result suggests that the criterion for consensus was met (see page 100 for criteria for consensus) for the groups' priorities for the exercise and physical activity they engaged with in a given day.

### **Agree or disagreement of groups' ranking for exercise and physical activity**

Respondents were asked whether or not they agreed with the groups' rankings in Round 4. Of the 70 respondents who answered this question, 41 (59%) agreed with the groups' ranking whilst 29 (41%) disagreed. This highlights that although there was consensus through statistically testing, subjectively some respondents had alternative views about the groups' ranking.

## **The reasons why people undertake exercise and physical activity**

### **Stability of ranks across the Rounds for the reasons why**

Table 5.9 shows the results for the ranked order of the categories for the reasons why pwMS engage in exercise and physical activity in Round 4. The findings suggest that the categories for the reasons why people with MS engage in exercise and physical activity were stable between Rounds 3 and Round 4. There were no displacements of any of the categories in Round 4. The category 'To improve MS symptoms' (ranked 1) retained the top rank across Rounds 3 and 4. Similarly the category 'For social reasons' (ranked 10) retained the lowest rank between Rounds 3 and 4.

Interestingly, there were some categories that retained their positions across the Rounds. That is, they were consistent throughout Rounds 2 through to Round 4. These were 'To keep active', 'Emotional wellbeing' and 'For self-esteem'.

**Table 5.9: The prioritised reasons why people with MS engage in exercise and physical activity (N=70).**

Categories	Frequency per category	Mean Rank
To improve MS symptoms	134	1.95
Out of necessity	170	2.49
To keep active	222	3.22
For mobility	284	4.11
Living with MS now and in the future	355	5.13
For self-reliance	397	5.76
Emotional wellbeing	466	6.73
For self-esteem	531	7.66
For flexibility	602	8.64
For social reasons	646	9.31

## **Levels of Agreement amongst the group for the reasons why people with MS undertake exercise and physical activities**

Kendall's co-efficient of concordance (W) was used to ascertain the overall agreement between the respondents' ranks in Round 4. The concordance was significant and the co-efficient was high indicating strong agreement amongst the group ( $W=0.723$ , chi-squared = 455.2, df=9, p=0.000). This result suggests that the criterion for consensus was met (see page 100 for criteria for consensus) for the

group for the reasons why pwMS undertake exercise and physical activity in a given day.

### **Agreement or disagreement of groups' ranking for the reasons why people with MS undertake exercise and physical activity**

Respondents were asked whether or not they agreed with the groups' ranking of the categories used in the study. 70 respondents answered this question. Of the 70, 44 (63%) agreed with the groups' ranking whilst 26 (37%) disagreed. The number of respondents who disagreed with the groups' ranking was interesting to note and suggests that although there was consensus objectively through testing, subjectively some respondents disagreed. This finding points to the difference between the groups' versus the individuals' priorities. However the reasons for this disagreement could not be ascertained through the Delphi method.

In summary, Round 4 demonstrated that there was consensus in community dwelling pwMS for the exercise and physical activity practices they engaged in as well as the reasons why they undertook these activities. Consensus was determined by stability between Rounds 3 and 4, as well as through statistical testing.

## **5.3 Discussion**

The purpose of this study was to identify the exercise and physical activity practices prioritised by pwMS living in the community and to determine whether or not as a group there was consensus in their chosen activities. The findings from this study have provided us with an entrance into the world of pwMS as well as some insight into the reasons why they undertake exercise and physical activity. Overall, the response rate throughout all four Rounds was good and exceeded the recommended level set at 70% by some researchers in order to enhance methodological rigor (Walker and Self, 1996; Sumsion, 1998).

Similarities in the socio-demographic profile of respondents in this study and other published MS groups relating to, female to male ratio (Prodinger *et al.*, 2010; Currie *et al.*, 2009; Einarsson *et al.*, 2006; O'Hara, De Souza and Ide, 2000), age range (Dlugonski *et al.*, 2012; Coenen *et al.*, 2011; Prodinger *et al.* 2010; Einarsson *et al.*, 2006; O'Hara, Desouza and Ide, 2000), type of MS classification albeit slight differences in proportions (Coenen *et al.*, 2011; Kasser, 2009; Einarsson *et al.*, 2006; O'Hara, De Souza and Ide, 2000 ), mean Barthel score (O'Hara *et al.*, 2002) and mean quality of life score (O'Hara *et al.*, 2002), suggest that these results might be comparable to other typical MS community dwelling populations. Overall, the study reveals that pwMS who responded to this survey irrespective of age, type of MS and disability engage in a broad range of exercise and physical activity practices in the community. However, it should be acknowledged that all information gathered in this study was based on respondents self reported data and were not clinically confirmed. Nevertheless, due to the small sample size the findings from this study are not generalisable to the wider MS population.

All respondents felt that MS had an impact (mild, moderate and severe) on their ability to engage in exercise and physical activity. The three most frequently reported symptoms were fatigue, weakness and mobility. Of these, fatigue was reported by more than half (n=63, 62%) of the sample and is similar to the patterns of fatigue found in a study of 267 pwMS, where approximately 75% were affected by fatigue (Lerdal *et al.*, 2007). It is widely acknowledged that fatigue is one of the most disabling symptoms experienced by pwMS (Asano *et al.*, 2013; Matthews, 1998) and has been reported as a barrier to engaging in exercise and physical activity (Asano *et al.*, 2013; Kayes *et al.*, 2011a; Beckerman *et al.*, 2010; Stroud, Minahan and Sabapathy, 2009a; Borkoles *et al.*, 2008). Despite reporting fatigue and a range of other symptoms, all respondents in this current study were engaged in some level of exercise and physical activity in the community.

### **5.3.1 Entrance into the world of pwMS in relation to exercise and physical activity**

Entrance to the world of pwMS was made possible through the use of the Delphi method. Findings from this study provided a snapshot view of exercise and physical activity from the lived experience of pwMS. In keeping with the application of the Delphi method, the views obtained throughout all the stages of the study were based on the expertise of people with knowledge and experience of living with MS (Keeney, Hasson and McKenna, 2011; Mckenna, 1994). These expert views have highlighted the diverse activities pwMS undertake in the community. Some of these activities were structured forms of exercise such as '*stretches*', '*activities without the use of weights*' and '*physiotherapy*'. Other activities were unstructured, such as '*self-care*', '*domestic activities*', '*leisure*' and '*transportation*'. Nevertheless, whether the activities were structured or unstructured, pwMS felt they were relevant and formed part of their daily routines.

In addition to the diverse activities, respondents placed high importance on daily life activities which were mainly unstructured. Unstructured activities such as '*self-care*', ranked 1<sup>st</sup>, were prioritised above structured activities, example '*activities without the use of weights*' (ranked 9<sup>th</sup>). These findings are similar to O'Hara and colleagues (2000) where MS participants identified exercise as one of their self-care practices but, similar to this study, these exercises (structured form) were lower in priority. However unlike this current study, their study was not focused on exercise and physical activity, instead they were interested in self-care practices as a whole in pwMS (O'Hara, De Souza and Ide, 2000). Nevertheless both studies suggest that community dwelling pwMS demonstrate preference towards unstructured forms of physical activity.

This study has expanded the findings of other studies reporting on the activities of pwMS (Weikert *et al.*, 2011; Currie *et al.*, 2009) but there were some key differences. Firstly, despite the use of questionnaires to elicit the activities pwMS undertake, all the studies used different methods to collect and analyse the information. Both studies (Weikert *et al.*, 2011; Currie *et al.*, 2009) used pre-

designed questionnaires as their data collection method, which could have limited the responses, whereas, this current study allowed participants to list the activities they were engaged in. This could explain some of the categories that were included in this study that perhaps were not included in the other studies. For example, the inclusion of categories such as, '*transportation*' (ranked 4<sup>th</sup>), '*family roles*' (ranked 6<sup>th</sup>) and '*activities done with technology*' (ranked 10<sup>th</sup>) which MS participants considered to be important to living in the community.

Secondly, the focus of the studies (Weikert *et al.*, 2011; Currie *et al.*, 2009) was different which resulted in different ways of analysing the data. Weikert and colleagues were interested in the most frequently chosen exercise and physical activity (Weikert *et al.*, 2011) whereas Currie and colleagues were more interested in the intensity of these activity and unfortunately did not itemise the activities their sample engaged in to allow for direct comparison (Currie *et al.*, 2009). Nevertheless, comparing this current study to Weikert and colleagues revealed that commonly reported activities based on frequency count might be different to those actually prioritised by people with MS. For example, despite identifying similar activities, Weikert and colleagues found that weight training and yoga were the first and third most commonly reported activity respectively amongst their participants. However in this study weight training and yoga were represented in the responses of Round 1 but were later eliminated during the selecting and limiting Round (Round 2). This is worth noting as it highlights that there is a difference between the most reported activities and how activities are chosen based on the individual's preferences. This finding has clinical implications as it highlights the importance of considering individuals' priorities as a way to help sustain engagement in exercise and physical activity. This current study found that pwMS prioritised exercise without the use of weights rather than exercises with the use of weights. In contrast, weight training is widely used in intervention studies (Saxton *et al.*, 2013; Sabapathy *et al.*, 2011; Dodd *et al.*, 2011; Coote *et al.*, 2009) and has been recommended in the recent NICE guidance (NICE, 2014). These reports relate to the use of weight training focussed on supervised sessions whereas this current study is based on self selected exercise and physical activity. That is, the activities that are prioritised as part of daily routines.

Thirdly, the research participants used in these studies were different. Weikert and colleagues included participants who only had relapsing remitting MS and were all ambulant (Weikert *et al.*, 2011). Currie did not specify the MS classification in their study, but stated that their participants ranged from mild to severe based on the disease severity scale (EDSS) (Currie *et al.*, 2009). Participants in this current study self-reported their classification of MS and its severity based on the impact of MS on their ability to engage in exercise and physical activity.

Overall, the uniqueness of this study compared to other studies examining the exercise and physical activity preferences of pwMS is that this current study not only identified the exercise and physical activity practices but also ascertained information about their priorities based on group consensus. As far as the researcher is aware this study is the first to gather such information using consensus building communication technique.

### **5.3.2 Insights into the reasons why pwMS engage in exercise and physical activity**

The reasons why pwMS in this study engaged in exercise and physical activity were also diverse. Overall, participants reported that they engaged in exercise and physical activity because of the physical, psychological and social benefits associated with these activities. Some of the benefits included '*to manage symptoms*', '*out of necessity*', '*to keep active*', '*for their self-esteem*', '*emotional well being*' and '*living life with MS now and in the future*'. These positive benefits were in relation to both structured and unstructured activities.

The physical, psychological and social benefits of exercise and physical activity reported in this study are consistent with other studies in pwMS (Van Der Linden *et al.*, 2014; Learmonth *et al.*, 2013; Dlugonski, Joyce and Motl, 2012; Kasser, 2009; O'Hara, De Souza and Ide, 2000; Solari *et al.*, 1999; Petajan *et al.*, 1996). However, most of these studies demonstrated these positive impacts based on the

experience of exercise and physical activity following an intervention program (Van Der Linden *et al.*, 2014; Learmonth *et al.*, 2013; Dlugonski, Joyce and Motl, 2012; Kasser, 2009). This study highlighted that the perceived benefits associated with exercise and physical activity extended beyond the confines of an intervention program to also include activities carried out as part of a typical day. This information is useful and relevant for health professionals to consider utilising and integrating activities pwMS prioritise as part of their daily routines as ways to improve physical activity levels in pwMS living in the community.

Of all the reasons cited in the Delphi Study about engaging in exercise and physical activity, '*to improve and maintain symptoms*' as a result of MS was highly ranked. These views about improving symptoms as a result of MS is supported by current evidence that exercise and physical activity improves strength and fitness (Debolt and McCubbin, 2004; Mostert and Kesselring, 2002; Petajan *et al.*, 1996), posture (van der Linden *et al.*, 2014), reduces pain (Dlugonski *et al.*, 2012), reduces fatigue (Oken *et al.*, 2004; Petajan *et al.*, 1996) and improves mobility (Collett *et al.*, 2011; Lord, Wade and Halligan, 1998). Interestingly, the category health and fitness, which is one of the key reasons cited in the literature for engaging in exercise and physical activity, was absent from the top 10 prioritised reasons why pwMS living in the community engage in exercise and physical activity. This absence is obvious in a study about exercise and physical activity and suggests that other factors were influencing the reasons pwMS engage in exercise and physical activity.

In addition to managing the symptoms of MS, participants provided evidence that their need '*to keep active*' and '*maintain mobility*', ranked 3<sup>rd</sup> and 4<sup>th</sup> respectively, were important. This view about keeping active is contrary to the existing evidence which suggests that pwMS are inactive (Motl, McAuley and Snook, 2005; Sandroff *et al.*, 2012). These results from this current study illustrate that as a group their intention is to be active and was one of the prime drivers for engaging in exercise and physical activity. This finding is interesting and begs for further exploration to understand their views about being active. However, the methodological approach used in this phase of the study was limited to explore the meanings behind the categories respondents ranked as important.

Similarly, the results from this study highlight the significance of mobility in the lives of pwMS. This focus on mobility as one the reasons pwMS engage in exercise and physical activity is not surprising, as research has demonstrated that mobility is one of the primary concerns in pwMS and one of the most cited reasons why referrals are made to physiotherapists (Sutliff, 2010; Zwibel, 2009; van Ash, 2011). In addition, studies have shown that engagement in exercise and physical activity improves mobility (Rietberg *et al.*, 2004) and pwMS who are less mobile tend to have a reduced quality of life, activities of daily living and productivity (Sutliff, 2010; Zwibel, 2009).

In addition to the physical reasons for engaging in exercise and physical activity, this study has also identified that prime reasons were also associated with the psychological benefits of these activities. These included improved '*self-reliance*', '*emotional wellbeing*' and '*self-esteem*' (ranked 6<sup>th</sup>, 7<sup>th</sup> and 8<sup>th</sup> respectively). This indicates a need for pwMS to look and feel good about themselves as well as a need to remain independent. The psychological benefits of exercise and physical activity are well known and a recent meta-analysis revealed that exercise training improves symptoms of depression in pwMS (Ensari, Motl and Pilutti, 2014). Other reports also indicate that exercise and physical activity are associated with emotional well being (Kasser, 2009) and improved quality of life (Motl and Gosney, 2008). In this Delphi study, the physical benefits of exercise and physical activity were ranked higher than the psychological benefits and might be a reflection of the impact of MS on disability and ability to function in day-to-day life activities. Nevertheless, taking into consideration the exercise and physical activity practices and the reasons why pwMS engaged with certain activities suggests that pwMS' preferences and views about exercise and physical activity traversed the functioning domains of the ICF.

## 5.4 Strengths and Limitations

The study was focused on pwMS living in the community and the views represented in this study are reflective of this population and not people with MS in other settings, such as inpatient based settings. As mentioned in the literature

review, the evidence base is biased towards pwMS with mild to moderate forms of the disease. As such, the recruitment strategy used broad inclusion criteria. By using broad inclusion criteria, this study was able to elicit data from a wide range of pwMS living in the community. This is one of the strengths of the study as the responses obtained are likely to be more representative of pwMS across the spectrum of disease progression and their experiences of living with MS. The recruitment strategy was successful but at the cost of having a long recruitment timeframe.

The strength of this study lies within the methodological structure of the technique. That is, a consensus building technique that allowed the researcher to capture the activities pwMS as a group prioritise the reasons why they undertake certain activities. However, a limitation of the study is that respondents' personal choice of activity and the reasons why they engaged with certain activities were not reflected, as the results were based on group consensus. This presented a potential tension between aiming for consensus, which is based on group-based opinion versus individual opinion. Also, this method despite its strength was also limited in that it could only provide a snapshot view of exercise and physical activity. Further exploration using another methodological approach would be necessary to gain a deeper understanding of the meaning of these prioritised activities and the reasons why they engaged in exercise and physical activity.

As mentioned in chapter 4, all the data collected in this study were self-reported. As such, the exercise and physical activity practices and the reasons why pwMS engage in exercise and physical activity were based on the views expressed by respondents with no additional data independently observed to verify that they actually carried out the reported activities. However, there is no reason to believe that the reports are not true, but they were not authenticated in this research design.

To enhance methodological rigor of the study, researchers have recommended that the response rate for each Round should be approximately 70% (Walker and Selfe, 1996; Sumsion, 1998). The response rate across all the Rounds of the Delphi was good and exceeded the recommended levels described in the literature except in

Round 1 where the response rate was 60%. This low response rate could have been attributed to the delay with the long recruitment period (approximately 6 months) to achieve the number of participants. However, the response rate for Rounds 2, 3, and 4 were 89%, 94.3% and 94% respectively. This provides an indication that participants were generally interested in the study and engaged with the research process.

Finally, the researcher acknowledged that the majority of participants were members of the MS Society. This is particularly important as it is known that people with MS who engage in MS support groups might not be representative of the wider MS population. These people have been found to be generally accepting of their MS, already supported and actively seek information (Plow, Resnik and Allen, 2009; De Souza, Ide and Neophytou, 2005; McLaughlin and Zeeberg, 1993).

## 5.5 Conclusion

Exercise and physical activity is one way of managing the symptoms of MS (Rietberg *et al.*, 2004) yet despite the positive benefits of exercise and physical activity, pwMS are considered to be inactive (Motl, McAuley and Snook, 2005; Sandroff *et al.*, 2012). Having an understanding of the types of exercise and physical activities people with MS engaged in and the reasons why they undertake these activities might help take researchers and clinicians further towards improving physical activity in this population.

This study has, for the first time, used a consensus building group communication technique to identify the exercise and physical activity pwMS prioritise as part of their daily routine and the reasons why they engage in these activities. These findings included people with different classifications of the disease (relapsing remitting, secondary progressive, primary progressive and benign), a wide range of functional levels (Barthel index range, 1-20) and who have all reported the impact of MS on their ability to engage in exercise and physical activity as mild, moderate or severe.

These findings have added to the existing body of knowledge that pwMS engage in a broad range of activities but revealed a tendency towards unstructured forms of activities that are a necessary part of daily life. The study has highlighted the reasons why pwMS engaged in exercise and physical activity, demonstrating the diversity and range of physical and psychosocial benefits these activities bring to their daily lives, albeit with stronger prioritisation of the physical benefits. These findings provided a snapshot view of exercise and physical activity in the lives of pwMS living in the community. However, the study also raises other questions about the meanings of the activities chosen and why certain activities were chosen over others. This question is developed in the next study (Chapter 6).

Finally, the outcome of the Delphi study which identified the top 10 exercise and physical activity practices and the reasons why pwMS undertake exercise and physical activity will be used as the research tool for the next two studies (2 and 3) in this thesis.

## **Chapter 6**

### **Study 2 Method: A qualitative exploration of exercise and physical activity in people with Multiple Sclerosis**

#### **6.0 Introduction**

This chapter details the qualitative method used to explore and understand the meanings ascribed to exercise and physical activity by people living with MS. That is, entrance through the eyes of people who experience life with a variable and progressive condition.

Qualitative methods are a type of social inquiry used to explore people's attitudes to, behaviour towards and experiences of life situations (Holloway and Wheeler, 2010; Creswell, 2009; Denzin and Lincoln, 2000). According to Denzin and Lincoln, researchers using qualitative methods aim to understand how people make sense of their everyday lives and how they bring meaning to the personal and social contexts in which they live. Rather than looking for a universal truth, these inquiries are often underpinned by an interpretative approach which respects the social world in which people live and the reality of their lived experiences within their worlds (Holloway and Wheeler, 2010; Snape and Spencer, 2009). Qualitative inquiry is widely used to gain a deeper understanding of findings generated from other data collection methods, such as questionnaires (Tod, 2010; Ritchie, 2009).

Results from the Delphi study (Study 1) highlighted that although consensus was achieved for the exercise and physical activity practices amongst respondents, some respondents appeared uncertain about some aspects of the prioritisation. As such, a qualitative approach was appropriate to add clarity and depth to the Delphi results and was commensurate with recommendations that Delphi researchers should consider using additional research methods in order to enhance the findings from a Delphi study (van Dijk, 1990; Engels and Kennedy, 2007).

Therefore, a qualitative method suited to this type of inquiry was used to expand the findings of the Delphi study and to gain an in-depth understanding about the meanings of exercise and physical activity in pwMS living in the community. The research questions to be addressed were:

- What are the views and opinions of pwMS living in the community about the prioritised exercise and physical activity practices identified from the Delphi study?
- What are the views and opinions of pwMS living in the community about the prioritised reasons why pwMS engaged in exercise and physical activity?
- What are the meanings of exercise and physical activity and the reasons why pwMS undertake these activities?

## **6.1 Study Design**

A qualitative approach incorporating in-depth semi-structured interviews and framework analysis (Tod, 2010; Kvale and Brinkmann, 2009; Spencer, Ritchie and O'Connor, 2009) was used to explore and understand the meanings of exercise and physical activity in pwMS living in the community. Framework Analysis will be discussed in more depth later (Section 6.9). Semi-structured interviews were chosen because the flexible design accommodates unexpected topics raised by participants whilst offering the researcher some control over the interview process (Tod, 2010).

As reported in Chapter 2, the results of qualitative studies have contributed to the evidence base highlighting the perceived physical, psychological and social benefits of exercise and physical activity to pwMS. However, despite this, only a few studies have considered the meanings of exercise and physical activity within the lived context of pwMS (Dlugonski, Joyce and Motl, 2012; Kasser, 2009; Borkoles et al., 2008).

The results of the Delphi Study provided a snapshot view of the meanings of exercise and physical activity within the context of the lives of pwMS. However,

one of the limitations of the Delphi method was the inability to explore in detail the respondents' views and opinions about exercise and physical activity, one of the known limitations of using questionnaires (Jones and Rattray, 2010). Therefore, in this study, interviews were chosen because the primary intent was to gather in-depth views from the perspectives of the respondents of the Delphi study. This focus on the individual allowed the researcher to explore, illuminate and understand the meaning of exercise and physical activity from the perspective of the individual and within the context of living life with MS (Lewis, 2009).

## **6.2 Ethical consideration**

The School of Health Sciences and Social Care Research Ethics Committee, Brunel University approved this study in September 2013, reference number 13/08/PhD/04 (Appendix 14).

Research ethics were carefully considered and adhered to. The majority of the issues considered were related to the protection of study participants. However, other considerations were made with respect to lone working within the community.

To ensure participants were fully informed about all aspects of the study and provided with sufficient time and space to reflect on the study before consenting (Holloway and Wheeler, 2010; Tod, 2010), all participants were provided with a research pack that included a cover letter, participant information sheet and consent form (Appendix 15a-c). As this study sought to recruit participants who had been involved in the Delphi Study, it was essential that they were aware and understood that this study was different to the previous one and as such consent for participation could not be assumed. The researcher offered to answer questions about the study and through discussion with each participant and signing of a consent form ensured that informed consent was obtained prior to the start of the interview.

The time allocated for each interview was approximately 1 hour. Participants were free to extend or to shorten this timeframe as it is well documented that pwMS may face challenges with fatigue and poor concentration (Matthews, 1998). To ensure comfort and reduce anxiety participants were made aware at the start of the interview that they could take rest breaks if needed. Participants were given adequate time to respond to interview questions and if they wished to move on to another question and come back to a particular question their preference was accommodated. Interviews may evoke negative emotions because reflecting on past or present circumstances can be psychologically painful (Holloway and Wheeler, 2010). The researcher was aware that research participants are sometimes unaware of these risks (Holloway and Wheeler, 2010) and therefore was prepared to stop the study and offer psychological support and signposting if the need arose.

Risks associated with the researcher working independently in the community were identified and minimised by drawing up a strategic plan (Appendix 15d).

### **6.3 Recruitment**

Following ethical approval all 70 participants who completed the previous Delphi study (Study 1) were invited to participate in this study and those interested were asked to return the signed consent form. The sampling method was one of convenience as participants were accessible to the researcher through prior involvement in the Delphi Study (Procter, Allan and Lacey, 2010). Completion of the four Round Delphi study was the main inclusion criteria as experience of the process was fundamental to addressing the research questions.

### **6.4 Participants**

Sixteen (12 females and 4 males) pwMS who completed the Delphi study were recruited. They were aged between 47 and 72 years. The type of MS varied across the group with the majority self-reporting to be diagnosed with either primary progressive (n=4) or secondary progressive (n=5) MS. Two participants were diagnosed as having relapsing remitting MS and five were unsure about the type of

MS. All participants reported that MS had an effect on their ability to engage in exercise and physical activity. Of the sixteen participants the majority were independently mobile using mobility aids. Two required assistance for mobility. Pseudonyms have been used to maintain anonymity.

## **6.5 Setting**

Study participants lived across England, with the majority within London and the southeast regions of the UK. Participants chose the setting for their interview. The majority chose to be interviewed at home which had the added advantages of offering a relaxed environment as well as contextualising their responses (Tod, 2010). Other choices participants chose included, a quiet room at the university or at MS therapy centres. The former was chosen as the participants wanted to see the environment of the researcher as well as have the opportunity to be outdoors. Interviews conducted at the MS therapy centres were for practical reasons as participants had weekly therapy sessions and organised interviews on these dates.

## **6.6 Topic guide and interview Process**

A semi-structured topic guide informed by the results from the Delphi study was developed to shape the areas to be discussed in the interview. A first draft of the topic guide was discussed with supervisors and amendments made. The second draft was then tested during a pilot interview process and minor changes made with respect to the ordering of the questions so that the interview flowed (see Appendix 15e). Section 6.7 describes the pilot study.

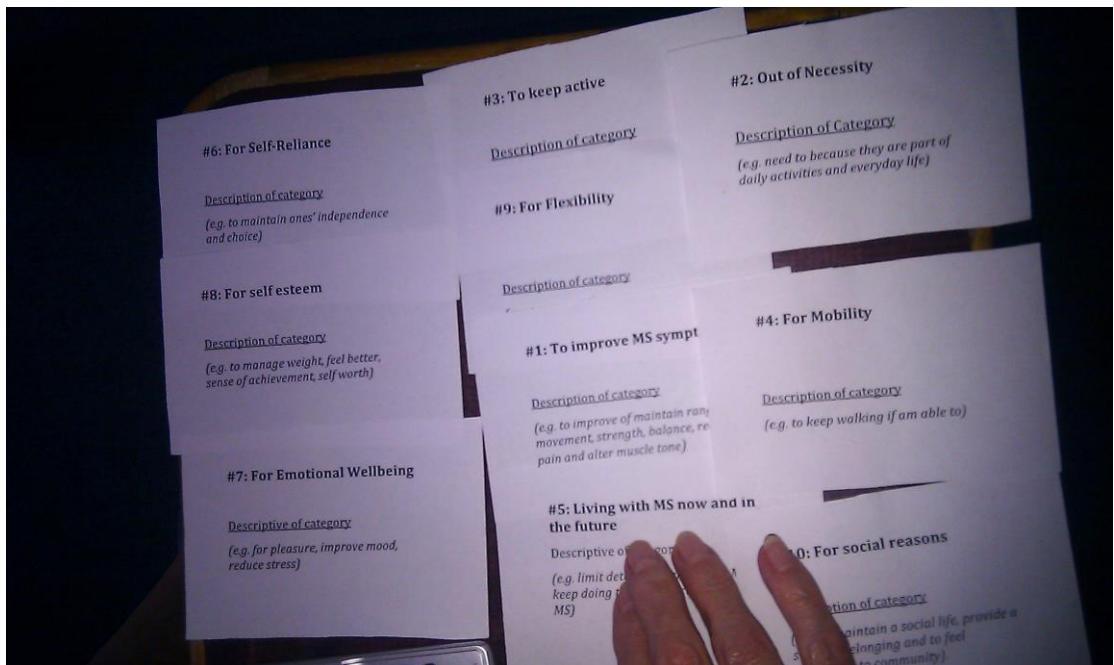
The interviews followed a four stage process similar to that of Arthur and Nazroo (2009) which were adapted and used to guide the interview process. The first stage of the interview was an introduction where the participant was reminded of the background and aim of the research, consent procedures and the right to withdraw if they wished. It was emphasised that their views and opinions were sought and there were no right or wrong answers. This was done to reduce

anxieties should their personal views differ from the general results of the Delphi study, which was bought about through group consensus.

The second stage of the interview involved talking broadly about exercise and physical activity. The aim was to explore personal descriptions of the terms exercise and physical activity. This is linked to the research questions, and was deemed important for participants to reflect on and describe what exercise and physical activity meant within their personal context. Their interpretation of exercise and physical activity would be used later during the analysis in shaping understanding of the meanings ascribed to exercise and physical activity.

The third section was more specific exploring the meaning of exercise and physical activity in the participants' daily life. Cue cards were used as a tool to facilitate the discussion (See Figure 6.1). Each displayed a category from the results of the Delphi study and their description. The cue cards were used as a prompt to help focus the interview and also detract from the strangeness of the interview process.

**Figure 6.1 showing participant using cue cards during the interview**



The final stage was used to ease out from the interview (“winding down”). Participants were given the opportunity to raise any other questions or concerns about the study before drawing the interview to a close.

## **6.7 Pilot Interview**

Piloting the tools for use in an interview is recommended especially for novice researchers to ensure tools are appropriate and to provide the opportunity to enhance interview techniques (Tod, 2010; Kvale and Brinkmann, 2009). In this study, the pilot interviews were used to assess the topic guide, to see whether or not the questions flowed, to ascertain whether the data produced was relevant to answering the research questions and to determine the length of time required to complete the interview (Tod, 2010). Piloting was also necessary to practice interviewing skills outside of the clinical context. This was important as with a background in physiotherapy the researcher is used to leading interviews within the clinical context. However within the research context the researcher needed to be flexible and less in control of the line of questioning and to follow discussions as put forward by research participants (Tod, 2010).

Two pilot interviews were carried out, one with an occupational therapy PhD student and the other with a physiotherapy colleague. They took between 45 and 60 minutes. This provided an indication of the length of time each interview might take. As a result of the pilot study, changes were made to the order of the questions used to commence the interview. Otherwise no changes were made to the content of the interview topic guide. Practically, the pilot interviews identified the need to ensure participants' comfort. For example, ensuring that their glasses were available as well as water should participants get tired or thirsty during the interview.

## **6.8 Data management**

All interviews were recorded using a digital recorder, which produced audio files that could be downloaded to a computer, stored and listened to later. Notes were

also taken during the interview to capture non-verbal communication (e.g. gestures, facial expressions) of participants as well as reflexively to capture the interview experience and its impact on the researcher (Tod, 2010). Excerpts from reflections can be found in the appendix (Appendix 15g). All interviews were transcribed verbatim. The transcribed interviews varied between 45 to 60 minutes in length. Following transcription the data were analysed using Framework Analysis (Ritchie and Spencer 1994).

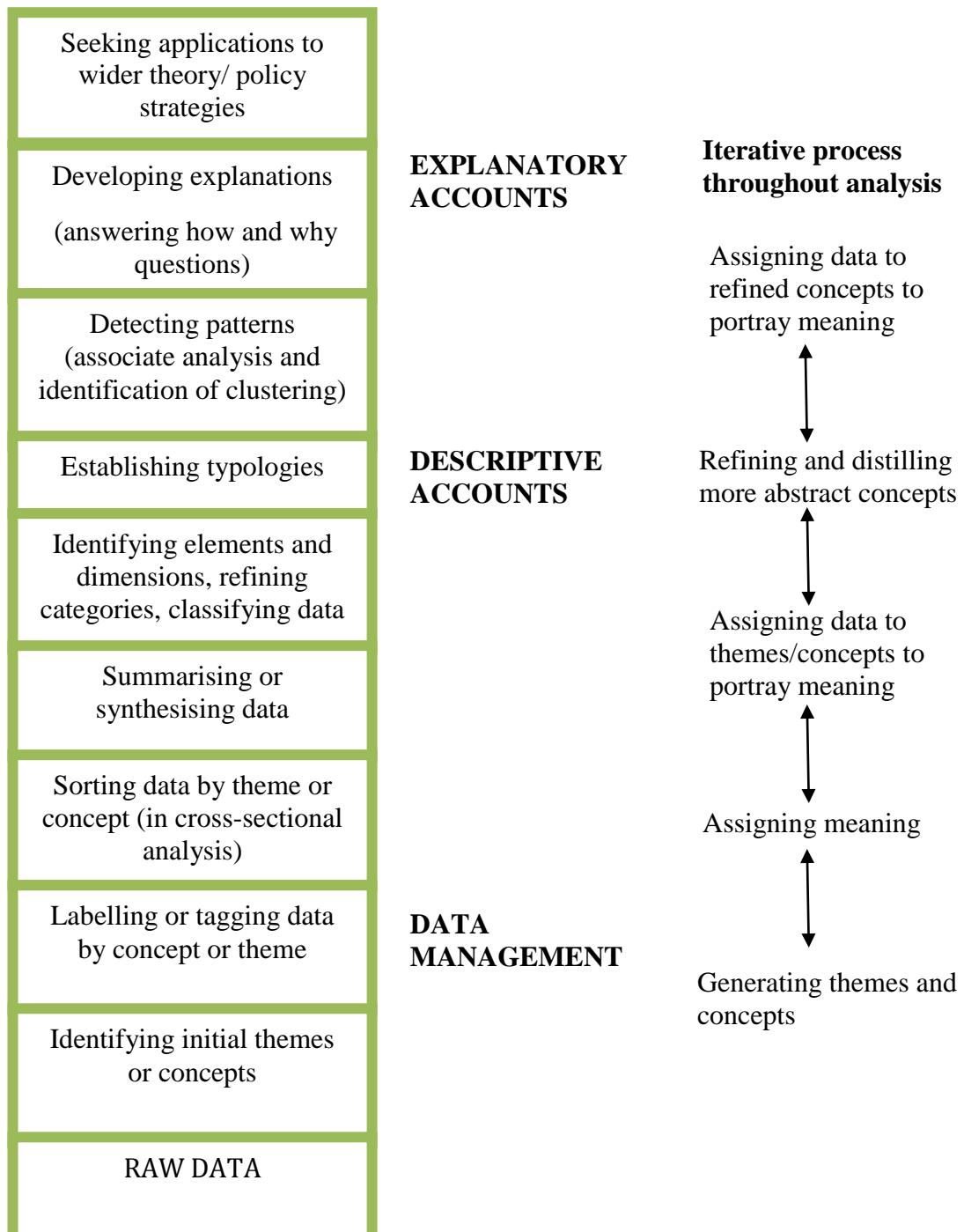
## 6.9 Analysis

Getting to grips with qualitative data analysis can be a difficult process. One reason attributed to this is the amount of data collected throughout the interview process (Pope, Zieblands and Mays, 2000). Spencer and colleagues (2009) developed what is termed “the analytical hierarchy” as a way to help researchers manage the different stages of the analysis in order to gain further insight into the meanings participants bring to their world (Spencer, Ritchie and O’Connor, 2009). Figure 6.2 shows a representation of the analytic hierarchy. The analytical hierarchy describes the process of analysis represented as a ladder whereby each rung is considered a platform from which the data can be viewed. These platforms allow the researcher to have a specific view of the data at different levels and facilitate the decision making process in the development of categories and the formations of emergent themes.

The concept of the analytical hierarchy is reflected in many different qualitative analytical approaches. These include but are not limited to Grounded Theory (Strauss and Corbin, 1998), Interpretative Phenomenological Analysis (Smith and Osborn, 2003), Thematic Analysis (Braun and Clarke, 2006) and Framework Analysis (Ritchie and Spencer, 1994). With respect to framework analysis, the ladder analogy describes how the researcher is orientated to the data at different levels of abstraction but the process is iterative. That is, the researcher can go back down the ladder to check that the analysis remains with, and is always grounded in, the data. Qualitative researchers agree that regardless of the chosen method of analysis the themes identified should reflect the world of the participants (Ritchie, Spencer and O’Connor, 2009; Pope, Zieblands and Mays, 2000). Other factors that

may contribute to the decision making process about the chosen method of analysis include the research question, time available to complete the study and the focus of the study (Spencer, Ritchie and O'Connor, 2009).

**Figure 6.2: The Analytic Hierarchy**



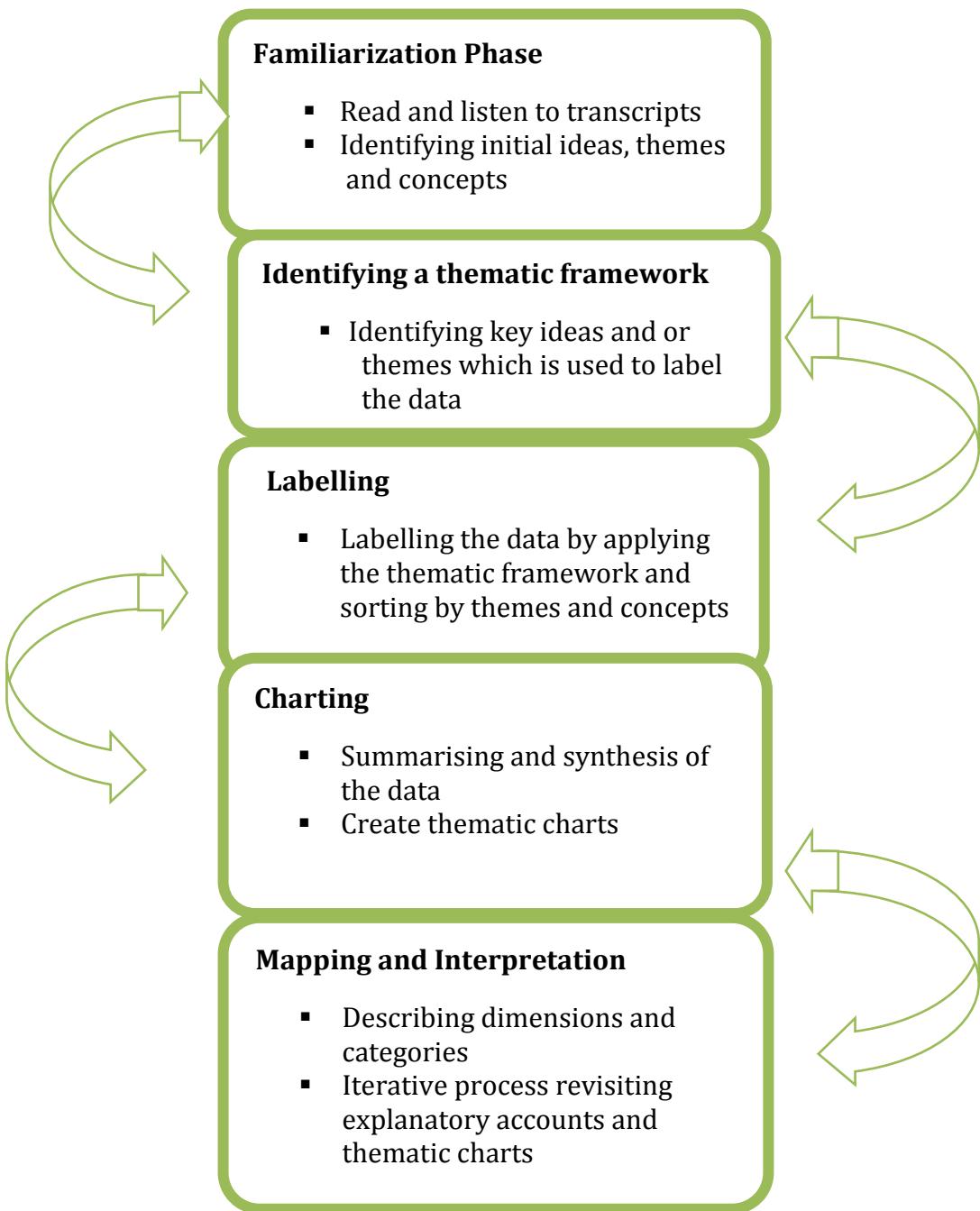
(Adapted from Spencer, Ritchie and O'Connor, 2009, p.212)

In this study, Framework analysis was chosen as the most appropriate method of analysis for two key reasons. Firstly, the interviews were in part framed by the outcome of the Delphi study (Study 1), which provided a set of categories that strongly informed the interview questions through the use of the topic guide. Secondly, this data analysis method provided a structured approach to the sorting, organising and interpretation of data. The strength of this method of analysis lies in the ability to provide an audit trail of the procedures used to analyse the data at each stage of the analysis using a matrix based system (Ritchie, Spencer and O'Connor, 2009) which enhances transparency within the study (Holloway and Wheeler, 2010). The technique involves 5 iterative stages of analysis and was used to guide the analysis of this study. Figure 6.3 shows each stage of the analysis.

### **6.9.1 Stage 1- The Familiarisation Phase**

This phase involved getting familiar with the data through reading the transcripts, making notes and listening to the interviews several times. Initial codes and ideas were identified deductively based on the categories from the Delphi study which formed the frame of the topic guide and also inductively to locate other ideas or themes that did not fit the topics. During this phase the researcher identified initial concepts that reflected participants' comments either by reading line by line or through thinking about the key emphasis of each paragraph. The researcher was keen throughout this phase to ensure that the concepts identified were as close to the meanings of participants as possible (Ritchie, Spencer and O'Connor, 2009).

**Figure 6.3: Stages in Framework Analysis**



(Adapted from Ritchie, Spencer and O'Connor, 2009)

### **6.9.2 Stage 2- Identifying a thematic conceptual framework**

This phase of the analysis involves re-reading the transcripts and making notes that reflect participants' thoughts and ideas. The topic guide as well as the research questions for the study informed the development of the conceptual thematic framework which was developed and refined during this phase until no further themes were identified. The development of the framework centred on responses generated from exploring the meanings of exercise and physical activity as well as the results from the Delphi Study. The initial conceptual framework yielded 20 different categories (Appendix 15h). The framework was discussed with the supervisory team and an agreement reached to focus the framework on the primary research questions. Therefore, issues associated with the experience of being involved in the Delphi study were not included in this thesis but will be published at a later date. The revised conceptual thematic framework was re-checked by returning to the transcripts to ensure that the main themes were included (see Figure 6.4). The revised conceptual framework, which contained 8 key themes, was discussed with the supervisory team prior to the next phase of the analysis.

**Figure 6.4: Conceptual framework Study 2 (Final)**

- |  |
|--|
| <b>1. Background/Demographic information</b>                               |
| 1.1 Age  |
| 1.2 Sex  |
| 1.3 Functional Level   |
| 1.4 Impact of MS on activity   |
| 1.5 Occupation/Employment Status   |
| 1.6 Type of MS   |
| 1.7 Other  |
| <b>2 The meaning of exercise in people with MS living in the community</b> |
| 2.1 Activities done with health professionals (+/- equipment)              |
| 2.2 Movement (organised, keep moving, puffy, repetitive, supportive)       |
| 2.3 Conscious activity/focused/set/intentional)                            |
| 2.4 Consequences and Benefits of exercise                                  |
| 2.5 Demanding (intensity/work, challenging/creates conflict)               |
| 2.6 Supports daily Routine/efficient                                       |
| 2.7 Feelings (feel good factor, sense of achievement), Boring              |
| 2.8 Location of activity (gym/home/outdoors)                               |
| 2.9 Other issues   |

- 3 The meaning of physical activity in people with MS living in the community**
- 3.1 Essential and part of daily life (Normal /how we live life)
  - 3.2 Feelings (mundane, fun, irrespective of feeling, feel good factor)
  - 3.3 PA is any movement (choose to do/Purposeful/practical movement)
  - 3.4 Physical type activities
  - 3.5 Reasons and benefits of physical activity
  - 3.6 Social element (beyond impairment and function to participation)
  - 3.7 Other
- 4 Relationship between exercise and physical activity**
- 4.1 Conscious versus unconscious activities (just do it/routine)
  - 4.2 Similarities (overlap/no difference/what's in a word, Incidental/accidental)
  - 4.3 Differences (no relationship)
  - 4.4 Energy expenditure (Discipline required)
  - 4.5 Other
- 5 Influencing Factors for exercise and physical activity**
- 5.1 Circumstances
  - 5.2 Having MS (MS related symptoms/experience of living with MS)
  - 5.3 Personal belief & desire (motto/do something/desire to be fit)
  - 5.4 Preference and Choice (Fun, Age)
  - 5.5 Prior education (Primary and or high school)
  - 5.6 Professional input (Attending MS therapy Centre /PT)
  - 5.7 Other
- 6 The top 10 activities reflect life with MS (Views about the top 10)**
- 6.1 Anchor activities (stretches, PT & act without weights supporting top 6)
  - 6.2 Identity (Separation of self from other pwMS & general population)
  - 6.3 Priorities depends on (age/personal choice, stage of disease, ability)
  - 6.4 Relevant for life with MS (Not always about fitness, Freedom /connectivity)
  - 6.5 Variability of activities (Strength in diversity/Incidental, desirable /necessary)
  - 6.6 Views about top 10 activities (chosen, order, missing, surprises, overlap)
  - 6.7 Other
- 7 Beyond coping to resilience (Views about the top 10 reason why)**
- 7.1 Conflict between physical and emotional
  - 7.2 Coping strategy (part of living with MS, Rule and challenge MS, Control& wellbeing, Normal life (how to live in the normal world, acceptance)
  - 7.3 Motivation for exercise and PA (sense of achievement/management weight)
  - 7.4 Organisation and Planning
  - 7.5 Participation
  - 7.6 Road map for MS journey (resilience, risk versus safety, Role of support)
  - 7.7 Views about the reasons why (Chosen, missing, surprises, age, stage of disease)
  - 7.8 Other
- 8 Loss and Reconciliation**
- 8.1 Compromise and reconciliation
  - 8.2 Loss of activity
  - 8.3 Loss of employment
  - 8.4 Loss of energy
  - 8.5 Loss of family and or friends
  - 8.6 Loss of identity
  - 8.7 Loss of independence
  - 8.8 Other

### 6.9.3 Stage 3- Labelling

The process of labelling involved applying the conceptual thematic framework to all 16 transcripts. All transcripts were labelled with the 8 key themes identified using the thematic framework. In accordance with the iterative process underlying principles that guide the analysis, the thematic framework was refined to reflect any new ideas that developed during the process (see Figure 6.5).

**Figure 6.5: Worked example of interview transcript and labelling**

Shelby: Interview transcript.

*Meaning Jct*

*Meaning PA*

24 D: For me it's, more than to.. have.. I can't do any exercise without help. So, Jane (wife) and I manage to do a bit.. everyday, when we are dressing, its ahh... physical activity and ahh... movement that I wouldn't normally have.

25 I: ok

26 [2.2] [2.5]

27 D: Because, I have no active movement. Any movement, it's passive, in other words is done by somebody else. Because I don't have any movement of any, no voluntary movement anyway. I believe in physiotherapy because hydrotherapy once a week and physiotherapy once a week. Those help me to maintain.amm... mobility, limited passive mobility of my limbs. Which is important because if you loose that, you can't even really get dressed. So by definition you probably, astoundingly bed ridden.

28 I: So, what the physio does or the hydrotherapy, would you classify that as exercise or as physical activity?

29 D: both

30 I: Both

31 [2.8]

32 [2.4]

33 D: its as a... a social element as well.

34 I: ok. So, then what do you think makes physical activity physical activity as oppose to exercise. Do you draw a distinction between the two?

35 [3.6]

36 D: Not really, because, my level of disability, only draws a blurr with those distinctions. I can't... If I can't move, I can't actually participate in physical activity. But if you extend that into socialising I can... but that's sort of a grey area really isn't?

37 I: hummm...

38 D: (sipping coffee with wife feeding..).

39 I: so for you then, amm.. so you've mentioned that you are involved in physiotherapy and involved in hydrotherapy. What else are you involved in?

40 D: Really, the remainder it is, I would put under the social category.

41 [7.5]

42 I: For example?

43 D: For example, I just want to sort of make this, amm.. distinction..

44 that if you are like me, in other words quadriplegic, then you have two options. You can continue to live in the abled body world and try to participate in as many.. social and wait... yeah... social activities,

45 [4.2] [3.6] [7.5]

46 No difference bw/r

47 EX PA

48 linked to social element

49 Social

50 PA

51 Interview D.M

52 2

## 6.9.4 Stage 4- Charting Phase

The charting phase is the final step in organising and managing the data (see Table 6.1). This phase further reduces the data by summarising the content of each labelled paragraph. A thematic matrix was created and organised to facilitate ease of analysing the data within themes or between cases in the study (Ritchie and Lewis, 2009). Once all the charts were completed they were printed to aid visualisation as per the preference of the researcher.

Nvivo 10 was used to organise and sort the data and facilitated cross checking between the original text and the labelled text to ensure that the main themes reflected each category (Silver and Lewins, 2010; di Gregorio and Davidson 2008). This was done in a number of ways, for example, through negative case reporting, reviewing the transcripts, analytic procedures and through critical discussions with the supervisory team. Examples of negative case reporting are highlighted in the next chapter under subthemes Physical impact of exercise and physical activity (see section 7.3.1 and Loss of employment (see section 7.5.2)

**Table 6.1: Worked example of charting phase**

Study 2						
	A	B	C	D	E	
1	1: Interview S.B Age = 60 Impact of MS on Exercise and Physical activity = Moderately affected Sex = Female Type of MS = Primary Progressive	A: 2.1 Activities done with Health professional Goes to physio once per week. Does ball and floor exercises with physio (24) Has pedal foot cycle at home, deep to conversion of exercise equipment at home, does not do exercises (24-28)	B: 2.2 Any movement of the body Movement that keeps her mobile and build muscle(32-16) Burn up calories doing exercise(\$5) with exercise you keep going even if you are tired(\$5-85)	C: 2.3 Consciously intentional activities something else...activities you don't do everyday (17-18) Has foot pedal cycle at home but don't do it daily, nevertheless she should. Has physio sessions weekly using a variety of exercises (24-28)	D: 2.4 Consequences and benefits of doing exercise Exercise to keep mobile and build muscles (32-36) Do ~5-10mins some days but other days don't do any, like something else you have to do (33)	E: 2.5 Demanding activities something else...activities you don't do everyday (17-18) Requires effort (49-50)
2	2: Interview C.G Age = 53 Impact of MS on Exercise and Physical activity = Moderately affected Sex = Male Type of MS = Primary Progressive	Goes to physio twice per week at MS the pay Centre(55) Use exercise equipment...but because spends most of the day in a room in the house, activity revolves around getting up from chair and going to loo (94-110)	Aerobic activity to get heart going so prevent sedentary life. Move fast to get out of breath to improve overall healthy lifestyle Personally thinks this is a good idea for ever all health (84-89).	Confined activity done in the gym (80) Focused activity using equipment, may involve walking (30)	No comment	Activities contained new/unable to run, can't swim because don't like walking barefoot and also getting into the pool and needing the loo (72-76)
3	3 : Interview K.M Age = 65 Impact of MS on Exercise and Physical activity = Moderately affected Sex = Female Type of MS = Unassigned	Did not mention anything in this column. Takes a holistic view to exercise and PA, does not use equipment or engage in exercise with physio (52)	Any movement is exercise does not have to be specific. Any movement forms part of daily life, like cooking (30-34) Other people view exercise as going to gym, jogging...that is specific but any movement that involves the body is exercise(36-39)	No comment	No comment	NO COMMENT
4	4 : Interview B.W Age = 63 Impact of MS on Exercise and Physical activity = Mildly affected Sex = Female Type of MS = Unassigned	Did not mention anything here	Not just any movement but movement in an organised way, ones that strengthen the core ms (77-78) Movement that keeps you fit and moving (122-125)	Organised movement(78) Can put into daily routine (87-89). Like this fact about exercise(89) Can pace self if tired (127-130)	Do exercises because of previous back problems associated with poor posture Exercise does not take long ~10mins Recently tried putting exercises into daily routine and think this is good to do (81-89) Exercises done to strengthen core muscles (81)	NO COMMENT
5						

### **6.9.5 Stage 5- Mapping and Interpretation Phase**

During this phase, the matrix- based charts were read and re-read across the themes and also across all participants. This allowed the researcher to get a sense of the data within the themes. This was an intensive phase of the analysis and required moving backwards and forwards between this phase and the charting phase. The benefits of Framework analysis allowed the researcher at this stage the ease with which to view summarised information across themes and within cases (Ritchie, Spencer and O'Connor, 2009).

Each chart was mapped separately to identify the key dimensions and associated major themes. A table was created for each participant with key dimensions and themes (see Table 6.2); from this the researcher identified similarities and differences within the data. The researcher also noted minor themes that did not fit the developed categories.

Flip charts were created to reflect the major themes along with their subthemes. During the interpretation phase the researcher re-examined themes related to the research questions. These were grouped and quotations were used to illustrate the themes. A fully worked example of the development of one of the main themes is presented in Appendix 15l.

**Table 6.2: Worked example of Mapping and Interpretation**

Name of theme: Views of the top 10 reasons why/ 7.1 Conflict between physical and emotional. Description: Dilemmas experienced/Which to tackle first the physical and emotional

Participants	Dimensions	What are they really saying
[REDACTED]	Physical and emotional linked-inter-related Influence of physical and emotional and vice versa	Inter-relatedness of Physical and emotional states of being The effect of exercise on physical and emotion states Personal belief
[REDACTED]	Importance of maintaining self esteem; +ve links with emotional and physical	Inter-relatedness of Physical and emotional states of being The effect of exercise on physical and emotion states Personal belief
[REDACTED]	Impact of depression –ve on physical Dilemma of what to tackle first- emotional/physical +ve effects of exercise on depression  Ability to do self-care is linked with independence, self-esteem and confidence. Transportation linked with independence, confidence and self-esteem	The effect of exercise on physical and emotion states Personal belief Dilemma with pwMS but also has clinical implications- what do you tackle first? Physical/emotional  Identity/ Linked with chart 6  Identity/ Linked with chart 6

## 6.10 Enhancing Rigor in Qualitative Research

The quality in qualitative research is judged by the ability to demonstrate consistency and accuracy of the entire research process (Tod, 2010). That is, from the selection of participants, development of tools through to the data collection and analytic procedures (Tod, 2010). Transparency in the research process is based on the principles of trustworthiness, which include credibility, transferability, dependability and confirmability (Holloway and Wheeler 2010; Lincoln and Guba 1985). In this study, these principles were adopted where possible to improve the quality of the study. For example, adequate descriptions of the methods, which include how participants were selected, and how data were

collected, transcribed and analysed, have been presented which enhances dependability. Similarly, detailed descriptions of the study participants along with excerpts from transcripts using quotations from the interviews, illustrated and supported the themes developed in this study and collectively enhanced the transferability and dependability of the findings related to the context used in this study. These will be reported in the following chapter.

Credibility is linked to enhancing the internal validity of the study (Lincoln and Guba, 1985). This was ensured through expanding the results of the Delphi study which revealed the activities pwMS prioritised as part of their daily routine and highlighted the meanings these activities held for pwMS living in the community. These multiple sources of data allowed for cross referencing findings from Study 1 and provided greater insight into understanding the meanings of exercise and physical activity in pwMS.

The researcher was involved in all the stages of the study and, as such would have influenced aspects of the study. Therefore to account for these influences on the study, a number of checks were employed. For example, the researcher kept a reflexive journal throughout the data collection process as well as during analysis of the data. Reflexivity is defined as “thoughtful, conscious self-awareness” (Finlay, 2002, p.532) and is believed to be an important aspect in qualitative research (Taylor, 2010; Lathlean, 2010; Snape and Spencer, 2009; Finlay, 2002). Reflexivity was used as a way to highlight the researcher’s influence on the study and make that influence clear to the readers of the thesis in order to make sense of the study with respect to the context in which the study was undertaken. For example, it allowed the researcher to stay grounded in a researcher rather than a clinical identity. Excerpts from this journal are presented in Appendix 15g. Also, transcripts from the interviews were shared with the supervisory team along with the data analysis process. Each stage of the analysis was reviewed by the supervisory team, and critical discussions ensued which questioned the thought processes of the researcher as well as allowed the researcher to justify themes developed through the analytic process. Additionally, findings were discussed informally with other professional peers, which helped to consolidate current

thoughts about the findings of the study. Collectively these checks enhanced the credibility of the findings.

## **6.11 Conclusion**

This chapter presented and justified the qualitative approach taken towards gaining a deeper understanding of the results from the Delphi study, which identified the exercise and physical activity practices of pwMS living in the community. It described the methods used to gather and analyse data from semi-structured interviews. A similar procedure was also used in analysing focus group data, which will be discussed in chapter 8.

## **Chapter 7**

### **Study 2: Interview Findings**

#### **7.0 Introduction**

This chapter details the findings from interviews exploring the meaning of exercise and physical activity in pwMS living in the community. Following an overview of the participants' profiles, five themes developed from the data, will be presented. The chapter will conclude by synthesising the key findings and their interpretations within the context of the study and will position the findings within the literature in relation to exercise and physical activity in pwMS.

#### **7.1 Demographic profile of study participants**

Sixteen (16) pwMS living in the community participated in the study. Of these, 12 (75%) were females and 4 (25%) males with ages ranging from 47 to 72 years. Functional abilities varied across the group with the majority (n=9) reporting that they were independent in mobility using mobility aids. Two participants reported that they were in current employment (paid or voluntary), the rest were retired either on medical grounds or had reached the age of retirement. Table 7.1 details the demographic profile of the sample. The type of MS varied across the group with 31% (n=5) and 13% (n=2) reporting that they had been diagnosed with primary progressive and relapsing remitting MS respectively.

All participants in the study reported some effect of MS on their ability to engage in exercise and physical activity. Of the 16 participants, 50% (n=8) reported that their ability to engage in exercise and physical activity was severely affected by MS. Others reported that they were either mildly (n=2, 12.5%) or moderately (n=6, 37.5%) affected.

**Table 7.1: Demographic profile of sixteen interview participants with multiple sclerosis**

Name	Age	Functional Level	Impact of MS on exercise and physical activity	Occupation	F/M	Type of MS
Grace	47	I- mobility without aid	Severely affected	Retired	F	RR
Tom	70	I- mobility with aid	Severely affected	Retired	M	SP
Anne	63	I-mobility with aid	Mildly affected	Volunteer	F	U
James	53	I-mobility with aid	Moderately affected	Retired	M	PP
Jill	47	I- mobility without aid	Severely affected	Unemployed	F	SP
John	62	D- powered wheelchair	Severely affected	Retired	M	PP
Harry	71	I- mobility with aid	Severely affected	Retired	M	U
Sue	50	I- mobility without aid	Severely affected	Retired	F	RR
Pam	65	I- mobility without aid	Moderately affected	Unemployed	F	U
Lily	66	I-mobility with aid	Mildly affected	Employed	F	PP
Linda	71	I-mobility with aid	Moderately affected	Retired	F	U
Eileen	72	I- powered wheelchair	Severely affected	Retired	F	U
Mary	60	I- mobility with aid	Moderately affected	Retired	F	PP
Ivy	68	I-mobility with aid	Severely affected	Retired	F	PP
Bev	55	I-mobility with aid	Moderately affected	Retired	F	SP
Carol	61	I- mobility without aid	Moderately affected	Retired	F	SP

Key: RR- Relapsing Remitting, SP-Secondary Progressive, PP-Primary Progressive, U- Unknown, M-Male, F- Female, I- Independent, D- Dependent

Following framework analysis, 5 major themes were developed from the data namely, '*a type of movement*', '*impact of exercise and physical activity*', '*it changes*', '*sense of loss*' and '*coping with MS*' (see Table 7.2). Each theme will be briefly introduced followed by detailed description of the subthemes. Illustrative participant quotations will be used to support the sub-themes. A reference for each illustration is provided using a pseudonym, key biographical details, gender and age, followed by a line number which links directly to the original transcript.

**Table 7. 2 Major themes and subthemes for the meaning of exercise and physical activity**

Main theme	Sub-theme
<b>A type of movement</b>	<ul style="list-style-type: none"> <li>▪ Exercise as specific and organised movement</li> <li>▪ Physical activity as part of daily routine</li> <li>▪ Relevant for life with MS</li> </ul>
<b>Impact of exercise and physical activity</b>	<ul style="list-style-type: none"> <li>▪ Physical impact</li> <li>▪ Psychological impact</li> <li>▪ Social impact</li> </ul>
<b>It changes</b>	<ul style="list-style-type: none"> <li>▪ Reflections on the past and ever changing present</li> <li>▪ Uncertain future</li> <li>▪ The influence on priorities</li> </ul>
<b>Sense of loss</b>	<ul style="list-style-type: none"> <li>▪ Loss of activity (loss of independence)</li> <li>▪ Loss of employment</li> <li>▪ Compromise and reconciliation</li> </ul>
<b>Coping with MS</b>	<ul style="list-style-type: none"> <li>▪ Normalcy</li> <li>▪ Control over physical symptoms</li> <li>▪ Exercise and physical activity frames the week</li> <li>▪ Support</li> <li>▪ "This is me"- identity</li> </ul>

## 7.2 A type of movement

The initial questions during the interview explored the understanding of the terms exercise and physical activity. From these descriptions participants highlighted features they associated with the words. The resulting theme is therefore deductively drawn from specific questions but was further inductively developed as will be demonstrated.

A common feature reported across all participants when describing their understanding of exercise and physical activity was that exercise and physical activity were about movement. However, the types of movements were understood based on certain attributing factors, namely, the specificity of the movement, purpose and relevance for living life with MS.

### **7.2.1 Exercise as specific and organised movement**

Multiple descriptions were used to illustrate the meanings of exercise with respect to movement. Some participants felt exercise was limited in time and space. Others felt that exercises were movements that were specific, separate and did not form part of one's daily routine, as illustrated by Sue.

*Exercise is something that, in a funny kind of way.. doesn't form part of one's, one's kind of routine... something that you make separate ..time for... amm.. but so, it's so... slightly more in isolation, to all the things that you would do... (Sue, 50 years, F, severely affected, line 91-94)*

This view was shared by other participants despite experiencing different levels of disability (e.g. Mary). Others also focused on the separate nature of exercise indicating that it required conscious thought and effort and consequently was not easily accommodated as part of everyday life:

*(big audible sigh).. if I, concentrate on it.. as a..a.. something that I do separately then yes I'd call it, exercise.. (Eileen, 72 years, F, severely affected, line 33-35)*

Ivy and Carol developed this point further suggesting that concentration was required to not only carry out exercises but in order to prevent injury during exercise, such as falls.

Other meanings attributed to exercise were movements that were organised, demanding and targeted specific muscles. Participants, irrespective of the impact of MS on their ability to engage in exercise, recounted similar attributes of exercise. For example, Anne who is mildly affected by MS felt that exercise required moving in an '*organised way*' (Anne, 63 years, F, mildly affected, line 77).

Others suggested that the concentration required was as a result of the necessity to target specific muscles in exercise. Jill, Grace and Linda expressed that exercise

provided the opportunity to target muscles that otherwise would not be exercised during routine daily activities.

*... I think with exercise you're using parts of your body that you don't normally use during the day. You know what I mean normal ... during normal everyday sort of running of a place, you don't normally ... I don't think you use the same muscles as you do when you exercise. I think that's probably it - that you use different muscles. And you're strengthening those ... or you're trying to strengthen those muscles which ... which do actually come in when you normally ... normal every day ... you find that you can do things better ... I think. (Linda, 71 years, F, moderately affected, line 482-493)*

Linda's excerpt indicates that while exercise in its doing is separate from everyday life, the impact of exercise can be felt within everyday function. This emphasis on impact is explored further in a later theme.

### **7.2.2 Physical activity as part of daily routine**

In contrast to exercise, physical activity was associated with daily routines and purposeful activities. Sue and Carol highlighted these in their descriptions of physical activity:

*Well, I mean moving, moving, any part of your body.. amm.. it could be deemed as being physical activity but I would also, include within physical activity, things like, I don't know, housework, gardening, amm...the things like that.. (Sue, 50 years, F, severely affected, line 32-35)*

*Physical activity around here, is lawn mowing, and you know, picking up rotten apples and sticking them in and dragging big sack stuff out the front...and ahhh.. You know, like I was up... trying to get up a ladder today, unsuccessfully, you know fitting the...you know ..sort of..(pointing at light bulb).. so you know, its, sort of, the practical stuff.. (Carol, 61 years, F, moderately affected, line 56-66).*

While these women, who are both independently mobile, described physical activity as activities that required considerable body movement such as domestic activities and gardening, others more physically limited by their MS had parallel descriptions within their everyday lives. Eileen for example required assistance for mobility and was physically restricted functionally also offered a sense that movement associated with physical activity was part of everyday life.

*Physical activity, is just physical activity. I mean, it's just part of reaching over to get things and lifting up a saucepan.. (Eileen, 72 years, F, severely affected, line 68-70)*

For Carol, Sue and Eileen any movement was associated with physical activity. However, this was more so a reality for Eileen who had not participated in formal exercise for over 20 years. Her main movements were associated with daily routine activities. Eileen's description of exercise had transitioned into performing daily life activities, these for her were considered to be exercise. This was a view shared by Tom and Sue:

*...yes.. obviously.. a, a, a mean, absolutely because... amm.. every time you move.. you are taking some form of physical activity ..obviously if you ..studiously, devote yourself to doing that that activity, on a , more prolonged or repetitive basis, it becomes exercise (Sue, 50 years, F, severely affected, line 50-54)*

While participants understood physical activity to be part of everyday routine they also highlighted its link to a specific purpose. That is the means by which daily activities are achieved. For example, James and Harry who were both independently mobile expressed these purposeful movements, albeit with different emphasis. James, who was diagnosed with primary progressive MS, deliberately engaged in any movement as a way to remain mobile. His determination was driven by the need to remain living in his two-storey house and to access all the areas of his home. James was aware that being diagnosed with primary progressive MS meant there might come a time when his mobility would be challenged:

*...physical activity, I need to move from here to there and use whatever I can do, to stand up, walk, move upstairs, that, that's all physical activity to me (James, 53 years, M, moderately affected, line 117-120)*

On the other hand, Harry expressed a nonchalant attitude towards physical activity. Harry was unaware of the type of MS he was diagnosed with. However, unlike James who had noticed a gradual decline in his mobility, Harry's mobility had been stable over the years. For Harry physical activity was described as an 'in the way' activity. That is, an activity that had to be done before other tasks could be achieved.

*(long pause) .. physical activity is... (long pause) taking up because it happens to be there and in the way of doing something else... one has to pass this particular area and, and within this area there is physical activity* (Harry, 71 years, M, severely affected, line 89-93)

While participants drew relatively clear distinctions between exercise and physical activity, as with Sue, some crossover was evident. As an example, for John, ascribing meanings to exercise and physical activity only “draws a blur”. John is 62 years old and has primary progressive MS. He relied on a tilt in space, powered wheelchair for mobility due to no upper or lower limb movements. When asked by the researcher about his understanding of exercise and physical activity he responded:

*... my level of disability only draws a blur with those distinctions. I can't...If I can't move, I can't actually participate in physical activity. But if you extend that into socialising I can.. but that's sort of a grey area really isn't?*  
(John, 62 years, M, severely affected, line 45-48)

For John, his understanding of physical activity was extended to the social context displaying a broader concept of physical activity:

*.. ammo... yes..but if I was going to write it down I would put physical activity and socialising in, somehow overlapping in the same bracket. Because, I can't really do anything physically, but I can socialise, I can enjoy meeting people like you, chat and have a very fulfilled life, really.* (John, 62 years, M, severely affected, line 124-128)

Throughout John’s interview he expressed this sense that physical activity should be viewed much broader than the physical aspects of life. He described himself as a quadriplegic, which is often perceived within the physical activity context as a restriction to movement. However, he expressed that despite his physical limitations, movement for him went beyond the physical; it was also about the interaction with other people, his environment and the wider community. Hence John had interpreted physical activity within the context of his environment and personal context.

### **7.2.3 Relevant for life with MS**

Although the illustrations above suggested that pwMS were actually quite clear in their descriptions of exercise and physical activity, the data revealed the complexity of these terms to everyday life. Participants felt that these types of movements (exercise and physical activity) overlapped and played a necessary '*part of living with MS*' (Lily, line 362). This subtheme was developed to illustrate that movements whether exercise or physical activity, were relevant for life with MS and helped to manage disability. Participants described noticeable changes in physical abilities, such as, loss of balance, flexibility and confidence when movements specifically related to formal exercise were not completed or ignored:

*.. I mean, for me, this (stretches) is really important.. because when I don't do this.. I feel the difference.. you know, the physical activities I do.. and you know the classes I choose to do.. and what I do at home, because for example.. I was on holiday last month and I didn't do anything.. I did a lot of walking.. because it was like a sight seeing holiday.. and I did a lot of walking than normal.. but amm.. when I came back.. when I went to the first yoga class I'd loss my balance! I'd lose my ability, you know, to be flexible in my back .. and kinda just lost confidence in my body.. and you know that was just for two weeks* (Pam, 65 years, F, moderately affected, line 244-252).

Similarly, reflecting on the Delphi results, participants drew references to the links between structured exercises and physical activity and the relevance for living with MS. They referred to '*stretches', 'physiotherapy' and' activities without the use of weights*' as supporting activities. They felt that those movements (exercise) supported physical activities such as, '*self-care', 'domestic', 'everyday life', 'transportation' and 'leisure activities'*'.

*...Amm.....because of my ... circumstances.. and all of these (touching cue cards representing stretches, physiotherapy, activities without the use of weights)... really they are actually supporting ammo certainly these two (pointing at cue cards representing transportation and leisure).. are possibly all of them really because ... my muscle tone gets so sort of.. brittle or some sort of, degraded then it has an impact on my driving, an impact on what I can do leisure activities. Although I understand that in the wheelchair you can do stuff but it's sort of, it gets a bit more difficult.. you know it just makes things a lot more complicated* (Bev, 55 years, F, moderately affected, line 543-556)

Despite the acknowledgement that exercise supported physical activity, participants also reiterated that it was the doing of the physical activity that remained the priority:

*Oh, I think, that the.. the most important things would be, well, I mean you start from the beginning of the day and I mean, you know, you're going to get washed and dressed and cleaning your teeth – that's really important (pointing to Self-care cue card) Ammo....I mean, If I put it there for ammm..In a sense it depends how you look at it.. because its everyday life activities like stairs, walking and that sort of thing, that, that's really important because if you can't do that, you know, then you're just stuck in bed for the day really*  
(Carol, 61years, F, moderately affected, line 199-128)

In summary, people with MS living in the community viewed exercise and physical activity as a type of movement. However, they had different views about these types of movement. For exercise, this movement was specific, conscious, organised and did not form part of daily routine. For physical activity, these movements were part of daily routine and driven by the purpose of the activity. Throughout their discourse they also implied that these movements were interconnected, with exercise supporting the continuation of physical activity and physical activity being flexible in its nature to also count as exercise. In addition, most participants believed that the movements associated with both exercise and physical activity were relevant for living in the community with MS.

### **7.3 The impact of exercise and physical activity**

This theme represents the impact of exercise and physical activity on the physical, psychological and social aspects of the person with MS. These will be described separately however there was an interweaving thread between the physical, psychological and social aspects of the individual.

#### **7.3.1 Physical impact**

Participants within the study commented on the impact of exercise and physical activity on the physical body. These were to improve muscle strength and physical fitness as well as to prevent physical deterioration and loss of mobility. These views were shared despite gender and levels of severity.

*It is more sort of ammo... a utility really... going back to the muscle loss... you know, it's just really to keep them sort of still there... so when I do need to use them... they, they will be functioning as well as they possibly can*  
(Bev, 55 years, F, moderately affected, line 101-105)

*Because I don't have any movement, no voluntary movement anyway... I believe in physiotherapy. I do hydrotherapy once a week and physiotherapy once a week. Those help me to maintain.. mobility, limited passive mobility of my limbs which is important because if you lose that, you can't even really get dressed. So by definition you're probably, astoundingly bed ridden.*

(John, 62 years, M, severely affected, line 31-36)

John, who had already lost all active movements in both upper and lower extremities, described the importance of engaging in passive range of movement exercises. These exercises for him were the difference between being bed ridden and still being able to get dressed in order to participate in social activities.

However, not all participants expressed the same attitude towards exercise as John. Grace's narrative portrayed an alternative view, which was expressed throughout her interview. She described how her body responded to exercise in rebellion but by engaging in daily activities (chores) she gained the same benefits as exercise:

*..when my body is quite stiff in the morning and whatever the mildest exercises they have given me..even that doesn't work because my body rebels ..but what I've found was, that, if I'm emptying the dishwasher which is very gentle movements.. taking up only a couple of things and putting them away ..it ,it's a chore... it's like ..you are doing.. its physical activity but at the same time that that just relaxes my muscles slowly....so that I could put them as exercise as well, but it is actually physical activity* (Grace, 47 years, F, severely affected, line 120-136)

This view that physical activity provided the same benefits as exercise was also shared by Jill and expanded to include physical fitness:

*.. my rum... my husband re-fitted our down stairs toilet a couple of years ago, because he decided that we can't afford to have it done, so he did it, he's a computer programmer, so it took a while!....he did it very nicely...but it took a couple of months!... and in the 2 or 3 months when I couldn't use the downstairs toilet I had to go upstairs,I noticed how much fitter it made me.*  
(Jill, 47 years, F, severely affected, line 48-51)

However, Jill also had the view that, based on her experience through exercise classes, formal exercises provided a quicker route to physical fitness than physical activities.

In relation to the impact on the physical body, the most cited reasons for engaging in exercise and physical activity were to prevent physical deterioration and to maintain mobility. Mobility was referred to in terms of the ability to walk as well as the ability to participate in functional transfers. For participants who were mobile, changes in mobility were perceived as a sign of deterioration, and exercise and physical activity were seen as a way to prevent this physical deterioration:

*I do them (exercise and physical activity) to keep mobile really, as much as possible.. yeah.. it is for mobility really and some of them helps to build up muscles.. not big muscles (laughing)...but.. (long pause)*  
(Mary, 60 years, F, moderately affected, line 32-36)

*....(breathes in) Well the exercise as I said I do, is at a centre, keeps me moving.. Because if I didn't do those sort of exercises that they do there, I would be in a wheelchair now, I know that, definitely, cause I'm going towards that way, but I'm slowly, slowly of course.*  
(Ivy, 68 years, F, severely affected, line 40-44)

Both participants as well as others in the study held the belief that keeping exercise central to their daily life activities limited the progression of not only the physiological symptoms associated with MS but also staved off rapid decline in mobility.

In summary, the impact of exercise and physical activity on the physical body were perceived as having similar benefits. The physical impact referred to by participants, was to improve physical fitness, prevent deterioration and to keep mobile.

### **7.3. 2 Psychological impact**

In addition to the physical benefits, participants also described the psychological impact of exercise and physical activity. This was noted irrespective of the physical abilities of study participants. For example, participants felt both exercise and physical activity gave the 'feel good factor', satisfaction, buzz and sense of achievement. Interestingly, participants referred to the '*feel good factor*' associated with exercise only after exercise. In other words, it was the effect of the exercise that was deemed positive and not the exercise itself. Conversely, the feel good factor associated with physical activity was linked both with the act of the activity, as well as the effects of doing the activity.

### **'The feel good factor'**

Linda, who had a positive attitude towards both exercise and physical activity, kept referring to the *feel good factor* throughout her interview.

*..Mom.. you feel better as well. It is a good feel ... feel good factor. Because I think although you sometimes go on Monday ... we sometimes go and I think 'Oh I don't want to do this'. But I do it, and I said to 'Alfred' (husband) when I come back, I'm glad I've done it because I feel better. Because I think ... I don't know what it is in your body that when you exercise it sort of seems to release all these bits and pieces and it makes you feel better.*

(Linda, 71 years, F, moderately affected, line 142-158)

Linda's reference was the '*feel good factor*' experienced following group exercise sessions. However, Mary who enjoyed gardening activities despite physical limitations also described the enjoyment of engaging in physical activity:

*I like doing it and also, I do count it as physical activity because it does involve a lot of going up and down the garden.. I know I've got a trolley but I have to take pots up and down! tools and stuff.. I mean, I can't stand and dig but I can weed (laughing) (Mary, 60 years, F, moderately affected, line 210-214)*

Despite the physical limitations imposed by quadriplegia, John also described the same psychological impact of exercise and physical activity but in a different context. Prior to his diagnosis with primary progressive MS, John described himself as an avid runner. However, running for him now, is not a literal physical act but more an act based on his imagination. Nevertheless both activities, one based in reality and the other a figment of the imagination, produced the same '*feel good factor*':

*I think running for me was always the way, of maintaining a level of physical fitness.. that makes you feel good. And physiotherapy, comes a close second to that. When I am having physiotherapy, I am running or metaphorically I am doing all the things that I really would do if I was able bodied. And my physios relates to that.. and...does that make sense? I am not sure if any of this is making sense (John, 62 years, M, severely affected, line 146-153)*

John's narrative above is interesting to note within the study as it indicates an awareness that his conceptualisation of the benefits of exercise and physical activity might be unusual. As such, it would appear that he was seeking some validation as to whether or not his ideas aligned with the researcher.

## **Sense of achievement**

A sense of achievement was associated with the positive psychological benefits of exercise and physical activity. This was expressed in the ability to carry out an activity as well as the satisfaction gained by engaging in such activities:

*Physical exercise can make you feel good, because you could think well ... all right, for instance you ... you bake – something turns out nice. You think 'Oh great, that's turned out well'. You know you cook a meal, you think ... somebody says 'Oh that was nice'. You know and I think ... it makes you feel good because you think well I've done that, you know somebody's enjoyed it.*  
(Linda, 71 years, F, moderately affected, line 1071-1079)

Mary and Anne expressed the same sense of achievement with formal exercises (e.g. Physiotherapy) and domestic activities. Both participants reported differences about the impact of MS on their ability to engage in exercise and physical activity. Mary, moderately affected by MS and Anne who is mildly affected by MS described this sense of achievement as grounded in the ability to accomplish a task, irrespective of how simple the task might be perceived by others:

*...washing up I probably do most days.. but I've now got a chair to sit on.. 'cause I can't stand very long depending .. sometimes I can hardly stand at all. Ammm..in the morning I'm better but I have a chair so it's nice.. yeah.. it's nice..I like washing up.. do things like that.. people don't realise.. when you can't do these things ..it's really nice when you can do them.. it's good when you've achieved it..*  
(Anne, 63 years, F, mildly affected, line, 266-273)

However, not all participants expressed these positive feelings associated with exercise and physical activity. For some participants exercise had negative connotations described as 'hard work', 'demanding', 'activities I can't do', 'activities I don't do', 'exhausting', 'extra', 'pain', 'effortful' and 'challenging'. Participants irrespective of their functional levels associated these feelings with exercise more frequently compared to physical activity.

*..so for me now, exercise is a little bit more sort of ...ammo..(sigh)..less fun!*  
(smiling).. *It is more sort of ammm a utility really...* (Bev, 55 years, F, moderately affected, line 100-101)

*Well, I am very well aware, that my back is not strong.. and, amm.. I should do, amm, exercises to strengthen that.. but I don't, I'm afraid.. amm.. One of the things I could do, is lean forward (demonstrating leaning forward) and,*

*and back again.. and do that.. at least probably 100 times a day (laughing).. at the moment, it, it causes me a certain amount of pain.. and amm.. I can't do it.. but I am aware, very aware that I should have done it in the past.. and I should be doing it now, but I am not.. (Eileen, 72 years, F, severely affected, line 45-54)*

Only two participants (Carol and Lily) discussed physical activity using negative terms. These were limited to references of household chores, for example, activities that included cleaning and cooking were referred to as dull and boring activities.

For participants the psychological impact of exercise and physical activity was frequently discussed in relation to the physical benefits. However, they described a thread that linked the physical and psychological states creating an inter-relationship between the two. When the physical and psychological states worked synchronously there was harmony. This resulted in the pwMS being motivated to engage in exercise and physical activity:

*If you keep active.. then you will be more flexible.. you would and you would have better self-esteem and emotional wellbeing.. and that would improve your mobility as well. (Mary, 60 years, F, moderately affected, line 305-307)*

Linda and Anne shared this view but also felt that when the physical and psychological states are out of harmony pwMS are less likely to engage in exercise and physical activity. For example when the person with MS is low in mood and or depressed.

*If you are depressed and miserable and felt bad about yourself.. the social thing wouldn't really happen. (Anne, 63 years, F, mildly affected, line 479-480)*

Some participants after reflecting on the results of the reasons why pwMS engage in exercise and physical activity expressed that the inter-relationship between the physical and the psychological aspects of the individual may cause a dilemma. That is, if someone is depressed they will not engage in exercise. On the other hand, benefits associated with exercise can lead to improved psychological states of an individual. However, which do you tackle first: the physical symptoms or the psychological symptoms? Pam expressed this dilemma in her interview:

*I feel tempted to stay in bed and not get up on a Friday morning but I know afterwards.. ok I am tired but gosh I feel so much better... and it does*

*mentally.. you know.. yoga I don't know what it is.. it's just so amazing the effect it has on your emotional wellbeing as well. I mean, I think any form of exercise does that.. it has been proven hasn't it.. (Pam, 65 years, F, moderately affected, line 573-579)*

And later added:

*.. but if you start it helps with the depression and it enables you ... I know, (Pam, 65 years, F, moderately affected, line 925-926)*

In addition to depression, Ivy expressed that stress might also have a negative impact on mobility as well as all the other potential reasons why pwMS engage in exercise and physical activity:

*.. cause you need to reduce stress, stress, is quite a strong, urmm has quite a strong effect on MS .. amm if you're in a stressful situation amm... that can stop you walking.. you know, so, urmm.. that's more important to keep this sort of, these sort of areas going a bit more than maintaining your independence if you like. If you're in a stressful situation.. amm it can, it can knock out quite a few of these things on here (pointing at cue cards of the other categories in the top 10 reasons why pwMS engage in exercise and physical activity) (Ivy, 68 years, F, severely affected, line 1110-1122)*

Ivy felt that the negative effects stress might have on the physical body needed adequate attention. After contemplation during the interview, Ivy was observed to be wrestling with this issue in an attempt to offer a solution to the researcher for this problem. After a few minutes of silence she suggested that in clinical practice the physical and the psychological issues should be dealt with at the same time.

### **7.3.3 Social Impact**

Anne described in the previous section that without the physical and the psychological benefits associated with exercise and physical activity, engagement in the social aspects of life would be affected. The social impact of exercise and physical activity were referred to in two main ways. Firstly, by the social interaction usually brought about through exercise classes. Secondly, through social connectivity, that is, connecting with others through leisure activities, transportation and activities done with technology.

## **Social Interaction through exercise classes**

Some participants mentioned that exercise classes were attended not only to engage in exercise but also as an opportunity to meet other pwMS irrespective of their level of disability:

*Mary: Physio.. Yes I probably count that as exercise because.. urmm we use a big ball and bounce up and down.. we exercise our jaws quite a lot.. we have been told to stop talking (laughing).. well because they are all about my age.. everyone there.. and they are not all in a wheelchair.. or trolleys and things, urm.. but nothing wrong with their minds..*

*I: So they get more out of the class than exercise?*

*Mary: ohh... its very much like social activity.. (laughing)*  
(Mary, 60 years, F, moderately affected, line 229-236)

*Partly, because, when I go for hydrotherapy, I know the people there. We have a laugh and a joke, so that's social. We pull each other's legs (laughing), and have a bit of fun and the same as yesterday afternoon, the physio comes round.. and we know her socially as well. So, that's an hour of physiotherapy, but coffee and fun as well. So the two things intermingle as well.* (John, 62 years, M, severely affected, line 79-85)

Mary and John's illustrations expressed that exercise classes were a form of social activity. There was space for participants to engage in friendly banter and humour, and to offer support to each other. This view was also shared by James who felt that these shared experiences went beyond the physical benefits often associated with engaging in exercise and physical activity. For James, exercise classes created greater fellowship where discussions were diverse (e.g. current therapies, general knowledge). These opportunities created a sense of community with other people with MS thereby reducing social isolation:

*...it's not a bad thing just to connect, otherwise I'd just sit here like a hermit. But I can go to this place and talk to people like me, and I get some benefit from doing that and the guy I'm talking to about that is worse off than me, he's in a wheelchair and but I see other people there who are more like me. We're in the same boat and uhh when we have a laugh, you know we just kind of, it's a social interaction. and...yeah, and it's important too. So what I'm saying, some of these things you get through other than physical activity.*  
(James, 53 years, M, moderately affected, line 718-728)

## Social Connectivity

The impact of exercise and physical activity on the social aspects of living in the community, centred on connectivity. Participants mentioned the importance of exercise and physical activity in connecting with others within the community. They expressed that connectivity was enhanced through *leisure activities, transportation and activities done with technology*. Physical activities rather than specific exercises were usually mentioned as helping to maintain a sense of connectivity. Leisure activities provided a way to connect with the wider community and doing the things they enjoyed:

*..well, you know, you're getting out and about you're seeing people and meeting people, you're keeping up some social contacts at the same time...*  
(Tom, 70 years, M, severely affected, line 250-252)

This need for connectivity with others was important to pwMS whereby engaging in leisure type activities was used as a way to reduce social isolation. In addition, the leisure activities mentioned by participants involved active participation. However, John who does not have any active movements described the same leisure activities as the other participants but emphasised the notion of '*being*' rather than an act of *doing* an activity. The inability to have expressions of '*being*' was according to John, disabling:

*... if you are like me, in other words quadriplegic, then you have two options. You can continue to live in the able- bodied world and try to participate in as many.. social and wait...yeah...social activities, going to the cinema, going for coffee and meeting friends, all of those things ..which is what we do (pointing at his wife). But if you are at your limitation, and allow your physical limitations to dictate to you what you do; you then become a disabled person.. always unable to participate in the able bodied world.* (John, 62 years, M, severely affected, line 56-64)

In addition to leisure activities participants felt that activities done with technology and transportation enhanced social connectivity. These activities allowed participation within the able-bodied world especially when there are physical restrictions imposed by the body as a result of MS. John was reliant on technology; without technology he explained that '*all other activities would be compromised*' (John, line 331). Activities done with technology started his day in contrast to the groups' opinion, which ranked self-care activities as number 1 in the Delphi study (Study 1):

*Number 1 is... well I like the activities because of technology as number 1, because as soon as I get up in the morning, everything involves technology...everything! (John 62 years, M, severely affected, line 296-298)*

Pam further expanded on the importance with activities done with technology especially by people severely affected by MS:

*I think people with severe disabilities, which you know leaves them house bound or you know, urm, having to depend on people to get them out of the home.. I think this is extremely important.. I mean it is a way of remaining connected. And I think, you know, for people, ..urm..it's a life-line if you can't leave home. (Pam, 65 years, F, moderately affected, line 216-221)*

Similarly, participants reported that transportation enhanced social connectivity. This was represented in the data in two ways. Firstly, participants expressed difficulties associated with accessing different modes of transportation, which limited engagement in activities they wanted to do:

*..I drive.. it's very rare that I don't.. because I can't get on a bus, can't get to the bus stop and climb on the bus.. I did go on a train last week.. went down to the coast (name removed), urm with a friend which was fine because, there's certain things that you've got to look out for.. like the gap between the platform and the train!.. (laughing).. they are atrocious aren't they?.. it's alright at the local station (name removed) and it's alright were we got off (name removed).. That was a means of getting somewhere...(Mary, 60 years, F, moderately affected, line 195-201)*

James shared similar views to Mary regarding the difficulties associated with accessing public transportation. He described that the additional demands of negotiating environmental barriers (access/steps, pavements), especially when mobility is challenged threatens social connectivity. These situations often require problem solving around the physical barriers by using personal transportation and making use of the provision of disabled parking bays in order to participate in social activities.

Secondly, transportation was represented in the data as facilitating the freedom of movement necessary to live a normal (John) and independent life (Pam):

*.. because for me, that's the only way I can get to my physio. Physiotherapy I wouldn't be.. I have the van, you've seen it... I wouldn't be able to do it. I couldn't go out and lead my normal life. Normal in inverted commas, life. But no, I am happy with that (transportation).*

*I: and you view that (transportation) as a form of activity.*

*John: yes..*

(John, 62 years, M, severely affected, *line 380-386*)

This freedom transportation provided pwMS who have physical restrictions not only enhanced social connectivity but was also seen as a way to meet the physical demands of daily life. For example, activities such as shopping, carrying groceries, visiting friends were made easier and provided a sense of independence for the pwMS:

*... so I think if you've got MS.. people drive for different reasons and again that's about keeping independence. You know, people would say.. do you want me to get your shopping or something if I am not very well but you know, I say no, it's ok if I can drive.. so you know.. I think it is important.* (Pam, 65 years, F, moderately affected, *line 350-353*)

These narratives suggest that with increasing disability the desire for social connectivity and the availability of technology supported physical activity to some level albeit minimally.

In summary, the above illustrations have demonstrated the impact of exercise and physical activity on the physical, psychological and social self. The movement associated with either exercise and physical activity provided the foundations on which people with physical limitation could sustain engagement in some form of activity that would enhance social interaction and connectivity with family, friends and the wider community.

## 7.4 “It Changes”

*It changes* was a dominant theme, which was apparent from most of the interviews. This major theme illuminated the changes in the meaning of exercise and physical activity over time in people with MS living in the community. These changes came about through reflections on past activities they once did, to the present activities they ought to do, and in some cases do not do, which creates a sense of an uncertain future where the impact of what they ought to do will play a significant role. Collectively this theme illustrates that the meaning of exercise and physical activity was contextualised to the progressive nature of MS and personal life situations.

#### **7.4.1 Reflections on the past and ever changing present**

Participants described changes in the meaning of exercise and physical activity over time. They reminisced over what they could do in the past as a measure of comparison for what they are able to do now. This changing nature of MS and its impact on the physical body was reflected in a number of transcripts. Mary for example, described the gradual changes in her physical abilities, where activities once taken for granted prior to MS, now required considerable thought. These changes over time had an impact on her daily activities:

*ohh yeah.. it has changed it because urm... I could pop down the road to get something from the shops.. but I can't now.. so, I can't just walk down the road! Everything is a major planning, expedition really if I'm going out! (laughing). Have I got my trolley, have I got my sticks.*  
(Mary, 60 years, F, moderately affected, line 71-74)

Ivy and James, diagnosed with primary progressive MS both described this rapid change in their physical abilities, which had a direct impact on the types of formal exercise they could engage in. For Ivy, prior to MS she described herself as being 'sporty' (Ivy, 522). She played badminton but she described that now with the progression of her MS she was no longer able to engage in that activity. She described badminton as a sport and would have placed it in the leisure category (Leisure- Study 1). For her, leisure has been now redefined to lower impact activities such as providing after school care or playing with grandchildren (Activities due to family roles- Study 1).

This was also reflected in James's interview. He was very active in the past and was involved in high school rugby, which influenced his understanding of exercise and physical activity. He had clear distinctions between the two. However since being diagnosed with MS he was less active and had to adapt his activities to suit his physical abilities.

*James: So I do some, but much less than I would have done in the past.*

*I: Okay, yes 'cause you were saying when you were well these were the activities that you would engage in but now you've found that the activities have changed. So the act...(interviewee interrupted sentence)*

*James: Uh, yes it has to be contained. I don't feel able to run out the house and run around the block.. uhm I don't swim because uhm two reasons, getting from a changing area to the pool in bare feet, I don't like, urm.. getting in the pool and needing the, the loo...*

(James, 53 years, M, moderately affected, line 68-76)

James' illustration highlights that in addition to the changes in the physical system as a result of MS, there were also signs implicating the autonomic system (reference to needing the loo). This illustration also alludes to the environmental challenges associated with leisure activities he now considers as a consequence of his MS.

Similarly, John who described himself as an avid runner in the past also commented on this gradual change in activity over the years which had a direct impact on the types of activities he engaged in:

*I think that's a gradual process. Because with MS over the last 10 years, when I was first diagnosed 10 years ago, very slowly and gradually, it's an insidious, amm.. deterioration, which forces you to compromise gradually, year by year! Ammm..in..amm... in ahh...compromising what you want to do and what you can do. (John, 62 years, M, severely affected, line 88-94)*

This illustration provided some insight into the dilemma pwMS might face where their preferred activity gradually became inaccessible due to the impact of MS. As a result they were positioned in a state of enforced compromise to find alternate activities that were more accessible and compatible with their current physical state.

In addition to the changes imposed as a result of MS, participants also described changes in meanings of exercise and physical activity as a result of present personal circumstances. Carol, for example, shared in her interview that she recently moved house from a smaller to a larger property. Her idea of exercise and physical activity has been changed as a result of this move and the requirements of maintaining this larger home space. Activities such as, cleaning and gardening were now more a priority compared to structured exercises.

Changes to the meaning of exercise and physical activity were also noted during the course of the Delphi Study, which ran for approximately 1 year and

emphasised this ever-changing nature of MS. This is highlighted in the illustration below where Bev described that with the breakdown in her marriage she saw changes not only to the activities she engaged in but also her priorities:

*.. so amm... when the first questionnaire went out.. that was ..that was very good and.. ammm ...and I was quite active then.. amm.. then ahh..my personal circumstances changed.. amm.. it's a bit weird.. I amm.. because I remember .. September Herb (husband) moved out and it was all a bit, a bit messy.. and then the subsequent questionnaires was fairly short.. and I remember the questions about amm... family relationships and every thing.. that was ... so that was ... that changing in my own sort of, outlook and you know my personal circumstances.. did make it more difficult, but I think if you looked at my own individual results you will see a real change in priorities* (Bev, 55 years, F, moderately affected, line 597-610).

These changes were also confirmed through the documentation of Bev's responses throughout the Rounds of the Delphi study (Study 1). For example in Round 1 the items listed were centred on activities done for the family (e.g. shopping for the family, meal for the family, tidy house for the family). This use of the word family accompanied the majority of her responses when asked to list the activities done as part of a typical day. Similarly, in Round 2, '*role in the family*' was selected (#5) as part of her top 10 exercise and physical activity, however in Rounds 3 and 4 '*role in the family*' was notably lower in rank compared to the other categories (ranked #8 in both Rounds).

#### **7.4.2 Uncertain future**

A number of participants described various levels of uncertainty over the future. These included but were not limited to changes in the body as a result of the aging process, the progressive nature of MS, the uncertainty about the type of MS and its implications for the future. For example, Mary illustrated that her uncertainty about the future stemmed not only in the physical changes but also the uncertainties around her diagnosis and hence prognosis of the disease:

*....Urm, this one, living with MS now and in the future.. I don't know how mine is going to progress. I don't even know what type of MS I've got.. urm.. I was told it was benign but I don't even know what that means.. it's not affecting any other part of my body apart from my left side, balance..* (Mary, 60 years, F, moderately affected, line 308-311).

The uncertainties about the future created different responses in the sample. Some participants displayed a willingness to adapt and change activities they were engaged in:

*.. it's very hard.. because when you think of peoples' limitations amm..or capabilities.. whether it be due to illness, or ammm.. age or whatever.. amm.. you know things change so obviously ..... exercise will change.. depending on your.. circumstances, ... as you get older you do a different type of.. I mean, I'm speaking for myself.. I do a different type of exercise than I would have.. I also do different things now that.. I've got MS, than before I had MS (Pam, 65 years, F, moderately affected, line 58-66).*

Pam understood that things would change, by reflecting on her experience of living with MS overtime. A similar thread was also reflected in Anne's account where, despite noting her physical deterioration, which limited the choice of activities, she remained optimistic about the future. Her attitude in response to the uncertainties about the future was to keep moving:

*.. hummm .... and in the future ..that's what you think about because.. well the one I've got you deteriorate (referring to the type of MS) .. but to keep that up as much as you can.. you can do certain things.. you will always be able to do certain things.. but ..like you will still be able to do certain things but it just gets less but whilst you're doing your exercise.. you can.. it makes you more likely to do these things that you need to do..(Anne, 63 years, F, mildly affected, line 498-505)*

Other participants displayed a mixture of subtle defiance but also a momentary fatalistic view of the future. This was seen in both John and James's illustrations. Both reported being diagnosed with primary progressive MS and at a similar stage of life whereby they are retired on medical grounds at the height of a successful career:

*...and I, I'm quite determined until I can't stay on my feet. Um..things will probably deteriorate when I get older uh I be in a wheelchair.*  
(James, 53 years, M, moderately affected, line 126-128)

*Living with MS now and in the future.. I guess we live one day at a time... if you, if you're unwise enough to read about MS.. particularly my primary progressive, you would probably amm...visit the beach and take the handbrake off... I don't know.. living with MS and in the future, one day at a time.. (John, 62 years, M, severely affected, line 502-506)*

### **7.4.3 It Changes: the influence on priorities**

Participants described how the changes in their bodily structure and function over time either as a result of MS, age or as a result of their present circumstances collectively had an impact on their priorities. As such, priorities became overwhelmingly influenced by their personal choice as well as their energy demands.

#### **Personal choice**

Participants reflected on the groups' priorities and considered their personal priorities. The illustrations in the previous section suggested that changes in exercise and physical activity were as a result of the progressive nature of MS and that activities were imposed rather than chosen. In contrast, participants also felt that there were additional influences such as personal and life choices. This was illustrated by Mary and further expanded by Grace where these personal influences dictated the choice and the personal meaning of the chosen activity:

*It's just a personal choice.. not agreeing with what everybody with MS.. may choose but that's my personal choice and I do these things out of necessity*  
(Mary, 60 years, F, moderately affected, line 344-345)

*amm.. for me.. this is, well, personally due to my lifestyle, I would feel like this is the way I would prioritise my life, the chores in my life .. yeah, yeah, regardless of anything, this would be the order I would work my life around.*  
(Grace, 47 years, F, severely affected, line 498-507).

Both narratives highlighted the individual nature associated with choice of activity. For example, whilst Grace's narrative indicated general agreement with the top 10 exercises and physical activities based on her life situation, Mary felt that 'out of necessity' should be ranked at number 1 (Study 1 results).

Exercise and physical activity were also prioritised based on inner desires. One participant, driven by the inner need to keep living at home, described choosing stair activities over other activities to ensure that he did everything necessary to remain at home. He shared during his interview that he loved his home. For James, it was a place where he had always wanted to live because of the natural beauty of

the surroundings as well as a place that held many memories of his children growing up. As such, he was very deliberate in this choice of activities and initiated discussions related to his priorities with his physiotherapist:

*...yeah I'm very conscious that, I want to continue using the stairs, cause we live in a house. So I don't want to lose the ability of going up the stairs.. and some of the exercise we do in the physiotherapy. I'm talking to the physio about that, but my number one priority is, that I want to stay living here and being able to walk upstairs. So I definitely , because stairs in there I would have that ah uh maybe that ought to be there (pointing at 'everyday life activities' cue card) (James, 53 years, M, moderately affected, line 537-544)*

### **Energy demands**

Participants described how the choice of activities was influenced by the availability of energy reserve. They described having a daily supply of available energy. Withdrawals from this energy reserve were dependent on the priority of the activity. Interestingly, the interplay between energy supply and demands ran throughout all the themes within the study. However, only women made reference to priorities with respect to energy demands:

*..every day with this illness, because you're aware that you've got this limited amount of energy if you like... I just plan one activity, if I've got to go to the shops, I just have one visit and the rest of the day I'll collapse in a heap..and you do one thing each day...well that's how you have to organise your life now, everything is, everything in your brain, what you do when you wake up is all organised around fatigue..and the time you've got to do things in.. even dressing.. when you were fit you used to sort of get washed and dressed in about half an hour; in your greatness... and when, but now you've got something that's holding you back all the time, you know it's going to take at least three quarters of an hour to an hour to get washed and dressed and up and out of bed ...which is ridiculous when you look back at it (Ivy, 68 years, F, severely affected, line 336-366)*

Ivy's illustration provides some insight into how pwMS organise and structure their lives in order to manage fatigue. This sense of weighing up the available energy and time, matched against the energy requirements of certain activities and their priorities, was observed in the data. For example, Jill expressed that her priorities were in order of family, home and exercise. After these activities were completed the remaining energy was attributed to exercise:

*... well for me.... my focus is on getting all the stuff I have to get done, done for the family and then any extra energy I can use on physio, I usually stretch, but yeah, it's extremely, it's extremely umr its extremely frustrating ...to get to the end of the day and think, I just haven't got the energy. I do, do it (exercise) in the mornings at home when I can because then I've got a bit of energy left still, but I've got a bit of, but convincing my children to assist with that isn't very easy (Jill, 47 years, F, severely affected, line 241-245)*

Sue also expanded on this view to suggest that further disruptions such as, life circumstances (busyness), responsibilities as a mother, fatigue and MS relapse might also threaten engagement in exercise and physical activity:

*... they change, they change on whether or not ahh... I am feeling particular tired that day.. amm.. or a space if I get incredibly busy or something, involved with my children or something like that.. then.. they will...the exercise for that day would suffer.. because it doesn't become a priority.. so it is about me, rather than my responsibilities as a mother... yeah.. and obviously if I am having a relapse or something.. the first thing that goes by the by is anything which is non-essential.. so, exercise or physical activity (laughing) is definitely the first one to suffer.. because I spend more time in bed as well.. (Sue, 50 years, F, severely affected, line 133-144)*

In summary, the changes in movement as a result of exercise and physical activity were dependent on the personal context (MS or personal situation) of the participants. The response to the changes experienced by pwMS living in the community led to the uncertainties about the future. In addition, the changes in movement were influenced by personal choice and energy demands of the activities.

## 7.5 Sense of Loss

The previous section considered the changing nature of living life with MS and how this impacts on exercise and physical activity. However, this change in capacity to engage in exercise and physical activity was also associated with the theme 'sense of loss'. This *sense of loss* was evident across all participants interviewed and was irrespective of gender, age, type of MS and the impact of MS on exercise and physical activity. Three subthemes to be reported on are loss of activity, loss of employment and compromise and reconciliation.

### **7.5.1 Loss of activity**

In exploring the meaning of exercise and physical activity participants described loss of activity. This loss was highlighted in discussions around exercise (structured exercises) and physical activity. For example, James, John and Tom described that they previously enjoyed running and cycling as their preferred exercise, but now had lost the ability to engage in those activities:

*I used to run around the block and neighbourhood, that kind of thing that's what I think of as physical activity (Pause)... uhm, these days I don't do any of those things. (James, 53 years, M, moderately affected, line 50-53)*

Similarly, participants also expressed this loss of activity in relation to unstructured forms of activity for example, leisure activities. Linda reported that in the past she enjoyed dancing and could dance for hours; however she was now unable to engage in those activities:

*.. I wish I could do the Zumba – I love dancing ... oh we used to dance for hours ... that's one thing I missed as well is dancing. Could do anything. (Linda, 71 years, F, moderately affected, line 773-776)*

This loss of activity also had an impact on the family in relation to how and where holidays were spent. For example, Bev expressed how she previously enjoyed holidays filled with activities of adventure. However, she described the inability to engage in those activities as a great loss:

*urm...exercise is, amm..a number of things.. I mean.. in the past I use to love walking and would walk for hours and this is a great loss to me.. and I am not really sort of ..amm... I realise I can't really do the walking I use to do.. I use to walk in ..in woods, hills, across hills, ammm... my idea of a holiday was ammm... ahhh...sort of.. Mountaineering .. (Bev, 55 years, F, moderately affected, line 90-95)*

Similarly, this feeling of great loss highlighted in Bev's illustrations suggests that this sense of loss went beyond the physical to the emotional aspects of the individual. This was further expanded during Ivy's interview. Ivy was an avid

painter. For her, this loss in ability to engage in this leisure activity proved overwhelming:

*This last year, it's almost two years ...I have to, I've had to give up painting because .. I'm right handed but.. my right hand...isn't steady enough.. and I'm not a loose, I'm not a loose painter... of water colour.. and I'm not going to start after all these years, trying to be a loose painter, I'd go mad, so ahmm,, I cannot keep my hands steady enough.. I mean I did for the last year hold it steady.. it's now got beyond, beyond holding steady so I've got to give that up.. which is something I really miss (Ivy, 68 years, F, severely affected, line 577-603)*

She further explained that this loss of activity was akin to the grieving process:

*.. ahmmm as I was saying, as you as you get worse, you lose, urm.. different abilities to do things.. and you sort of, especially with my art, you sort of go through a temporary, what do they call it? A temporary sort of grieving time.. it's a loss (Ivy, 68 years, F, severely affected, line, 686-695)*

Another participant, Eileen, did not use the word grieving during her interview. However, there was a sense throughout the interview that she too was remorseful about the loss of ability to transfer and mobilise. This loss was not directly related to MS but because of an incident, which resulted in the dislocation of her hip joint. Following the incident she stated that she “*gave up on exercise*”. She expressed during the interview that she regretted making that decision years ago. Her message now to other pwMS is to keep moving and not to make the same mistake she made.

### **7.5.2 Loss of Employment**

The loss of activity which was usually as a result of physical changes in the body also had a direct impact on employment. This was particularly highlighted in two participants' accounts where they described the frustrations and the stresses associated with loss of employment. Bev told a story about how she hid her diagnosis from her employers in order to keep her job. However as MS progressed she eventually had to resign from her job. Anne, on the other hand had a different experience with her employers. She was a teacher by background; her employers were aware of her diagnosis and provided adequate support. However, due to restructuring within her department, she was moved to another location. She

found this new working environment challenging to navigate, as her mobility got worse and eventually gave up her job.

*.. the amount of walking I did was a lot worse.. amm... I blame the local authority for that! (laughing). Because we had this really big art room and I was getting so that I couldn't really walk around it! And the kids were saying.. "you should go home miss" but I mean.. they were very sweet.. but yeah.. That was when my MS affected what I was doing..... I stuck at it for just about a year, I think.. I finished about at the end of the year..*  
(Anne, 63 years, F, mildly affected, line 649-656)

James had a different experience from that of Bev and Anne. James was a managing director of a company and shared that despite enjoying his job he now appreciated not having to work:

*Uhm, so I have the luxury of not having to work and I can spend time looking at these programmes which otherwise I wouldn't have watched because I had to work (laughing). So uh I do I must say I enjoy my life as it is now without having to work and being uh and having income from retiring. .... I'm happier with this situation. I try not to say that to my friends because they work... (smiling)..a hundred times, I love it, it's great and my wife says. "now come on honey, just cool it... cause they'd all love to retire" (James, 53 years, M, moderately affected, line 227-247)*

This excerpt highlights the relief experienced of not having to work. This relief was associated with having the time to enjoy life without the stressful demands associated with some types of employment. This suggests that loss of employment is not always conceived in a negative way.

### **7.5.3 Compromise and Reconciliation**

In the sections above, the illustrations depicted a sense of loss. However, not all participants expressed this deep sense of loss as demonstrated above with James' attitude towards loss of employment. Participants also described the ability to compromise with certain activities and reconciled this with the nature of MS and the impact MS had on exercise and physical activity. Also, rather than being overwhelmed by the loss of activity, participants expressed a conscious decision to adapt by choosing other activities that helped to maintain a fulfilled life.

Six participants spoke about compromise and reconciliation throughout their interviews. Some participants talked about their lost ability to engage in certain types of activities but also described a state where they refused to allow loss to become a limiting factor and actively searched for other types of activities to be involved in. An example of this was John who unlike all the other participants in the study did not have any movements in his upper or lower limbs and was confined to a tilt in space wheelchair. John relied on other people, mostly his wife, to assist with mobility in the wheelchair and to assist with all other aspects of his care. Yet John had resolved not to be defined by the activities he was unable to do:

*...For instance, I was a very active runner. I was a pilot, both things that I cannot do anymore, but I can reconcile that to a certain extent. Because I still mix with the same people, who I use to run with or I use to fly with. So, I have that...I'm trying to think what the right word is. It's a sort of reconciliation. It's a compromise that allows me to still exist, in the world that I am very familiar with, notwithstanding my physical restrictions.*  
*(John, 62 years, M, severely affected, line, 96-102)*

For John the changes as a result of MS had an impact on his ability to engage in exercises as well as employment. Despite his inability to fulfil his role as a pilot he still met up with his colleagues. John suggested that compromising and coming to terms with the changes in activities allowed the extension of his existence.

Other participants, Ivy, James and Pam described reconciliation in other ways. For Ivy, she reconciled and accepted that the progressive nature of MS as well as fatigue meant that the energy demands for certain activities were great compared to the average population. James reported that he was reconciled to his mobility getting worse and instead of walking to the shops he did online shopping (James, line 139). Similarly, Pam took a pragmatic view about compromise and reconciliation. She expressed a willingness to adjust and engage in other activities should she become unable to engage in her preferred activities:

*.. yes and what your preferences are.. I mean, obviously you tend to do the things that you enjoy and that you are very good at.. and when you are not very good because of a physical disability or something then, you either give up (laughing) or you move on to something else .. which you are capable of doing (Pam, 65 years, F, moderately affected, line 72-77)*

In summary, participants described exercise and physical activity in terms of sense of loss. They described multiple losses such as, loss of activity, loss of employment and loss of independence. Loss of activity (exercise and physical activity) had an impact not only on the physical self but also the emotional aspects of life where some participants displayed being at times overwhelmed by the losses in activity. Nevertheless, despite the losses participants also demonstrated the ability to compromise certain activities and reconciled themselves to the changes in their lives caused, directly or indirectly by living with MS.

## 7.6 Coping with MS

Although participants expressed a deep sense of loss, emerging from the transcripts was also a sense that despite this loss, exercise and physical activity were used as a way of coping with MS. These activities when utilised enabled a sense of normalcy and control over physical symptoms, which added structure to their lives as well as providing the necessary support to cope with the disease.

### 7.6.1 Normalcy

With the changing and unpredictable nature of MS, participants expressed that they coped in different ways. One way was to maintain a sense of normalcy in their life through engaging in exercise and physical activity:

*...to keep us..I suppose as normal as we can be! Amm... make sure that we can keep life going.. going as it is in the normal world...(Lily, 66 years, F, mildly affected, line 460-462)*

*I do those things (referring to exercise) because they're important to be able to have a normal life.. um... But when I think of going down the gym and doing all those sorts of things then that would be to improve MS symptoms, but life doesn't completely depend on looking after my MS – it's like, you know, there are other things that I also consider to be important. Um.... it's out of necessity.. yeah, I'd say that is why I do things, just for, you know... because, I like to.. I have to do it... and I like to, and because it's going to make me feel good (Carol, 61years, F, moderately affected, line 380-387)*

Lily and Carol expressed in their illustrations this sense of normalcy using the average population as a frame of reference for 'normal'. However, Carol's illustration suggests that whilst there was a certain expectation that pwMS should

engage in exercise and physical activity as a way to improve their physical symptoms, she was keen to emphasise that there were other aspects of life that were just as important.

### **7.6.2 Control over physical symptoms**

In addition to the sense of normalcy, participants also expressed that exercise and physical activity were used as a way of coping with the physical symptoms associated with MS. This was reflected in Ivy, Jill and Eileen's interviews. All these participants rated the impact of MS on their ability to engage in exercise and physical activity as severe:

*.. what to make, yes, you do them to try and keep going as long as possible really, ah... to keep one active to maintain function and to keep transferring and so yeah that's why you do the exercise..... but all, all those all those things there (pointing at the cue cards) (Ivy, 68 years, F, severely affected, line 1024-1027)*

*urm....I...I don't use a stick or a chair indoors at home, so walking up and down the stairs and walking around the home and out in the garden for me is, physical activity that I want to keep going as long as possible... maintaining... yeah.... being able to move on my own*  
(Jill, 47 years, F, severely affected, line 42-46)

Jill and Ivy described that engaging in these activities enabled the longevity of the activities as well as a way to maintain independence in the activities deemed necessary for daily living.

### **7.6.3 Exercise and physical activity frames the week**

Participants expressed that exercise and physical activity provided a form of structure that held life together. This was another way in which participants described how they coped with MS. This was noticeable in both Bev and Eileen's illustrations. They have two varying levels of disability and both have differences in terms of their preferred activity. Bev is independently mobile using a walking aid and had a positive attitude towards exercise. Eileen on the other hand was independently mobile using a powered electric wheelchair but confessed to not being exercise focused. For Bev it was the formal exercises that framed her week and provided something to look forward to:

*.... so.. classes do sort of, they give a framework to my week. so you know, I would think.. oh its x day, so x day this time I will be going to.. pilates class or there would be y day.. and, if I go to the physio sort of session.. I would go to that.. because I am not working now if I didn't have that structure to my day... ammm... I could see the whole thing sort of falling apart! You know, there would be no reason to..* (Bev, 55 years, F, moderately affected, line 141-150)

Alternatively, for Eileen, physical activity (not exercise) formed a vital part of her week. In her interview she spoke about her involvement in many types of activities namely, self care, leisure and domestic type activities. Despite her physical limitations and inability to engage in formal exercise programmes, she too expressed how her daily activities provided a sense of structure to her week.

#### **7.6.4 Support**

Support provided by family, friends and the Therapy Centre in engaging in exercise and physical activity was viewed as a way of coping with MS. For Anne, the formal support with exercise provided by the MS therapy centre was a way to adapt to the variability of MS, age and the need to be fit:

*It's good that you can actually do something about it because for a lot of people you can't.. but I'm lucky.. because I didn't find out about the MS therapy centre for a long, long time. Yeah... so.. I suppose it came about at a time when I could fit it in with my life as well. Cause I was thinking ..I'm getting older and I need to do something that keeps me fit.. and I'd finish work so I suppose it just came at the right time.. because the physios don't know about it.. because not everybody knows about it.. you know..*  
(Anne, 63 years, F, mildly affected, line 544-553)

Grace, Pam and Lily described the informal support provided by family and friends that kept them motivated to engage in exercise:

*Because I know when I am not well.. the last thing I want to do is meditate and then do yoga later on.. I just want to lie on the sofa and read a book or watch TV or not move at all. So it's really hard work to motivate yourself. How do you motivate yourself?.. and luckily I've got this amazing friend who..you know, happens to be the best yoga teacher in the world I think.*  
(Pam, 65 years, F, moderately affected, line 544-553)

However, for Grace, it was the informal support from the family with physical activities around the house on days when fatigue was a problem.

*.. yeah like today...I am not so bad...so am doing stuff.. like I did a bit of chores around the house and hopefully it will continue .. and ammm some days am not able to do very much.. I mean cooking he (pointing to husband) goes to*

*work in the afternoon and sometimes he has to make dinner and then go (laughing) .. so it is just like that...*  
(Grace, 47 years, F, severely affected, line 305-314)

For Lily, having the convenience of an indoor home gym, personal trainer and family provided the necessary support needed to maintain both structured exercise and physical activity. For her this level of support helps her to continue living with MS.

*.. ammm... yeah...and I think that we...amm... providing we have support...amm to continue. Or I have support rather to continue my life as I am at the moment, which I can't see changing... amm... yeah... ammm... you know its.....that's all I can say.* (Lily, 66 years, F, mildly affected, line 483-487)

These quotations highlight the importance of support from family and friends in sustaining engagement in exercise and physical activity. However, this support was not one directional but rather reciprocal in nature. For example, participants described how they felt family members depended on them for support:

*Okay then, there you go. So, that means then, if she does the shopping then she does the cooking. Uhm, housework I I try to do some, uhm I I don't like to get down low. I can hoover, I can hoover for Britain if you want me to. Uhm I can clean a sink and uh, I don't mind bending over the loo and cleaning a loo so I try muck in and do something*  
(James, 53 years, M, moderately affected, line 333-338)

*Well, the boys are still at home. I mean, one is in the process of buying a house so he will not be here much longer.. They do get into a mess when they try to iron shirts.. "mom.. which way to put it" .. oh let me do it! (laughing)* (Mary, 60 years, F, moderately affected, line 154-156)

A similar view expressed by Jill who has teenage children:

*"Mom! MOM"!! (shouting) "where are my trainers" .. ohh..man.. no.. bless them*  
(Jill, 47 years, F, severely affected, line 444-445)

Support whether from individuals and or volunteer organisations was important to pwMS. However there was also a sense that pwMS provided support to the family. A term referred to here as reciprocal support based on shared relationships between the pwMS and others.

### **7.6.5 “This is me”- Identity**

Exercise and physical activity was used as a way of coping with MS. However participants were also keen to be recognised for their individuality and not always thought of as the person with MS. The concept “this is me” formed a sub-theme through the analysis which summed up the identity of participants.

Participants described how exercise and physical activity helped to preserve as well as shape their identity:

*...amm.... This is me..at the centre, my self-worth and then branching off that, is sort of like, erm risk and safety...and then stuff I do ..ammmm.. like, acupuncture, reflexology, ammm.. and then..out of the home activities because obviously when I, go outside of the home, I am perceived as, being of more risk of falling over ..and then we get back down to here... and ... amm...symptoms, which is sort of like, an awful sort of, ahh (sigh).... people with things about.. with dealing with fatigue.. dealing with foot drop, dealing with, ammm...muscle strength ..and ... the very background to that is, my concern is like muscle loss if I'm not doing enough stuff... ahh... I, I lose the muscles. It is one of the, use it or lose it.. (Bev, 55 years, F, moderately affected, line 37-44)*

Bev admitted during the interview that she felt that her identity was being threatened when in contact with healthcare professionals. She felt health professionals shaped who she was by her diagnosis. “This is me, at the centre” highlighted one aspect of person centeredness. She wanted to be seen as an individual before being seen as a person with MS who had disability associated with the disease. She emphasised the point that management of MS should be linked to the individual’s priorities and what pwMS felt was important.

Within the participant narratives identity resonated in two ways. On one hand, identity was described based on the individual and the individuals’ role within the family. There was a sense that their choice of activities (exercise or physical activity) was dependent on their role in the home. Mainly women and more specifically the women who had young children expressed this view. In this context, participants’ choices were more associated with physical activity. They prioritised the activities that needed to be done because of either their caring role as a mother or grandmother as well as looking after the home. This role as a mother was evident in Jill and Grace’s interview:

*. yeah, I think, because, well for me that is..... that is up there (pointing at cue card showing Self-care activities- Study 1) because I have to get Tom to school so I have to go out , I can't just slop about in my pyjamas I have to get up and out and force the rest of the family out the door in the morning, urm.. which obviously involves a bit of every day as well (pointing at cue card showing Everyday life activities- Study 1) and then I do the domestic stuff...and then the dinner and then the homework, and urm yeah, and in between I try and fit my exercise routine in, which is a bit ad hoc at times, but there you go (Jill, 47 years, F, severely affected, line 235-239)*

*....so earlier when they (children) were in school ..I would like to visit the parents evening and things like that so then that would be prioritised. I would be prioritising those things. So exercise just keeps going down (Grace, 47 years, F, severely affected, line 348-351)*

Activities that involved the family over traditional exercise programs were being prioritised as part of their daily life. Some participants referred to these activities as incidental exercise. Incidental because they do not set out to do exercise but by carrying out these activities they turned into exercise.

*I must admit.. I, I remember.. seeing that ,that ( pointing to cue card activity due to family roles) was very low down. Amm... before, and being quite surprised.....so that is activities due to family roles...but then I suppose it depends on whether you've got children or not.... amm.. and I think that's a huge, huge distinction.. amm... ahhh..because you know.. I would put this you know, right up top. Ammm.. as being you know, yes.. yes.. and then that would come third.. amm.. in terms of you know.. prioritising.. (Sue, 50 years, F, severely affected, line 165-175)*

This pattern was also similar to participants who were grandparents. Within their role as grandparents, they were doing activities that they counted as exercise.

These were usually unstructured forms of physical activity. The activities they were involved in were diverse and spanned more than formal types of exercise.

Both Lily and Ivy expressed their joy of having grandchildren but also the energy demands of those activities, which for them made the activities a form of exercise:

*I..I've been..as I said earlier..very fortunate to have a loving family.. and...with young grandchildren ..amm...it's just the best I've ever had..so I find activities with the family especially important at the moment (Lily, 66 years, F, mildly affected, line 269-272)*

Participants felt that these activities done because of their role within the family were vital for their health and wellbeing. They also expressed that these activities

helped to shift the focus from self with MS to their children and grandchildren. They saw these activities as investing in the next generation.

*..... it's a tiring exercise having the children here, but they do keep you... they keep your mind focused ... how can I put it? On ahmm.. other.. it's another field of living if you like ..I don't know if I've put that right.. (laughs) another area of interest I suppose?*

*I: you mean beyond your MS?*

*Ivy: yes, yes, it's totally different from the MS*

(Ivy, 68 years, F, severely affected, line 812-821)

The above illustrations demonstrated the use of exercise and physical activity in preserving the identity of participants. These activities were carried out as part of their role within the home and the family unit. In addition, participants expressed that exercise and physical activity was also used to shape their identity. For example, Eileen does not do any structured exercises because of her physical limitations. She is limited because exercise causes her pain. However despite pain she felt certain activities had to be done in order to be considered a human being. These human activities were self-care, domestic activity and everyday life activities:

*.. because they are things that I do.. I.. do that everyday (pointing to cue card-self-care)..washing and dressing.. I do that!(pointing to cue card -Domestic activities) Ammm.. shopping and cooking.. and housework.. and making.. everyday.. I do that every day (pointing to cue card-activities due to technology).. I mean.. if I didn't do that (pointing to cue card- self care activities).. I wouldn't feel human! (laughing)... and, ahh.. shopping and well, cooking anyway or getting myself a meal.. I... that I wouldn't feel human if I didn't do that.. amm.. the computer, the next one the computer.. what is it? Activities done with technology.. I could last you know, if I couldn't do that.. you know, I would survive. So that's why I chose them in that order.. and again... transportation is very important to me.. and I do it most days.. but again ... I, you know, the world wouldn't fall in.. the sky wouldn't fall in if I didn't do it.. do you know that, that children story? That Chicken Licken (Children's story) always thought that the sky was gonna fall in (laughing).... so when there is a total tragedy I say the sky is gonna fall in.. so, amm.. gardening, reading, Zumba and visiting friends.. yes I like to do those but those.. nearly every day if I can but I can survive, if I don't.(Eileen, 72 years, F, severely affected, line 224-249)*

Eileen provided some insight into different types of activities. She expressed that certain activities such as, *activities done with technology, transportation and leisure*

were considered important but without engagement in what she classified as human activities (e.g. self care, domestic activities) her life would be a total tragedy. Her account suggests that she highly valued these activities that helped her to maintain a sense of self. Eileen felt that if she were unable to engage in these activities she would feel less than human.

Participants also expressed that their identity was shaped by, participating in certain activities. The activities referred to were self-care (Ranked 1), transportation (Ranked 4) and domestic type activities (Ranked 3). Participants' accounts suggested that engaging in these activities were linked to their independence, self-esteem, confidence and personal dignity. They also spoke of the interconnectedness between independence, self- esteem and confidence:

*Again, this number 1 (pointing to cue card -self -care) doesn't surprise me because for a lot of people... ammm...would limit it.. you know, physical abilities are so important just to be able to maintain that level of importance in personal care.. I mean... I think in that.. you know, for yourself esteem, for your confidence.. and you know for your independence.. I just.. am not surprised. So those two (referring to self-care and activities done with technology) (Pam,65 years, F, moderately affected, line 229-237)*

Formal exercise programmes were also mentioned as a way to shape one's identity, through self-image and self esteem.

*Mm ... I think yes, I think ... as I say you exercise and you feel better, therefore that's going to help your self-care. I mean it doesn't apply to that, it doesn't ... because I mean you do that automatically ... but I think self-care, I think if you exercise it makes you feel better, therefore you're going to look after yourself more (Linda, 71 years, F, moderately affected, line 817-824)*

In summary, exercise and physical activity was a way of coping with the disease. However, participants described the strategies used not only for coping with MS but also in maintaining their identity, which symbolised much more than having a diagnosis with MS. Participants desired to be known for their individuality and used exercise and physical activity was a way to shape and preserve their sense of self.

## **7.7 Discussion**

The purpose of the study was to give participants the opportunity to reflect on the results of the Delphi study and, through this, to gain a deeper understanding about the meaning of the exercise and physical activity in pwMS living in the community. The 5 major themes resulting from analysis were, '*a type of movement*', '*impact of exercise and physical activity*', '*it changes*', '*sense of loss*' and '*coping with MS*'. The purpose of this section is to synthesise the key ideas from the main themes and to foreground the voice of the participants in understanding what exercise and physical activity mean from their perspective. These themes will be discussed to highlight that the lived experiences of pwMS shaped the meanings they ascribe to exercise and physical activity. In addition, the section will also demonstrate that pwMS have a multidimensional and complex view of exercise and physical activity.

### **7.7.1 Ascribing meaning to exercise and physical activity: the perspective of pwMS**

Participants generally agreed with the categories included in the results of the Delphi study (Study 1). However, the narratives illustrated that the selected priorities of exercise and physical activity and the meaning ascribed to these priorities were primarily conceptualised within the context of their lived experience. The interviews highlighted different layers of meanings amongst participants and within the same participants. Meanings ascribed to exercise and physical activities were driven by the importance of the activities to the individual as well as the impact these activities have on the physical and psychosocial aspects of life.

Collectively, participants expressed that exercise and physical activity were about movement. Movements, whether structured (exercise) or unstructured, (physical activity) were deemed meaningful and relevant for living life with MS. However, participants' descriptions of movements associated with exercise and those associated with physical activity were interesting to note. For example, exercise was associated with movements that were inflexible and as such, limited to time and space. This inflexible nature of exercise meant that engaging in these activities

(structured activities) required conscious effort and intention, as these activities did not naturally form part of daily life. Conversely, physical activity was seen as more flexible. These movements were a necessary and highly valued part of living life. For pwMS, this flexibility afforded by physical activity meant that these movements could be easily integrated into life and offered the added bonus of counting towards exercise. Participants irrespective of gender, and functional level put forward these descriptions of exercise and physical activity, which highlighted the value and importance of these activities as being integral to living life with MS.

Although there was a sense that physical activity was preferred due to its flexible nature, pwMS also acknowledged the value of engaging in exercise (structured activity) as a way to support participation in physical activity (unstructured activity). For example, they described that engaging in structured activities such as *stretches, physiotherapy and activities done without the use of weights* enabled them to carry out their *self-care, everyday life activities and domestic activities* more efficiently. This central focus on daily life activities was interesting to note in the study as some researchers have highlighted that completing activities of daily living is one of the challenges faced by pwMS irrespective of their level of disability (Currie *et al.*, 2009; Einarsson *et al.*, 2006; Måansson and Lexell, 2004). These challenges were also identified within this study. However participants provided added insight to suggest that despite these challenges, daily life activities were meaningful and pointed to the interrelation that exists between exercise and physical activity as facilitating participation in these meaningful activities. Also, for participants in this current study, exercise not only supported participation but also provided the means necessary to maintain some level of independence in daily life and social activities. To the researcher's knowledge these interpretations of both forms of activities from the perspectives of pwMS have not been previously reported in the literature. These new insights deepen the current understanding of the meaning of exercise and physical activity in this population.

Additionally, in ascribing meaning to exercise and physical activity pwMS expressed belief about the *impact on the physical, psychological and social aspects of life*. For example, in relation to the physical impact, participants irrespective of

their disability, as seen in the narratives with Bev (moderately affected-independent mobility) and John (severely affected- wheelchair user), both expressed that exercise and physical activity led to improved physical fitness and prevented deterioration of physical symptoms. These benefits are widely reported in both quantitative and qualitative literature related to exercise and physical activity in pwMS (Petajan *et al.*, 1996; Solari *et al.*, 1999; van der Linden *et al.*, 2014; Stroud, Minahan and Sabapathy, 2009a; Kasser, 2009; Dodd *et al.*, 2006; Motl *et al.*, 2006). However, this current study has provided further insights and extended the work of other qualitative studies (Dlugoski, Joyce and Motl, 2012; Kasser, 2009; Borkoles *et al.*, 2008) in emphasising not only the benefits of these activities such as improvement in body structure and function but also the relevance of these activities in managing disability in all areas of life. Examples include accessing, connecting and participating in activities within the home and community.

Similarly, irrespective of physical limitations, pwMS also expressed that exercise and physical activity had a positive impact on psychological aspects of their lives. Participants described two key psychological benefits of exercise and physical activity, namely, '*the feel good factor*' and '*sense of achievement*'. Interestingly, whereas these psychological benefits have been associated with structured exercise (Dlugoski, Joyce and Motl, 2012; Kasser, 2009; Stroud, Minahan and Sabapathy, 2009a; Motl *et al.*, 2006; Dodd *et al.*, 2006) participants in this current study reported the same psychological benefits with activities, such as, gardening and baking. For participants in this current study, it was the satisfaction gained from engaging in these activities that were considered meaningful and that mattered in the face of a progressive illness.

The psychological impact expressed by pwMS pointed to their positive attitude towards exercise and physical activity. These positive attitudes have been extensively reported on within the literature as motivations for engaging in exercise and physical activity (Learmonth *et al.*, 2013; Dlugoski, Joyce and Motl, 2012; Stroud, Minahan and Sabapathy, 2009a; Dodd *et al.*, 2006). However, not all participants reported positive attitudes towards exercise and physical activity. References were made about exercise and physical activity (mainly domestic

activities) as being dull and boring although more negative word associations were linked to exercise, for example, painful, difficult and challenging. These negative word associations reflected some participants' perceptions towards exercise and therefore their preference towards unstructured physical activity. These general attitudes, whether positive or negative, highlight the differences in activity preferences amongst community dwelling pwMS. As such it is important for health professionals who work within the area of exercise and physical activity to find the activity that best suits the preferences of pwMS, as what might be a facilitator to engaging in exercise and physical activity to one person might be a barrier to another.

In addition to the physical and psychological benefits of exercise and physical activity participants spoke about the social benefits in two ways. Firstly, they described the benefits of participating in group based activities, where the advantages were not only about exercising the physical body but the interaction with other pwMS (for example the banter and peer support) and the creation of an environment where informal learning is fostered. Similar findings are widely reported in the literature with respect to peer support, acceptance and camaraderie (Dodd *et al.*, 2006; van der Linden *et al.*, 2014; Kasser, 2009; Dlugonski, Joyce and Motl, 2012; Motl *et al.*, 2006; Aubrey and Demain, 2012; Ploughman *et al.*, 2012; Learmonth *et al.*, 2013). However, in this study, participants' descriptions about the social benefits went beyond the remit of a group exercise session and included unstructured forms of activity (physical activity) more generally that involved connecting with others as well as the external environment. This new knowledge was the second way in which participants described the social benefits of exercise and extends the existing evidence base to suggest that engagement in physical activity enhanced social connectivity. The activities referred to with social connectivity were in relation to transportation, leisure activities, and technology (ranked 4<sup>th</sup>, 5<sup>th</sup> and 10<sup>th</sup> respectively in Study 1) and were mentioned across the sample irrespective of level of disability.

The inclusion of these categories supports the broad perspectives held by pwMS in relation to exercise and physical activity; a view that went beyond the physical

body. In fact, this view challenges the concept that exercise and physical activity were not only associated with activities of the body but are also about how the body interacts with the external environment. For example, it was interesting to note how *transportation* was ranked highly in the Delphi study (Study 1), which was a study about the exercise and physical activity practices of pwMS yet in other studies it has been often identified as a barrier to exercise and physical activity (Coenen *et al.*, 2011; Borkoles *et al.*, 2008; Einarsson *et al.*, 2006) and a major concern facing pwMS (Einarsson *et al.*, 2006). The interviews provided some insight, which might explain what appears as a paradox. Some participants mentioned environmental factors such as accessing public transportation as a hindrance to engaging in physical activity (e.g. Mary's narrative). Negotiating transport systems, whilst easily navigated by most of the public, can be challenging to people with disability. For some who do not have a strategy or lack confidence, it may be that avoidance is the safest option.

However, participants' accounts about transportation also provided an alternative perspective that illuminated the interaction between the body and the external environment. For example, the ability to drive an adapted car meant that they could get to work or visit the theatre and or get the shopping done. Within this same context transportation was perceived as a facilitator of exercise and physical activity and maintaining these activities was important to maintaining independence and connecting with others within the community. Similar views were also reflected about other categories such as leisure and activities done with technology (Study 1). The inclusion of these categories revealed a sense of liberation from the physical restrictions imposed by the disease and thereby provided greater control over their life situations.

In ascribing meaning to exercise and physical activity, pwMS shifted the traditional ways of viewing exercise as an act of 'movement' to encompass also the act of 'being'. Participants in this current study, were aware of the progressive nature of MS and valued participation in exercise and physical activity as a way to limit physical deterioration. However, their accounts also suggested that in the event of physical deterioration they would be able to adapt and utilise activities that provided a sense of purpose and satisfaction to their lives.

This duality in the meaning of exercise and physical activity has not been reported in the literature. That is, the concept that pwMS valued both activities that required higher and lower levels of participation as being meaningful. This finding highlights another aspect within a participation paradigm where 'being' as opposed to 'doing' symbolised their activity preferences. Activities that involved being with family and friends for example, through the use of technology and transportation reduced the sense of feeling isolated. Social isolation concerns pwMS (McLaughlin and Zeeberg, 1993) as such, they are likely, as revealed in this current study, as in others, to take steps to reduce the impact of social isolation (Learmonth *et al.*, 2013; Kasser, 2009; Finlayson and van Denend, 2003).

### **7.7.2. A multidimensional view of exercise and physical activity**

In the previous section ascribing meaning to exercise and physical activity was discussed in relation to two themes namely, '*a type of movement*' and '*impact of movement of the physical, psychological and social*' aspects of life. In addition, the narratives extended and enveloped a deeper meaning of exercise and physical activity, which was permeable, and contextualised to the experience of living with a chronic progressive condition. The key findings from three main themes will be discussed in this section, namely, '*it changes*', '*sense of loss*' and '*coping with MS*'. These themes, though reported separately, were interconnected and provided insights from the experiential perspective that pwMS held a multidimensional and complex view of exercise and physical activity.

The theme '*it changes*' described the changes in exercise and physical activity practices overtime. These changes were imposed largely through the disease process and its impact on individuals' physical abilities. The responses to these changes were either optimism or pessimism. Optimism was highlighted by participants' general acceptance that some activities previously enjoyed were now inaccessible either due to physical challenges or environmental changes. This optimistic attitude revealed a willingness to adapt and change exercise and physical activity practices.

Others expressed a pessimistic outlook on life, which was associated with the uncertainty due to the variable nature of MS and uncertainty about the future. Participants with this view contemplated the idea that activities that were achievable then might be lost or unachievable in the future. As such, these pessimistic views, which at times were transient in nature, were one of the drivers that motivated engagement in exercise and physical activity. Both the optimistic and pessimistic views expressed in this study have been reported in the literature. Studies have identified that due to the changes in body structures and functioning as a result of the progressive nature of the disease, pwMS constantly made decisions about, the types of activities they engaged in, modifying activities, getting help in doing an activity or giving up on the activity all together (Toombs, 1995; Finlayson and Denend, 2003; Ploughman *et al.*, 2012). Therefore, this present study highlights the need to support pwMS during these transitory phases and to adjust activities accordingly to reflect these changes.

An interesting finding in this study was that the changes pwMS experienced were influenced by factors including personal choice, the environment, energy demands versus energy expenditure and the prioritisation of certain activities. The latter two factors, prioritisation and energy demands resonated throughout participants' accounts. Key points from the accounts will be highlighted to demonstrate how prioritisation and energy preservation were used to manage the changes associated with MS, which in turn had an impact on the exercise and physical activity practices of pwMS.

The use of prioritisation has been demonstrated in the wider MS literature (Reynolds and Prior, 2003; Finlayson and Denend, 2003) and has been specifically recommended as an area that requires further research in relation to exercise and physical activity (Dlugonski, Joyce and Motl, 2012). It is apparent from the findings of this current study that the use of prioritisation as a strategy to manage changes associated with MS was common. There were three key insights about priorities in community dwelling pwMS. Firstly, this study demonstrated the types of exercise and physical activity pwMS prioritise. For example routine daily activities were prioritised over structured forms of exercise. Secondly, the study provided insight into the reasons why pwMS living in the community engaged in exercise and

physical activity. Thirdly, further insights were provided about how decisions were made about what activities were prioritised. For example, participants revealed that changes in physical ability, their role within the family, energy demands and time were central to how decisions around engagement in exercise and physical activity were made. Knowledge of these prioritisation strategies used by pwMS suggests that their self-selected exercise and physical activity practices were the outcome of several levels of negotiations for example, self, family and energy trade-offs. Understanding these strategies from the perspectives of pwMS might help practitioners support pwMS more effectively in their decision making about exercise and physical activity.

With reference to energy demands, the study highlighted that changes in exercise and physical activity practices were driven by balancing energy demands and expenditure, in order to manage fatigue. This is an important finding as fatigue is one of the most reported symptoms experienced by pwMS (Krupp, 2003; Matthews, 1998) and is considered to be a significant barrier to engaging in exercise and physical activity (Asano *et al.*, 2013; Kayes *et al.*, 2011b; Borkoles *et al.*, 2008; Lerdal *et al.*, 2007). These decision-making skills based on their lived experience of MS meant that activities that required urgent attention or activities that were meaningful to the individual were prioritised. Exercise and physical activity were therefore planned and organised around the availability of energy, time and priorities. This could explain one of the reasons why structured forms of activities (physiotherapy, stretches and activities without the use of weights) occupied the lower ranks of the top 10 activities. Therefore, this finding suggests that prioritisation of unstructured activities over structured activities was used as a strategy to provide a sense of control over fatigue. This is commensurate with the findings from Smith and colleagues (2011) who identified that pwMS used exercise and the benefits associated with exercise (physical and psychosocial) to gain control over fatigue. These personal factors from the perspectives of pwMS highlighted that decisions about exercise and physical activity were driven by priorities and that for pwMS, prioritisation was a necessary strategy to provide a sense of control over their symptoms, especially symptoms associated with fatigue.

This multidimensional view of exercise and physical activity from the experiences of pwMS was also evident in the theme Sense of loss where participants reported multiple losses; loss of activity, loss of independence and loss of employment. Participants' narratives highlighted the spiralling nature of loss, which started with physical deterioration but impacted other areas of life and could have explained the emotional unease observed within the study. For example, in Ivy's narrative, changes to her body structure (muscle weakness and sensory changes) as a result of the deteriorating nature of MS led to a gradual loss in ability to paint; an activity that she has enjoyed doing for years. Whilst the focus in this narrative was on physical restrictions that resulted in the loss of activity, there were other factors that created further losses. This was highlighted in Anne's narrative; she also described changes to body structure and function however, for her it was the environmental restrictions that led to loss of employment. The net result of these losses was the emotional unease experienced by participants. Ivy described this as "going through a temporary sort of grieving" (Ivy, line 695).

This sense of loss has been highlighted in the literature but is often centred on physical loss specifically related to mobility losses (Finlayson and Denend, 2003). Interestingly, whilst Finlayson and Denend (2003) focused on loss this current study did not use loss in the topic guide. *Sense of loss* was developed from participants' discourse around exercise and physical activity within the context of living with a progressive illness. The findings reveal that losses occurred at multiple levels and were not only limited to loss of mobility but also included loss of activities (structured and unstructured) in general, loss of employment and loss of independence. These multiple losses reflected the impact physical loss had on the emotional aspects of participants' lives.

### **7.7.3 Exercise and physical activity: a way of coping with MS**

Exercise and physical activity was seen as a way of coping with the dynamic changes associated with MS. This was one of the major themes developed from the study. It highlighted the use of exercise and physical activity as a strategy for coping not only with living life with MS but also in maintaining a sense of self.

People with MS have developed different methods of coping with the disease, which have been cited in the wider MS literature. In fact, in a study completed by O'Hara and colleagues (2000), coping was ranked as the number one self-care strategy in pwMS living in the community (O'Hara, De Souza and Ide, 2000). In their study, coping was characterised as the cognitive or behavioural strategies pwMS use to manage their symptoms (O'Hara, De Souza and Ide, 2000). Other ways of coping described in the literature was through the use of humour as well as seeking information (Plow, Resnik and Allen, 2009; De Souza, Ide and Neophytou, 2005; Reynolds and Prior, 2003; McLaughlin and Zeeberg, 1993).

Reference to coping in relation to exercise and physical activity has been mixed. For example, in one study, participants who actively engaged in exercise and physical activity coped better with the effects of MS compared to people who were considered to be inactive (Plow, Resnik and Allen, 2009). However, another study, which included participants who were considered to be physically active, reported the opposite (Borkoles *et al.*, 2008). The authors found that the general demands of life made it difficult to cope with MS and saw this as a limiting factor to engaging in the exercise and physical activity (Borkoles *et al.*, 2008). In this current study, an example of the use of exercise and physical activity as a method of coping was expressed through having established routines over the course of the week. Participants highlighted that routine activities framed their week. For pwMS having an established routine reclaimed some control over MS, provided a way to offset MS symptoms and created a sense of normalcy. These findings have added to the existing evidence to suggest that exercise and physical activity was not only used to manage the symptoms associated with or as a consequence of MS but also as a way to cope with life.

Another way in which participants described ways of coping with MS was through their support network. This level of support was either through formal services provided by the state or informal support provided by family. However, what was highlighted in this study was the reciprocal nature of support. Participants were dependent on the support of their family and friends to fulfil their roles, but the reverse was also true where family members and friends also depended on pwMS. Studies have identified that pwMS have a variety of support systems which range

from physical, emotional and financial assistance which they have gained from individuals including, family, friends, employers and strangers (Galushko *et al.*, 2014; Golla *et al.*, 2012; Strupp *et al.*, 2012; Ploughman *et al.*, 2012). Whilst this level of support is meaningful and necessary for pwMS, this study also highlighted that reciprocity was integral to supporting and maintaining exercise and physical activity practices; where pwMS felt that they also provided support for the stability of the family structure. These findings detail how exercise and physical activity are intricately involved in negotiations of coping at multiple levels and emphasises the notion that ‘one size does not fit all’ in the management of MS.

#### **7.7.4 The complexity of exercise and physical activity: the experiential perspective**

The experiential perspectives of pwMS revealed a complex view of exercise and physical activity. In-depth exploration of the findings interpreted by the sub-theme '*identity*' exposed areas of this complexity by the use of exercise and physical activity as strategies to shape as well as preserve identity. For example, participants expressed that engaging in exercise and physical activity (mostly the unstructured forms of activity) preserved their role/s within the family or home. Similarly, participants described the use of exercise and physical activity as a tool to shape their identity. Examples included the use of structured and unstructured forms of activities to improve self-esteem, self-image and personal dignity.

Participants were resolute in their desire to shape and preserve their identity. The impact of chronic illness on identity has been documented in the literature (Charmaz, 1995). Charmaz (1995) asserts that the experience of living with a chronic illness can lead to disruptions in the relationship between the body and self which subsequently leads to changes in one’s identity. Whereas this assertion was evident in some participants in this study what was interesting was the sense that participants used exercise and physical activity as a strategy for maintaining their identity. This was one method of coping with life. Their role within the home as a parent and or partner superseded having an identity framed by MS, even in

the presence of severe disability. *Roles within the home*, especially looking after children are not often reported in exercise and physical activity studies as a form of activity. However, for participants in this study, engaging in physical activities around the home or outdoors (unstructured activities) were done out of necessity and counted as exercise which, contributed to their health and wellbeing (e.g. Ivy and Eileen). Therefore, exercise and physical activity for community dwelling pwMS was not separate to but rather embedded in their lives.

These external factors mentioned by pwMS, provided some insight into the complexity of exercise and physical activity in pwMS and suggest that engagement and participation in activities were driven and shaped by personal meanings and priorities. This complex view of exercise and physical activity was unique to the participants in this study and revealed the multiple factors that drove decisions around exercise and physical activity.

Collectively, all the major themes and their subthemes point to the varied and complex views through which interpretations of exercise and physical activity were filtered. These views illuminate a diverse source from which pwMS gathered information to support their experiential knowledge base. These sources include, but were not limited to, physiotherapists, MS therapy centres, friends and the Internet. Similar ways of knowing have been reported in the literature (Ploughman *et al.*, 2012; Malcomson, Lowe-Strong and Dunwoody, 2008; McLaughlin and Zeeberg, 1993). In this study pwMS sought information and made decisions about how to apply this knowledge to their daily lives. These diverse ways of knowing were particularly evident in this phase of the study and provided insights into how pwMS gathered information about exercise and physical activity. It is known that pwMS are information seekers (De Souza, Ide and Neophytou, 2005; O'Hara, De Souza and Ide, 2000; McLaughlin and Zeeberg, 1993) and want to be informed about MS, treatment options and the future with MS (Golla *et al.*, 2012).

The experiential view into the world of pwMS has contributed to the existing evidence base about some of the exercise and physical activity practices as well as the meaning of exercise and physical activity in pwMS. The majority of the studies

that explored the meaning of exercise and physical activity did so after an intervention programme (Van Der Linden *et al.*, 2014; Learmonth *et al.*, 2013; Dlugonski, Joyce and Motl, 2012; Smith *et al.*, 2011; Plow, Resnik and Allen, 2009; Kasser, 2009; Borkoles *et al.*, 2008; Dodd *et al.*, 2006). These studies provide insight based only on engagement in supervised exercise programs. They were limited in being able to provide insight into what actually happens within the community following the end of an intervention when people have returned to their daily routines in life. However, this current study has filled that gap in answering the research questions about the exercise and physical activity practices of pwMS and the meanings they ascribed to these activities. It highlights the complexity and the multidimensionality of the world of pwMS and how they ascribed meanings to exercise and physical activity through the lens of their lived experience. This also highlights that pwMS might not be experts in exercise prescriptions but their expertise lies within their unique lived experience.

These insights from the experiential view of the world of pwMS support the call for taking a comprehensive approach to the management of people living with a chronic illness (Nicholls and Gibson, 2010; Roberts, 1994; De Souza, 1990). This new knowledge about the world of pwMS from their perspective can contribute to the way in which health professionals approach exercise and physical activity with pwMS living in the community. It highlights that pwMS weigh up activities based on whether or not they fit into their daily lives. These findings also highlight that their preferred activities were influenced by personal factors such as; time, energy demands and availability, personal circumstances, priorities and the meanings these activities have to the individual. Also, these factors were dynamic and subject to change due to the variability of MS and demands of daily life.

## 7.8 Strengths and Limitations of the Study

This study was grounded in a qualitative approach. It used semi-structured interviews to elicit views and opinions from the perspectives of pwMS about the meaning of exercise and physical activity. The number of participants in this study is consistent with qualitative methods (Tod, 2010; Ritchie, Spencer and O'Connor,

2009). This study provided the means to expand the findings from the Delphi study (Study 1) and added insight into why certain exercise and physical activities were chosen and prioritised; an added strength of this thesis. Walker and Selfe (1996) asserted that allowing participants to elaborate on the results from the Delphi phase of a study helps to validate findings and provide a stronger rationale for consensus gained.

It should also be acknowledged that the researcher with a background in physiotherapy conducted all the interviews as well as analysed the data. As such, this might have influenced the findings. In addition, participants were aware of the researcher's professional background and as such, might have adjusted their views accordingly. As mentioned in the methods chapter (see Chapter 6), to account for any influence on the study by the researcher, a number of checks were employed.

## **7.9 Conclusion**

This phase of the study provided a deeper understanding of the meaning of exercise and physical activity in pwMS living in the community. This study supports as well as extends the existing evidence base about the meanings of exercise and physical activity from the experiences of pwMS. That is, the experiential perspective. This perspective highlighted that pwMS held a multidimensional and complex view of exercise and physical activity. These views assert that exercise and physical activity were more than movement. For pwMS, movement was purposeful and not simply confined to the remit of engaging in exercise and physical activity in and of itself. In fact, it was how participants coped and lived life with a progressive neurological condition. These movements whether structured or unstructured extended beyond the confines of body structure, function and disability. These activities were contextualised and embedded in daily life as well as necessary to shape and preserve their identity.

## **Chapter 8**

### **Study 3 Methods: A qualitative exploration of physiotherapists' perceptions about exercise and physical activity**

#### **8.0 Introduction**

This chapter will describe the method used to explore physiotherapists' perceptions about exercise and physical activity through reflections on the findings from the Delphi study (Study 1).

#### **8.1 Purpose and study aims**

The results from the Delphi Study (Study 1) provided a glimpse of the exercise and physical activities pwMS prioritised as well as the reasons why they undertake these activities during their daily routine. Physiotherapists play a crucial role as part of the MDT in the management of MS using exercise and are considered experts in exercise and physical activity (see Chapter 1). The findings from study 1 and 2 revealed insights into how pwMS conceptualise exercise and physical activity, which might have clinical implications for health professionals who work with pwMS within the community. Specifically what those implications are will be explored in the next phase of the research with physiotherapists' views and experiences as the focus of investigation.

Therefore, the purposes of this study (Study 3) were threefold. The first was to explore physiotherapists' interpretation of exercise and physical activity. Secondly, to explore physiotherapists' views and opinions about the results obtained from the Delphi study. Thirdly, to ascertain whether or not reflections on the findings of the Delphi study could potentially influence current physiotherapy practice.

The two studies, one exploring exercise and physical activity from the perspectives of pwMS (Study 2) and the other exploring professionals' perceptive of exercise

and physical activity (Study 3) were conducted in parallel. Both studies (Study 2 and Study 3) used the results from the Delphi (Study 1) to guide discussions. The research questions to be addressed were:

- What does exercise and physical activity mean to physiotherapists working with people with MS in the community?
- What are the views and opinions of physiotherapists' regarding the results of the Delphi Study, which identified the top 10 prioritised exercise and physical activity practices in people with MS living in the community?
- Does reflection on the results of the Delphi Study inform physiotherapy practice in the community?

## 8.2 Focus groups

As mentioned in chapter 6, qualitative research is best suited to gain in-depth understandings about a phenomenon and their meanings to the individual and their social context (Denzin and Lincoln, 2000). Whereas in Study 2 interviews were deemed the method of choice that allowed the researcher to focus on the perspective of pwMS, this study (Study 3) utilised focus groups as the best suited method because of one of the key benefits of using group interactions. That is, using group interactions to illuminate the perspectives' of physiotherapists in relation to exercise and physical activity within the context of working within the community (Goodman and Evans, 2010; Finch and Lewis, 2009). These group discussions are strategically designed and flexible enough to elicit perceptions, attitudes, experiences and feelings about a topic of interest in a setting that reflects life based interactions. In other words, settings where participants play a dual role of being the influencer as well as being influenced through group discussions (Finch and Lewis, 2009).

Focus groups are widely used in healthcare research to gauge group opinions about a shared topic of interest (Goodman and Evans, 2010; Kitzinger, 1994; Wilkinson, 1998). Research using focus groups methods have helped to improve

clinical practice from both health professionals' and service users' perspectives. For example, Caspari and colleagues (2013) used focus groups to explore opinions and attitudes towards promoting dignity in people with neurological conditions. Similarly, Learmonth and colleagues (2013) used focus groups to explore attitudes towards group based exercise programs in people with MS. Both studies significantly contributed to the existing evidence base, one through the lens of professionals and the other through the lens of service users.

### **8.2.1 Advantages and Disadvantages of using focus groups**

#### **Advantages**

A number of advantages of using focus groups have been cited within the literature. One key advantage is the ability to gather information from more than one person all within one space, at the same time and around a topic of shared interest, thereby creating a wealth of information (Goodman and Evans, 2010; Kitzinger, 1994; Wilkinson, 1998). The rich and diverse views expressed emerge not only through the interaction and interplay of personalities but also through the amelioration or the surrender of strongly held views (Goodman and Evans, 2010; Kitzinger, 1994). Data emerging through this type of interaction amongst research participants is neither captured using quantitative designs nor certain qualitative designs, for example, one to one interviews.

Another advantage of focus groups is their capacity to elicit views on a shared topic of interest as well as to cause reflections on similar situations by triggering memories (Finch and Lewis, 2009). It was anticipated that participants in Study 3 would discuss the findings from the Delphi Study by reflecting and recounting their experiences of working with this client group in the clinical setting. In addition, focus groups have the added advantage of shared ownership. Goodman and Evans (2010) point out that people feel less pressured to be the focus of attention when they are part of a larger group and as responses are shared across the group the feeling of needing to always offer a response is reduced.

### **Disadvantages of Focus Groups**

There are limitations to focus group methods. One key limitation is the negative effects of group dynamics (Finch and Lewis, 2009; Goodman and Evans, 2010). That is, the nature of individuals within the group and how they relate to each other may have a negative impact on the group. This may occur because of personality conflicts or misunderstandings, which make facilitating a focus group challenging (Goodman and Evans, 2010; Kitzinger, 1995).

Specifically related to this study, the researcher was aware that some focus groups had a wide range of clinicians where some might hold a more senior rank than others as well as groups where participants were known to each other. These circumstances could influence the data collected and have implications for group dynamics (Finch and Lewis, 2009; Kitzinger, 1994), for example participants with strongly held views could dominate the session. In these circumstances the researcher has a key role in managing the flow and exchanges of ideas within the group. Reiterating at the start of the group about equality is suggested in the literature as one way of managing these issues and was undertaken in this study as part of the ice-breaking process (Finch and Lewis, 2009; Goodman and Evans, 2010).

Another limitation is dealing with the issue of confidentiality within the context of the group (Goodman and Evans, 2010). The researcher's role is to reiterate the importance of confidentiality; however, the researcher has limited control over what might be discussed outside the group (Goodman and Evans, 2010). Issues relating to confidentiality were reiterated at the beginning and end of each focus group session.

### **8.3 Study Design**

A qualitative approach incorporating three focus groups and framework analysis was used to explore and understand physiotherapists' perceptions about exercise and physical activity, based on reflections on the Delphi Study.

## **8.4 Ethical Considerations**

This study was approved by the School of Health Sciences and Social Care Research Ethics Committee, Brunel University (Reference number 13/09/PhD/01, Appendix 16a) and Research and Development approval from Buckinghamshire Healthcare NHS trust (Reference RXQ/577, Appendix 16b) for one focus group (Focus group 1).

Ethics procedures followed were similar to that of Study 2. Ethics considered were related to confidentiality, anonymity, consent and the right to withdraw from the study (Appendix 17a). All information related to these were included in the participant information sheet and reiterated prior to the start of each focus group. Signed consent forms were collected prior to the start of the focus group.

## **8.5 Sample**

Convenience sampling was used to recruit participants to all the focus groups (Procter, Allan and Lacey, 2010). This method of sampling was used because of the unique nature of the study, which required specific participants to answer the research questions. As such, this sampling method was crucial to ensure that the physiotherapist chosen had the necessary clinical as well as community experience to participate in the study. Physiotherapists were included if they had experience in working with pwMS in the community at band 6 level and upwards. These physiotherapists would be more suited to give their views and opinions as they have the knowledge and experience of working with pwMS. Physiotherapists were excluded if they had no experience working in the community and no experience working with people with MS (Appendix 17b).

## **8.6 Recruitment Strategies**

Focus groups require all participants to be available in one designated time and place (Finch and Lewis, 2009; Gerrish and Lacey, 2010), which poses specific

challenges to recruitment. To overcome this, a three-strand strategy for recruitment was implemented.

The first strategy was to raise awareness of the study at an event organised by a local clinical interest group: The Association of Chartered Physiotherapists in Neurology (ACPIN). Members of ACPIN have a keen interest in a wide range of neurological conditions including MS. Permission was sought from the organisers of the event to advertise the study.

The second strategy involved emailing managers of community teams asking them to raise awareness of the study with their staff, and passing on the study information to other teams. The participants who registered interest were dispersed across a wide geographical location. Therefore a central location was found and volunteers who were able to attend on the specified dates and times participated.

The third strategy involved contacting physiotherapists working within the MS Therapy Centres to invite them to participate in the study. They fit the inclusion criteria and had the advantage of a different type of experience to physiotherapists who worked within the NHS. For practical reasons these participants were not mixed with those from the NHS because as a group they had identified a specific meeting that was best suited for them within their normal working hours.

Recruiting participants to the focus groups posed many challenges, mainly around sample size. Therefore, for practical reasons the size of the focus groups was dependent on physiotherapists who were interested in the study. Recommended size of a focus group ranges from four (Kitzinger, 1994) to fourteen per group (Goodman and Evans; Ritchie, Spencer and O'Connor, 2009) and the aim was to recruit a minimum of 12 participants. However, the number of participants recruited was based on the practicalities associated with interest ( $n=24$ ) and availability ( $n=14$ ).

## **8.7 Participants**

Fourteen physiotherapists were recruited and formed three focus groups. The first focus group (FG1) included five (n=5) community-based neuro-physiotherapists, four of whom were based within the same NHS trust but worked on different sites. The fifth participant was based in a similar community outpatient setting outside the local area but known to some members of the group. All participants were senior physiotherapists working at either band 6 or band 7.

The second focus group (FG2) included four senior physiotherapists at band 6 level with experience working with pwMS in the community. The third focus group (FG3) comprised 5 physiotherapists working at a MS Therapy Centre with experience up to managerial level. One physiotherapist, at band 5 level participated in the focus group due to having had 2 years' experience of working within this specialised MS Therapy Centre. Also, as the focus group was conducted as part of their regular team meeting the decision was made by the researcher to include rather than exclude this participant from the active research process. This decision was double checked with the ethics committee, which confirmed that participants' willingness to engage in the process did not breech any ethics relating to the study. No further research and development approval was required for both focus groups (FG2 and FG3).

## **8.8 Development of the topic guide**

As in study 2 the topic guide was developed based on the Delphi results. However, one key difference between the topic guide in Study 2 and that of Study 3 was the addition of a topic regarding clinical applicability of the Delphi results.

The topics covered included, the meanings of exercise and physical activity, physiotherapists' perspective of the Delphi results and the implications for clinical practice within the community. The first draft of the topic guide was discussed with supervisors and minor amendments made. The final version of the topic guide is provided in the appendix (see Appendix 17c).

## **8.9 Conducting the three focus groups**

The three groups were held at an agreed time and location that suited participants between November 2013 and January 2014. Two groups were held at participants' place of work, one outside working hours (NHS based group) and one during the team meeting slot within working hours (Charity based). The third group, made up of physiotherapists across a wide geographical area was held in a meeting room in London.

The researcher, who had previous experience of facilitating focus groups, facilitated all three groups. Creating a good atmosphere is considered essential for running a successful group (Finch and Lewis, 2009). Light refreshments were made available to participants before the group started. This was a good way to create a relaxed atmosphere especially for groups held after working hours. Secondly, the researcher arranged the rooms so that participants and researcher sat in a circle. This was done to ensure inclusivity and equality to avoid inadvertently setting up power dynamics, as the researcher was aware that some participants had more senior roles compared to others (Finch and Lewis, 2009).

All the focus groups followed a similar pattern as set out by the topic guide. However, the researcher was not bound by the topic guide and at points exercised the freedom to explore thoughts and ideas based on the responses from each group. The groups followed a similar pattern to that already presented in Study 2 (Section 6.6) where the discussions started broadly then focused on specific topics (Arthur and Nazroo, 2009). For example, the focus groups commenced by providing relevant background information related to Study 1, which was followed by exploring physiotherapists' understanding of exercise and physical activity. This was thought to be a good way of starting the focus group before focusing on participants' views and opinions about the results of the Delphi study and its influence on clinical practice.

Similar to study 2, the same cue cards were used as visual aids to guide the discussions. The cards consisted of the key categories that resulted from the Delphi study, along with their descriptors for the top 10 exercise and physical

activities, as well as the top 10 reasons why people engage in exercise and physical activity. They were small enough to fit on a table and mobile enough to be moved around during discussions. Other researchers have used cue cards to facilitate group discussions (Kitzinger, 1994).

For quality assurance, after every major topic the main points were summarised to clarify and or confirm views expressed. This was one way of validating the study (Goodman and Evans, 2010). Furthermore, all participants, especially those who were more reserved, were given the opportunity to express their views (Finch and Lewis, 2009). Active participation was encouraged by asking questions, for example, “anything else you want to say about this before we move on?”, or asking, whether or not anyone else had a different view or different experience.

## **8.10 Data Collection and Analysis**

The focus groups were recorded using a digital recorder and transcribed verbatim by an independent professional transcriber. Confidentiality and anonymity were maintained during the process of transcription. Following transcriptions, each focus group’s recording was listened to numerous times and checked for accuracy. Only minimal changes were made to each transcript which usually consisted of professional jargon, for example, abbreviations were transcribed in full. Notes were taken during the focus groups and reflections written after each group. Both were transferred to a reflective diary along with other thoughts and feelings about the study (see Appendix 17i).

### **Data Analysis**

Focus groups were analysed guided by the principles of Framework Analysis (Ritchie, Spencer and O’Connor, 2009). Similar to the analysis in Study 2 a deductive and inductive approach was used. The analysis followed the outline used in Chapter 6 (Section 6.9), which described five levels of analysis. These included, the familiarisation phase, the thematic conceptual framework phase, the labelling phase, the charting phase and finally the mapping and interpretation phase.

Although the outline and structure of the analysis was similar to that of the interviews, there were some key differences. These differences are brought about by the characteristic of focus groups (Ritchie, Spencer and O'Connor, 2009). These characteristics played a role in analysing focus group data, as they influence the direction and outcome of the study (Kitzinger, 1994). These characteristics, highlighted by Ritchie and colleagues (2009) were:

- *Group dynamics*
- *Interactions between participants*
- *Uneven coverage- wherein some participants speak less or more on a particular aspect of the discussion*
- *Less extensive coverage- as a result of the time constraints of the group hence some participants unwittingly comment more than others.*
- *The influence of other views*

(Adapted from: Ritchie, Spencer and O'Connor, 2009 p. 258)

These characteristics were noted during the process of analysing the focus group data, along with noting general agreement, emotions and opposing views that occurred during the group discussions (Ritchie, Spencer and O'Connor, 2009; Webb and Kevern, 2001). All the themes developed from the data were reviewed and discussed with the supervisory team.

### **Development of themes**

The focus groups were analysed separately. Each focus group recording was listened to repeatedly to remind the researcher about the interactions amongst participants and general feelings within the group. Webb and Kevern (2001) argued that the interaction and the emotional tone of the focus groups should be part of the analysis, but often they are not reflected in research publications. Similarly, each transcript was read several times and initial notes, thoughts and feelings recorded. Themes were created deductively and inductively, which reflected the thoughts and general impressions of each group. Nvivo 10 was used to organise and sort data, which allowed the researcher ease of moving backwards,

and forwards between the original transcript and labelled text (Silver and Lewins, 2010; di Gregorio and Davidson, 2008).

During the analysis, similar patterns within the data were identified and merged in order to identify the main themes, thereby creating a thematic conceptual framework (Ritchie, Spencer and O'Connor, 2009). This thematic framework was used to label the text of all the focus groups (Appendix 17e). Following labelling, a matrix chart was created and organised to reflect the themes across the data set and with reference to each participant (Appendix 17f). This chart was used to identify patterns that were similar and different within the data. During this process, participants' quotations were maintained to ensure that interpretations were grounded in the data. The researcher explored themes that were related to answering the research questions. Major themes along with their subthemes were developed and discussed with the supervisory team. Following critical discussions with the supervisory team, adjustments were made in some instances to the major themes and or subthemes. See Appendix 17h for full worked example of a development of a theme.

## **8.11 Enhancing rigor in focus groups**

Quality in qualitative research is judged by the ability to demonstrate consistency and accuracy of the entire research process (Tod, 2010). Ways of enhancing rigor in relation to credibility, dependability and transferability (Lincoln and Guba, 1985) have already been presented in Chapter 6 (section 6.10) and were also adopted in this study (Study 3). Specifically, related to the focus group, data were analysed as a conversation due to different participants making contributions at different points of the discussions, as well as highlighting the emotions such as tensions which adds another dimension to understanding the data collected (Webb and Kevern, 2001). Similar to Study 2, the researcher was involved in all the stages of the research, which might influence aspects of the study. As such, similar to Study 2 a number of checks were employed which included supervisors reviewing the development of themes, discussions about the findings with other professional peers, as well as reflexivity (see Appendix 17i).

## **8.12 Conclusion**

This chapter presented focus groups as the most appropriate method to explore physiotherapists' perception of exercise and physical activity based on their reflections on the Delphi study. This phase of the research complemented the findings from the Delphi study. It described how participants were selected and their data collected and analysed using framework analysis.

## **Chapter 9**

### **Study 3: Focus Group Findings**

#### **9.0 Introduction**

This chapter details the findings for physiotherapists' perceptions of exercise and physical activity based on their reflections on the outcome of the Delphi study.

Fourteen physiotherapists (12 Females, 2 Males) with experience of working with pwMS in the community participated in three focus groups. Participants in all three focus groups irrespective of their seniority interacted well throughout the group discussions. The researcher observed a yielding and an allowing of views to be expressed even if they were not the most common opinion of the entire group. Table 9.1 shows the demographic profile of each participant using pseudonyms.

**Table 9.1: Demographic profile of study participants**

<b>Participant</b>	<b>FG</b>	<b>Name</b>	<b>Gender</b>	<b>Age</b>	<b>Band</b>	<b>Location</b>
1	FG1	Jackie	Female	29	Band 6	Community-NHS
2	FG1	Rita	Female	35	Band 7	Community -NHS
3	FG1	Florence	Female	37	Band 7	Community- NHS
4	FG1	Gillian	Female	38	Band 7	Community -NHS
5	FG1	Sharon	Female	33	Band 6	Community -NHS
6	FG2	Anna	Female	27	Band 6	Community- NHS
7	FG2	Debbie	Female	50	Band 6	Community- NHS
8	FG2	Gail	Female	26	Band 6	Community- NHS
9	FG2	Avril	Female	48	Band 6	Community-NHS
10	FG3	Vigi	Female	34	Band 6	MS therapy Centre
11	FG3	Sheryl	Female	44	*Band 5	MS therapy Centre
12	FG3	Gloria	Female	40+	Mx	MS therapy Centre
13	FG3	Shane	Male	30	Band 6	MS therapy Centre
14	FG3	Al	Male	57	Mx	MS therapy Centre

Key: FG1- Focus Group 1, FG2-Focus Group 2, FG3- Focus Group 3, Mx- Manager, \* met criteria based on experience

Following framework analysis, four major themes were developed from all focus group discussions. These were, '*blurred terminologies*', '*influencing factors for the meaning of exercise and physical activity*', '*when professional expertise meets experiential expertise*' and '*the resolve*'. The themes and related subthemes relevant to this phase of the study (Study 3) are presented in Table 9.2. Each theme will be briefly introduced followed by detailed descriptions of the subthemes. Illustrative quotations will be used to support the sub-themes. Consistent with the use of focus groups it was difficult to attribute quotes specifically and with accuracy to each participant. Nevertheless, references for each illustration will be given by using some key detail such as, abbreviations to note facilitator (Fac) and respondent (R), a numbering system to denote changes in respondents quotation (e.g. R1, R2), a focus group number to denote references made by the three focus groups (e.g. FG1) and a line reference number that may be linked directly to the original transcript.

**Table 9.2: Major themes and subthemes for physiotherapists' perceptions of exercise and physical Activity**

Main Theme	Sub-theme
<b>Blurred terminologies</b>	Attributes of exercise and physical activity "I kind of don't agree with my own definition"
<b>Influencing factors for the meaning of exercise and physical activity</b>	Training versus pragmatism in the community External factors: Use of language, government initiatives coupled with lack of resources
<b>When professional expertise meets experiential expertise</b>	Creation of inner tensions Making sense of Delphi Results
<b>The Resolve</b>	Positive re-enforcement of current practice Re-evaluation of current practice

## **9.1 Blurred terminologies**

As a precursor to reflecting on the results of the Delphi study physiotherapists discussed their understanding of exercise and physical activity. From these discussions participants described the sense that exercise and physical activity were intricately linked and as such, describing the two separately proved challenging. This led to some contradictions emerging within the focus groups as definitions were being negotiated between other participants as well as through self-reflection. Two subthemes namely, '*attributes of exercise and physical activity*' and '*I kind of don't agree with my own definitions*' reflect the discussions across all three focus groups.

### **9.1.1 *Attributes of exercise and physical activity***

Participants across all three focus groups described exercise and physical activity based on its attributes. For exercise, inherent attributes expressed were that these were formal activities that had a set structure and provided a certain level of challenge to the individual:

- R1      *I was just thinking sort of more formal things like going to a gym class or you know going out for a run or you know joining something that's kind of a ... sort of seen as a sport or a ... you know something more formal really..*
- R2      *Activity, fitness ...*
- R3      *Challenges.. set yourself some challenges. And um ... you know you want to get your heart rate up to a certain level for a certain amount of time. And um ... or you want to do a certain distance in a certain time, you want to beat your ... your previous record*  
*(FG3, 159-185)*
- R      *Whether it's targeting a specific muscle group or whether it's targeting your general fitness, cardiovascular fitness*  
*(FG1, 167-168)*
- R      *Yeah I felt something similar, exercises maybe an activity that has a direct focus. So for increasing you know cardiovascular output, or fitness or endurance or strengthening*  
*(FG2, 205-208)*

Participants expressed that the inclusion of the word ‘challenge’ was necessary for any activity to be described as exercise. Other participants shared this concept (FG1, FG2). However they went further to state that exercise had other specific attributes. These were based on the focus of the activity. For example, exercise had to target specific muscles and be goal directed in order to increase heart rate, fitness, strength and performance. Interestingly, participants’ reference to goals reflected predominantly the physiological attributes of exercise. In other words, the underlying attributes of these activities held the essential components needed to gain the benefits associated with exercise.

In contrast, physical activity was associated with different attributes such as a non-specific activity, less demanding but could count as exercise (depending on intensity) and goal directed as part of daily living:

*R Any movement, activity that has some effort required (laughs)  
(FG2, 256-268)*

*R1 Well different types of activity ... a variety ...*

*R2 Getting off the sofa. (laughter) Anything that doesn't involve just sitting I think.*

*R1 Yeah, finding the remote (laughter)  
(FG3, 231-238)*

*R1 Things like walking the dog, walking to the shops, carrying the shopping.*

*R2 As its maybe a less intensive form of exercise (inaudible)  
(FG1, 270-274)*

As a whole, participants acknowledged some distinctions between exercise and physical activity associated with the specificity and focus of the activities. That is, exercise is specific and structured but physical activity is non-specific and unfocused. Collectively, participants agreed that both exercise and physical activity were forms of activities, where one was intensive (exercise) and the other less intensive (physical activity). These were the common grounds shared between participants and across all the groups. However the interconnection and overlapping that exists between exercise and physical activity as well as how they

are used interchangeably in clinical practice led to some challenges in ascribing meanings to both:

R     *I found it quite difficult to separate out exercise and physical activity. I sometimes lump them together. So ... because for some people physical activity ... exercise is a type of physical activity ... and physical activity can be a type of exercise depending on how you use it.*  
*(FG1, 220-225)*

These debates led to participants re-evaluating their own descriptions of exercise and physical activity and reasoning out loud the sense of uncertainty with their definitions of exercise and physical activity.

#### **9.1.2 “I kind of don’t agree with my own definition”**

During the focus group, the researcher heard the audible moans and sighs when asked to define exercise and physical activity (FG2). There was also a sense (based on facial expressions and body language) almost questioning why both words were separated. In trying to capture what these gestures meant the researcher asked participants to express how they found describing both terms:

Fac     *Okay. So ... how easy was that*

R1     *Not very. Not very ... you split it up like that...*

R2     *I think if you’d have said just ‘exercise’ and then not said ‘physical activity’ I would have given a different answer.*  
*(FG2, 174-186)*

After hearing the descriptions of exercise and physical activity of their peers this started a series of confessions by other participants revealing the difficulties involved in describing both terms. This view then filtered throughout the group where other participants agreed that their definition was up for questioning and negotiations:

Fac     *Uhuh, okay. Anything else you want to add*

R1     *The same. I kind of don’t agree with my own definition ...*

R2      *Yeah me too ... that's funny how I ... yeah, yeah ... I feel like that as well. ... it's because you've asked us to ...*

R3      *Yeah I feel like that as well.*

R2      *... differentiate between the two, and thinking of exercise as being structured in some way. So as you said about you know to achieve a specific end. And physical activity – basically anything that gets your heart rate above where you're resting ... so could be anything.* (FG2, 215-233)

This notion that physical activity could be “anything” was the view that caused some uncertainty over the meaning of exercise and physical activity. This led to series of reasoning to substantiate their claims or negotiating with others why it was so difficult to define.

One participant expressed that physiotherapists view exercise and physical activity as the same:

R      *I mean there is a bit of an overlap, I felt as a physio, you see it sort of ... it's difficult to differentiate between exercise and physical activity, isn't it? Because to us, as physiotherapists, I think you feel it's much the same*  
(FG3, 242-246)

Other participants expressed that they use both forms of activities (exercise and physical activity) as a way to encourage and sustain activity levels in pwMS. However, they also expressed that based on their experience there was also a heightened realisation that exercise can become boring for both therapist and patient after a while and as such therapists adjust treatment programs using activities that are relevant and meaningful to the pwMS. The suggestion here is that meaning and relevance of an activity was synonymous with the use of physical activities:

R1      *And also you know sort of trying to embed it into something that they do every day as a way to keep them doing it, to sustain it, rather than you know ... like I've worked here for sort of 7 ... 6 years now, so I've seen a few patients over time. And you see that they stop doing exercise programmes, they get bored with them ... I get bored if I do exercise – I get bored with doing the same thing. So you do start to once you've been seeing people for longer start to think hang on, you've got to try and make it a bit more relevant, a bit more exciting, a bit more meaningful, a bit more ... if you really are going to help people to build exercise and physical activity into their*

*everyday ... I mean I still think specific exercises are useful for certain things*  
R2     *...and certain individuals.*  
      *(FG1, 370-387)*

Participants shared how exercise was incorporated into daily activities under the guise of physical activity:

- R1     *I think also with physical activity you kind of are working towards them not realising that they're doing it if that makes sense. Just that ... and maybe incorporating exercise within that physical activity so it doesn't become something that they ...*
- R2     *a burden*  
      *(FG2, 311-318)*

Incorporating physical activity into daily routines was viewed as a way to reduce the burden of having to think about doing an activity. However despite embracing this concept some participants viewed this practically as incorporating structured forms of activities into daily routines. This is illustrated in the dialogue between two participants in FG1:

- R1     *I probably spend more time talking about the physical things you do everyday, to keep going with those and try and increase those to.. then ... so that would be more things like walking the dog, going to the shops, going up the stairs ...*
- R2     *Or even that putting ... you know saying to them when you're doing your washing, technically you're doing a squat every time you're doing your washing, so making sure you're not getting someone else to do it because it's a bit difficult, try and do that activity, because that's part of your exercise, but you're not having to think about 'Oh I'm doing my physical exercises'.*  
      *(FG1, 311-325)*

In summary, the above sections highlighted some of the intricacies with describing exercise and physical activity. Participants described both terminologies by thinking about the attributes of both words, reflecting on how they run in parallel in meaning but also the difficulty with separating the two. This led to negotiations, re-descriptions and trying to reason their professional stance as well as their experience of working with pwMS.

## **9.2 Influencing factors for the meaning of exercise and physical activity**

Participants were asked about what influenced their understanding of exercise and physical activity. A number of factors were discussed across the groups. Based on the analysis of group discussions, two subthemes were developed namely, '*pragmatism in the community*' and '*external factors*' such as the use of language and government initiatives.

### ***9.2.1 Training versus pragmatism in the community***

Participants in two focus groups (FG2 and FG3) reflected on their undergraduate training and felt this laid the foundations for their understanding of exercise and physical activity. In both focus groups participants felt that undergraduate training led to physiotherapists being more prescriptive in their treatment designs and tended to be more exercise focused. However, they expressed that when working with people living in the community they had to be more pragmatic in treatment designs:

R1      *Yeah I think the reality of working versus potentially what you learn in the classroom. I think ... you're in a room full of physiotherapy students who are all ... you know we're relatively keen, we're relatively interested in exercise and how that affects the body. But it would almost seem when you go out to work that the majority of the population don't think like that. So therefore you end ... I don't know, I mean this is definitely how I felt ... you end up kind of changing maybe from prescribing set exercises to okay well what is our overall goal here, you know, and then maybe changing it. Because if people want to walk they might not want to do loads and loads of ... I don't know, sit to stands for example, because all they want to do is walk. I don't know.*

Fac      *So you're saying that it's the reality of the people that you're working with that has helped you to change ... not really change, but view ... you're viewing exercise and physical activity in a different way.*

R2      *Yeah, yeah. You need to get a lot more pragmatic don't you (FG2, 345-376)*

Participants also expressed that the rehabilitation ethos of working in the community had a direct influence on their understanding of exercise and physical activity. They made reference to the working culture of neurologically inclined community teams. These teams were set up to support the use of a functional approach to management and goal setting, both of which lie at the heart of managing people with long-term conditions in the community:

R      *Well I think it depends a little bit on your sort of working environment, your team set-up and also you sort of mentioned about sort of goals, things like that. If you're thinking in a more functional sense and considering the whole sort of holistic picture of the individual you're wanting to just generally increase their activity*  
*(FG1, 359-368)*

Participants within the MS Therapy Centre described that their ethos was to place more of an emphasis on movement, which encompassed a wide variety of activities rather than to focus on exercise. They implied that by using the word movement (exercise and physical activity) they were subscribing to a functional approach to management:

R1      *I find that with patients though. I try not to talk about doing exercise at home now, I try and talk about doing movement – we're concentrating on your movement here, so movement control, so we get an opportunity ... you know sitting ... from the dining room chair to standing, and your posture, just movement.*

R2      *It's a more functional approach isn't it, more functional activity.*

R1      *Yeah*  
*(FG3, 300-311)*

Participants also expressed how their experience of working within the community led to adapting treatment approaches based on the clients' attitude towards exercise with increased considerations for physical activity:

*R I suppose if I'd given a patient ... say some exercises to do ... you know a sheet of targeted home exercises to target either like specific strengthening work, then I would use the word 'exercise' – here are your exercises. ... we've been doing lots of ... partly to do with where we're working and looking at goals, we've sort of changed ... well I've certainly changed a bit more to consider physical activity and to reinforce to patients that the physical things you do every day can be a form of exercise, so that they try ... because some patients that I've found when you mention the word 'exercise' they go 'Oh my God, you're going to tell me I've got to join the gym' and to them it seems 'How can I go from doing nothing to ... there's a physio telling me to do exercise?' (FG1, 296-315)*

Using a holistic approach was also alluded to in FG2, although while this term was not used participants described a shift towards an individualised approach (FG2, 396-418). That is, tailoring exercise and physical activity specific to the person with MS.

### **9.2.2 External Factors**

External factors such as the '*use of language*' and '*government initiatives*' have been referred to as influencing how people think about exercise and physical activity.

#### **Use of language**

Participants expressed the importance of the use of language when describing exercise and physical activity to people living in the community. They made references to how language could either positively or negatively affect the way people think about exercise and physical activity. They cited examples of how the media portrayed exercise using only structured forms of activity that might negatively influence the general public:

- R1 I think it's just sort of general language and general usage. Say the media for example, if they talk about exercise, they're going to be talking about the more formal stuff aren't they, not talking about just walking up the stairs or doing the garden.*
- R2 Yeah but still with the media with the whole sports and you know fitness and you know lose weight and that stuff. You know it doesn't (inaudible)*

R1      *Probably puts people off actually isn't it?*

R2      *Yeah.*

R1      *So the language is really important isn't it?*

R2      *Yeah.*

*(FG3, 278-296) general agreement amongst the group.*

*Use of language* was also discussed in FG1 where participants acknowledged that expressions of the terms exercise and physical activity differed between people and groups (e.g. patients, public, media and therapists) and recognised the importance to adjust language based on the individuals' history. This was particularly with reference to pwMS where exercise was a new concept and such activities were only considered because of their diagnosis.

### **Government Initiatives coupled with lack of resources**

The other external factors expressed points to government initiatives and lack of resources in clinical practice. The direction of long-term management has been driven mainly by different government initiatives, such as the expert patient (DOH, 2001) as well as the 'start active stay active' programmes (DOH, 2011). These initiatives whose emphasis is positioned within the self- management concept had influenced physiotherapists' understanding of exercise and physical activity.

Participants described that despite patients wanting to be seen for active physiotherapy, and likewise physiotherapists feeling the need to continue treatment especially when working with complex patients, they found themselves bowing to the external pressures that were usually driven from these initiatives in combination with a general lack of resources in the community. They described how these combined effects pushed them down the self-management route in order to facilitate earlier discharge from active therapy:

R      *And I'm sure a little bit of a ... not the push ... cos to me as a physio it makes sense, but in the NHS ... right so we work in the NHS – you can't ... you can't keep people ... we're not allowed, and we can't see*

*people every week for exercise for stretches. And mainly from a resource point of view initially, but also in terms of sort of the self management, you know the expert patient, you know facilitating patients to manage their conditions ... I think you then end up looking at exercise in a very different sort of way, cos it's not something that they're coming to you for – you're trying to encourage them to take on board the principles and then do it in their everyday life.*  
*(FG1, 462-475)*

Participants expressed that these government led initiatives indirectly infiltrated the way they viewed exercise and physical activity:

*R      And whether that sort of joins in with you know these initiatives of ... you know general health initiatives about you know people getting off a bus the stop earlier ... you know there's been a lot about that hasn't there? So whether it's just we're sort of including some of those things in what we would say*  
*(FG1, 327-337)*

There was a sense that some of the government led initiatives constrained how they viewed exercise and physical activity and also raised concerns about whether or not the direction of these generalised government led initiatives reflected patients' current need.

In summary, ascribing meaning to exercise and physical activity proved challenging for physiotherapists. The discussions presented suggest that in attempting to describe both terms they drew on their theoretical knowledge of exercise and physical activity and to some extent their experience of working with pwMS in the community. Also, a shift was noted in the quotes, which suggest that physiotherapists acknowledged that the purpose of exercise was not only to improve the physiological attributes (e.g. increased heart rate), which was evident at the beginning of the focus groups discussions. They adjusted their views to a more client centred approach when considerations were made about physical activity. In addition, physiotherapists expressed external factors, such as the use of language and government led initiatives, which also influenced not only their perception of exercise but also the perception of the general public towards exercise and physical activity.

### **9.3 When professional expertise meets experiential expertise**

The previous sections considered participants' descriptions of exercise and physical activity based on their theoretical knowledge and to some extent their experiences of working with pwMS. However, when participants reflected on the results of the Delphi study various attitudes were observed. The theme, '*when professional expertise meets experiential expertise*', exposes some of these attitudes within the study. These attitudes were evident in the narratives of participants within the NHS as well as the MS Therapy Centre and challenged their understanding about the therapeutic approach used in the management of pwMS in the community. Two subthemes, which illuminated these attitudes, were '*creation of inner tensions*' and '*making sense of the Delphi results*'.

#### **9.3.1 Creation of inner tensions**

The creation of inner tensions was highlighted mainly by the attitudes of participants towards the results of the Delphi study. Most participants described a mixture of reactions and views. Some words used to describe their feelings were 'surprised', 'not surprised', 'feeling sad' and 'ridiculous', but these views were not static within their interactions. Participants who stated initially that they were surprised with the results of the Delphi study, after reflection and through discussions with other participants changed their views during the process.

#### **Surprised or not surprised?**

Within two focus groups (FG1 and FG2) most participants expressed that they were not surprised by the results of the top 10 activities identified and prioritised by pwMS living in the community. They felt the results were indicative of their experience of working in the community:

*Fac Okay, so are there any surprises there?*

*R1 No.*

*R2 Not really.*

*Fac So you expected what they've said ... you would expect that, okay.*

R3 *I think when you ask people what they're having difficulty with, if you think of a patient, the things they bring up first are looking after themselves, being ... not being ... you know the things that frustrate them when you talk about their physical restrictions are things like 'I can't do this, I can't get round my house, I can't look after my children, I can't drive the car' – they're always the ... they don't ever say 'Well I can't do physio' – that's not how they ... that's not really how they ... I mean they often say they want physio, but it's these things ... these you know self-care, everyday (pointing at cue cards) – they're the things that they will say ...*  
*(FG1, 572-593)*

Participants in FG2 deliberated about whether they were surprised or not and through this discussion highlighted the mismatch between what pwMS identified and prioritised and what they as professionals were trained to address:

- Fac *So are there any surprises there?*
- R1 *No we are near the bottom of the list, aren't we (laughs) – physiotherapy.*
- R2 *But that might ... that's not something you can ... unless you've got the money, elect to do.*
- R3 *I don't even necessarily think it's that surprising necessarily, it's just it's interesting to see I suppose. And I think it's really turned it on its head if you think of ... I don't know for me definitely, so from 7 to 10, or 7 to 9 – that's kind of what we maybe were trained to really do with patients.*  
*(FG2, 467- 481)*

One participant within the same focus group made an alternative comment. She was generally surprised by the results of the study as she felt the study would reveal the top 10 most popular exercise routines. That is, activities based on her understanding of exercise, which she conceptualised as formal, specific and structured forms of activities:

- R *It seems ridiculous but I suppose ... it wasn't how I was thinking, more than I'm surprised. I was kind of ... because of the exercise thing that I conceded in my head, it was more like you know what's the most popular way to exercise rather than ... more just activity*  
*(FG2, 813-818)*

Other participants within the group acknowledged her view but reemphasized that based on their clinical experience the top 10 activities were reflective of some pwMS and as such was not surprising.

The third focus group, which included physiotherapists from a local MS Charity, expressed the same level of surprise over the inclusion of certain categories of the top 10. These categories were activities due to family roles and transportation, which led to debates amongst participants:

- Fac     *So are there any surprises here to you? ... based on your knowledge?*
- R1       *I wouldn't have thought driving was a physical activity.*
- R2       *Yeah I was thinking about driving.*
- R1       *Public transport yeah, but I wouldn't have thought driving. Having to walk to get a bus?*
- R2       *But it's the effort that they take to do it.*
- (several people speaking)
- R1       *Yeah, no I mean fair enough, but it never occurs to me that ...*
- R4       *Yeah but they consider it as an exercise of physical activity that ...*  
(inaudible – several people speaking)
- R2       *I mean getting ready to go out, and then going out and then getting back ...*
- R4       *It's the effort – they're so knackered, aren't they, they're so tired.*
- R2       *Or getting in and out of a car, Just the logistics of going out.*
- R3       *I think that's probably what they're talking about.*
- R1       *No I think that means that you don't actually really think about ... you know you just think well that's just getting in the car and going somewhere. But actually if that is something that they're thinking of as physical activity maybe we need to plan ..more around it.. and think a bit more about (laughs) how it fits (inaudible)*  
(FG3, 385-439)

The above illustrates tensions arising from the professionals' understanding versus the experiential understanding of exercise and physical activity. The

experiential view of exercise and physical activity challenged the concept of what some physiotherapists perceived as exercise and physical activity. For some, it challenged them to think beyond the act of driving as well as all the physical components associated with driving. Whilst physiotherapists acknowledged the influence and the importance of physical activity, this section also highlighted that the concept of exercise still dominated at some level.

A similar attitude emerged when the focus groups were presented with the results from the top 10 reasons why people with MS engaged in certain activities. Some words used to describe participants' attitudes towards the results were, intrigued, a general sense of surprise about the order and inclusion of some categories:

- R1     *... I, like that there 'to improve the MS symptoms' I would ... like range of movements, strength ... to me that seems so impairment based, which the activities they did weren't impairment reasons, they were much more participation reasons. And these self-esteem, emotional wellbeing (pointing at cue cards) – I would have thought they would have been much higher up. And improving your balance for example would have been at the bottom. I'm quite surprised at that. Out of necessity I ... I kind of ... understand ... you know like getting up, getting dressed ...*
- R2     *Yeah would be quite high up (several people speaking)*  
*(FG1, 957-970)*

The above illustration reflected the views expressed by the other groups (FG2 and FG3) and highlighted a sense of bewilderment about the reasons pwMS reported for engaging in exercise and physical activity. There appeared to be a genuine lack of understanding from the professionals' perspective in light of what they perceived to be a mismatch between what pwMS say they do and the reasons why they engage in such practices. This apparent mismatch identified by the therapists created inner tensions within themselves as well as amongst their peers as they contemplated whether or not realistically these claims made by pwMS fitted the therapeutic approach based on their professional knowledge of MS. Most of this unease was centred on, '*to improve MS symptoms*' being ranked at number 1:

- R1      *I think the focus on improving MS symptoms is interesting, rather than sort of managing or coping with MS symptoms.*
- R2      *Yes number 1 is ...*
- R1      *I mean how much proof do we have that anything actually really improves the basics. I mean I think we tend to sort of maybe focus more on managing. I mean yeah we do like to improve function, but how much of what sort of the exercises do actually helps improve the symptoms. So I'm not sure ...*  
*(FG3, 1072-1084)*

The clinical dilemma was further expressed through participants feeling inadequate to improve physical symptoms in pwMS especially being aware of the disease progressive trajectory. Physiotherapists empathised with pwMS as they felt inadequate to fulfil the expectations of pwMS regarding the benefits of exercise and physical activity:

- R1      *I don't know I feel a bit 'Oh but sometimes I can't change that' do you know I'm a little bit ...*
- R2      *Yeah, we could give it from our point of view*
- R1      *Yeah and I feel a bit like 'Oh but I might not be able to improve your MS symptoms and I wish that I could, but I'm not always convinced that the intervention I do will.'*
- R3      *It's more giving them the management strategies for that symptom rather than being able to make it what we think is better. So it's just making them aware that it is a normal thing to have.*
- R1      *I know but it's things like you know when the weakness is so great that it doesn't matter, all the different exercises in the world to target hip abduction and they just don't have the power and the strength and ability to target that in order to be able to stand and not completely collapse on that side ... you know and kind of going 'Oh God we've been doing this for 6 weeks and actually it's still not getting any better and it's probably not going to.' And that is an MS symptom still, you know weakness.. So I often feel yeah a little bit like 'Mm' ... but yeah I mean you can always affect range I suppose*  
*(FG2,1356- 1389)*

Interestingly, whilst physiotherapists expressed concerns about the physical impact of exercise and physical activity there was more support for the categories revealing the psychological impact of exercise and physical activity: These views were consistent across FG1 and FG2. However, participants in FG3 had an alternative view. They agreed with the perspective of the pwMS and supported their decision (Study 1) in relation to the order of the reasons they engaged in exercise and physical activity:

R1      *If they need all this though to be able to achieve that ... so they're actually going in the right direction.*

R2      *Yeah 6, 7 and 8 are all sort of psychological elements. Just interested how they ... they're sort of in the middle, aren't they - middle to lower order. Whereas the upper order are all functionally biased to maintain their self-reliance or self independence*  
*(FG3, 1129-1138)*

These illustrations highlighted some of the disparity in views amongst physiotherapists. It also highlighted some lack of confidence in the perceived physical benefits of exercise and physical activity in pwMS.

### **9.3.2 Making sense of the Delphi Results**

After voicing views and opinions which revealed the inner tensions based on the results of the Delphi study, the tone and language transitioned to a phase where participants attempted to understand the experiences of pwMS. They understood that the top 10 activities were also functional activities that needed to be done as part of ones' daily routine:

R1      *...if you haven't got the energy to get washed and dressed then you're not going to do anything else are you?*

R2      *It is functionally biased.*

Fac      *So functionally biased, the first.*

R2      *Yeah first three.*

Fac      *First three. And why do you say functionally biased?*

- R2      *Well me as an individual, I would like to keep my independence. And if you look at each one of 1(Self-care activities), 2 (Everyday life activities) and 3 (Domestic activities) – by being able to do those I keep my independence....*
- R1      *And probably if they cannot achieve the first three they won't be able to do the rest. (FG3, 876-903)*

Similar to the above, there was a shared understanding about why the category, '*to improve MS symptoms*' was ranked as number 1 in the Delphi Study:

- R1      *You can kind of understand that being number 1.*
- R2      *Which one?*
- R3      *To improve MS symptoms because if it's the kind of overriding thing in your life then you probably think oh if only this was a bit better than all the other things would fall into place a bit more. But then the actions that you're taking are not really targeted towards that. (FG2, 1250-1262)*

Seemingly this new understanding noted within the discussions of physiotherapists occurred through the acknowledgement that pwMS used a language familiar to physiotherapists:

- R1      *But just on the specifics of I guess what ... I completely get what you're saying, but the description of that is very classic, you know – maintain range of movement, strength, balance ... alter muscle tone.*
- Fac      *And they talk like that.*
- R2      *God they've had too many of us shouting at them (laughter) (FG2, 1282-1293)*
- R1      *They obviously listen to what we say.*
- Fac      *(laughs) That's number 1 (To improve MS symptoms). Yeah.*
- R1      *They've been taught to say that.*
- (FG3, 1064-1068)*

Physiotherapists reflected on the inclusion of physiotherapy and other activities that physiotherapists might draw on in managing MS and expressed that pwMS were using physiotherapy as "a means to an end" (FG1, line 597). Most participants in FG1 felt that physiotherapy type activities (stretches,

physiotherapy, activities without the use of weights) supported the first three activities (self-care activities, everyday life activities, and domestic activities) pwMS prioritised as important.

There was this new sense across the group that in light of the Delphi results physiotherapists should enable pwMS to make the link between structured (exercise) and the unstructured forms of activities (physical activity) in a way that is meaningful to pwMS:

*R1 And I think unless they see that what you're asking them to do is going to somehow improve these top six, you can see that their motivation to do it is not great. So if you can ... you might give them stretches to do, but unless you sort of try and attach that exercise to a particular ... I don't know 'It'll help you walk the dog more easily' or 'You'll be able to bend down to ...' I don't know ... Put your shoes on. ... load the washing ... put your shoes on ... then I think it starts to make more sense to them.*  
*(FG1, 624-636)*

However, there was still a lingering concern about whether or not the exercise and physical activity pwMS engaged in was adequate to contribute towards levels of fitness. This level of fitness was in line with what they expressed in earlier section, for example, improved heart rate. Following contemplation some participants concluded that the results of the top 10 activities identified and prioritised by pwMS living in the community had little to do with exercise:

*R The only thing is it sounds more like people are thinking about their priorities in terms of what's important to them, and not so much how much physical activity and exercise they get from those things. If I was to look at the order I would think yeah that makes sense that someone would prioritise, that's most important, you know self-care first then everyday life activities etc ... but whether they would feel ... if they then reflected on that and thought do I get the most amount of exercise and physical activity from those things, I wonder if (inaudible) differences (FG1, 761-772)*

This view was also shared by the comments made in FG2 where participants felt some of the activities listed will not lead to the physiological attributes associated with exercise:

*R There's some things that are quite highly rated, I'd say barely qualify as any kind of physical activity ... like reading and cleaning your teeth. Obviously you need some physical capacity to do them, but in terms of having any kind of effect on you ... cleaning your teeth is possibly not keeping you fit*  
*(FG2, 492-498).*

Physiotherapists within the MS centre shared similar views but also acknowledged some of the challenges pwMS living in the community experience due to severity in disabilities and as such may choose activities accordingly:

*R But also you know looking at these activities, they're activities actually where we wouldn't have thought of these activities – they're looking at them through their eyes where they're limited with their physical ability. So actually playing a game with the Wii at home with a TV, with the interaction, or doing ... 'cos you can do physical activity with a Wii ... for them they feel they're able to do some of it, and perhaps they're not embarrassed. (FG3, 698-707)*

Participants felt that the choices made by pwMS in relation to exercise and physical activity were no different from the choices physiotherapists make within their own personal lives:

*R1 But I think ... I mean I don't know, I mean I hate the gym, like and I never go to the gym ever, and I don't have any disability. But it's like the last thing that I would ever want to do, so I often think we shouldn't be then forcing our patients to go to the gym, because I couldn't think of anything worse than being in a room with a load of weights and people exercising.*

*R2 Like classes.*

*R1 I love classes, I absolutely love exercise classes.*  
*(FG2, 708-719)*

Participants realised the impact personal choice might have on decisions regarding the types of activities people in general engage in.

## 9.4 The Resolve

In order to address the third research question participants were asked whether or not the results of the Delphi study could inform current physiotherapy practice in the community. The majority of the participants felt that over the years there had been a shift in approach to managing long-term conditions in the community. This shift was attributed to the ethos of most community rehabilitation teams that have an emphasis on MDT working and goal setting. Discussions across all three focus groups centred on the '*positive re-enforcements to current practice*', which supported the functional approach to management. Within this context, they also acknowledged the need to re-evaluate some aspects of the physiotherapy approach to managing pwMS in the community.

### 9.4.1 *Positive reinforcements of current practice*

The majority of participants expressed that the Delphi results validated or supported current physiotherapy practice and emphasised the importance of using a functional approach to managing pwMS within the community:

*Fac So does this affirm or not what you already do?*

*R1 Yeah I think it does, yeah.*

*R2 I think we've certainly been trying to .. not move away, but sort of really think about when you give someone exercises to do, like and by exercises I mean you know specific exercises targeting specific issues, that you try and be a bit more thoughtful about putting it into some sort of functional context.  
(FG1, 1188-1198)*

This view was also shared by physiotherapists working within the MS Therapy Centre who extended this idea to emphasise the importance of choosing activities that are meaningful to the individual and incorporating them into their daily lives:

*R Just getting out of bed for some of them is quite an effort, isn't it, so it's um ... and I think as soon as you say 'I want you to do 10 of those' you know they switch off ... most people switch off anyway, don't they, so it is about sort of trying to incorporate it into their daily life that doesn't seem such a chore.  
(FG3, 1233-1239)*

The positive re-enforcement of current practice was also highlighted by the results of the Delphi study in validating the use of goal setting in the community.

Participants felt they already used goal setting in pwMS as a way to focus treatment on every day activities. However, they felt pwMS would have prioritised physiotherapy over other activities:

R1 *It supports the use of our goals really, because we try and make our goals very focussed on their day to day activities and what they want to achieve, so actually this makes ...*

R2 *It's quite reassuring.*

R1 *Yeah.*

R2 *I thought it might come out the other way that they would want to attend appointments and come for ... Just to feel that they're doing something to make themselves better.*  
*(FG1, 670-684)*

In addition to goal setting, some participants expressed that the results of the study (Delphi study) highlighted the value of working together with different members of the Multidisciplinary Team (MDT) and pointed to the interconnectedness of roles within the multidisciplinary team:

R *Does this not also look like a multidisciplinary team as well, like you're seeing ... as a physiotherapist you would learn from other professions that would help you address these as such ... because like in self-care it is washing and dressing. Which classically is an occupational therapist role isn't it? Um ... seeing it from you know ... but we can impact on that gradually with just the movements and things they need to do as well.*  
*(FG2, 1768-1777)*

Participants within FG3 reflected on the importance of having the support of a clinical psychologist to work alongside physiotherapists in encouraging pwMS to be more active. They reminisced how this form of support was helpful in the past but was now lacking within MDT. This resulted in physiotherapists having to assume a dual role dealing with the physical and the psychological manifestations

of MS. They cited examples such as attempting to manage cognitive and anxiety related problems but often lacking in those skills:

R       *... it should be a combined approach. And we get quite good at being psychologists I think because we have to listen a lot, and from our experience we can give advice that is useful. But we're obviously not qualified psychologists, so a lot of our physio is psychology, but it does help to have that experience to help people adjust to their changing life with MS, and to keep them where they are if we can. ...*  
*(FG3, 1266-1286)*

#### **9.4.2 Re-evaluation of current practice**

This sub-theme highlights that despite the '*positive re-enforcements to current practice*' which is validated through the use of a functional approach to management, goal setting and MDT working, there was still room for improvement in these areas. One area the results from the Delphi study highlighted was the need to use a comprehensive approach to management. Participants highlighted the activities that needed further attention during physiotherapy assessment and treatments were *transportation* (ranked 4<sup>th</sup>), *leisure* (ranked 5<sup>th</sup>), *activities with family roles* (ranked 6<sup>th</sup>) and *activities done with technology* (ranked 10<sup>th</sup>) as these were not usually considered during goal setting. There was a sense that these activities were not at the forefront of physiotherapy assessment:

R       *Yeah that's kind of not really things that I think that I would ... I feel that I don't focus enough on and maybe ... yeah, that (pointing at cue cards) would be one of the areas, whereas I think maybe the first three and your last you know 7 to 9 anyway you'd think about. But maybe those middle three I would kind of brush over*  
*(FG2, 892-899)*

Other participants within the same focus group expanded this concept and challenged the state of current practice:

R1       *See I think that one (pointing at activities due to family roles) I don't really address, and I think that's probably 'cos I don't have children and my family don't live nearby. So I think that's probably something that is good to have brought up.*

R2      *Yeah. And I think it would really challenge maybe how you do work. 'Cos I think you know when you think about it in like in patient settings if we are having difficulty either setting goals or achieving outcomes or whatever for the patient, we would definitely get friends and family in, and maybe we don't do that enough in the real community environment where that person is living*  
*(FG2, 921-936)*

Participants in FG1 also shared this view. They felt that the Delphi results revealed the driving force behind the reasons why pwMS engaged in exercise and physical activity, which challenges the way current treatment programs are designed:

Fac      *So now having a sense of the top ten in terms of what they say they do and the reasons why they do what they do, how relevant is that do you think for clinical practice ... how relevant is this information?*

R1      *Really massively, massive, hugely.*

R2      *Yeah.*

R3      *That's what drives them ...*

R1      *Yeah, 'cos if you're asking them to do ... like if someone asks you to do something and you couldn't see the point and you didn't know why and you didn't see it would be any benefit to you ... I mean okay you might do it for a week or so to think well I'll do it ... just cos I've been told to do it ... but your heart is not in it, and you are not engaged with it, and you are not motivated to do it.*

R3      *And especially if it's a boring exercise then you're even less likely to do it.*

R1      *So I don't see that they would be any different. Especially when life's hard ... you know sometimes life's quite tough going, so why on earth would you want to spend your time doing something that you really see no value in, you know.*  
*(FG1, 1156-1186)*

Physiotherapists in light of the Delphi results saw the value of having a wider view of the exercise and physical activity based on the experiences of pwMS. Based on their reflections and through discussions with the group they began to reconsider their own description of exercise and physical activity:

R      *I thought it was interesting seeing what a lot of patients consider to be activities that I've never really thought of as being activities, and maybe*

*trying to incorporate that a little bit more into the goal setting, which I would say I don't necessarily do (laughs). It certainly yeah makes you think what things are regarded as a physical exertion*  
*(FG3, 1224-1231)*

However some participants despite embracing this wider view of exercise and physical activity and reconsidering their initial descriptions of exercise and physical activity (as seen in the previous subtheme '*making sense of the Delphi results*') returned to having a central focus on the physiological attributes of exercise and physical activity. In addition, they went back to their original ideas highlighting the strong influence undergraduate training had on their description of exercise and physical activity. They considered in light of the Delphi results that undergraduate training required greater flexibility with the types of activities being taught in the management of pwMS long term conditions, be less prescriptive and incorporate patients' priorities in treatment designs:

R1      *I think it might be a good expectation or understanding to set when you're training like ...*

R2      *Yeah.*

R1      *... you were saying about in your room of 20 something usually fit young people, and this kind of model of ... just to get an understanding of you know ... getting this mind set of ...*

R2      *Absolutely what is important to people.*  
*(FG2, 856-866)*

By the end of the focus groups participants expressed the challenges associated with working with people with disability especially when theoretical and practical applications were misaligned. As clinicians they expressed the desire to do what was best for their clients. However, the Delphi results highlighted the disparity between 'professionals' best' and 'patients' best':

R      *I know, and I think that that's the thing though isn't it, because there's that real difficult thing of going 'This is what I think would really help you' .. you know this is what I know from my theory and my background knowledge' and you know ... I mean I don't think that it is necessarily evidence, it's what you know you feel and what we feel that this would be the best thing for you. But ... so many of them just don't want it - they just don't want what we think's best. And maybe that's okay, and I think*

*that that's kind of... yeah ... I'm definitely feeling a lot like that.  
(laughter) (FG2, 739-752)*

In summary, the findings highlight the reactions when professionals' with expert knowledge of exercise and physical activity in pwMS meet the experiential expertise of those who live with MS. The series of reactions revealed inner tensions between physiotherapists based on their reflections on the Delphi results, which then challenged their own convictions about how they ascribe meaning to exercise and physical activity. In making sense of the Delphi results some physiotherapists adjusted their initial views and opinions trying to fit their perspectives as physiotherapists into the perspective of pwMS. The illustrations highlighted some areas where this adjusting to the perspectives of pwMS transitioned to some sort of resolve; demonstrated by the '*positive re-enforcement of current practice*' which included the use of goal setting and taking a functional approach to management. In addition, there was also the '*re-evaluation of current practice*' where physiotherapists felt that the results of the Delphi study had implications both for clinical practice and undergraduate training.

## **9.5 Discussion**

This qualitative study explored the views and opinions of physiotherapists in relation to the exercise and physical activity practices of pwMS living in the community as identified by the outcome of the Delphi study (Study 1). In order to answer the research questions, views and opinions were elicited from three focus groups consisting of a total of 14 physiotherapists who work within the NHS and MS Therapy Centre. All physiotherapists who participated in the focus groups had a wide range of experience ranging from senior clinicians to therapy managers. Using Framework analysis (Ritchie, Spencer and O'Connor, 2009) four major themes were developed across the focus groups. The views expressed by physiotherapists who worked within the NHS and the MS Therapy Centre were similar and collectively informed the major themes and related subthemes.

The following sections will discuss the key findings in relation to the research questions from Study 3. These include:

- Ascribing meaning to exercise and physical activity
- When professional expertise meets experiential expertise
- Reflections on clinical practice

### **9.5.1 Ascribing meaning to exercise and physical activity: The physiotherapists' perspective**

Physiotherapists found ascribing meaning to exercise and physical activity challenging. This was observed across all the focus groups and irrespective of the clinical experience of the therapist. Some participants expressed that they had never been asked to describe exercise and physical activity hence the difficulty vocalising what exercise and physical activity meant. Nevertheless, they all agreed that exercise and physical activity involved movement and acknowledged that pwMS irrespective of levels of disability could and should participate in these movements.

Physiotherapists drew on the underlying physiological attributes of exercise and physical activity as a way to differentiate the two terms. For example, movements associated with exercise were intensive and those associated with physical activity were less intensive. However, interestingly whereas physiotherapists reported that they used both exercise and physical activity in clinical practice, their discussions presented evidence that their natural default position was towards exercise that led to health and fitness. This focus on exercise reflected threads of their professional identity in relation to exercise prescriptions where physiotherapists are perceived as experts in exercise provision; a view supported and promoted by different professional bodies both internationally and nationally (WCPT, 2014; CSP, 2011). In addition, physiotherapists in this study as well as in other studies have expressed similar traits of their professional identity as experts in exercise prescriptions (Mulligan *et al.*, 2011). This is not surprising as exercise prescription is embedded in all levels from undergraduate training through to

clinical practice. This tendency to focus on exercise with an emphasis on fitness might be limiting the scope of physiotherapists in clinical practice and risks excluding other types of activity that might be necessary for health and general wellbeing as indicated by the discussions within the focus groups.

This study provided support that physiotherapists' understanding of exercise and physical activity was influenced by their professional knowledge, which reflected their diverse ways of acquiring information. These sources include, national guidelines (NICE), government initiatives (national and local), media and through interaction with pwMS. Collectively, these different sources guided their decision making in the management of MS in the community. These differing ways of managing neurological conditions have been reported in the literature and have been found necessary for promoting physical activity in people with disability (Mulligan *et al.*, 2011). However, this current study has extended those findings to also highlight that at times these diverse knowledge bases might have competing agendas especially when working with people with long-term progressive conditions. For example, physiotherapists expressed that various government initiative and or guidance might not reflect the current needs of pwMS and in some cases they are driven to facilitate discharge despite acknowledging that patients could benefit from more 1:1 therapeutic interventions to achieve greater gains in their functional ability. These challenges often found physiotherapists negotiating between what they think professionally versus what the guidance or existing evidence suggests.

Physiotherapists in this study felt that drawing from the different sources required a certain level of pragmatism and flexibility. This was specifically in reference to conflicts that might occur between knowledge gained from the existing evidence and knowledge gained through clinical experience. For example, physiotherapists felt that working with pwMS in the community required different skills, which were less prescriptive and required a pragmatic management approach especially in pwMS where exercise was a new concept. Similar findings have been reported in the literature whereby health professionals, including physiotherapists reported the need to be flexible and creative in their approach in the management of fatigue in pwMS who engage in exercise (Smith *et al.*, 2013b). The authors further

explained that this flexibility and creativity was borne out of experience, trial and error with working with pwMS over time (Smith *et al.*, 2013b). This level of pragmatism is often required in managing people living with a variable and progressive illness. The views of physiotherapists in this current study, suggest that having greater flexibility within the treatment framework which includes both research evidence and evidence from clinical experience might result in greater choice for pwMS rather than a one size fits all approach to exercise and physical activity.

In relation to exercise and physical activity the current research evidence base only presents half the story in pwMS. As mentioned in the Chapter 2, the majority of the studies related to exercise and physical activity in pwMS are positioned within the quantitative paradigm. Only a few studies explored the meaning of exercise and physical activity from the patients' perspective (Van Der Linden *et al.*, 2014; Learmonth *et al.*, 2013; Dlugonski, Joyce and Motl, 2012; Smith *et al.*, 2011; Kasser, 2009; Plow, Resnik and Allen, 2009; Borkoles *et al.*, 2008; Dodd *et al.*, 2006). Due to the lack of published research on patients' views, opinions and experiences about exercise and physical activity, physiotherapists have little information on what matters to pwMS living in the community. The lack of sufficient evidence supports the call for more studies exploring the meaning of exercise and physical activity in pwMS in order to rebalance the existing evidence base.

### **9.5.2 When professional expertise meets experiential expertise**

The professionals' perspective provided some insight into the attitudes of physiotherapists. It highlighted that the experiential perspective (pwMS) challenged the knowledge base that grounded physiotherapists' understanding of exercise and physical activity as evidenced by the mixed reactions across the focus groups (FG1-3). For example, physiotherapists could identify with some of the benefits of exercise and physical activity reported by pwMS to the physical, psychological and social aspects of the individuals' life. As such they were at ease

with the perceptions of pwMS that exercise and physical activity improved *flexibility, mobility, self-esteem and emotional wellbeing*. However, there was some unease and debates over the inclusion of other categories such as *transportation, activities due to family roles, activities done with technology and to improve and maintain MS symptoms* (Study 1). These debates were particularly evident with the latter (*to improve MS symptoms*) as physiotherapists questioned whether or not exercise interventions improved MS symptoms. These views highlight some of the challenges with translating research evidence into the reality of clinical practice. The reasons for these disparities could be explained in two ways. Firstly, as discussed in Chapter 2 and alluded to in the previous section, there is widespread research evidence that supports the use of exercise and physical activity to improve MS symptoms (Ensari, Motl and Pilutti, 2014; Rietberg *et al.*, 2004). However, this evidence is predominantly related to pwMS who are mildly or moderately affected by MS whereas, the individuals more likely to be seen in clinical practice are those moderately or severely affected by MS. The research evidence for the benefits of exercise and physical activity in people severely affected by MS is inconclusive (Toomey and Coote, 2012). Secondly, it demonstrates the differences between objective markers used by physiotherapists to denote improvement as opposed to the subjective experiences that denote perceived improvements. This was interesting to note within the study and illuminated the differences between the perspectives of physiotherapists shaped by their professional experience and that of pwMS shaped by their lived experience.

In addition, the mixed reactions expressed across the focus groups pointed to the theoretical model that guided their professional practice. For example, they sought to objectify the claims made by pwMS, which is a trait of the biomedical model of practice (Nicholls and Gibson, 2010). This inherent trait challenged whether or not they utilised a holistic approach to management as they stated in the focus groups discussions. Underlying theoretical models that guide clinical practice are not usually explicit either in research or clinical practice. Mudge and colleagues (2014) presented an auto ethnographical account of two physiotherapists' reflections on their models of practice. Their reflections revealed

that whilst they claimed to have practiced within a holistic framework, which embraced a patient centred approach, their accounts showed threads of the biomedical approach which lingered within their practice ideology (Mudge, Stretton and Kayes, 2014). They felt that the existence of the biomedical approach caused conflict between their perspectives and that of their patients. They also highlighted that holding onto threads of the biomedical approach limited their ability to fully embrace a more holistic approach to practice (Mudge, Stretton and Kayes, 2014).

In this current study, participants stated that they had shifted from the biomedical model, yet threads of the biomedical ideals were apparent in their discussions. This was evident in their use of language that utilised aspects of the biomedical as well as the bio-psychosocial models of practice. For example, whilst some physiotherapists expressed a holistic view (physical, psychological and social) of exercise and physical activity others were focused on a one-dimensional view; that is physical performance and fitness. This highlighted the existence of views along a continuum of different theoretical models of practice spectrum; whereby some participants were within the biomedical frame and others transitioning along that frame of practice to a more holistic view. As such, the views of those transitioning and those with the biomedical frame collided.

These findings suggest that physiotherapists working within the biomedical frame were challenged by the experiential (subjective) experiences of pwMS. It also, highlighted that physiotherapists should be aware of their theoretical framework, which guides their practice as one shaped predominantly by the biomedical approach might be limited based on the findings of the study from the perspective of pwMS (Studies 1 and 2), which revealed aspects of pwMS' subjective experiences. Physiotherapists over the years have been keen to move away from the medical model (Roberts, 1994) and adopt other models of practice that reflect a more holistic view (Nicholls and Gibson, 2010; Leplege *et al.*, 2007; Roberts, 1994), however, as evident from this study, this can be difficult in practice.

Another aspect of the findings in relation to the mixed reactions illuminated the gap that exists between professional expertise and experiential expertise (Mudge, Stretton and Kayes, 2014; Smith *et al.*, 2013b; Rothwell *et al.*, 1997; Toombs, 1993). That is, whilst physiotherapists considered their views and opinions within the context of activities done to and for the body, pwMS did not limit their responses to expressions about activities to the body but reflected a broader and more holistic view of exercise and physical activity. People with MS expounded the concept of exercise and physical activity within the context of their lives. This supports previous findings where health professionals by nature seek to prioritise health whereas the complexity of the lived experiences of the patient might prioritise other areas of life, such as family roles (Smith *et al.*, 2013b). These findings demonstrate that the experiential perspective of pwMS living in the community illuminated areas of oversight from professional perspectives.

### **9.5.3 Reflections on clinical practice**

At the start of the focus group discussions, participants had stated their positions about exercise and physical activity, in terms of their inherent attributes and the benefits associated with these activities. However, over the course of the discussions and through self-reflections in light of the results from the Delphi study, a series of changes were noted in the narratives. These changes pointed to the co-construction of views through negotiation and the reconstruction of opinions based on what physiotherapists think pwMS need. For example, physiotherapists reconstructed their views about exercise and physical activity to a much broader concept than that of physical fitness. This highlighted their willingness to adapt and change their previously held views about exercise and physical activity in order to meet the needs of pwMS albeit not always succeeding, which they admitted. Nevertheless evident within their discussions was a shift from the position of exercise to improve aspects of the body structure and function of the individual to thinking more about activity and at some level of participation.

Physiotherapists reflected on the results of the Delphi study and made judgements about existing clinical practice. They expressed that the results of the Delphi

validated some aspects of physiotherapy practice, such as, taking a multidisciplinary team (MDT) approach to the management of MS in the community. As mentioned in chapter 1, due to the multiplicity of symptoms and associated disability, collaboration is necessary and beneficial in providing a comprehensive approach to the management of MS (NICE, 2014; Khan *et al.*, 2011; De Souza, 1990) and MDT working is one way in which health professionals cope in managing the variability and progressive nature of MS (Smith *et al.*, 2013b; Carter *et al.*, 1998). This study (Study 3) also highlighted that in addition to collaborative working, the experiences of pwMS in relation to exercise and physical activity also pointed to the overlapping of roles, which extended beyond physiotherapy boundaries but was a necessary part of providing a holistic approach to community dwelling pwMS. Therefore signposting pwMS to the appropriate professional is an essential part of MDT working.

Similarly, physiotherapists expressed that the Delphi results highlighted the importance of goal setting. All physiotherapists within the study reported being involved in and valued the role of goal setting in managing MS in the community. Goal setting is one of the key pillars that underpin neurological physiotherapy practice (Playford *et al.*, 2000; Baker *et al.*, 2001; Ashford, 2005; Playford *et al.*, 2009; Levack *et al.*, 2006) and has been recommended for pwMS (NICE, 2014). Other studies have also identified the importance of goal setting that focuses on the needs of the individual (Mudge, Stretton and Kayes, 2014), as well as a tool to facilitate and enhance exercise and physical activity (Mulligan *et al.*, 2011; Motl *et al.*, 2011b). However, despite the widespread use of goal setting, physiotherapists in this study expressed that the Delphi results highlighted the need to focus more on patient related priorities. They felt that pwMS (Study 1) were using their individual priorities as the driving force or the motivation to engage in exercise and physical activity.

Another component of goal setting identified by physiotherapists in this study was the importance of not only setting goals with the individual but also involving family members and friends. Having these support systems was viewed as additional tools to motivate pwMS to improve physical activity levels. This finding is supported by the goal setting literature and emphasises the need of engaging in

collaborative goal setting which takes into consideration the expectations of patient, family, and rehabilitation team (EMSP, 2012; Wade, 2009).

Reflecting on the Delphi results, physiotherapists expressed concerns around the top 10 activities pwMS identified and prioritised. The major concern was whether or not these chosen activities provided the necessary intensity to lead towards physical fitness. Though a legitimate question, this was not the focus of the current study and further research is necessary to answer this question. However, what this study highlighted was that in the absence of a cure for MS, the emphasis over the years has been on managing the disease. Therefore, there is a need to move the evidence base a step further from managing MS to supporting people to live life well with MS.

Overall, these views about exercise and physical activity presented by physiotherapists highlighted the mismatch that might exist between their professional opinions and the views of pwMS living in the community. A probable source of this mismatch might be the different perspectives from which exercise and physical activity are viewed. As already discussed (see Chapter 7), the movements pwMS engaged in were not always related to physical fitness. Instead, the movements they engaged in encompassed a multifaceted complex way of how they live their lives by navigating their way using activities that are meaningful to them, as well as, the activities that provide an opportunity for the things and people they valued in life.

## **9.6 Strengths and Limitations**

This study was grounded in a qualitative approach, which utilised focus groups as the most appropriate data collection method to elicit views and opinions from the perspectives of physiotherapists in relation to exercise and physical activity. Focus groups provided complementary views of the Delphi study findings (Study 1). One of the benefits of using this method was its ability to unearth the hidden beliefs and or attitudes of physiotherapists in relation to exercise and physical activity. This was demonstrated by the tensions and debates as result of the revelation of

the exercise and physical activity practices of pwMS. Likewise, this demonstrated the added benefit of using focus groups to explore different views on a topic that has the potential to challenge personally held views and clarify opinions or lead to the adjustments previously held views (Goodman and Evans, 2010; Finch and Lewis, 2009).

Limitations relating to this study are acknowledged. The first is related to the small sample. There is little consensus among qualitative researchers about the number of participants required in focus groups (Goodman and Evans, 2010; Kitzinger and Barbour, 1999). However in this study, the number of participants though small was deemed adequate to gain in-depth insights about exercise and physical activity from the professionals' perspective. As mentioned in chapter 8, recruiting participants to the focus groups was challenging. However, despite the small size and experience levels, group interactions were good as observed by lively discussions and debates. Kitzinger and Barbour (1999) pointed out that group interaction might be affected by a hierarchical structure. However, this was not the case in the focus groups. Overall, there was an openness to share views and opinions whether or not they were popular with other participants in the focus groups.

It should be acknowledged that the researcher with a background in physiotherapy was involved in conducting the focus groups as well as data analysis processes, which might influence aspects of the study. Also physiotherapists were aware of the researcher's professional background and as such, might have adjusted their views accordingly. As mentioned in the methods chapter (see Chapter 8), to account for these influences on the part of the researcher a number of checks were employed.

Another limitation was centred on finding appropriate locations to conduct the focus groups due to financial restraints. As such, the location of choice was not suitable to all participants who had initial interest in the study, which might have excluded views from other physiotherapists working in the community. Furthermore, as the study was based on pwMS living in the community, the findings from study 3 were limited to physiotherapists working in the community,

from both the National Health Service and a MS Therapy Centre. Therefore with the small sample size these findings should be interpreted with caution.

## **9.7 Conclusion**

This chapter presented the findings from three focus groups conducted with physiotherapists working in the community with pwMS. A total of four major themes along with subthemes were developed across the focus groups.

Discussions pertaining to physiotherapists' understanding of exercise and physical activity were similar to those expressed by people with MS (Study 2). However, physiotherapists described exercise and physical activity as movement with a focus on the physiological attributes which resonated predominately within the body structure, function and activity domains of the ICF albeit with some reference to participation.

Comparing this study (Study 3) to the previous study (Study 2) the differences in perspectives regarding exercise and physical activity were highlighted. For people with MS living in the community their perspectives of exercise and physical activity were expressed through their lived experience. For health professionals their perspectives of exercise and physical activity were expressed through their theoretical knowledge based from undergraduate training and were influenced by experience of working with people with MS. Both perspectives are equal and valuable to understanding the complex nature of exercise and physical activity in people living with a progressive neurological condition

# **Chapter 10**

## **Main Discussion**

### **10.0 Introduction**

The studies in this thesis explored the exercise and physical activity practices, priorities and their meanings to pwMS living in the community. The information gained from the perspectives of pwMS (Study 1) was later presented to physiotherapists who worked in the community to elicit their views about the exercise and physical activity practices performed by pwMS. Overall, this thesis has demonstrated that pwMS are not necessarily inactive instead they are active doing other activities that are not overtly visible to the professionals' conceptualisation of exercise and physical activity; but nonetheless meaningful within the context of how pwMS live their lives with a progressive condition. This chapter draws together three studies in order to explore the interactions of the key findings from pwMS and physiotherapists. The chapter will conclude by considering the potential clinical applications of the findings as well as the strengths and limitations of this thesis.

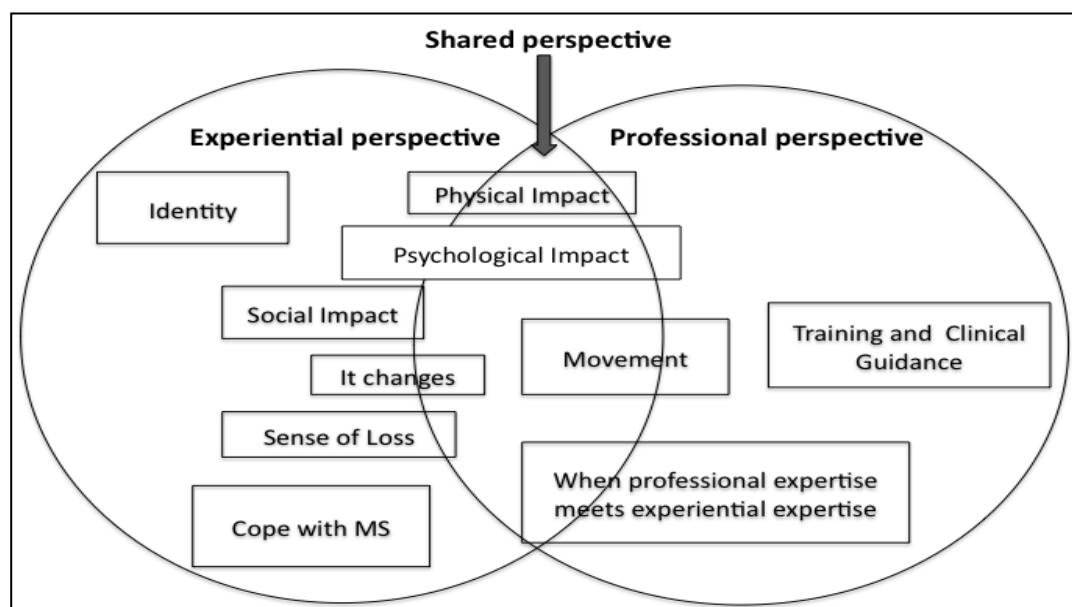
### **10.1 The meaning of exercise and physical activity: a matter of perspectives**

Exploration of the meanings of exercise and physical activity for community dwelling pwMS revealed key features that suggest that physical activity more so than exercise was about movement. This view was further expanded to highlight that exercise and physical activity were also more than movement; it was about using these activities as way to shape and preserve their sense of self, cope and live life with a progressive neurological condition.

Concepts derived from physiotherapists' reflection on the exercise and physical activity practices of pwMS highlighted that exercise more so than physical activity was about movement. Physiotherapists shared the view of pwMS that these

movements had a positive impact on the physical and the psychosocial aspects of life. However, whereas pwMS ascribed meaning to exercise and physical activity with a focus on living life to the fullest despite the progressive nature of the condition, physiotherapists' discussions were focussed on the impact of exercise and physical activity in managing MS with more of an emphasis on the physiological attributes of movement. When these findings were compared and drawn together it became apparent that the meaning of exercise and physical activity was a 'matter of perspectives'; whereby the experiential and professional perspectives had specific differences but also some common ground. These perspectives are conceptually illustrated in Figure 10.1. Aspects of the experiential and the professionals' perspectives have already been discussed in chapters 6 and 8 respectively. It is acknowledged that there were areas within the perspectives where they were no overlaps, for example, '*identity*' and '*cope with MS*', from the perspectives of pwMS, and '*training and clinical guidance*' from the perspectives of professionals. These dominant areas exist because of the two different perspectives from which meanings about exercise and physical activity are underpinned; because pwMS are not trained specifically in exercise and physical activity and physiotherapists are unable to fully understand the lived experience of how pwMS cope with MS. The focus of the next section will be on the shared perspective.

**Figure 10.1: The meaning of exercise and physical activity from the perspective of pwMS and physiotherapists**



### **10.1.1 Shared Perspective**

The concept of the shared perspective highlights areas of similarities between pwMS and physiotherapists about how they ascribe meaning to exercise and physical activity. These similarities were exemplified by descriptions of exercise and physical activity as movements that were diverse and included a wide range of structured and unstructured activities. In addition, views were shared with reference to the benefits of movement whether structured or unstructured on the physical, psychological and social aspects of life. For example, both physiotherapists and pwMS acknowledged the benefits of exercise and physical activity on improving mobility, flexibility, self-esteem, emotional wellbeing and enhancing participation in activities in the community. All these benefits are widely reported in the literature (van der Linden *et al.*, 2014; Learmonth *et al.*, 2013; Dlugonski *et al.*, 2012; Kasser, 2009; Dodd *et al.*, 2006).

The existence of a shared perspective highlighted multiple sources of acquiring information about exercise and physical activity. On one hand, the discussions pointed to the interaction between pwMS and physiotherapists, which focused on the exchange of information from either past and or present clinical interactions. This interaction noted between pwMS and physiotherapists was not surprising as pwMS are likely to be seen by a physiotherapist over the course of the disease (De Souza, 1990; NICE, 2014) and as a result, might accumulate knowledge about healthcare practices and its potential benefits to the lived experience. On the other hand, it was evident that there were other sources through which knowledge about exercise and physical activity were obtained including associations with other pwMS and voluntary organisations such as MS Therapy Centres (see Chapter 6) (Ploughman *et al.*, 2012; McLaughlin and Zeeberg, 1993). This suggests that information about exercise and physical activity is not only influenced through the clinical interactions but also by utilising other sources of information including the lived experience.

Interestingly, the findings from this thesis (Studies 1-3) highlighted that whilst pwMS and physiotherapists expressed similar views about the meaning of exercise

and physical activity, closer inspection of their discussions indicate subtle nuances suggesting that these views were not equally shared. For example, although both physiotherapists and pwMS mentioned the positive impacts of exercise and physical activity to the physical, psychological and social aspects of life, physiotherapists' narratives majored on the impact of exercise and physical activity on the physical and psychological self, whilst pwMS majored on the impact on the social aspects of living life. Therefore for pwMS, exercise and physical activity was more about participation within the home and community. Engaging in leisure activities such as shopping, theatre and coffee were viewed as meaningful, as such, they were more likely to engage in the activities that created opportunities and the possibilities for such engagement. This was in contrast to physiotherapists whose views were limited to the bio-psychological outcome of exercise and physical activity, for example physical fitness.

In addition, subtle nuances were noted in the discussions with pwMS and physiotherapists about the '*physical*' and '*psychological impact*' of exercise and physical activity. For example, whilst physiotherapists acknowledged the positive physical impact of exercise and physical activity to pwMS, they were more cautious in their reporting and spoke more confidently instead about the positive '*psychological impact*'. In contrast for pwMS there were no clear demarcation between the '*physical*' and '*psychological impact*' of exercise and physical activity as they felt that the benefits were intertwined and difficult to isolate. This subtle but apparent divergence in their discussions highlights that pwMS gauge how they think about symptoms associated with MS, and the impact of exercise and physical activity in symptom management, differently to physiotherapists.

Similarly, these subtle nuances within the shared perspectives were also seen in the concepts of '*sense of loss*' and '*it changes*' (Study 2). These themes were developed from the perspectives of pwMS and although not reported as themes from the study with physiotherapists (Study 3), the concepts of '*sense of loss*' and '*it changes*' were evident in physiotherapists' discussions albeit in a limited way. For example, physiotherapists acknowledged that pwMS, due to progressive nature of MS, experienced loss and changes within their physical body which as a consequence had an impact on their ability to engage in exercise and physical

activity. However, whilst physiotherapists' responses reflected these themes based on the impact on the body, pwMS' discussions extended beyond the body to include, loss of family, loss of employment and loss of independence.

A similar pattern was noted with the theme '*it changes*' (Study 2). For example, the responses of physiotherapists focused on the changes that might occur to the physical body as a result of MS. In contrast pwMS' discourse reflected the ever-changing nature of MS as a result of changes in their personal circumstances and priorities. These changes experienced by pwMS had the potential to either influence their exercise and physical activity practices or for some it created a sense of uncertainty and vulnerability about the future. Although these changes highlighted by pwMS have been identified in other studies (Ploughman et al., 2012; Kasser, 2009), this study demonstrated how these changes had a profound impact on the choice of activity (exercise and physical activity) as well as the motivating factors for engaging in certain types of activities in pwMS.

These subtle nuances illuminate a potential knowledge gap that exists between the experiential and professional perspectives in ascribing meaning to exercise and physical activity. It demonstrates that although physiotherapists were able to empathise with pwMS as well as understand some aspects of the experiential perspective they were not able to fully reflect on the lived experience of pwMS. This gap in knowledge between the experiential and the professional perspective is also highlighted by Kay Toombs about living with a chronic illness (Toombs, 1993) and is now also revealed in the area of exercise and physical activity. These nuances within the shared perspective exposed the inherent focus of physiotherapists to predominantly limit meanings ascribed to exercise and physical activity to the physical body. An outlook, which centres on managing the clinical features, associated with MS rather than an expansive view, which also includes managing and supporting life activities. These findings acknowledge the importance of using views from the experiential perspective to remind clinicians that management of symptoms is only one aspect of living life with MS.

The concept of the shared perspectives within this study offers some insight into the experiential and professionals' ways of thinking. This was observed and

interpreted as the existence of a two-way dynamic movement of views, where pwMS whose thinking shaped by their lived experience appeared to move towards the physiotherapists' ways of thinking and vice versa. This was exemplified through the use of a common language between the pwMS and physiotherapists. This dynamic movement of views point towards a place of mutual understanding within the context of exercise and physical activity that signifies a collaborative relationship between pwMS and physiotherapists. However, this place of mutual and collaborative understanding was unstable, as also present within the data were critical points where life circumstances (e.g. *coping, identity, priorities, preferences*) for pwMS and professional circumstances (e.g. *training and clinical guidance*) for physiotherapists created tensions that kept pulling both pwMS and physiotherapists back into what grounded their perspectives of exercise and physical activity. As a result, pwMS defaulted to their lived experience underpinned by the concept that exercise and physical activity was beyond movement and more about living life with MS. Similarly, physiotherapists defaulted to their professional experience directed by the concept that exercise and physical activity was about movement with an emphasis on the bio-psychological attributes of movement.

Finally, with respect to the joint collaboration between pwMS and physiotherapists, the shared perspective supports the need for joint collaborative working across different professional bodies involved with pwMS. This was evidenced by the prioritised exercise and physical activity practices and their meanings reported by pwMS, which in some cases went beyond the scope of physiotherapy practice. For example, working in partnership with occupational therapists, clinical psychologists and charity organisations to access and support the activities deemed meaningful to pwMS. This finding is supported by the recent NICE guidance for pwMS (NICE, 2014, EMSP, 2012) where MDT working is emphasised as being an important component of rehabilitation in pwMS (Playford *et al.*, 2000; Ashford, 2005). However whether or not current health service provisions mirror the joint and cross-collaborative working necessary to support the exercise and physical activity practices of community dwelling pwMS warrants further investigation as this was not the focus of this current study.

These insights added new knowledge to the existing evidence base about exercise and physical activity in pwMS and physiotherapists. Within the current evidence base it is thought that the views of health professionals and patients differ (Golla *et al.*, 2012; Rothwell *et al.*, 1997). Whilst this thesis supports this view, it also extends those findings to suggest that the differences are complex due to the different lenses through which the meanings are filtered. That is, pwMS drew on their lived experience which included some aspects of the professional knowledge whilst physiotherapists drew on their professional knowledge which influenced but was not fully expansive of the experiential perspective. Therefore understanding the subjective experiences of pwMS and grounding these in research evidence through collaborative working with health professionals is essential in sustaining and promoting exercise and physical activity in community dwelling pwMS.

## 10.2 Significance of the findings

The previous sections have presented and discussed the findings central to this thesis, which identified that the meanings ascribed to exercise and physical activity were contextualised to the perspectives of either the lived experience of pwMS or the professional experience of physiotherapists who work with pwMS. Both perspectives (experiential and professional) reflected different sources of evidence and raises questions about the relevance of both knowledge bases in its application to clinical practice.

As discussed in chapter 1, evidence-based practice remains one of the core standards of a wide range of health professional organisations including the Chartered Society of Physiotherapists (CSP) (CSP, 2012; College of Occupational Therapists (COT), 2015). However there is some debate about what constitutes evidence. The original definition of evidence-based practice states that it is the use of the best available evidence (e.g. patient views, research and clinical expertise) to inform decisions about the management of individuals (Sackett *et al.*, 1996). This view of evidence-based practice is endorsed by a panel of experts who published a consensus statement about evidence-based practice which points out the importance of utilising research evidence, clinical expertise and patient preferences (Dawes *et al.*, 2005). However, it is acknowledged that within the area

of research the nature of the evidence is graded based on a hierarchical grading system where systematic reviews and meta-analyses are considered the strongest forms of evidence (Gerrish and Lacey, 2010). In contrast, due to the descriptive and interpretative nature of the studies included in this thesis, which has a predominant focus on the views and opinions of pwMS and physiotherapists (Studies 1-3) a lower rank would be assigned based on the hierarchies of evidence.

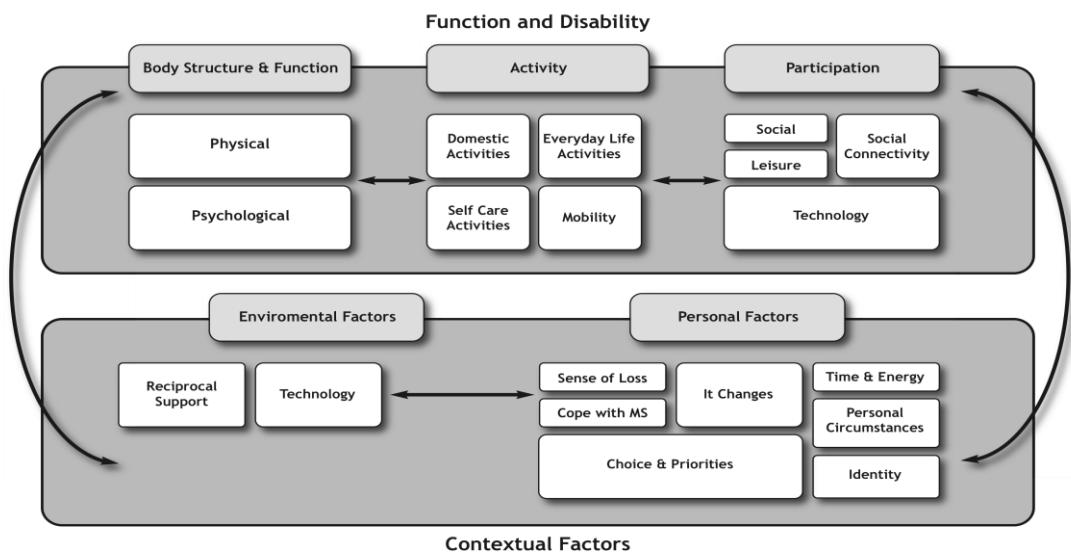
Nevertheless, the findings from this study highlight the importance of hearing the views of people who experience living with a long-term condition and health professionals who work with these individuals. Both sources (pwMS and physiotherapists) of evidence have contributed to the existing evidence base in relation to exercise and physical activity and have identified the knowledge gap as well as the overlap that exists between the experiential and the professional perspectives as highlighted in the previous section (see Chapters 7 and 9 and section 10.1.1). In addition, the findings highlight the importance of hearing the views of pwMS, which is relevant to inform or influence clinical practice and/or policy guidance on how to support pwMS living in the community. An extension of these findings from the physiotherapists' perspective (Study 3) indicates the need for more considerations of the experiential perspective on exercise and physical activity to inform research and clinical practice.

As mentioned in Chapter 1, the ICF framework (WHO, 2001), developed in collaboration with health professionals and lay people using principles underpinned by the bio-psychosocial model is widely used as a mean to assess and monitor the needs of pwMS. This framework is closely aligned to physiotherapy practice and is widely used in people with disabilities including pwMS (Karhula *et al.*, 2013; Hamed, Tariah and Hawamdeh, 2012; Coenen *et al.*, 2011; Khan and Pallant, 2007; Rimmer, 2006). It is well established as part of the rehabilitation process which allows clinicians, including physiotherapists, to think holistically about their patients (Shumway-Cook and Woollacott, 2007; Rimmer, 2006; Edwards, 2002). As highlighted in chapter 2, most of the existing interventions using exercise and physical activity in the management of MS were based on addressing problems identified at the body structure, function and activity levels with limited focus on other domains of the ICF. In addition, studies from the

patients' perspectives especially related to the meaning of exercise and physical activity are limited.

The ICF is used in this thesis as the theoretical framework to position the findings in relation to current physiotherapy practice. As such, the findings from the three studies were mapped onto the domains (WHO, 2001), in order to explore how the experiential and professional perspectives were represented and reflected within the ICF. Conceptually, the findings from the perspectives of pwMS (Studies 1 and 2) could be represented throughout all the domains of the ICF (see Figure 10.2).

**Figure 10.2 Representation of the experiential (pwMS) perspective in relation to the ICF**

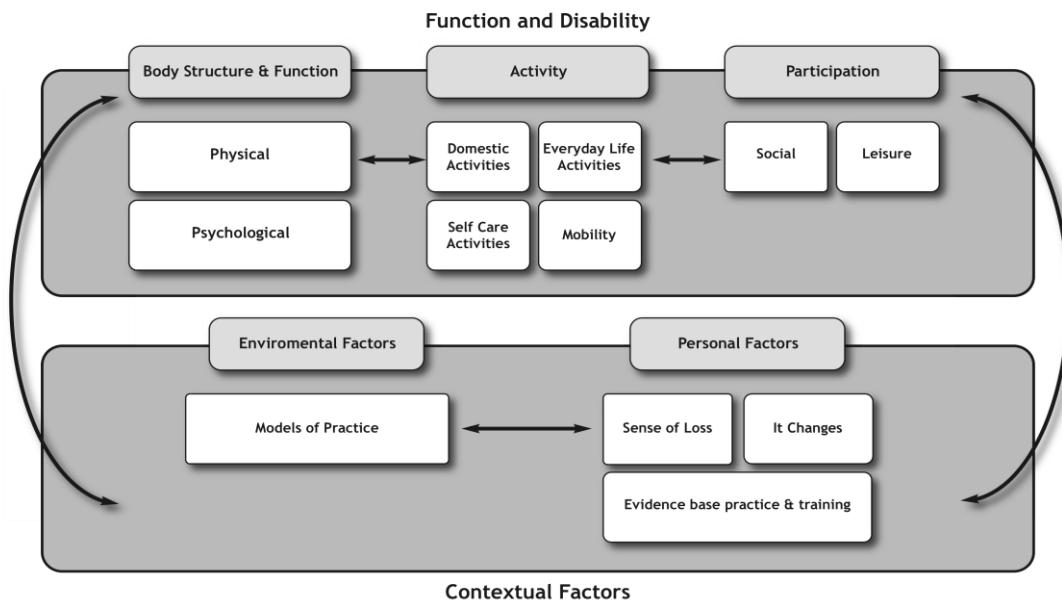


The diagram highlights that the exercise and physical activity practices and the meanings pwMS ascribed to exercise and physical activity fit within the ICF model across the domains of function and disability and contextual factors. This supports the applicability of the ICF to the lived experience of pwMS in relation to exercise and physical activity.

In addition, the findings from professionals' perspective were also mapped on to the ICF conceptually to ascertain how their views about exercise and physical activity fit within this model (Figure 10.3). The representation of the

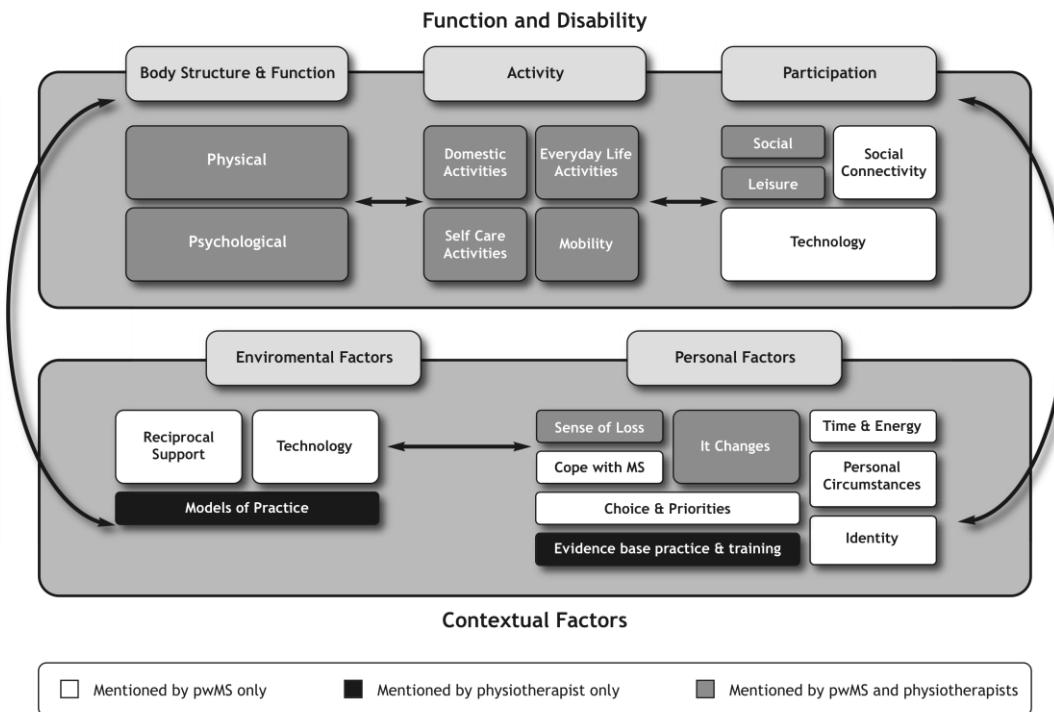
physiotherapists' perspective highlights less focus on the participation and contextual factors domains. In contrast, the representation of pwMS had more dominant representation in these domains.

**Figure 10.3 Representation of the professional (physiotherapists) perspective in relation to the ICF**



Both perspectives were then merged to compare and contrast the views of pwMS and physiotherapists within the context of this study (see Figure 10.4). It illustrates each domain and highlights that certain domains of the ICF had greater influence on how pwMS and physiotherapists ascribed meaning to exercise and physical activity. These influences will be discussed to highlight areas of overlaps and areas of dominance.

**Figure 10.4 Representation of the experiential and professional perspective in relation to the ICF.**



As mentioned in an earlier chapter (see Chapter 7), pwMS adopted a participatory mind set as highlighted by discussions around social connectivity. As such, they were more likely to engage in activities that connected with other people. This was in contrast to physiotherapists whose concerns revolved around whether or not the activities pwMS prioritised would have direct impact on their physical performance (see Chapter 9). These findings would suggest that for physiotherapists, higher weighting and priority was given to the body structure, function and activity domains rather than participation domains of the ICF in ascribing meaning to exercise and physical activity.

In contrast, the functioning and disability domains reflected a different weight of influence for pwMS compared to physiotherapists. For example, findings from Study 1 and Study 2 revealed that perceptions of pwMS about exercise and physical activity were dynamic and diverse and could be reflected across all the domains of the ICF. This was exemplified by the inclusion of certain categories such as transportation and activities involving technology, which were prioritised

by pwMS. The inclusion of technology was interesting and traversed the participation and environmental domains. For example, pwMS described technology as a form of activity to facilitate higher education; as well as the use of technology as a communicative device necessary for organising daily routines. These were not mentioned by physiotherapists in the study and signify the holistic nature of the views of pwMS in relation to exercise and physical activity. Also, interestingly the findings from Study 2 revealed that in ascribing meaning to exercise and physical activity pwMS were influenced pre-dominantly by the participation and contextual factors domains; more specifically the personal factors. In other words, the dynamic patterns noted in the study were strongly influenced by these contextual factors.

These contextual factors, which included the environmental and specifically the personal factors, shaped pwMS' perspectives (see Figure 10.4), for example, '*coping with MS*', '*identity*', '*energy demands and availability*', '*time constraints*', '*personal choice and priorities*'. Study 2 revealed that identifying these contextual factors might provide insights to promote and sustain physical activity levels in pwMS. These contextual factors influenced decisions about exercise and physical activity practices and their meanings, which in turn influenced decisions about the types of activities pwMS engaged in and the reasons for engagement. These findings concur with other researchers who have also identified that contextual factors play a significant role in influencing the other domains such as functioning and disability in pwMS as well as in people living with other forms of disability (Hamed, Tariah and Hawamdeh, 2012; Wee and Lysaght, 2009; Khan and Pallant, 2007; van der Ploeg *et al.*, 2004). Therefore understanding the influence contextual factors play in pwMS is important especially to health professionals who use exercise and physical activity as treatment strategies. Lack of understanding and insight into these contextual issues render pwMS seemingly inactive to the professionals' view whereas the studies (Studies 1 and 2) in this thesis portray a different picture where pwMS are active on other priorities in other contexts.

Physiotherapists' responses did not fit neatly into the ICF framework. As mentioned in the previous section, physiotherapists' shared aspects of the themes '*sense of loss*' and '*it changes*' which represents the personal factors of pwMS. This

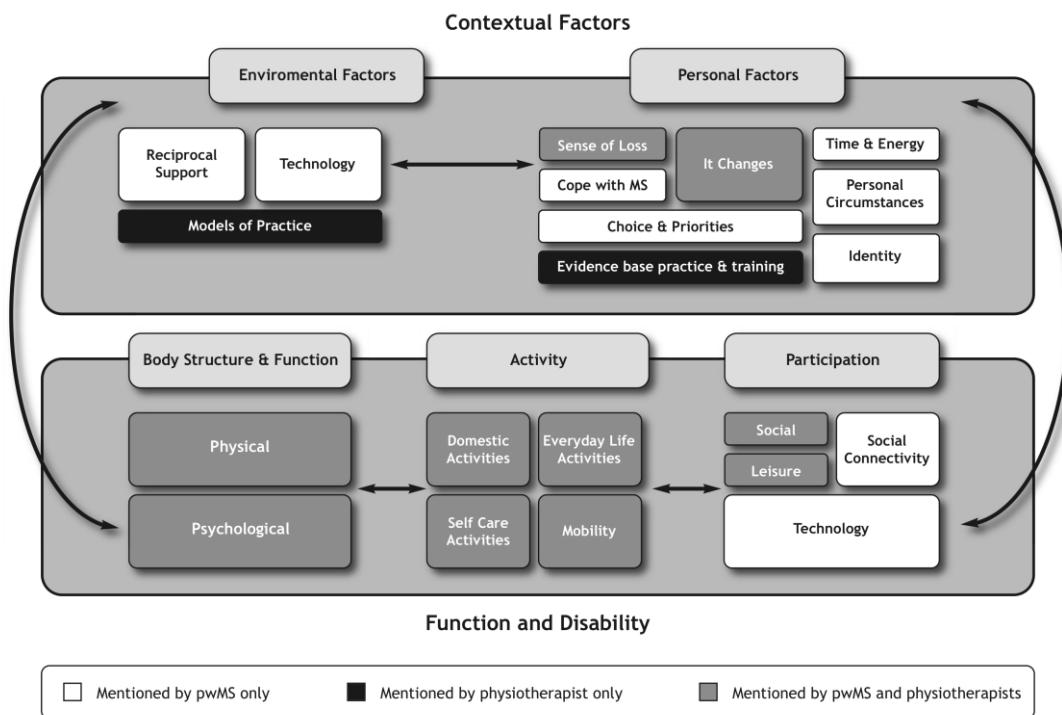
finding suggests that physiotherapists do consider some aspects of the personal factors identified by pwMS. However, physiotherapists did not make the link as to how these personal factors might influence engagement in exercise and physical activity beyond the physical aspects of the individuals' life. In addition, the findings from the physiotherapists' perspectives highlight that their views about exercise and physical activity were also shaped by their own contextual factors, which were external to pwMS but influenced decisions around their management in the community. These factors included their professional knowledge based on evidence-based practice and training (personal factors) as well as models of practice, which could be represented under environmental factors.

Interestingly, the findings from the perspective of pwMS demonstrated that the exercise and physical activity practices as well as their meanings to pwMS were heavily influenced through participation and the personal factor domains. In fact, the results from the perspectives of pwMS not only provided insight into the importance of these ICF domains to pwMS but also how the experiential perspective challenged the traditional orientation of the ICF framework.

The contextual factors, in particular, the personal factors were the major drivers directing decisions around exercise and physical activity practices and the meanings pwMS ascribed to exercise and physical activity. It was these personal factors that determined whether or not pwMS engaged in exercise and physical activity. For example, the personal factor domain revealed aspects of their identity, preferences, priorities, and how they cope and live with the progressive nature of MS. Current interpretation of the ICF implies that the contextual factors interact with the functional and disability domains (WHO, 2001). Whilst this is true, this study extended this view to also suggest that for community dwelling pwMS, the contextual factors did not only influence the functional and disability domains but dictated what happened at the functional and disability domains. Having considered the views put forward by pwMS, the importance of how these views were expressed and the heavier weight attributed by the contextual factors, the researcher was forced to reconsider the orientation of the ICF by one hundred and eighty degrees. This flip suggests that the contextual factors played a more major

role than previously thought in relation to the exercise and physical activity practices and the meanings pwMS ascribed to these practices (see Figure 10.5).

**Figure 10.5 Reorientation of the ICF based on the experiential and professionals perspective of exercise and physical activity**



Having an awareness of the interactions between the contextual factors and the function and disability domains is necessary to build a greater understanding in the area of exercise and physical activity in community dwelling pwMS. As such, physiotherapists and other exercise professionals working in the community should give more focused attention to these domains when designing and implementing rehabilitation strategies or programs for pwMS living in the community as a way to engage and sustain exercise and physical activity in this population.

In summary, the conceptual model based on the findings from the three studies could be represented within the ICF. The model illustrates the interaction of the ICF domains in relation to the meanings ascribed to exercise and physical activity based on the perspectives of pwMS and physiotherapists. It highlights that whilst

pwMS were predominately influenced by participation and personal factors, physiotherapists were predominately influenced by the function and disability domains albeit with less reference to participation. In addition to the other findings presented and interpreted in the previous sections, this thesis also adds to the existing evidence in relation to exercise and physical activity and provides evidence that the perception of exercise and physical activity in pwMS is not static and limited to any one domain within the ICF model. Instead it highlights a complex concept, which is dynamic in nature, traversing between functioning and disability and contextual factors (personal and environmental) with personal factors having a greater influence on decisions made about exercise and physical activity in pwMS.

### **10.2.1 Clinical implications of the findings**

The findings from all three phases have implications for clinical practice some of which have already been highlighted in the previous sections. This study included two sources of information, one extracted from the experiential perspective and the other from the professionals' perspective. Exploring both sources of information suggests a 'rethink' about how exercise and physical activity are viewed by health professionals and points towards taking a more holistic approach in order to reflect the preferences and priorities of community dwelling pwMS.

The key findings from the experiential perspective have not only identified the exercise and physical activity preferences and priorities of pwMS but also what these activities mean to pwMS. Having an understanding of these activities and their meanings provides some insight into the way health professionals specifically physiotherapists might approach exercise and physical activity in pwMS living in the community. For example, pwMS preferred engaging in exercise and physical activity practices that they valued and considered meaningful for living life with MS. This suggests that exercise and physical activity for community dwelling pwMS was more than managing MS symptoms and also about the importance of participating in life activities, how they coped with life and maintained a sense of self. This finding challenges the state of the current evidence as highlighted in

Chapter 2 (see systematic reviews and meta-analyses) in relation to exercise and physical activity which has a prominent focus on utilising interventions that manage symptoms predominantly at an impairment and activity level (Rietberg *et al.*, 2004; Motl and Gosney, 2008; Andreasen, Stenager and Dalgas, 2011; Ensari, Motl and Pilutti, 2014). It is argued here that whilst those studies have helped shaped our understanding that exercise is beneficial and safe in pwMS, it is now time to extend those boundaries, as interventions with such focus are limited in scope to fully address exercise and physical activity preferences of community dwelling pwMS. Therefore there is a need for physiotherapists to expand the existing boundaries of current interventions beyond impairment and activity to also permeate the participation domains of the ICF. This will involve creating opportunities to design interventions reflecting this participatory aspect of exercise and physical activity and develop tools to monitor such interventions with a participatory focus.

In addition, aspects of the findings highlight that the activities pwMS prioritise unearth insights into their sedentary behaviours. Sedentary behaviour is defined as “*any waking behaviour characterised by an energy expenditure ≤ 1.5 Metabolic Equivalent of Task (MET) while in a sitting or reclining posture*” (Sedentary Behaviour Research Network, 2012). It is thought that pwMS are sedentary (Sandroff *et al.*, 2012) and spend approximately 8 hours per day in sedentary behaviours (Cavanaugh *et al.*, 2011); a timeframe that is thought to be comparable to that of the general population (Hubbard *et al.*, 2015). The findings from studies 1 and 2 highlight the variability in sedentary behaviours of pwMS over a typical day. This is an important finding as there is evidence to suggest that increased time spent in sedentary behaviours might be associated with an increased risk of cardiovascular disease and diabetes (Motl *et al.*, 2011a; Marrie *et al.*, 2008). Therefore physiotherapists should consider when prescribing exercise and physical activity programmes not only the types of activities but also the position activities are completed in and the energy expended during specific activities as these might be another route to improve physical activity in pwMS. However this warrants further investigations to substantiate this claim.

Another interesting finding relates to external barriers of exercise and physical activity within the context of the current health system which may have played a role in restricting the promotion of exercise and physical activity in pwMS. As mentioned in chapter 2 a number of studies have identified barriers to exercise and physical activity such as factors related to the individual and their environment (e.g. fatigue, access) (Kayes *et al.*, 2011b; Plow, Resnik and Allen, 2009; Borkoles *et al.*, 2008; Dodd *et al.*, 2006). In addition, external factors such as lack of knowledge of professionals have also been described as a barrier (Learmonth *et al.*, 2013; Kayes *et al.*, 2011a; Borkoles *et al.*, 2008). However this thesis extends this further to suggest that health professionals' understanding of exercise and physical activity may have also been a barrier to exercise and physical activity. This would implicate not only health professionals but is also inclusive of the existing health system with respect to limited resources for service provision. Within physiotherapists' discussions (Study 3) there was this sense that they were being constrained by service demands and expectations, which had an impact on what they would realistically offer pwMS. This suggests that in order to promote exercise and physical activity in pwMS service provision within the community needed to consider the experiential perspective in order to adequately reflect the needs of pwMS and deliver a truly person-centred approach to care.

### **Exercise and physical activity- a person-centred approach**

The concept of a person-centred approach has been around for decades yet it remains a newly developed and evolving concept within rehabilitation (Leplege *et al.*, 2007). Person-centred approach is currently considered to be "*an approach to practice that is established through the formation and fostering of therapeutic relationships between all care providers, patients and others significant to them in their lives*" (McCormack *et al.*, 2010; p.13). Person-centred approach acknowledges the uniqueness of individuals (Redman, 2004), recognises the value about what is important (McCormack and McCance, 2006), respects the autonomy and seeks to respond to the preferences of individuals (Coulter, 2002).

Person-centredness is at the heart of current health service policies and guidance within the United Kingdom (NICE, 2014; The Health Foundation, 2014; DOH, 2005). This drive towards person-centeredness aims to provide the opportunity within clinical practice to rebalance the inequalities and power dynamics that exist between health professionals and individuals (McCance, McCormack and Dewing, 2011). That is, moves from the existing medical model with a central focus on the disease, to that of a more holistic approach where the '*person*' is at the centre of care. However, McCance and colleagues (2011) assert that whilst this outcome is desired, one of the challenges remain translating the concept of person-centredness into clinical practice.

Findings from this thesis contribute to some aspects of the underlying concept of person-centred approach and might provide some insight into translating person-centredness into clinical practice. As discussed in chapter 1 and section 10.2, the ICF was used as the theoretical framework to underpin this thesis and is widely used in physiotherapy practice. The concept of person-centredness and that of the ICF are intertwined by their underlying principles of taking a holistic approach, in-keeping with a focus away from the disease process and to one that embodies the physical, psychosocial and contextual aspects of the individual (Leplege *et al.*, 2007; WHO, 2001).

This thesis took a 'bottom up' approach to explore the priorities and meanings of exercise and physical activity from the perspectives of pwMS living in the community and to examine the clinical implications of these from the physiotherapists' perspective. In doing so, the findings highlight that whilst physiotherapists already utilise some exercise and physical activities prioritised by pwMS in the management of MS they (physiotherapists) acknowledged that certain activities were not focused on in clinical practice (Study 3). Examples of these include, *activities done because of role in the family, transportation and technology*. This key finding points to the importance of taking a person-centred approach to exercise and physical activity by acquiring knowledge about the exercise and physical activity practices that matters from the perspectives of pwMS who have experience of living with a progressive neurological condition. By inherently focusing on what matters to an individual might be one way of engaging

and sustaining exercise and physical activity in pwMS. However, future research would be warranted to explore this further.

Furthermore, whilst pwMS acknowledged the importance of the physical and psychosocial aspects of life, it was indeed the contextual factors, specifically the personal factors that dictated their exercise and physical activity practices and the reasons why they engaged in exercise and physical activity (Studies 1 and 2). The personal factors domain within the ICF is not fully developed and as a result the impact of these personal factors might be overlooked. Based on the findings from the experiences of pwMS, it was the personal factors that were the overriding factors that led to decisions about whether or not activities were considered or prioritised. Therefore, by addressing these personal factors, which include the preferences and priorities of pwMS, will help health professionals consider, respond to and deliver person-centred care.

The researcher acknowledges that the premise of the findings from this thesis is built on the foundations of using a group-based consensus building approach (Delphi Method-Study 1). This approach theoretically does not neatly position itself within the concept of person-centredness, as person-centredness is individualistically driven (The Health Foundation, 2014; Redman, 2004; Coulter, 2002). However, through expansion of the findings using an individualistic approach (Interviews- Study 2) further insights were gained into the meanings ascribed to exercise and physical activity. Based on combining the findings from both studies (Studies 1 and 2), it is argued here that the exercise and physical activity practices prioritised by pwMS and the reasons why they engaged in exercise and physical activity provide the foundations necessary to initiate discussions about exercise and physical activity at an individual level.

One of the core guiding principles of person-centred care is considering the individual preferences (The Health Foundation, 2014; Redman, 2004; Coulter, 2002). In this thesis, pwMS expressed their preferences and their priorities about their exercise and physical activity practices and the meanings they ascribe to exercise and physical activity. Their views and opinions about exercise and physical activity included and extended beyond the health related benefits of

exercise and physical activity to living life. Without knowledge and understanding about the values and or the meanings of exercise and physical activity to the lived experience of pwMS, delivering person-centred care would be a challenge.

### **Exercise and physical activity – the collaborative relationship**

Another aspect of these findings indicates the importance of understanding the different points of view that exist between pwMS and health professionals in relation to the meaning of exercise and physical activity. It illuminates the collaborative relationship between pwMS and therapists and the impact this relationship might have on enriching the therapeutic experiences of pwMS. In the past rehabilitation was viewed as an act done to someone, where patients were seen as passive recipients in the rehabilitation process (Nicholls and Holmes, 2012). Current therapeutic and rehabilitation models point towards a client centred approach, where patients are considered as active participants in aspects of their care (NICE, 2014; The Health Foundation, 2014; DOH, 2005; Leplege *et al.*, 2007). This active participation involves therapists and pwMS co-constructing meaning at different points within the clinical encounter (e.g. during goal setting) (EMSP, 2012).

Aspects of co-constructing meaning through the collaborative relationship between pwMS and physiotherapists were observed throughout this thesis especially within the shared perspective. The shared perspective revealed the coexistence of shared knowledge, shared meanings and understanding within the context of exercise and physical activity. As highlighted in the previous section, common views were shared but with subtle differences. This shared collaborative relationship highlighted two main insights. Firstly, that shared views did not necessarily mean that both parties ascribed meanings in the same way. For example, understanding that self –selected exercise and physical activity might not be health and fitness driven but more socially and context driven. Therefore being aware of and understanding these drivers will help the collaborative relationship between health professionals and pwMS in the community. It highlights the need for health professionals to actively listen to the views of pwMS at all stages

(assessment, intervention, goal planning and reassessment) of the therapeutic process which is integral to addressing exercise and physical activity in line with the preferences and priorities of pwMS. This listening skill is crucial to collect the relevant information necessary to inform the decision making process between health professionals and patients (Edwards and Richardson, 2008).

For the shared collaborative relationship to be effective it is important that pwMS feel able to be open and transparent within the clinical encounter about their exercise and physical activity preferences. Similarly, there is a need for physiotherapists to support pwMS' preferred activities without judgements. Openness and transparency between pwMS and physiotherapists is necessary to enrich the collaborative relationship and has the added advantage of making negotiations easier to manage which ultimately affect the decision making process within the clinical encounter.

Throughout the data collection phase (Study 2 and Study 3), the Delphi cue cards with the top 10 exercise and physical activity practices and the reasons why pwMS engaged in exercise and physical activity were used as a tool to facilitate discussions around exercise and physical activity. This opened up the avenue to initiate conversations about preferences, priorities, intentions and expectations of pwMS. This was an interesting observation, which suited the research process but could also be used within the clinical encounter to initiate conversations with pwMS especially those who find it difficult to articulate their goals. Therefore it could be seen as a way to support and optimise therapeutic approaches to managing pwMS living in the community. However, further research would be necessary to explore this suggestion further.

At the heart of this thesis is unpacking the meaning of exercise and physical activity from the perspectives of community dwelling pwMS. It highlights areas of misunderstandings between health professionals and pwMS in part due to a dearth of research evidence from the perspective of pwMS necessary to guide clinicians. This thesis demonstrates that pwMS view exercise and physical activity as a way of living life with MS which is not necessarily always about health and fitness. Therefore understanding where health professionals' skills can be used to

influence changes, and support pwMS to live life with MS is paramount in moving forward in promoting exercise and physical activity in pwMS. This thesis suggests that through collaboration with pwMS, physiotherapists can begin to understand their role in supporting pwMS living in the community. But this requires further shifts in how physiotherapists view exercise and physical activity. That is, a willingness by physiotherapists to adjust their perspective about exercise and physical activity which might differ from the perspective of community dwelling pwMS. Physiotherapists are well placed to be creative, utilise their skills to help pwMS build their confidence and support them to access the activities they deem meaningful to living life with MS.

### **10.3 Strengths and limitations**

The strengths and limitations have been considered individually for each study (see Chapters 5, 7, 9). This section considers the strengths and limitations for the thesis as a whole.

MS is a complex, variable and progressive condition. In order to understand the priorities and meanings pwMS ascribed to exercise and physical activity a mixed methods approach was used. The strength of this approach lies in its flexibility to allow this topic to be explored from different perspectives as well as to facilitate a richer, in-depth understanding that would otherwise be limited through the use of only one method (Creswell *et al.*, 2011; Tashakkori and Teddlie, 2010). Three studies were used to address the research questions, two of which were complementary (Study 2 and Study 3) to the primary study (Study 1) but collectively brought deeper knowledge and understanding to exercise and physical activity from the perspective of community dwelling pwMS and physiotherapists.

One key limitation is that study participants were community dwelling pwMS as such the findings do not extend to pwMS who are in cared for facilities such as, hospitals or nursing homes. Nevertheless they (pwMS) have consistently contextualised exercise and physical activity to their lived experience. That is, how they live life with MS in the community.

## **10.4 Conclusion**

This chapter presented a triad perspective for the priorities and meanings of exercise and physical activity in pwMS and physiotherapists. A conceptual model underpinned by the findings of this thesis illustrated the diverse perspectives of the meaning of exercise and physical activity. The chapter demonstrated the commonalities that exist within the shared perspective, which were underpinned by shared knowledge and understanding the meanings associated with exercise and physical activity. Areas of dominance were also highlighted whereby the meaning of exercise and physical activity was underpinned by experiential and professional knowledge. These areas of dominance were shaped by either the experience of living with a progressive disease or by managing people with a progressive illness.

The thesis highlights that despite having the same discussions centred on exercise and physical activity the interpretations by pwMS and physiotherapists were mixed. The study revealed common views, however, there were distinct differences in their perceptions about the meanings of exercise and physical activity. The shared components could be as a result of the therapeutic encounter between physiotherapists and pwMS. However, their differences reflected the worlds in which they lived. Physiotherapists working with pwMS should be aware of these similarities as well as differences and use these as a way to access, support and promote exercise and physical activity in pwMS.

The conceptual model was further expanded to illustrate how these findings fit within the theoretical framework of the ICF. It highlights areas of overlap and areas of influence that had a substantial impact on different domains of the ICF. These influencing factors, specifically the personal factors in pwMS can have a significant impact on the ability to engage in exercise and physical activity. Therefore, in order to deliver a patient centred approach, physiotherapists should identify the contextual factors and utilise these to engage with pwMS as this might provide an avenue to maintain and sustain exercise and physical activity in pwMS.

# **Chapter 11**

## **Conclusions and Recommendations**

### **11.0 Introduction**

This chapter concludes the study exploring the meaning of exercise and physical activity for pwMS. The main findings from the three studies of the research will be summarised. A section highlighting the key recommendations for clinical practice and directions for further research in the area of exercise and physical activity will be presented.

### **11.1 Overview of the Research**

Exercise and physical activity has been found to be beneficial to pwMS yet despite the known benefits pwMS are inactive (Sandroff *et al.*, 2012; Motl, McAuley and Snook, 2005). This thesis argued that attempts to address inactivity have done so using predominately professionally driven (top down) approaches, utilising predominately one form of inquiry (quantitative studies) with a focus on structured forms of activity which reflects primarily one component of physical activity; that is exercise. Also, despite the existence of numerous studies in relation to exercise and physical activity, only a few have explored the meanings of these activities using a bottom up approach; that is from the perspectives of pwMS who live in the community. The existing evidence centred around this area is sparse and has several limitations associated with the demographic profile of participants, such as, gender bias (Dlugonski, Joyce and Motl, 2012), those mildly or moderately affected by MS (Learmonth *et al.*, 2013; Dlugonski, Joyce and Motl, 2012; Kasser, 2009; Borkoles *et al.*, 2008) and studies conducted usually within the context of exploring meanings based on participation following exercise interventions (Van Der Linden *et al.*, 2014; Learmonth *et al.*, 2013; Kasser, 2009).

This thesis has addressed those gaps and added to the existing body of knowledge by highlighting the views and opinions of community dwelling pwMS irrespective of levels of disability (mild, moderate, severe) about the meanings they ascribed to exercise and physical activity and the reasons why they undertook these activities.

These new insights from the perspectives of pwMS have added to current understanding of exercise and physical activity and have clinical relevance to health professionals who use exercise and physical activity interventions when working with pwMS.

The uniqueness of this thesis was exemplified by the sample used to elicit views and opinions about exercise and physical activity. For example, views were collected from pwMS across widespread regions of England, with a wide range of disabilities determined by the Barthel Index (1-20) and self reported that MS had an impact on their ability to engage in exercise and physical activity (mild, moderate and severe). These widespread views are valuable as they created the opportunity to hear the opinions of pwMS about exercise and physical activity, especially those severely affected by the disease as they are rarely represented in research (quantitative, qualitative and mixed methods). Similarly, the sample used in Study 3 included physiotherapists who work within the National Health Service (NHS) and charity based service (MS Therapy Centre). To the researcher's knowledge, physiotherapists who work within charity-based organisations are rarely accessed for research purposes.

## **11.2 Findings overall**

Collectively the findings illuminate the concept of exercise and physical activity from the perspective of pwMS and physiotherapists. They offer a glimpse into the realities that exists in pwMS and physiotherapists, as well as how these might conflict and but also co-exist. As highlighted in the literature review addressing inactivity using exercise and physical activity is complex and current understanding about these concepts from the perspective of pwMS are limited.

This thesis has provided insights and identified the importance of exercise and physical activity in helping pwMS achieve the outcome of living life with MS. That is, insights into the wide range of exercise and physical activities practiced by pwMS and the reasons why some activities took priority over others. The evidence presented from the perspectives of pwMS revealed that the priorities and meanings they ascribed to exercise and physical activity were porous and did not appear to be confined to textbook descriptions of exercise and physical activity.

Participants' (pwMS) descriptions reflected permeable borders that stretched beyond the professionals' interpretations, which were limited to movement, to living life with MS. For example, exercise and physical activity are often expressed within the literature as activities used to manage the symptoms of MS (Petajan and White, 1999). Physiotherapists (Study 3) in this thesis also supported this view. However, for pwMS, exercise and physical activity extended beyond managing symptoms. It was about living life to the full irrespective of physical restrictions. Acknowledging their restrictions they focused on participation in its widest sense through a variety of activities.

All three studies (Studies 1-3) provided some insight into the intricacies associated with exercise and physical activity illuminating a triad (three) perspective. That is, two dominant perspectives, one grounded by the experiences of living with MS and the other by the experiences of therapeutic work with pwMS in the community. These dominant perspectives shaped the views and opinions of pwMS and physiotherapists about how exercise and physical activity was conceptualised. The existence of a shared perspective between pwMS and physiotherapists provided the third perspective which was exemplified by shared meaning, shared understanding and shared knowledge about exercise and physical activity. What was interesting to note within the shared perspective was the commonality in the views expressed by pwMS and physiotherapists. However, these views were not equally shared because of the differences which grounded each perspective. Understanding the shared and the differences in perspectives is relevant for establishing the foundations necessary for a person-centred approach to the management of pwMS in the community.

It is recognised that physiotherapists have a sphere of influence in the management of MS because of their knowledge and expertise in exercise and physical activity (CSP, 2011; WCPT, 2014). However, evident in the thesis was that physiotherapists understood only a glimpse of the life of pwMS. During the clinical encounter, pwMS '*pick and choose*' what they wanted from their interaction with physiotherapists and incorporated their choice into their daily life. In other words, pwMS constantly refine, remould and rebuild activities in their life for the purpose of helping them live life in the community.

The clinical applications of the findings from all the studies provided additional insights, understandings and ideas that might inform the management of pwMS in the community. For example, the studies in this thesis have uncovered nuanced understanding of the construct of exercise and physical activity that may help practitioners see beyond their professional assumptions about the meanings of exercise and physical activity. Reflections on the findings using the ICF framework expanded this and further highlighted that pwMS took a holistic approach to exercise and physical activity. Whilst professionals refer to this holistic approach theoretically, their concept of exercise and physical activity remained limited in scope with a focus on the physical body (structure and function) and activity domains of the ICF. This was in contrast to pwMS, whose discussions reflected that the meaning of exercise and physical activity included but were not limited to these domains of the ICF, but instead reflected all the domains with a greater emphasis on participation and the personal factors. These personal factors were the driving force behind the prioritised activities and determined whether or not activities were either sustained or enhanced.

### **11.3 Recommendations and future research**

Due to the nature of the methods used in this study, the findings cannot be generalised beyond the sample used in this study. The aim of this thesis was to bring greater understanding to the meaning of exercise and physical activity from the perspectives of pwMS and to ascertain whether or not these meanings reflect physiotherapists' conceptions of exercise and physical activity. As such, interpretation of the findings and judgements rests upon the reader who is able to reflect on the findings and ascertain whether or not they fit within their context. Nevertheless, despite the methodological approach the researcher has a responsibility to demonstrate how these findings might inform people who work with pwMS, which include volunteer organisations and clinicians.

#### **Recommendations for health professionals**

- Health professionals working specifically with pwMS should be aware of the diverse descriptors used for exercise and physical activity and seek

ways to discover how individuals with MS view exercise and physical activity.

- Health professionals working specifically with pwMS should be aware that the meanings of exercise and physical activity might change to reflect changes in the physical, psychological and social aspects of the lives of pwMS. This finding supports the need, as advised by the NICE guidance (NICE, 2014), for having established reviews for pwMS living in the community.
- Educators working in Higher Education with a responsibility for training health professionals especially physiotherapists should as part of the curriculum create opportunities whereby students can develop broader skills that reflect prescribing both structured and unstructured activities for people living with long term conditions.

### **Recommendations for Rehabilitation**

- Rehabilitation programmes should wherever possible utilise a wide variety of structured (exercise) and unstructured (physical activity) activities to engage and support pwMS living in the community. Considerations should be made for more activities that involve participation in the community, for example, leisure type activities and seek opportunities to facilitate and support pwMS in completing these activities.
- Physiotherapists should be aware that the reasons why pwMS living in the community engage in exercise and physical activity goes beyond the physical self and includes the psychosocial aspects of their lives. Therefore, physiotherapists should consider the use of the ICF framework as a tool to aid discussions, especially with respect to the contextual factors that might influence either positively or negatively engagement in exercise and physical activity. Taking this approach will help deliver a more focused patient-centred approach to rehabilitation.
- Physiotherapists should be aware of and acknowledge their own preconceptions about the meaning of exercise and physical activity underpinned by their professional knowledge and be mindful that these assumptions might differ in pwMS living in the community. As such,

physiotherapists should be flexible to adopt models, such as, the ICF that reflect both the objective and subjective experiences of pwMS. In addition physiotherapists should develop a more collaborative relationship with pwMS in order to understand their subjective experiences of exercise and physical activity.

- Physiotherapists should note that pwMS do not only engage in exercise and physical activity to manage MS symptoms, but also as a way to connect with others as well as cope with living life with MS.

### **Recommendations for future research**

- Future research should explore whether or not the activities community dwelling pwMS identified and prioritised as part of their daily routine improve physical activity levels and contribute to physical fitness. In other words, to ascertain whether or not these accumulated routine activities performed over a period of a day, week or months might contribute to physical fitness.
- Researchers should consider further development of the exercise and physical activity guidelines by incorporating a broader range of activities.
- Further qualitative research is needed to explore physiotherapists' views about exercise and physical activity in pwMS to unearth specific attitudes whilst working with this population. This would allow comparison of the findings with physiotherapists who participated in this study.
- Further research should ascertain whether or not current health services enhance or restrict collaborative partnership between pwMS and other health professionals, in accessing and sustaining exercise and physical activity practices in pwMS living in the community.

Finally, this thesis demonstrated the wealth of information gleaned from exploring exercise and physical activity from the perspectives of pwMS and physiotherapists. It highlighted some of the challenges that exist in working with pwMS; some of which have been borne out of limited understanding about the meanings ascribed to exercise and physical activity from the experiences of pwMS living in the

community. As further research uncovers more insights from the lived experiences of pwMS the gaps that exist between pwMS and physiotherapists might be narrowed. This will continue the shift from the inherent focus on symptom management to reflect also how pwMS can be supported to live life well with MS in the community. Health professionals have the capacity to build confidence and support pwMS to access activities that are meaningful to living life with MS.

## References

- Adler, M. and Ziglio, E. (1996) '*Gazing into the Oracle: The Delphi Method and its application to Social Policy and Public Health*', United Kingdom: Jessica Kingsley Publishers Ltd.
- Alderson, P. (2004) 'Ethics ', in Fraser, S., Lewis, V., Ding, S., Kellett, M. and Robinson, C. (eds.) *Doing Research with Children and Young People*. London: SAGE.
- Alonso, A., Jick, S.S., Olek, M.J. and Hernán, M.A. (2007) 'Incidence of multiple sclerosis in the United Kingdom: Findings from a population-based cohort', *Journal of neurology*, 254(12), pp. 1736-1741.
- American College of Sports Medicine (2010) *ACSM's resources for clinical exercise physiology: musculoskeletal, neuromuscular, neoplastic immunologic and hematologic conditions*. 2nd edn. Baltimore: Wolters Kluwer.
- Andreasen, A.K., Stenager, E. and Dalgas, U. (2011) 'The effect of exercise therapy on fatigue in multiple sclerosis', *Multiple Sclerosis*, 17(9), pp. 1041-1054.
- Anthony, W., and Gidugu, V. (2012) 'Systematic Review of the Effects of Exercise and Physical Activity on Psychological and Quality of Life Outcomes for Individuals with Multiple Sclerosis, 1996-2011', Boston University, Sargent College, Center for Psychiatric Rehabilitation.  
<http://www.bu.edu/drrk/research-syntheses/multiple-sclerosis/effects-of-exercise/>
- Arthur, S. and Nazroo, J. (2009) 'Designing Fieldwork Strategies and Materials', in Ritchie, J. and Lewis, J. (eds.) *Qualitative Research Practice: A Guide for Social Science Students and Researchers*. London: SAGE, pp. 109-137.
- Asano, M., Duquette, P., Andersen, R., Lapierre, Y. and Mayo, N.E. (2013) 'Exercise barriers and preferences among women and men with multiple sclerosis', *Disability & Rehabilitation*, 35(5), pp. 353-361.

Ashburn, A. and De Souza, L.H. (1988) 'An approach to the management of multiple sclerosis', *Physiotherapy Practice*, 4(3), pp. 139-145.

Ashford, S (2005) 'Client Health Education and Empowerment through Physiotherapy in Neurorehabilitation', In Scriven, A. (ed.) *Health promoting practice: the contribution of nurses and allied health professionals*. China: Palgrave MacMillan, pp. 168-180.

Aubrey, G. and Demain, S. (2012) 'Perceptions of group exercise in the management of multiple sclerosis', *International Journal of Therapy and Rehabilitation*, 19(10), pp. 557-565.

Aveyard, H. (ed.) (2010) *Doing a Literature Review in Health and Social Care: A practical guide*. 2nd Edition edn. USA: The McGraw-Hill Companies.

Baker, S.M., Marshak, H.H., Rice, G.T. and Zimmerman, G.J. (2001) 'Patient participation in physical therapy goal setting', *Physical Therapy*, 81(5), pp. 1118-1126.

Bandura, A. (1977) 'Self Efficacy: toward a unifying theory of behaviour change. Psychological review', 84, 191-215 ', *Psychological review*, 84, pp. 191-215.

Barlow, J., Wright, C., Sheasby, J., Turner, A., and Hainsworth, J. (2002) 'Self-management approaches for people with chronic conditions: a review' *Patient education and counseling*, 48(2), pp.177-187.

Barlow, J., Edwards, R. and Turner, A. (2009a) 'The experience of attending a lay-led, chronic disease self-management programme from the perspective of participants with multiple sclerosis', *Psychology & Health*, 24(10), pp. 1167-1180.

Barlow, J., Turner, A., Edwards, R. and Gilchrist, M. (2009b) 'A randomised controlled trial of lay-led self-management for people with multiple sclerosis', *Patient education and counseling*, 77(1), pp. 81-89.

Bates, M.J. (1989) 'The design of browsing and berrypicking techniques for the online search interface', *Online Information Review*, 13(5), pp. 407-424.

Beckerman, H., De Groot, V., Scholten, M.A., Kempen, J.C.E. and Lankhorst, G.J. (2010) 'Physical activity behavior of people with multiple sclerosis: Understanding how they can become more physically active', *Physical Therapy*, 90(7), pp. 1001-1013.

Beer, S., Khan, F. and Kesselring, J. (2012) 'Rehabilitation interventions in multiple sclerosis: an overview', *Journal of neurology*, 259(9), pp. 1994-2008.

Ben-Zacharia, A.B. (2011) 'Therapeutics for multiple sclerosis symptoms', *Mount Sinai Journal of Medicine*, 78(2), pp. 176-191.

Beretta, A. (1996) 'A critical review of the Delphi technique.', *Nurse Research*, 3, pp. 79-89.

Biesta, G. (2010) Pragmatism and the philosophical foundations of mixed methods research. *Sage handbook of mixed methods in social and behavioural research. Second edition*, pp.95-118.

Bjarnadottir, O.H., Konradsdottir, A.D., Reynisdottir, K. and Olafsson, E. (2007) 'Multiple sclerosis and brief moderate exercise. A randomised study', *Multiple Sclerosis*, 13(6), pp. 776-782.

Blass, E. (2003) 'Researching the future: Method or madness?', *Futures*, 35(10), pp. 1041-1054.

Bombardier, C.H., Cunniffe, M., Wadhwani, R., Gibbons, L.E., Blake, K.D. and Kraft, G.H. (2008) 'The efficacy of telephone counseling for health promotion in people with multiple sclerosis: a randomized controlled trial', *Archives of Physical Medicine & Rehabilitation*, 89(10), pp. 1849-1856.

Borkoles, E., Nicholls, A.R., Bell, K., Butterly, R. and Polman, R.C.J. (2008) 'The lived experiences of people diagnosed with multiple sclerosis in relation to exercise', *Psychology and Health*, 23(4), pp. 427-441.

- Bouchard, C., Blair, S. and Haskell, W. (2012) *Physical Activity and Health*. Second Edition edn. USA: Human Kinetics.
- Boulkedid, R., Abdoul, H., Loustau, M., Sibony, O. and Alberti, C. (2011) 'Using and reporting the Delphi method for selecting healthcare quality indicators: A systematic review', *PLoS ONE*, 6(6).
- Brace, N., Kemp, R., Snelgar, R. (2012)'SPSS for Psychologists', 5<sup>th</sup> Edition, Palgrave MacMillan, Hampshire.
- Braun, V., and Clarke, V. (2006) 'Using thematic analysis in psychology', *Qualitative research in psychology*, 3(2), pp.77-101.
- Brazier, J.E., Harper, R., Jones, N.M.B., O'Cathain, A., Thomas, K.J., Usherwood, T. and Westlake, L. (1992) 'Validating the SF-36 health survey questionnaire: New outcome measure for primary care', *British medical journal*, 305(6846), pp. 160-164.
- Broekmans, T., Roelants, M., Feys, P., Alders, G., Gijbels, D., Hanssen, I., Stinissen, P. and Eijnde, B.O. (2011) 'Effects of long-term resistance training and simultaneous electro-stimulation on muscle strength and functional mobility in multiple sclerosis', *Multiple Sclerosis*, 17(4), pp. 468-477.
- Brønnnum-Hansen, H., Koch-Henriksen, N. and Stenager, E. (2004) 'Trends in survival and cause of death in Danish patients with multiple sclerosis', *Brain*, 127(4), pp. 844-850.
- Bryman, A. (2006) 'Integrating quantitative and qualitative research: How is it done?', *Qualitative Research*, 6(1), pp. 97-113.
- Buck, A.J., Gross, M., Hakim, S. and Weinblatt, J. (1993) 'Using the Delphi process to analyze social policy implementation: A post hoc case from vocational rehabilitation', *Policy Sciences*, 26(4), pp. 271-288.
- Bury, M. (1982) 'Chronic illness as biographical disruption', *Sociology of Health and Illness*, 4(2), pp. 167-182.

Campbell, S. M., Cantrill, J. A., Roberts, D. (2000). 'Prescribing indicators for UK general practice: Delphi consultation study', *British Medical Journal*, 321(7258), pp. 425-428

Caron-Flinterman, J.F., Broerse, J.E.W. and Bunders, J.F.G. (2005) 'The experiential knowledge of patients: a new resource for biomedical research?', *Social science & medicine*, 60(11), pp. 2575-2584.

Carter, A., Daley, A., Humphreys, L., Snowdon, N., Woodroffe, N., Petty, J., Roalfe, A., Tosh, J., Sharrack, B. and Saxton, J.M. (2014) 'Pragmatic intervention for increasing self-directed exercise behaviour and improving important health outcomes in people with multiple sclerosis: A randomised controlled trial', *Multiple Sclerosis*, 20(8), pp. 1112-1122.

Carter, H., McKenna, C., MacLeod, R. and Green, R. (1998) 'Health professionals' responses to multiple sclerosis and motor neurone disease', *Palliative medicine*, 12(5), pp. 383-394.

Caspari, S., Aasgaard, T., Lohne, V., Slettebø, Å., and Nåden, D. (2013) 'Perspectives of health personnel on how to preserve and promote the patients' dignity in a rehabilitation context', *Journal of clinical nursing*, 22 (15-16), pp.2318-2326.

Caspersen, C.J., Powell, K.E. and Christenson, G. (1985) 'Physical activity, exercise and physical fitness: definitions and distinctions for health-related research', *Public health reports*, 100(2), pp. 126-131.

Cavanaugh, J.T., Gappmaier, V. O., Dibble, L. E., and Gappmaier, E. (2011), 'Ambulatory activity in individuals with multiple sclerosis', *Journal of neurologic physical therapy*, 35(1), pp. 26-33.

Charmaz, K. (1995) 'The body, identity, and self', *The Sociological Quarterly*, 36(4), pp. 657-680.

Chartered Society of Physiotherapy (2012) Core Standards of physiotherapy Practice. London. Chartered Society of Physiotherapy.

Chartered Society of Physiotherapy (2011) Physiotherapy works: multiple sclerosis (MS) available at:

<http://www.csp.org.uk/publications/physiotherapy-works-multiple-sclerosis-ms> (accessed June 2013)

Chang, E., Ho, C.K., Yuen, AC., Hatcher, D. (2003) 'A study of clinical nursing research priorities in aged care: A Hong Kong perspective', *Contemporary Nurse*, 15 (3), pp. 188-198.

Cheng, E., Crandall, C., Bever Jr., C., Giesser, B., Haselkorn, J., Hays, R., Shekelle, P. and Vickrey, B. (2010) 'Quality indicators for multiple sclerosis'.', *Multiple Sclerosis*, 16(8), pp. 970-980.

Cherryholmes, C. (1992) 'Notes on pragmatism and scientific realism ', *Educational Researcher*, 21, pp. 13-17.

Chief Medical Officers of England, Scotland, Wales, and Northern Ireland (2011) ***Start active, stay active: a report on physical activity from the four home countries' Chief Medical Officers.*** Available at:  
[http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_128209](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_128209) (Accessed: March 2012).

Clibbens, N., Walters, S. and Baird, W. (2012) 'Delphi research: issues raised by a pilot study', *Nurse researcher*, 19(2), pp. 37-44.

Coenen, M., Basedow-Rajwich, B., König, N., Kesselring, J. and Cieza, A. (2011) 'Functioning and disability in multiple sclerosis from the patient perspective', *Chronic Illness*, 7(4), pp. 291-310.

Cohen, RA., Kessler, HR., Fischer, M. (1993) 'The Extended Disability Status Scale (EDSS) as a predictor of impairments of functional activities of daily living in multiple sclerosis', *Journal Neurological Sciences*, 115(2), pp.132–135.

College of Occupational Therapists. <https://www.cot.co.uk/> (accessed March 2015)

- Collett, J., Dawes, H., Meaney, A., Sackley, C., Barker, K., Wade, D., Izardi, H., Bateman, J., Duda, J. and Buckingham, E. (2011) 'Exercise for multiple sclerosis: A single-blind randomized trial comparing three exercise intensities', *Multiple Sclerosis*, 17(5), pp. 594-603.
- Collin, C., Wade, D.T., Davies, S. and Horne, V. (1988) 'The Barthel ADL Index: A reliability study', *International disability studies*, 10(2), pp. 61-63.
- Compston, A. and Coles, A. (2008) 'Multiple sclerosis', *The Lancet*, 372(9648), pp. 1502-1517.
- Compston, A., MacDonald, I., Noseworthy, J., Lassman, H., Miller, D., Smith, K. and Wekerle, H. (1998) *McAlpine's Multiple Sclerosis*. 3rd Edition edn. London: Churchill Livingstone.
- Compston, A. and Coles, A. (2002) 'Multiple sclerosis', *The Lancet*, 359(9313), pp. 1221-1231.
- Confavreux, C., Vukusic, S., Moreau, T. and Adeleine, P. (2000) 'Relapses and progression of disability in multiple sclerosis', *New England Journal of Medicine*, 343(20), pp. 1430-1438.
- Cook, D.J., Mulrow, C.D. and Haynes, R.B. (1997) 'Systematic reviews: Synthesis of best evidence for clinical decisions', *Annals of Internal Medicine*, 126(5), pp. 376-380.
- Coote, S., Garrett, M., Hogan, N., Larkin, A. and Saunders, J. (2009) 'Getting the balance right: A randomised controlled trial of physiotherapy and exercise interventions for ambulatory people with multiple sclerosis', *BMC Neurology*, 9.
- Coulter, A., Stationery Office HMSO Great Britain, & Nuffield Trust for Research and Policy Studies in Health Services. (2002). The autonomous patient: ending paternalism in medical care (pp. 106-21). London: TSO.

Creswell, J. (2009) *Research Design*. 3rd Edition edn. California: SAGE Publications, Inc.

Creswell, J.W., Klassen, A., Clark, V. and Smith, K. (2011) 'Best practices for mixed methods research in the Health Sciences', Maryland: *National Institute of Health*.

Crisp, J., Pelletier, D., Duffield, C., Adams, A. and Nagy, S. (1997) 'The Delphi method?', *Nursing research*, 46(2), pp. 116-118.

Crotty, M. (1998) *The Foundations of Social Research: Meaning and Perspective in the Research Process*. London: SAGE Publications.

Currie, A., Knox, K., Glazebrook, K. and Lawrence, B. (2009) "Physical Activity Levels in People with Multiple Sclerosis in Saskatchewan"., *International Journal of MS Care*, 11, pp. 114-120.

Dajani, JS., Sincoff, MZ., and Talley, WK. (1979) 'Stability and agreement criteria for the termination of Delphi studies', *Technological forecasting and social change*, 13(1), 83-90.

Dalgas, U., Stenager, E., Jakobsen, J., Petersen, T., Hansen, H.J., Knudsen, C., Overgaard, K. and Ingemann-Hansen, T. (2009) 'Resistance training improves muscle strength and functional capacity in multiple sclerosis', *Neurology*, 73(18), pp. 1478-1484.

Dalkey, N. and Helmer, O. (1963) 'An Experimental Application of the Delphi Method to the use of experts', *Management Science*, 9(3), pp. 458-467.

Dalkey, NC. (1969). 'The Delphi Method: an Experimental Study of Group Opinion', The RAND Corporation, Santa Monica, California.

Daly, J., Chang, E. M., Bell, P.F (1996). Clinical nursing research priorities in Australian critical care: a pilot study. *Journal of Advanced Nursing*, 23(1), 145-151.

- Dawes, M., Summerskill, W., Glasziou, P., Cartabellotta, A., Martin, J., Hopayian, K., Porzsolt, F., Burls, A. and Osborne, J. (2005) 'Sicily statement on evidence-based practice', *BMC Medical Education*, 5(1).
- Day, J. and Bobeva, M. (2005) 'A generic toolkit for the successful management of Delphi studies', *EJBRM*, 3(2), pp. 103-116.
- De Souza, L., Ide, L. and Neophytou, C. (2005) 'Promoting Health through a Self-help Care Model for the Management of Multiple Sclerosis', In Scriven, A. (ed.) *Health promoting practice: the contribution of nurses and allied health professionals*. China: Palgrave MacMillan, pp. 195-208.
- De Souza, L. and Bates, D. (2012) 'Multiple Sclerosis', in Stokes, M. and Stack, E. (eds.) *Physical Management for Neurological Conditions*. 3rd edn. Elsevier Churchill Livingstone, pp. 89-115.
- De Souza, L.H. (1990) *Multiple Sclerosis: Approaches to management*. London: Chapman and Hall.
- De Souza, L.H. (1983) 'Physiotherapy for multiple sclerosis patients', *Lancet*, 1(8339), pp. 1444.
- DeBolt, L.S. and McCubbin, J.A. (2004) 'The Effects of Home-Based Resistance Exercise on Balance, Power, and Mobility in Adults with Multiple Sclerosis', *Archives of Physical Medicine and Rehabilitation*, 85(2), pp. 290-297.
- Delbecq, A. L., Van de Ven, A. H., and Gustafson, D. H. (1975) '*Group techniques for program planning: A guide to nominal group and Delphi processes*'. Glenview, IL: Scott, Foresman.
- Denscombe, M. (2003) 'The good research guide: for Small-scale Research Projects'. 2<sup>nd</sup> Edition. UK, Open University Press.
- Denzin, N. and Lincoln, Y. (2000) 'The Discipline and Practice of Qualitative Research ', in Denzin, N. and Lincoln, Y. (eds.) *Handbook of Qualitative Research* 2nd Edition edn. USA: SAGE Publications, Inc., pp. 1-28.

Department of Health (2001), *The Expert Patient. A New Approach to Chronic disease Management in the 21st Century*. DH, London.

Department of Health (2005) 'The National Service Framework for Longterm Conditions', Department of Health, London.

Department of Health (2011) *Start Active Stay Active*. Available at:  
<https://www.gov.uk/government/publications/start-active-stay-active-a-report-on-physical-activity-from-the-four-home-countries-chief-medical-officers>  
(Accessed: July 2012)

di Gregorio, S. and Davidson, J. (2008) *Qualitative Research for Software Users*. UK: McGraw Hill, Open University Press.

Dlugonski, D., Joyce, R.J. and Motl, R.W. (2012) 'Meanings, motivations, and strategies for engaging in physical activity among women with multiple sclerosis', *Disability and rehabilitation*, 34(25), pp. 2148-2157.

Dodd, K.J., Taylor, N.F., Denisenko, S. and Prasad, D. (2006) 'A qualitative analysis of a progressive resistance exercise programme for people with multiple sclerosis', *Disability & Rehabilitation*, 28(18), pp. 1127-1134.

Dodd, K.J., Taylor, N.F., Shields, N., Prasad, D., McDonald, E. and Gillon, A. (2011) 'Progressive resistance training did not improve walking but can improve muscle performance, quality of life and fatigue in adults with multiple sclerosis: A randomized controlled trial', *Multiple Sclerosis*, 17(11), pp. 1362-1374.

Dolan, J.G. (2008) 'Shared decision-making – transferring research into practice: The Analytic Hierarchy Process (AHP)', *Patient education and counseling*, 73(3), pp. 418-425.

Duffield, C. (1993). The Delphi technique: a comparison of results obtained using two expert panels. *International journal of nursing studies*, 30(3), 227-237.

Durstine, J., Peel, J., LaMonte, M., Keteyuan, S., Fletcher, E. and Moore, G. (2009) 'Exercise Is Medicine', in J. Larry Durstine, Geoffrey E. Moore, Patricia L. Painter and Scott O. Roberts (ed.) *ACSM's Exercise Management for persons with Chronic Diseases and Disabilities* 3rd Edition edn. Europe: Human Kinetics, pp. 21-30.

Ebers, G.C., Bulman, D.E. and Sadovnick, A.D. (1986) 'A population-based study of multiple sclerosis in twins', *New England Journal of Medicine*, 315(26), pp. 1638-1642.

Edwards, I. and Richardson, B. (2008) 'Clinical reasoning and population health: Decision making for an emerging paradigm of health care', *Physiotherapy Theory and Practice*, 24(3), pp. 183-193.

Edwards, S. (2002) *Neurological Physiotherapy*. Second Edition edn. Edinburgh: Churchill Livingstone.

Einarsson, U., Gottberg, K., Fredrikson, S., von Koch, L. and Holmqvist, L.W. (2006) 'Activities of daily living and social activities in people with multiple sclerosis in Stockholm County', *Clinical rehabilitation*, 20(6), pp. 543-551.

Engels, T., and Kennedy, H.(2007) 'Enhancing a Delphi study on family-focused prevention', *Technological forecasting and social change*, 74(4), pp.433-451.

Ensari, I., Motl, R.W. and Pilutti, L.A. (2014) 'Exercise training improves depressive symptoms in people with multiple sclerosis: Results of a meta-analysis', *Journal of psychosomatic research*, 76(6), pp. 465-471.

European Multiple Sclerosis Platform (EMSP) (2012) 'Recommendations on Rehabilitation Services for Persons with Multiple Sclerosis in Europe'. Available at: [www.emsp.org](http://www.emsp.org). Accessed 2014.

Fangerau, T., Schimrigk, S., Haups, M., Kaeder, M., Ahle, G., Brune, N., Klinkenberg, K., Kotterba, S., Möhring, M. and Sindern, E. (2004) 'Diagnosis of multiple sclerosis: Comparison of the Poser criteria and the new McDonald criteria', *Acta Neurologica Scandinavica*, 109(6), pp. 385-389.

- Ferguson, F., Brownlee, M. and Webster, V. (2008) 'A Delphi study investigating consensus among expert physiotherapists in relation to the management of low back pain.', *Musculoskeletal Care*, 6(4), pp. 197-210.
- Finch, H., and Lewis, J. (2009) 'Focus Groups', In Ritchie, J. and Lewis, J. *Qualitative Research Practice: A Guide for Social Science Students and Researchers*. Ritchie, J., Lewis, J. edn. London: SAGE Publications, pp. 170-198.
- Finlay, L. (2002). "Outing" the researcher: The provenance, process, and practice of reflexivity. *Qualitative health research*, 12(4), 531-545.
- Finlayson, M., Plow, M. and Cho, C. (2010) 'Use of physical therapy services among middle-aged and older adults with multiple sclerosis', *Physical Therapy*, 90(11), pp. 1607-1618.
- Finlayson, M. and van Denend, T. (2003)'Experiencing the loss of mobility: Perspectives of older adults with MS', *Disability and rehabilitation*, 25(20), pp. 1168-1180.
- Finlayson, M., Van Denend, T. and Hudson, E. (2004) 'Aging with multiple sclerosis', *The Journal of neuroscience nursing : journal of the American Association of Neuroscience Nurses*, 36(5), pp. 245-251, 259.
- Flachenecker, P. and Stuke, K. (2008) 'National MS registries', *Journal of neurology*, 255(6), pp. 102-108.
- Freeman, J., Ford, H., Mattison, P., Thompson, A., Clark, F., Ridley, J. and Haffenden, S. (2002) *Developing MS Healthcare Standards: evidence-based recommendations for service providers. A joint publication by the Multiple Sclerosis Society of Great Britain and Northern Ireland and the MS Professional Network, Spring*. (Accessed: July 2012).
- Freeman, J. and Thompson, A. (2000) 'Community Services in multiple sclerosis: still a matter of chance.', *Journal Neurology Neurosurgery Psychiatry*, 69, pp. 728-732.

- Freeman, J.A. (2001) 'Improving Mobility and functional independence in persons with multiple sclerosis', *Journal Neurology*, 248(4), pp. 255-259.
- Freeman, J.A., Langdon, D.W., Hobart, J.C. and Thompson, A.J. (1997) 'The impact of inpatient rehabilitation on progressive multiple sclerosis', *Annals of Neurology*, 42(2), pp. 236-244.
- Freeman, J.A., Langdon, D.W., Hobart, J.C. and Thompson, A.J. (1996) 'Health-related quality of life in people with multiple sclerosis undergoing inpatient rehabilitation', *Neurorehabilitation and neural repair*, 10(3), pp. 185-194.
- Freeman, J. and Allison, R. (2004) 'Group exercise classes in people with multiple sclerosis: a pilot study', *Physiotherapy Research International*, 9(2), pp. 104-107.
- Freeman, J.A., Gear, M., Pauli, A., Cowan, P., Finnigan, C., Hunter, H., Mobberley, C., Nock, A., Sims, R. and Thain, J. (2010) 'The effect of core stability training on balance and mobility in ambulant individuals with multiple sclerosis: A multi-centre series of single case studies', *Multiple Sclerosis*, 16(11), pp. 1377-1384.
- Gaber, T.A.-K., Oo, W.W., Gautam, V. and Smith, L. (2012) 'Outcomes of inpatient rehabilitation of patients with multiple sclerosis', *NeuroRehabilitation*, 30(2), pp. 97-100.
- Galushko, M., Golla, H., Strupp, J., Karbach, U., Kaiser, C., Ernstmann, N., Pfaff, H., Ostgathe, C. and Voltz, R. (2014) 'Unmet needs of patients feeling severely affected by multiple sclerosis in Germany: A qualitative study', *Journal of palliative medicine*, 17(3), pp. 274-281.
- Georgiou, C. E., Espahbodi, S., De Souza, L. H. (2012) 'Preparing for the world of work: an exploratory study of disabled students' experiences of work placement', *Journal of Education and Work*, 25(5), pp.523-536.
- Gerrish, K. and Lacey, A. (2010), *The Research Process in Nursing*. Sixth Edition. United Kingdom: Wiley-Blackwell.

Godin, G. and Shephard, RJ. (1985) 'A simple method to assess exercise behavior in the community', *Canadian Journal Applied Sports Sciences*, 10, pp.141-146.

Golla, H., Galushko, M., Pfaff, H. and Voltz, R. (2012) 'Unmet needs of severely affected multiple sclerosis patients: The health professionals' view', *Palliative medicine*, 26(2), pp. 139-151.

Gompertz, P., Pound, P. and Ebrahim, S. (1994) 'A postal version of the Barthel Index', *Clinical rehabilitation*, 8(3), pp. 233-239.

Goodman, C. (1987) 'The Delphi technique: a critique.', *Journal of advanced nursing*, 12, pp. 729-734.

Goodman, C. and Evans, C. (2010) 'Focus Groups', In Gerrish, K. and Lacey, A. (eds.) *The Research Process in Nursing*. Sixth Edition. United Kingdom: Wiley-Blackwell, pp. 358-368.

Gosney, J.L., Scott, J.A., Snook, E.M. and Motl, R.W. (2007) 'Physical activity and multiple sclerosis: Validity of self-report and objective measures', *Family and Community Health*, 30(2), pp. 144-150.

Greatorex, J. and Dexter, T. (2000) 'An accessible analytical approach for investigating what happens between the rounds of a Delphi study', *Journal of advanced nursing*, 32(4), pp. 1016-1024.

Green, B., Jones, M., Huges, D. and Williams, A. (1999) ' Applying the Delphi technique in a study of GPs information requirement ', *Health and Social Care in the Community*, 7(3), pp. 198-205.

Greene, J. (2006) 'Toward a Methodology of Mixed Methods Social Inquiry', *Research in the Schools*, 13(1), pp.93-98.

Guba, E. (1990) 'The Alternative Paradigm dialogue', in *The Paradigm Dialogue*. Newbury: SAGE, pp. 17-30.

Gupta, U.G. and Clarke, R.E. (1996) 'Theory and application of the Delphi technique: A bibliography (1975-1994)', *Technological Forecasting and Social Change*, 53(2), pp. 185-211.

Hale, L.A., Smith, C., Mulligan, H. and Treharne, G.J. (2012) 'Tell me what you want, what you really really want..: Asking people with multiple sclerosis about enhancing their participation in physical activity', *Disability and rehabilitation*, 34(22), pp. 1887-1893.

Hamed, R., Tariah, H. and Hawamdeh, Z. (2012) 'Personal factors affecting the daily functioning and well-being of patients with multiple sclerosis using the international classification of functioning model', *International Journal of Mental Health*, 41(4), pp. 47-61.

Hanson, W.E., Plano Clark, V.L., Petska, K.S., Creswell, J.W. and Creswell, J.D. (2005) 'Mixed methods research designs in counseling psychology', *Journal of Counseling Psychology*, 52(2), pp. 224-235.

Hasson, T. and Barnett DB. (2002) 'Delphi type methodology to develop consensus on the future design of EMS systems in the United Kingdom', *Emergency Medicine Journal*, 19 (2), 155-159.

Hasson, F. and Keeney, S. (2011) 'Enhancing rigour in the Delphi technique research.', *Technological Forecasting and Social Change*, 78(9), pp. 1695-1704.

Hasson, F., Keeney, S. and McKenna, H. (2000) 'Research guidelines for the Delphi survey technique', *Journal of advanced nursing*, 32(4), pp. 1008-1015.

Hicks, C. (2004) *Research Methods for Clinical Therapists: Applied Project Design and Analysis*. Fourth Edition edn. United Kingdom: Churchill Livingstone.

Higgins, JPT. and Green, S. (2011) 'Cochrane Handbook for Systematic Reviews of Interventions version 5.1.0 (updated March 2011). The Cochrane Collaboration: available at: <http://www.cochrane-handbook.org> (accessed June 2013).

- Hobart, J.C., Lamping, D.L. and Thompson, A.J. (1996) 'Measuring disability in neurological disease: validity of the self-report Barthel Index (abstract)', *Journal Neurology*, 243(suppl2): S25, pp. S25.
- Hobart, J., Freeman, J. and Thompson, A. (2000) 'Kurtzke scales revisited: The application of psychometric methods to clinical intuition', *Brain*, 123(5), pp. 1027-1040.
- Hobart, J.C., Lamping, D.L., Freeman, J.A., Langdon, D.W., McLellan, D.L., Greenwood, R.J. and Thompson, A.J. (2001) 'Evidence-based measurement: Which disability scale for neurologic rehabilitation?', *Neurology*, 57(4), pp. 639-644.
- Hogan, N. and Coote, S. (2009) 'Therapeutic interventions in the treatment of people with multiple sclerosis with mobility problems: a literature review', *Physical Therapy Reviews*, 14(3), pp. 160-168.
- Holloway, I. and Wheeler, S. (2010) *Qualitative Research in Nursing and Healthcare*. Third Edition edn. United Kingdom: Wiley-BLackwell.
- Hubbard, E. A., Motl, R. W., and Manns, P. J. (2015), 'The descriptive epidemiology of daily sitting time as a sedentary behavior in multiple sclerosis', *Disability and health journal*, 8(4), pp. 594-601.
- Hung, HL., Altschuld, JW., Lee, YF (2008) 'Methodological and conceptual issues confronting a cross-country Delphi study of educational program evaluation', *Evaluation and Program Planning*, 31(2), pp. 191-198.
- Hurwitz, B.J. (2011) 'Analysis of current multiple sclerosis registries', *Neurology*, 76(1 SUPPL. 1), pp. S7-S13.
- Jairath, N. and Weinstein, J. (1994) 'The Delphi methodology (Part One): a useful administrative approach', *Canadian journal of nursing administration*, 7(3), pp. 29-40.
- Jette, AM. (2006) 'Toward a common language for function, disability, and health', *Physical Therapy*, 86(5), pp. 726-734.

Jette, A.M. (1994) 'Physical disablement concepts for physical therapy research and practice', *Physical Therapy*, 74(5), pp. 380-386.

Johnson, R., and Onwuegbuzie, A. (2004) 'Mixed methods research: A research paradigm whose time has come', *Educational researcher*, 33(7), pp.14-26.

Johnson, R., Onwuegbuzie, A., and Turner, L. (2007) 'Toward a definition of mixed methods research', *Journal of mixed methods research*, 1(2), pp.112-133.

Jones, M., and Rattray, J. (2010) 'Questionnaire Design', In Gerrish, K. and Lacey, A. (eds.) *The Research Process in Nursing*. Sixth Edition. United Kingdom: Wiley-Blackwell, pp. 369-380.

Karhula, M.E., Kanelisto, K.J., Ruutiainen, J., Hämäläinen, P.I. and Salminen, A.- (2013) 'The activities and participation categories of the ICF Core Sets for multiple sclerosis from the patient perspective', *Disability and rehabilitation*, 35(6), pp. 492-497.

Kasser, S. (2009) 'Exercising with multiple sclerosis: Insights into meaning and motivation', *Adapted Physical Activity Quarterly*, 26(3), pp. 274-289.

Kayes, N.M., McPherson, K.M., Schluter, P., Taylor, D., Leete, M. and Kolt, G.S. (2011a) 'Exploring the facilitators and barriers to engagement in physical activity for people with multiple sclerosis', *Disability and rehabilitation*, 33(12), pp. 1043-1053.

Kayes, N.M., McPherson, K.M., Taylor, D., Schlüter, P.J. and Kolt, G.S. (2011b) 'Facilitators and barriers to engagement in physical activity for people with multiple sclerosis: A qualitative investigation', *Disability and rehabilitation*, 33(8), pp. 625-642.

Keeney, S., Hasson, F. and McKenna, H. (2001) 'A critical review of the Delphi technique as a research methodology for nursing.', *International journal of nursing studies*, 38(2), pp. 195-200.

Keeney, S., Hasson, F. and McKenna, H.P. (2011) *The Delphi Technique in Nursing and Health Research* West Sussex, UK: Wiley-Blackwell.

Keeney, S., Hasson, F. and McKenna, H.P. (2001) 'A critical review of the Delphi technique as a research methodology for nursing', *International journal of nursing studies*, 38(2), pp. 195-200.

Keeney, S., Hasson, F., and McKenna, H.(2006) 'Consulting the oracle: ten lessons from using the Delphi technique in nursing research', *Journal of advanced nursing*, 53(2), pp. 205-212.

Kesselring, J. (2004) 'Neurorehabilitation in multiple sclerosis - What is the evidence-base?', *Journal of Neurology, Supplement*, 251(4), pp. IV/25-IV/29.

Kesselring, J. and Beer, S. (2005) 'Symptomatic therapy and neurorehabilitation in multiple sclerosis', *Lancet Neurology*, 4(10), pp. 643-652.

Khan, F., Ng, L. and Turner-Stokes, L. (2009) 'Effectiveness of vocational rehabilitation intervention on the return to work and employment of persons with multiple sclerosis', *Cochrane Database of Systematic Reviews*, (1).

Khan, F. and Pallant, J.F. (2007) 'Use of international classification of functioning, disability and health (ICF) to describe patient-reported disability in multiple sclerosis and identification of relevant environmental factors', *Journal of Rehabilitation Medicine*, 39(1), pp. 63-70.

Khan, F., Turner-Stokes, L., Ng, L., Kilpatrick, T.J. and Amatya, B. (2011) 'Multidisciplinary Rehabilitation for adults with Multiple Sclerosis', *Cochrane Database Systematic Reviews*.

Kitzinger, J. (1994) 'The methodology of focus groups: the importance of interaction between research participants', *Sociology of health & illness*, 16(1), 103-121.

Kitzinger, J. (1995) 'Qualitative research: introducing focus groups', *British Medical Journal*, 311(7000), pp. 299-302.

- Kitzinger, J., and Barbour, R. (1999) 'Introduction: the challenge and promise of focus groups' in R. Barbour and J. Kitzinger (eds) *Developing Focus Group Research: Politics, Theory and Practice*, London, Sage.
- Klaren, R. E., Motl, R. W., Dlugonski, D., Sandroff, B. M., & Pilutti, L. A. (2013). Objectively quantified physical activity in persons with multiple sclerosis. *Archives of physical medicine and rehabilitation*, 94(12), 2342-2348.
- Knaster,E., Yorkston,K., Johnson,K., McMullen, K., Ehde,D. (2011) 'Perspectives on Self-Management in Multiple Sclerosis: A Focus Group Study', *International Journal MS Care*, 13, pp 146-152.
- Koch-Henriksen, N. and Sørensen, P.S. (2010) 'The changing demographic pattern of multiple sclerosis epidemiology', *The Lancet Neurology*, 9(5), pp. 520-532.
- Kraft, G. (1998) 'Rehabilitation principles for patients with multiple sclerosis', *Journal of Spinal Cord Medicine*, 21(2), pp.117-120.
- Krupp, L.B. (2003) 'Fatigue in multiple sclerosis: Definition, pathophysiology and treatment', *CNS Drugs*, 17(4), pp. 225-234.
- Kurtzke, J. (1983) ' Rating neurological impairment in multiple sclerosis: an Expanded Disability Status Scale (EDSS)', *Neurology*, 33, pp. 1444-1452.
- Kvale, S. and Brinkmann, S. (2009) '*Interviews: Learning the Craft of Qualitative Research Interviewing*', Los Angeles, Calif., Sage.
- Lacey, A. (2010) 'The Research Process', In Gerrish, K. and Lacey, A. (eds.) *The Research Process in Nursing*. Sixth Edition. United Kingdom: Wiley-Blackwell, pp. 13-26.
- Lathlean, J. (2010) 'Qualitative Analysis', In Gerrish, K. and Lacey, A. (eds.) *The Research Process in Nursing*. Sixth Edition. United Kingdom: Wiley-Blackwell, pp. 423-436.

- Latimer-Cheung, A.E., Pilutti, L.A., Hicks, A.L., Martin Ginis, K.A., Fenuta, A.M., MacKibbon, K.A. and Motl, R.W. (2013) 'Effects of exercise training on fitness, mobility, fatigue, and health-related quality of life among adults with multiple sclerosis: A systematic review to inform guideline development', *Archives of Physical Medicine and Rehabilitation*, 94(9), pp. 1800-1828.
- Learnmonth, Y.C., Marshall-Mckenna, R., Paul, L., Mattison, P. and Miller, L. (2013) 'A qualitative exploration of the impact of a 12-week group exercise class for those moderately affected with multiple sclerosis', *Disability and rehabilitation*, 35(1), pp. 81-88.
- Lee, I., Shiroma, E.J., Lobelo, F., Puska, P., Blair, S. and Katzmarzyk, P. (2012) 'Effect of physical inactivity on major non-communicable diseases worldwide: An analysis of burden of disease and life expectancy', *The Lancet*, 379(9838), pp. 219-229.
- Legard, R., Keegan, J., Ward, K ' In-depth Interviews' (2009), in Ritchie, J. and Lewis, J. *Qualitative Research Practice: A Guide for Social Science Students and Researchers*. Ritchie,J., Lewis, J. edn. London: SAGE Publications, pp. 138-169.
- Leplege, A., Gzil, F., Cammelli, M., Lefeve, C., Pachoud, B. and Ville, I. (2007) 'Person-centredness: Conceptual and historical perspectives', *Disability and rehabilitation*, 29(20-21), pp. 1555-1565.
- Lerdal, A., Gulowsen Celius, E., Krupp, L. and Dahl, A.A. (2007) 'A prospective study of patterns of fatigue in multiple sclerosis', *European Journal of Neurology*, 14(12), pp. 1338-1343.
- Levack, W.M.M., Taylor, K., Siegert, R.J., Dean, S.G., McPherson, K.M. and Weatherall, M. (2006) 'Is goal planning in rehabilitation effective? A systematic review', *Clinical rehabilitation*, 20(9), pp. 739-755.
- Lewis, J. (2009) 'Design Issues', in Ritchie, J. and Lewis, J. (eds.) *Qualitative Research Practice: A Guide for Social Science Students and Researchers*. London: SAGE, pp. 47-76.

- Lincoln, Y., and Guba, E. (1985) *Naturalistic Inquiry*. London, Sage.
- Lindquist, I., Engardt, M., Garnham, L., Poland, F. and Richardson, B. (2006) 'Physiotherapy students' professional identity on the edge of working life', *Medical teacher*, 28(3), pp. 270-276.
- Linstone, H. and Turoff, M. (1975) 'Philosophical and Methodological Foundations of Delphi ', in Linstone, H. and Turoff, M. (eds.) *The Delphi Method: Techniques and Applications* Massachusetts: Addison-Wesley Publishing Company, pp. 17-36.
- Lintern, T.C., Beaumont, J.G., Kenealy, P.M. and Murrell, R.C. (2001) 'Quality of life (QoL) in severely disabled multiple sclerosis patients: Comparison of three QoL measures using multidimensional scaling', *Quality of Life Research*, 10(4), pp. 371-378.
- Lord, S.E., Wade, D.T. and Halligan, P.W. (1998) 'A comparison of two physiotherapy treatment approaches to improve walking in multiple sclerosis: A pilot randomized controlled study', *Clinical rehabilitation*, 12(6), pp. 477-486.
- Lorig, K. R., Sobel, D. S., Stewart, A. L., Brown Jr, B. W., Bandura, A., Ritter, P., Gonzalez, VM., Laurent, DD and Holman, HR. (1999) 'Evidence suggesting that a chronic disease self-management program can improve health status while reducing hospitalization: a randomized trial', *Medical care*, 37(1), pp. 5-14.
- Lorig, K.R., Ritter, P.L. and Plant, K. (2005) 'A disease-specific self-help program compared with a generalized chronic disease self-help program for arthritis patients', *Arthritis & Rheumatism*, 53, pp.950-957.
- Lublin, F.D., Reingold, S.C. (1996) 'Defining the clinical course of multiple sclerosis: results of an international survey. National Multiple Sclerosis Society (USA) Advisory Committee on Clinical Trials of New Agents in Multiple Sclerosis', *Neurology*, 46 (4),pp.907-911.

- Lui, K.C. and Hui, S.S.C. (2009) 'Participation in and Adherence to Physical Activity in People With Physical Disability', *Hong Kong Physiotherapy Journal*, 27, pp. 30-38.
- Mackenzie, I.S., Morant, S.V., Bloomfield, G.A., MacDonald, T.M. and O'Riordan, J. (2014) 'Incidence and prevalence of multiple sclerosis in the UK 1990-2010: a descriptive study in the General Practice Research Database.', *Journal of neurology, neurosurgery, and psychiatry*, 85(1), pp. 76-84.
- Maher, C.G., Sherrington, C., Herbert, R.D., Moseley, A.M. and Elkins, M. (2003) 'Reliability of the PEDro scale for rating quality of randomized controlled trials', *Physical Therapy*, 83(8), pp. 713-721.
- Mahoney, F. and Barthel, D. (1965) 'Functional evaluation: the Barthel Index', *Maryland State Medical Journal*, 14, pp. 61-65.
- Malcomson, K.S., Lowe-Strong, A.S. and Dunwoody, L. (2008) 'What can we learn from the personal insights of individuals living and coping with Multiple Sclerosis?', *Disability and rehabilitation*, 30(9), pp. 662-674.
- Månnsson, E. and Lexell, J. (2004) 'Performance of activities of daily living in multiple sclerosis', *Disability and rehabilitation*, 26(10), pp. 576-585.
- Marrie, R.A., Horwitz, R., Cutter, G., Tyry, T., Campagnolo, D. and Vollmer, T. (2008) 'Comorbidity, socioeconomic status and multiple sclerosis', *Multiple Sclerosis*, 14(8), pp. 1091-1098.
- Marrie, R.A. and Horwitz, R.I. (2010) 'Emerging effects of comorbidities on multiple sclerosis', *The Lancet Neurology*, 9(8), pp. 820-828.
- Matthews, B. (1998) 'Symtoms and signs of Multiple Sclerosis', in Compston, A., Ebers, G.C., Lassman, H., McDonald, I., Matthews, B. and Wekerle, H. (eds.) *McAlpine's Multiple Sclerosis*. 3rd edn. UK: Churchill Livingstone, pp. 145-190.

- McAuley, E., Motl, R.W., Morris, K.S., Hu, L., Doeksen, S.E., Elavsky, S. and Konopack, J.F. (2007) 'Enhancing physical activity adherence and well-being in multiple sclerosis: A randomised controlled trial', *Multiple Sclerosis*, 13(5), pp. 652-659.
- McCance, T., McCormack, B., and Dewing, J (2011) An exploration of person-centredness in practice. *Online Journal of Issues in Nursing*, 16(2), 1
- McCormack, B. and McCance, T.V. (2006) Development of a framework for person-centred nursing. *Journal of advanced Nursing*, 56(5), 472-479.
- McCormack, B., Dewing, J., Breslin, E., Coyne-Nevin, A., Kennedy, K., Manning , M., Tobin, C., Pee;o-Kilroe, L. (2010) The implementation of a model of person-centred practice in older person settings final report. Office of the Nursing Services Director, Health Services Executive. Dublin, Ireland.
- McCrone, P., Heslin, M., Knapp M., Bull, P., Thompson, A. (2008) 'Multiple Sclerosis in the UK: Service Use, Costs, Quality of Life and Disability', *PharmacoEconomics*, 26(10), pp. 847-860.
- McDonald, W.I., Compston, A., Edan, G., Goodkin, D., Hartung, H.-, Lublin, F.D., McFarland, H.F., Paty, D.W., Polman, C.H., Reingold, S.C., Sandberg-Wollheim, M., Sibley, W., Thompson, A., Van Den Noort, S., Weinshenker, B.Y. and Wolinsky, J.S. (2001) 'Recommended diagnostic criteria for multiple sclerosis: Guidelines from the International Panel on the Diagnosis of Multiple Sclerosis', *Annals of Neurology*, 50(1), pp. 121-127.
- McIlfatick, S.J. and Keeney, S. (2003) 'Identifying cancer nursing research priorities using the Delphi technique', *Journal of advanced nursing*, 42(6), pp. 629-636.
- McKenna, H. (1994) 'The Delphi technique: A worthwhile approach for nursing?', *Journal of advanced nursing*, 19, pp. 1221-1225.
- McLaughlin, J. and Zeeberg, I. (1993) 'Self-care and multiple sclerosis: A view from two cultures', *Social science & medicine*, 37(3), pp. 315-329.

Melcon, M.O., Correale, J. and Melcon, C.M. (2014) 'Is it time for a new global classification of multiple sclerosis?', *Journal of the neurological sciences*, 344(1-2), pp. 171-181.

Mokkink, L.B., Terwee, C.B., Patrick, D.L., Alonso, J., Stratford, P.W., Knol, D.L., Bouter, L.M. and De Vet, H.C.W. (2010) 'The COSMIN checklist for assessing the methodological quality of studies on measurement properties of health status measurement instruments: An international Delphi study', *Quality of Life Research*, 19(4), pp. 539-549.

Morgan, D.L. (1998) 'Practical strategies for combining qualitative and quantitative methods: Applications to health research', *Qualitative health research*, 8(3), pp. 362-376.

Mostert, S. and Kesselring, J. (2002) 'Effects of a short-term exercise training program on aerobic fitness, fatigue, health perception and activity level of subjects with multiple sclerosis', *Multiple Sclerosis*, 8(2), pp. 161-168.

Motl, R.W. (2014) 'Lifestyle physical activity in persons with multiple sclerosis: The new kid on the MS block', *Multiple Sclerosis*, 20(8), pp. 1025-1029.

Motl, R.W., Arnett, P.A., Smith, M.M., Barwick, F.H., Ahlstrom, B. and Stover, E.J. (2008a) 'Worsening of symptoms is associated with lower physical activity levels in individuals with multiple sclerosis', *Multiple Sclerosis*, 14(1), pp. 140-142.

Motl, R.W., Dlugonski, D., Pilutti, L., Sandroff, B. and McAuley, E. (2012a) 'Premorbid physical activity predicts disability progression in relapsing-remitting multiple sclerosis', *Journal of the neurological sciences*, 323(1-2), pp. 123-127.

Motl, R.W., Dlugonski, D., Wójcicki, T.R., McAuley, E. and Mohr, D.C. (2011b) 'Internet intervention for increasing physical activity in persons with multiple sclerosis', *Multiple Sclerosis*, 17(1), pp. 116-128.

- Motl, R.W., Fernhall, B., McAuley, E. and Cutter, G. (2011a) 'Physical activity and self-reported cardiovascular comorbidities in persons with multiple sclerosis: Evidence from a cross-sectional analysis', *Neuroepidemiology*, 36(3), pp. 183-191.
- Motl, R.W. and Goldman, M. (2011) 'Physical inactivity, neurological disability, and cardiorespiratory fitness in multiple sclerosis', *Acta Neurologica Scandinavica*, 123(2), pp. 98-104.
- Motl, R.W., McAuley, E. and Snook, E.M. (2007) 'Physical activity and quality of life in multiple sclerosis: Possible roles of social support, self-efficacy, and functional limitations', *Rehabilitation Psychology*, 52(2), pp. 143-151.
- Motl, R.W., McAuley, E. and Snook, E.M. (2005) 'Physical activity and multiple sclerosis: A meta-analysis', *Multiple Sclerosis*, 11(4), pp. 459-463.
- Motl, R.W., McAuley, E., Wynn, D., Sandroff, B. and Suh, Y. (2012b) 'Physical activity, self-efficacy, and health-related quality of life in persons with multiple sclerosis: analysis of associations between individual-level changes over one year', *Quality of Life Research*.
- Motl, R.W., McAuley, E., Wynn, D., Suh, Y., Weikert, M. and Dlugonski, D. (2010) 'Symptoms and physical activity among adults with relapsing-remitting multiple sclerosis', *Journal of Nervous and Mental Disease*, 198(3), pp. 213-219.
- Motl, R.W., Snook, E.M., Wynn, D.R. and Vollmer, T. (2008b) 'Physical activity correlates with neurological impairment and disability in multiple sclerosis', *Journal of Nervous and Mental Disease*, 196(6), pp. 492-495.
- Motl, R., and Gosney, J. (2008) 'Effect of exercise training on quality of life in multiple sclerosis: A meta-analysis', *Multiple Sclerosis*, 14 (1), pp. 129-135
- Motl, R.W., Snook, E.M., McAuley, E. and Gliottoni, R.C. (2006) 'Symptoms, self-efficacy, and physical activity among individuals with multiple sclerosis', *Research in nursing & health*, 29(6), pp. 597-606.

Mudge, S., Stretton, C. and Kayes, N. (2014) 'Are physiotherapists comfortable with person-centred practice? An autoethnographic insight', *Disability and rehabilitation*, 36(6), pp. 457-463.

Muir Gray, J.A (2004) 'Evidence based policy making', *British Medical Journal*, 329(7473), pp. 988-989.

Mulligan, H., Fjellman-Wiklund, A., Hale, L., Thomas, D. and Häger-Ross, C. (2011) 'Promoting physical activity for people with neurological disability: Perspectives and experiences of physiotherapists', *Physiotherapy Theory and Practice*, 27(6), pp. 399-410.

Mulligan, H., Trehearne, G.J., Hale, L.A. and Smith, C. (2013) 'Combining self-help and professional help to minimize barriers to physical activity in persons with multiple sclerosis: A trial of the "Blue prescription" approach in New Zealand', *Journal of Neurologic Physical Therapy*, 37(2), pp. 51-57.

*Multiple Sclerosis* (2009). Available at: <http://www.mssociety.org.uk/about-ms/index.html>. (Accessed: March 2011).

Naci, H., Fleurence, R., Birt, J. and Duhig, A. (2010) 'Economic burden of multiple sclerosis: A systematic review of the literature', *PharmacoEconomics*, 28(5), pp. 363-379.

Nagi, S. (1965) 'Some conceptual issues in disability and rehabilitation', in Sussman , M. (ed.) *Sociology and Rehabilitation*. Columbus Ohio: , pp. 100-113.

National Collaborating Centre for Chronic Conditions (Great Britain), and Chartered Society of Physiotherapy (Great Britain). (2004) '*Multiple sclerosis: national clinical guideline for diagnosis and management in primary and secondary care*', Royal College of Physicians.

Neuendorf, K. (2002) *The Content Analysis Guidebook*. CA: SAGE.

Ng, A.V. and Kent-Braun, J.A. (1997) 'Quantitation of lower physical activity in persons with multiple sclerosis', *Medicine and science in sports and exercise*, 29(4), pp. 517-523.

NICE (2014) Multiple sclerosis: Management of multiple sclerosis in primary and secondary care. Available at: <http://www.nice.org.uk/guidance/cg8> November, 2014).

NICE (2003) *National Institute for Clinical Excellence (NICE) Management of Multiple Sclerosis in primary and secondary care. Clinical Guidelines 8*. London: NICE.

NICE, (2010) *The National Collaborating Centre for Chronic Conditions: Multiple Sclerosis. National Clinical Guideline for diagnosis and management in primary and secondary care*. Available at:  
<http://www.nice.org.uk/guidance/index.jsp?action=folder&r=true&o=30079>  
(Accessed: June 2012).

Nicholls, D.A. and Gibson, B.E. (2010) 'The body and physiotherapy', *Physiotherapy Theory and Practice*, 26(8), pp. 497-509.

Nicholls, D.A. and Holmes, D. (2012) 'Discipline, desire, and transgression in physiotherapy practice', *Physiotherapy Theory and Practice*, 28(6), pp. 454-465.

Nortvedt, M., Riise, T., Myhr, K., Nyland, H. (1999). 'Quality of life in multiple sclerosis measuring the disease effects more broadly', *Neurology*, 53(5), pp. 1098-1098.

Noseworthy, J., Lucchinetti, C., Rodriguez, M. and Weinshenker, B. (2000) 'Multiple Sclerosis', *New England Journal of Medicine*, 343(13), pp. 938-952.

O'Cathain, A., Murphy, E. and Nicholl, J. (2008) 'The quality of mixed methods studies in health services research', *Journal of Health Services Research and Policy*, 13(2), pp. 92-98.

O'Cathain, A., Murphy, E. and Nicholl, J. (2007) 'Why, and how, mixed methods research is undertaken in health services research in England: A mixed methods study', *BMC Health Services Research*, 7.

O'Connell, R., Murphy, R., Hutchinson, M., Cooke, G. and Coote, S. (2003) 'A controlled study to assess the effects of aerobic training on patients with multiple sclerosis.', *14th International World Confederation for Physical Therapy*. Barcelona: RR-PL-2105.

O'Hara, L., Cadbury, H., De Souza, L. and Ide, L. (2002) 'Evaluation of the effectiveness of professionally guided self-care for people with multiple sclerosis living in the community: A randomized controlled trial', *Clinical rehabilitation*, 16(2), pp. 119-128.

O'Hara, L., De Souza, L.H. and Ide, L. (2000) 'A Delphi study of self-care in a community population of people with multiple sclerosis', *Clinical rehabilitation*, 14(1), pp. 62-71.

Oken, B.S., Kishiyama, S., Zajdel, D., Bourdette, D., Carlsen, J., Haas, M., Hugos, C., Kraemer, D.F., Lawrence, J. and Mass, M. (2004) 'Randomized controlled trial of yoga and exercise in multiple sclerosis', *Neurology*, 62(11), pp. 2058-2064.

Paliwoda, S. (1983) 'Predicting the future using Delphi.', *Management Decision*, 21(1), pp. 31-36.

Pallant, J. (2010) *SPSS Survival manual: A step by step guide to data analysis using the SPSS program*. 4th Edn, England: The McGraw Hill-companies.

Patten, S.B., Beck, C.A., Williams, J.V.A., Barbui, C. and Metz, L.M. (2003) 'Major depression in multiple sclerosis: A population-based perspective', *Neurology*, 61(11), pp. 1524-1527.

Patti, F., Ciancio, M., Cacopardo, M., Reggio, E., Fiorilla, T., Palermo, F., Reggio, A. and Thompson, A.J. (2003) 'Effects of a short out-patient rehabilitation treatment on disability of multiple sclerosis patients', *Journal Neurology*, 250, pp. 861-866.

Patton, M. (1990) 'Qualitative evaluation and research methods'. 2nd Edition. Newbury Park CA: SAGE.

Patwardhan, M. B., Matchar, D. B., Samsa, G. P., McCrory, D. C., Williams, R. G., and Li, T. T. (2005) 'Cost of multiple sclerosis by level of disability: a review of literature', *Multiple Sclerosis*, 11(2), pp. 232-239.

Pelzang, R. (2010) Time to learn: understanding patient-centred care. *British journal of nursing*, 19(14), 912-917.

Perry S (1994) 'Living with Multiple Sclerosis'. Newcastle upon Tyne: Atheneum Press.

Petajan, J.H., Gappmaier, E., White, A.T., Spencer, M.K., Mino, L. and Hicks, R.W. (1996) 'Impact of aerobic training on fitness and quality of life in multiple sclerosis', *Annals of Neurology*, 39(4), pp. 432-441.

Petajan, J.H. and White, A.T. (1999) 'Recommendations for physical activity in patients with multiple sclerosis', *Sports Medicine*, 27(3), pp. 179-191.

Pilutti, L.A., Platta, M.E., Motl, R.W. and Latimer-Cheung, A.E. (2014) 'The safety of exercise training in multiple sclerosis: A systematic review', *Journal of the neurological sciences*, 343 (1-2), pp.3-7.

Playford, E.D., Dawson, L., Limbert, V., Smith, M., Ward, C.D. and Wells, R. (2000) 'Goal-setting in rehabilitation: Report of a workshop to explore professionals' perceptions of goal-setting', *Clinical rehabilitation*, 14(5), pp. 491-496.

Playford, E.D., Siegert, R., Levack, W. and Freeman, J. (2009) 'Areas of consensus and controversy about goal setting in rehabilitation: A conference report', *Clinical rehabilitation*, 23(4), pp. 334-344.

Ploughman, M., Austin, M.W., Murdoch, M., Kearney, A., Fisk, J.D., Godwin, M. and Stefanelli, M. (2012) 'Factors influencing healthy aging with multiple sclerosis: A qualitative study', *Disability and rehabilitation*, 34(1), pp. 26-33.

- Plow, M.A., Resnik, L. and Allen, S.M. (2009) 'Exploring physical activity behaviour of persons with multiple sclerosis: A qualitative pilot study', *Disability and rehabilitation*, 31(20), pp. 1652-1665.
- Polman, C.H., O'Connor, P., Havrdova, E., Hutchinson, M., Kappos, L. and Miller, D.H. (2006) 'A Randomised, placebo-controlled trial of Natalizumab for relapsing Multiple Sclerosis', *New England Journal of Medicine*, 354(9), pp. 899-910.
- Polman, C.H., Reingold, S.C., Banwell, B., Clanet, M., Cohen, J.A., Filippi, M., Fujihara, K., Havrdova, E., Hutchinson, M., Kappos, L., Lublin, F.D., Montalban, X., O'Connor, P., Sandberg-Wollheim, M., Thompson, A.J., Waubant, E., Weinshenker, B. and Wolinsky, J.S. (2011) 'Diagnostic criteria for multiple sclerosis: 2010 Revisions to the McDonald criteria', *Annals of Neurology*, 69(2), pp. 292-302.
- Pope, C., Ziebland, S., Mays, N. (2000) 'Qualitative research in health care: analysing qualitative data', *British Medical Journal*, 320 (7227), pp. 114-116
- Pope, C., Mays, N. and Popay, J. (2007) '*Synthesising qualitative and quantitative health evidence: A guide to methods*'. McGraw-Hill International.
- Poser, C.M. (2005) 'The diagnosis and management of multiple sclerosis', *Acta Neurologica Scandinavica*, 112(3), pp. 199-201.
- Poser, C.M. and Brinar, V.V. (2001) 'Diagnostic criteria for multiple sclerosis', *Clinical neurology and neurosurgery*, 103(1), pp. 1-11.
- Poser, C.M., Paty, D.W., Scheinberg, L., McDonald, W.I., Davis, F.A., and Ebers, G.C. (1983) 'New diagnostic criteria for multiple sclerosis: Guidelines for research protocols', *Annals of Neurology*, 13, pp. 227-231.
- Powell, C. (2003) 'The Delphi technique: Myths and realities', *Journal of advanced nursing*, 41(4), pp. 376-382.

- Powell, K.E., Heath, G.W., Kresnow, M.-, Sacks, J.J. and Branche, C.M. (1998) 'Injury rates from walking, gardening, weightlifting, outdoor bicycling, and aerobics', *Medicine and science in sports and exercise*, 30(8), pp. 1246-1249.
- Procter, S., Allan, T., Lacey, A. (2010) 'Sampling', In Gerrish, K. and Lacey, A. (eds.) *The Research Process in Nursing*. Sixth Edition. United Kingdom: Wiley-Blackwell, pp. 142-152.
- Prodinger, B., Weise, A.P., Shaw, L. and Stamm, T.A. (2010) 'A Delphi study on environmental factors that impact work and social life participation of individuals with multiple sclerosis in Austria and Switzerland', *Disability and rehabilitation*, 32(3), pp. 183-195.
- Rabadi,MH., and Vincent, AS. (2013) 'Comparison of the Kurtzle expanded disability status scale and the functional independence measure: measures of multiple sclerosis-related disability', *Disability Rehabilitation*, 35(22), pp. 1877-1884.
- Rae-Grant, AD., Turner, AP., Sloan, A., Miller, D., Hunziker, J., Haselkorn, J. (2011) 'Self-management in neurological disorders: systematic review of the literature and potential interventions in multiple sclerosis care', *Journal of Rehabilitation Research Development* 48 (9).pp. 1087-1100.
- Rauscher, L. and Greenfield, B.H. (2009) 'Advancements in contemporary physical therapy research: Use of mixed methods designs', *Physical Therapy*, 89(1), pp. 91-100.
- Redman, R. W. (2004). Patient-centered care: an unattainable ideal? *Research and theory for nursing practice*, 18(1), 11-14.
- Reynolds, F. and Prior, S. (2003) " Sticking jewels in your life": exploring women's strategies for negotiating an acceptable quality of life with multiple sclerosis', *Qualitative Health Research*, 13(9), pp. 1225-1251.

Richards, R., Sampson, F., Beard, S. and Tappenden, P. (2002) 'A Review of the natural history and Epidemiology of multiple sclerosis:Implications for Resource allocation and health economic models.', *Health Technology Assessment*, 6(10), pp. 1-85.

Ridley, D. (2008) *The Literature Review: A Step-by-Step Guide for students*. London: SAGE.

Rietberg, M.B., Brooks, D., Uitdehaag, B.M. and Kwakkel, G. (2004) 'Exercise therapy for multiple sclerosis.', *Cochrane database of systematic reviews*, (3).

Rietberg, M.B., Van Wegen, E.E., Uitdehaag, B.M., De Vet, H.C. and Kwakkel, G. (2010) 'How reproducible is home-based 24-hour ambulatory monitoring of motor activity in patients with multiple sclerosis?', *Archives of Physical Medicine and Rehabilitation*, 91(10), pp. 1537-1541.

Rietberg, M.B., Van Wegen, E.E.H., Kollen, B.J. and Kwakkel, G. (2014) 'Do patients with multiple sclerosis show different daily physical activity patterns from healthy individuals?', *Neurorehabilitation and neural repair*, 28(6), pp. 516-523.

Rimmer, J.H. (2006) 'Use of the ICF in identifying factors that impact participation in physical activity/rehabilitation among people with disabilities', *Disability and rehabilitation*, 28(17), pp. 1087-1095.

Riñon, A., Buch, M., Holley, D. and Verdun, E. (2011) 'The MS Choices Survey: Findings of a study assessing physician and patient perspectives on living with and managing multiple sclerosis', *Patient Preference and Adherence*, 5, pp. 629-643.

Ritchie, J and Spencer, L (1994), 'Qualitative data analysis for applied policy research', In Bryman and Burgess, eds., *Analysing Qualitative Data*, London: Routledge, pp.173-194.

Ritchie, J. and Lewis, J. (2009) *Qualitative Research Practice: A Guide for Social Science Students and Researchers*. London: SAGE Publications.

Ritchie, J. (2009) 'The applications of Qualitative methods to Social Research', in Ritchie, J. and Lewis, J. *Qualitative Research Practice: A Guide for Social Science Students and Researchers*. Ritchie, J.; Lewis, J. edn. London: SAGE Publications, pp. 24-46.

Ritchie, J., Spencer, L. and O'Connor, W. (2009) 'Carrying out Qualitative Analysis', in Ritchie, J. and Lewis, J. (eds.) *Qualitative Research Practice: A Guide for Social Science Students and Researchers*. UK: SAGE, pp. 219-262.

Roberts, P. (1994) 'Theoretical Models of Physiotherapy', *Physiotherapy*, 80(6), pp. 361-366.

Rodriguez, M., Siva, A., Ward, J., Stolp-Smith, K., O'Brien, P. and Kurland, L. (1994) 'Impairment, disability, and handicap in multiple sclerosis: A population-based study in Olmsted County, Minnesota', *Neurology*, 44(1), pp. 28-33.

Romberg, A., Virtanen, A., Aunola, S., Karppi, S.-., Karanko, H. and Ruutiainen, J. (2004) 'Exercise capacity, disability and leisure physical activity of subjects with multiple sclerosis', *Multiple Sclerosis*, 10(2), pp. 212-218.

Romberg, A., Virtanen, A. and Ruutiainen, R. (2005) 'Long-term exercise improves functional impairment but not quality of life in multiple sclerosis', *Journal of neurology*, 252(7), pp. 839-845.

Rossier, P. and Wade, D T. (2002) 'The Guy's Neurological Disability Scale in patients with multiple sclerosis: a clinical evaluation of its reliability and validity', *Clinical Rehabilitation*, 16 (1), pp. 75 - 95.

Rothwell, P.M., McDowell, Z., Wong, C.K. and Dorman, P.J. (1997) 'Doctors and patients don't agree: Cross sectional study of patients' and doctors' perceptions and assessments of disability in multiple sclerosis', *British medical journal*, 314(7094), pp. 1580-1583.

Rowe, G. and Wright, G. (1999) 'The Delphi technique as a forecasting tool: issues and analysis', *International Journal Forecasting*, 15, pp. 353-375.

Rowe, G., Wright, G. and Bolger, F. (1991) 'Delphi: A reevaluation of research and theory', *Technological Forecasting and Social Change*, 39(3), pp. 235-251.

Sá, M.J. (2013) 'Exercise therapy and multiple sclerosis: a systematic review', *Journal of neurology*, , pp. 1-11.

Sabapathy, N.M., Minahan, C.L., Turner, G.T. and Broadley, S.A. (2011) 'Comparing endurance- and resistance-exercise training in people with multiple sclerosis: A randomized pilot study', *Clinical rehabilitation*, 25(1), pp. 14-24.

Sackett, D.L., Rosenberg, W.M.C., Gray, J.A.M., Haynes, R.B. and Richardson, W.S. (1996) 'Evidence based medicine: What it is and what it isn't. It's about integrating individual clinical expertise and the best external evidence', *British medical journal*, 312(7023), pp. 71-72.

Sackman, H. (1975) *Delphi Critique* Lexington, Massachusetts: Lexington Books.

Salminen, A. L., Kanelisto, K. J., Karhula, M. E. (2014) 'What components of rehabilitation are helpful from the perspective of individuals with multiple sclerosis?', *Disability and Rehabilitation*, 36(23), pp.1983-1989.

Sandelowski, M. (2000) 'Focus on research methods: Combining qualitative and quantitative sampling, data collection, and analysis techniques in mixed-method studies', *Research in Nursing and Health*, 23(3), pp. 246-255.

Sandroff, B.M., Dlugonski, D., Weikert, M., Suh, Y., Balantrapu, S. and Motl, R.W. (2012) 'Physical activity and multiple sclerosis: New insights regarding inactivity', *Acta Neurologica Scandinavica*, 126(4), pp. 256-262.

Saxton, J.M., Carter, A., Daley, A.J., Snowdon, N., Woodroffe, M.N., Petty, J., Roalfe, A., Tosh, J. and Sharrack, B. (2013) 'Pragmatic exercise intervention for people with multiple sclerosis (ExIMS Trial): Study protocol for a randomised controlled trial', *Contemporary Clinical Trials*, 34(2), pp. 205-211.

- Schapiro, R.T. (2002) 'Pharmacologic options for the management of multiple sclerosis symptoms', *Neurorehabilitation and neural repair*, 16(3), pp. 223-231.
- Scheibe, M., Skutsch, M., Schofer, J. (1975) 'Experiments in Delphi Methodology', In Linstone, H. and Turoff, M. (eds.) *The Delphi Method: Techniques and Applications* Massachusetts: Addison-Wesley Publishing Company, pp. 262-282.
- Schmidt, R.C. (1997) 'Managing Delphi surveys using nonparametric statistical techniques', *Decision Sciences*, 28(3), pp. 763-774.
- Sedentary Behaviour Research Network (2012) 'Letter to the Editor: Standardized use of the terms sedentary and sedentary Behaviours', *Applied Physiology, Nutrition and Metabolism*, 37(3), pp. 540-545.
- Shannon-Baker, P. (2015). Making paradigms meaningful in mixed methods research. *Journal of Mixed Methods Research*, DOI: 10.1177/1558689815575861.
- Sharrack, B. and Hughes, R.A.C. (1999) 'The Guy's neurological disability scale (GNDS): A new disability measure for multiple sclerosis', *Multiple Sclerosis*, 5(4), pp. 223-233.
- Shumway-Cook, A. and Woollacott, M. (2007) *Motor Control: Translating Research into Clinical Practice*. Third Edition edn. USA: Lippincott Williams and Wilkins.
- Siegel, S. and Castellan, N. (1988) *Nonparametric statistics for the behavioural Sciences*. 2nd edn. New York: McGraw-Hill.
- Silver, C. and Lewins, A. (2010) 'Computer Assisted Qualitative Data Analysis', in McGaw, B., Peterson, P. and Baker, E. (eds.) *The International Encyclopedia of Education*. 3rd edn. Elseview.

Smith, J.A. and Osborn, M. (2003) 'Interpretative phenomenological analysis'. In Smith, J.A. (ed) *Qualitative psychology: a practical guide to research methods*. London: Sage, pp. 51-80.

Smith, C., Hale, L., Olson, K. and Schneiders, A.G. (2009) 'How does exercise influence fatigue in people with multiple sclerosis', *Disability and rehabilitation*, 31(9), pp. 685-692.

Smith, C., Olson, K., Hale, L.A., Baxter, D. and Schneiders, A.G. (2011) 'How does fatigue influence community-based exercise participation in people with multiple sclerosis?', *Disability and rehabilitation*, 33(23-24), pp. 2362-2371.

Smith, C.M., Hale, L.A., Mulligan, H.F. and Treharne, G.J. (2013a) 'Participant perceptions of a novel physiotherapy approach ("Blue Prescription") for increasing levels of physical activity in people with multiple sclerosis: A qualitative study following intervention', *Disability and rehabilitation*, 35(14), pp. 1174-1181.

Smith, C.M., Hale, L.A., Olson, K., Baxter, G.D. and Schneiders, A.G. (2013b) 'Healthcare provider beliefs about exercise and fatigue in people with multiple sclerosis', *Journal of Rehabilitation Research and Development*, 50(5), pp. 733-743.

Snape, D. and Spencer, L. (2009) 'The Foundations of Qualitative Research', in Ritchie, J. and Lewis, J. (eds.) *Qualitative Research Practice: A guide for Social Science Students and Researchers*, pp. 1-23.

Snook, E.M. and Motl, R.W. (2009) 'Effect of exercise training on walking mobility in multiple sclerosis: A meta-analysis', *Neurorehabilitation and neural repair*, 23(2), pp. 108-116.

Solari, A., Filippini, G., Gasco, P., Colla, L., Salmaggi, A., La Mantia, L., Farinotti, M., Eoli, M. and Mendozzi, L. (1999) 'Physical rehabilitation has a positive effect on disability in multiple sclerosis patients', *Neurology*, 52(1), pp. 57-62.

- Somerset, M., Campbell, R., Sharp, D.J. and Peters, T.J. (2001) 'What do people with MS want and expect from health-care services?', *Health Expectations*, 4(1), pp. 29-37.
- Sosnoff, J.J., Finlayson, M., McAuley, E., Morrison, S. and Motl, R.W. (2014) 'Home-based exercise program and fall-risk reduction in older adults with multiple sclerosis: Phase 1 randomized controlled trial', *Clinical rehabilitation*, 28(3), pp. 254-263.
- Spencer, L., Ritchie, J., O'Connor, W. (2009) 'Analysis: Practices, Principles and Processes', in Ritchie, J. and Lewis, J. *Qualitative Research Practice: A Guide for Social Science Students and Researchers*. Ritchie, J.; Lewis, J. edn. London: SAGE Publications, pp. 199-218.
- Steadman, T.L. (2012) '*Medical dictionary for the health professions and nursing*', 7<sup>th</sup> edition. UK: Wolters Kluwer Health- Lippincott Williams and Wilkins.
- Steiner, W.A., Ryser, L., Huber, E., Uebelhart, D., Aeschlimann, A. and Stucki, G. (2002) 'Use of the ICF model as a clinical problem-solving tool in physical therapy and rehabilitation medicine', *Physical Therapy*, 82(11), pp. 1098-1107.
- Strauss, A., and Corbin, J. (1998) '*Basics of qualitative research: Procedures and techniques for developing grounded theory*'. ed: Thousand Oaks, CA: Sage.
- Stroud, N., Minahan, C. and Sabapathy, S. (2009a) 'The perceived benefits and barriers to exercise participation in persons with multiple sclerosis', *Disability and rehabilitation*, 31(26), pp. 2216-2222.
- Stroud, N.M. and Minahan, C.L. (2009b) 'The impact of regular physical activity on fatigue, depression and quality of life in persons with multiple sclerosis', *Health and Quality of Life Outcomes*, 7.
- Strupp, J., Hartwig, A., Golla, H., Galushko, M., Pfaff, H. and Voltz, R. (2012) 'Feeling severely affected by Multiple Sclerosis: What does this mean?', *Palliative medicine*, 26(8), pp. 1001-1010.

Stuifbergen, A.K. and Rogers, S. (1997) 'Health Promotion: An Essential Component of Rehabilitation for Persons with Chronic Disabling Conditions', *Advances in Nursing Science*, 19(4), pp. 1-20.

Stuifbergen, A.K. (1997) 'Physical Activity and Perceived Health Status in Persons with Multiple Sclerosis', *Journal of Neuroscience Nursing*, 29(4), pp. 238-243.

Stuifbergen, A.K., Blozis, S.A., Harrison, T.C. and Becker, H.A. (2006) 'Exercise, Functional Limitations, and Quality of Life: A Longitudinal Study of Persons With Multiple Sclerosis', *Archives of Physical Medicine and Rehabilitation*, 87(7), pp. 935-943.

Stuifbergen, A.K. and Roberts, G.J. (1997) 'Health promotion practices of women with multiple sclerosis', *Archives of Physical Medicine and Rehabilitation*, 78(12, Supplement 5), pp. S3-S9.

Stuifbergen, A.K., Becker, H., Blozis, S., Timmerman, G. and Kullberg, V. (2003) 'A randomized clinical trial of a wellness intervention for women with multiple sclerosis', *Archives of Physical Medicine and Rehabilitation*, 84(4), pp. 467-476.

Sutliff, M.H. (2010) 'Contribution of impaired mobility to patient burden in multiple sclerosis', *Current medical research and opinion*, 26(1), pp. 109-119.

Sutherland, G., and Andersen, M. B. (2001) 'Exercise and multiple sclerosis: physiological, psychological, and quality of life issues', *Journal of Sports Medicine and Physical Fitness*, 41(4), pp. 421-432.

Sumsion, T. (1998) 'The Delphi technique: an adaptive research tool', *The British Journal of Occupational Therapy*, 61(4), pp.153-156.

Tashakkori, A. and Creswell, J.(2007) 'The new era of mixed methods', *Journal of mixed methods research*, 1(1), pp. 3-7.

Tashakkori, A. and Teddlie, C. (eds.) (2010) *Mixed Methods in Social and Behavioral Research*. Second edn. UK: SAGE.

Taylor, B. (2010) *Reflective Practice for Healthcare Professionals*. Third Edition. United Kingdom: The McGraw Companies.

The Health Foundation (2014) Person-centred care made simple. Available at:  
<http://personcentredcare.health.org.uk/> (accessed: Novemeber 2015)

Tod, A. (2010) 'Interviewing', In Gerrish, K. and Lacey, A. (eds.) *The Research Process in Nursing*. Sixth Edition. United Kingdom: Wiley-Blackwell, pp. 345-357.

Toombs, S.K. (1993) '*The meaning of Illness: A Phenomenological Account of the Different Perspectives of Physician and Patient*', Netherlands: Kluwer Academic Publishers.

Toombs, S.K. (1995)'The lived experience of disability', *Human Studies*, 18(1), pp.9-23.

Toomey, E. and Coote, S.B. (2012) 'Physical rehabilitation interventions in nonambulatory people with multiple sclerosis: A systematic review', *International Journal of Rehabilitation Research*, 35(4), pp. 281-291.

Topping, A. (2010) ' The Quantitative-Qualitative Continuum', In Gerrish, K. and Lacey, A. (eds.) *The Research Process in Nursing*. Sixth Edition. United Kingdom: Wiley-Blackwell, pp.129-141.

USDHHS. (1996) *Physical Activity and Health: A Report of the Surgeon General*. Atlanta: Department of Health and Human Services, Centers for Disease Control and Prevention, National Center for Chronic Disease Prevention and Health Promotion.

Valdez, AM. (2009) 'So much to learn, so little time: educational priorities for the future of emergency nursing', *Advanced Emergency Nursing Journal*, 31(4), pp.337-353.

van Asch, P. (2011) 'Impact of mobility impairment in multiple sclerosis 2-patients' perspectives', *European Neurological Review*, 6(2), pp. 115-120.

van de Berg, M., Dawes, H., Wade, D., Newman, M., Burridge, J., Izadi, H. and Sackley, C. (2006) 'Treadmill training for individuals with multiple sclerosis: a pilot randomised trial.', *Journal of Neurology, Neurosurgery & Psychiatry*, 77, pp. 531-533.

Van Der Linden, M.L., Bulley, C., Geneen, L.J., Hooper, J.E., Cowan, P. and Mercer, T.H. (2014) 'Pilates for people with multiple sclerosis who use a wheelchair: Feasibility, efficacy and participant experiences', *Disability and rehabilitation*, 36(11), pp. 932-939.

Van Der Ploeg, H.P., Van Der Beek, A.J., Van Der Woude, L.H.V. and Van Mechelen, W. (2004) 'Physical activity for people with a disability: A conceptual model', *Sports Medicine*, 34(10), pp. 639-649.

Van Dijk, J. A. (1990) 'Delphi questionnaires versus individual and group interviews: A comparison case', *Technological forecasting and social change*, 37(3), pp. 293-304.

Van Tulder, M., Furlan, A., Bombardier, C., Bouter, L. (2003) 'Updated method guidelines for systematic reviews in the Cochrane collaboration back review group', *Spine*, 28(12), pp. 1290-1299.

Vazirinejad, R., Lilley, J. and Ward, C. (2008) 'A health profile of adults with multiple sclerosis living in the community', *Multiple Sclerosis*, 14(8), pp. 1099-1105.

Verhagen, A.P., De Vet, H.C.W., De Bie, R.A., Kessels, A.G.H., Boers, M., Bouter, L.M. and Knipschild, P.G. (1998) 'The Delphi list: A criteria list for quality assessment of randomized clinical trials for conducting systematic reviews developed by Delphi consensus', *Journal of clinical epidemiology*, 51(12), pp. 1235-1241.

- Vickrey, B.G., Hays, R.D., Genovese, B.J., Myers, L.W. and Ellison, G.W. (1997) 'Comparison of a generic to disease-targeted health-related quality-of-life measures for multiple sclerosis', *Journal of clinical epidemiology*, 50(5), pp. 557-569.
- Wade, D.T. (2009) 'Goal setting in rehabilitation: An overview of what, why and how', *Clinical rehabilitation*, 23(4), pp. 291-295.
- Wade, D.T. and Collin, C. (1988) 'The Barthel ADL Index: A standard measure of physical disability?', *International disability studies*, 10(2), pp. 64-67.
- Wade, M.G. and Ellis, M.J. (1971) 'Measurement of free-range activity in children as modified by social and environmental complexity.', *American Journal of Clinical Nutrition*, 24(12), pp. 1457-1460.
- Walker, A. and Selfe, J. (1996) 'The Delphi Method: a useful tool for the allied health researcher.', *British Journal of Therapy and Rehabilitation*, 3, pp. 677-681.
- Walker, A.M. (1994) 'A Delphi study of research priorities in the clinical practice of physiotherapy', *Physiotherapy*, 80(4), pp. 205-207.
- Ware, J. and Sherbourne, C. (1992) 'The MOS 36-item short form health survey(SF-36): A conceptual framework and item selection.', *Medical Care*, 30, pp. 473-483.
- Webb, C. and Kevern, J. (2001) 'Focus groups as a research method: A critique of some aspects of their use in nursing research', *Journal of advanced nursing*, 33(6), pp. 798-805.
- Weber, R. (1990) '*Basic Content Analysis*' 2nd edn. London: SAGE publications.
- Wee, J., and Lysaght, R. (2009) 'Factors affecting measures of activities and participation in persons with mobility impairment' *Disability & Rehabilitation*, 31(20), pp. 1633-1642.

- Weikert, M., Dlugonski, D., Balantrapu, S. and Motl, R. W. (2011) 'Most Common Types of Physical Activity Self-Selected by People with Multiple Sclerosis', *International Journal of MS Care*, 13(1), pp. 16-20.
- White, L.J. and Dressendorfer, R.H. (2004) 'Exercise and multiple sclerosis', *Sports Medicine*, 34(15), pp. 1077-1100.
- Wilkinson, S. (1998) 'Focus groups in health research. Exploring the meanings of health and illness', *Journal of Health Psychology*, 3(3), pp. 329-348.
- Williams, P.L. and Webb, C. (1994) 'The Delphi technique: a methodological discussion', *Journal of advanced nursing*, 19(1), pp. 180-186.
- Willoughby, E.W. and Paty, D.W. (1988) 'Scales for rating impairment in multiple sclerosis: A critique', *Neurology*, 38(11), pp. 1793-1798.
- World Confederation for Physical Therapy (WCPT) (2014) Policy Statement: Description of physical Therapy, available at:  
<http://www.wcpt.org/policy/ps-descriptionPT> (accessed April 2015)
- World Health Organization (2001), International classification of functioning, disability and health: ICF, World Health Organization, Geneva.
- World Health Organisation: [http://www.who.int/topics/physical\\_activity/en/](http://www.who.int/topics/physical_activity/en/)  
(Accessed: March 2011).
- Woudenberg, F. (1991) 'An evaluation of Delphi', *Technological Forecasting and Social Change*, 40(2), pp. 131-150.
- Ziglio, E. (1996) 'The Delphi Method and its Contribution to Decision-Making', in Adler, M. and Ziglio, E. (eds.) *Gazing into the Oracle*. Jessica Kingsley Publishers, pp. 3-31.
- Zwibel, H.L. (2009) 'Contribution of impaired mobility and general symptoms to the burden of multiple sclerosis', *Advances in Therapy*, 26(12), pp. 1043-1057.

## Appendix 1: The 2010 McDonald Criteria for Diagnosis of MS

Clinical Presentation	Additional Data Needed for MS Diagnosis
$\geq 2$ attacks <sup>a</sup> ; objective clinical evidence of $\geq 2$ lesions or objective clinical evidence of 1 lesions with reasonable historical evidence of a prior attack <sup>b</sup>	None <sup>c</sup>
$\geq 2$ attacks <sup>2</sup> ; objective clinical evidence of 1 lesion	Dissemination in space, demonstrated by: $\geq 1$ T2 lesion in at least 2 of 4 MS-typical regions of the CNS (periventricular, juxtacortical, infratentorial, or spinal cord) <sup>d</sup> ; or Await a further clinical attack <sup>a</sup> implicating a different CNS site
1 attack <sup>a</sup> ; objective clinical evidence of $\geq 2$ lesions	Dissemination in time, demonstrated by: Simultaneous presence of asymptomatic gadolinium- enhancing and non-enhancing lesions at any time; or A new T2 and/or gadolinium-enhancing lesion(s) on follow-up MRI, irrespective of its timing with reference to a baseline scan; or Await a second clinical attack <sup>a</sup>
1 attack <sup>a</sup> ; objective clinical evidence of 1 lesion (clinically isolated syndrome)	Dissemination in space and time, demonstrated by: For DIS: $\geq 1$ T2 lesion in at least 2 of 4 MS-typical regions of the CNS (periventricular, juxtacortical, infratentorial, or spinal cord) <sup>d</sup> ; or Await a second clinical attack <sup>a</sup> implicating a different CNS site; and For DIT: Simultaneous presence of asymptomatic gadolinium- enhancing and non-enhancing lesions at any time; or A new T2 and/or gadolinium-enhancing lesion(s) on follow-up MRI, irrespective of its timing with reference to a baseline scan; or Await a second clinical attack <sup>a</sup>
Insidious neurological progression suggestive of MS (PPMS)	1 year of disease progression (retrospectively or prospectively divided) plus 2 of 3 of the following criteria: 1. Evidence of DIS in the brain based on $\geq 1$ -T2 lesions in the MS-characteristic (periventricular, juxtacortical, infratentorial) regions 2. Evidence for DIS in the spinal cord based on $\geq 2$ T2 lesions in the cord 3. Positive CSF (isoelectric focusing evidence of oligoclonal bands and/or elevated IgG index)

If the Criteria are fulfilled and there is no better explanation for the clinical presentation, the diagnosis is "MS"; if suspicious, but the Criteria are not completely met, the diagnosis is "possible MS"; if another diagnosis arises during the evaluation that better explains the clinical presentation, then the diagnosis is "not MS."

a An attack (relapse; exacerbation) is defined as patient-reported or objectively observed events typical of an acute inflammatory demyelinating event in the CNS, current or historical, with duration of at least 24 hours, in the absence of fever or infection. It should be documented by contemporaneous neurological examination, but some historical events with symptoms and evolution characteristic for MS, but for which no objective neurological findings are documented, can provide reasonable evidence of a prior demyelinating event. Reports of paroxysmal symptoms (historical or current) should, however, consist of multiple episodes occurring over not less than 24 hours. Before a definite diagnosis of MS can be made, at least 1 attack must be corroborated by findings on neurological examination, visual evoked potential response in patients reporting prior visual disturbance, or MRI consistent with demyelination in the area of the CNS implicated in the historical report of neurological symptoms.

b Clinical diagnosis based on objective clinical findings for 2 attacks is most secure. Reasonable historical evidence for 1 past attack, in the absence of documented objective neurological findings, can include historical events with symptoms and evolution characteristics for a prior inflammatory demyelinating event; at least 1 attack, however, must be supported by objective findings.

c No additional tests are required. However, it is desirable that any diagnosis of MS be made with access to imaging based on these Criteria. If imaging or other tests (for instance, CSF) are undertaken and are negative, extreme caution needs to be taken before making a diagnosis of MS, and alternative diagnoses must be considered. There must be no better explanation for the clinical presentation, and objective evidence must be present to support a diagnosis of MS.

d Gadolinium-enhancing lesions are not required; symptomatic lesions are excluded from consideration in subjects with brainstem or spinal cord syndromes.

MS= multiple sclerosis; CNS= central nervous system; MRI=magnetic resonance imaging; DIS= dissemination in space; DIT= dissemination in time; PPMS= primary progressive multiple sclerosis; CSF=cerebrospinal fluid; IgG= immunoglobulin G

Adapted from Polman *et al.*, 2010

**Appendix 2a: An example of search terms and studies identified from Academic Search Complete database**

	<b>Search Terms</b>	<b>Number of studies identified</b>
Search Term 1	Multiple Sclerosis OR MS	27378
Search Term 2	Search Term 1 AND Exercise OR Exercise Therapy	520
Search Term 3	Search Term 2 AND Physical Activity	111
Search Term 4	Search Term 3 AND Qualitative	6
Search Term 5	Search Term 3 AND Lived Experience	0
Search Term 6	Search Term 3 AND Meaningful Activities	2
Search Term 7	Search Term 3 AND Patient Perspectives	1
Search Term 8	Search Term 3 AND Patient Voice	0
Search Term 9	Search Term 3 AND Community	30
Search Term 10	Search Term 1 AND 2 AND 3 AND Delphi Method	0
Search Term 11	Search Term 1 AND 2 AND 3 and mixed methods	0

**Total studies identified from Academic Search Complete database = 39**

## Appendix 2b: The effectiveness and safety of exercise and physical activity in pwMS

<b>Author /Country</b>	<b>Aims</b>	<b>Reviewed studies included</b>	<b>Conclusion/ Limitations</b>
Rietberg et al., 2004 Netherlands	To determine the effectiveness of exercise therapy in pwMS in relation to ADLs and HQoL	Petajan et al 1996 Jones et al 1999 Wiles et al 2001 Mostert 2002 Carter and White 2003 O'Connell et al., 2003 DeBolt and McCubbin 2004 Lord et al 1998 Solari et al 1999	Strong evidence in favour of exercise therapy compared to no exercise, improved muscle strength, exercise tolerance and mobility related activity. Moderate evidence for improved mood.  <i>Limitations:</i> no control for confounding factors eg. Participant variability, dose of exercise (intensity, duration and frequency). Participants included were either mildly or moderately affected by MS.
Sa 2013 Portugal	To investigate the effects of exercise therapy in pwMS between 2004-2012	Cattaneo et al 2007 Dalgas et al 2010 Dettmers et al 2009 Dodd et al 2011 McCullagh et al 2008 Miller et al 2011 Mutluay et al 2007 Oken et al. 2004 Romberg et al 2004 Romberg et al 2004 Surakka et al 2004	Exercise therapy is beneficial for improving muscle strength, balance, fatigue and QoL in pwMS and is recommended as part of the rehabilitation of pwMS.  <i>Limitations:</i> Benefits of exercise therapy to different demographic profile is inconclusive, effects of exercise therapy based on dose remains to be determined, difficult to pool data due to the different outcome measures used.

<b>Author /Country</b>	<b>Aims</b>	<b>Reviewed studies included</b>	<b>Conclusion/ Limitations</b>	
Snook and Motl 2009  USA	To determine the effects of exercise training on mobility in pwMS	Petajan et al., 1996 Rodgers et al., 1999 Debolt and McCubbin 2004 Freeman and Allison 2004 Oken et al 2004 Romberg et al 2004 Schulz et al 2004 White et al 2004 Gutierrez et al 2005 Jones et al 1999 Husted et al 1999 Patti et al 2003 Yates et al 2002	Kileff and Ashburn 2005 Romberg et al, 2005 van den Berg 2006 Rasova et al 2006 Taylor et al 2006 Ayan Perez et al 2007 Bjarnadottir et al 2007 Newman et al 2007 Rampello et a., 2007	Exercise training improves walking mobility (small improvement $g=0.19$ (95%CI, 0.09-0.28).  <i>Limitations:</i> The majority of the studies reviewed included participants with EDSS score of 4, which meant that they were ambulant without mobility aid and mild to moderately affected by MS. The majority of the studies were conducted in exercise facilities, with only two reporting exercise interventions performed within the home environment.
Toomey and Coote 2012  Ireland	To evaluate the evidence regarding physical rehabilitation interventions in non-ambulatory pwMS.  All studies up to 2011	Smith and Hale 2006 Svensson et al 1994 Klefbeck and Hamrah Nedjad 2003 Baer and Lewis 1987 Freeman et al 1997 Grasso et al 2005 Kinnman et al 1997 & 2000 Flensner and Lindencrona 1999 & 2002 Baker et al., 2007	Giesser et al 2007 Gosselink et al 2000 Hamer and Hills 1991 Peterson 2001 Capello et al 1995	Trends of improvement following some rehabilitation interventions noted but no high-grade evidence for benefit in pwMS that are non-ambulant. Evidence is inconclusive.  <i>Limitations:</i> inconsistencies in the studies reviewed, not all RCTs, varied interpretation of the EDSS in studies included in the reviews, which limits interpretation of results. Also, outcome measures mainly impairment and activity based.

<b>Author /Country</b>	<b>Aims</b>	<b>Reviewed studies included</b>	<b>Conclusion/ Limitations</b>
Motl and Gosney 2008  USA	To examine the effects of exercise interventions on QoL in MS	Petajan et al., 1996 Mostert and Kesselring 2002 Romberg et al, 2005 van den Berg 2006 Rasova et al 2006 Oken et al 2004 Schulz et al 2004 White et al 2004 Kileff and Ashburn 2005 Navipour et al 2006 Taylor et al 2006 Sutherland et al 2001 McAuley et al 2007	Exercise had small improvement in QoL. Aerobic exercises had more of a positive effect on QoL compared to non-aerobic interventions. Interventions lasting <3 and > 3 months resulted in statistically significant improvement in QoL however interventions lasting <3 months had a bigger effect.  <i>Limitations:</i> Did not address the methodological quality of the studies included in the reviews. Did not account for demographic profile (e.g. age, gender and types of MS) in studies.
Anthony and Gidugu (2012)  USA	To examine the effectiveness of exercise and physical activity on psychological and quality of life outcomes in pwMS	Petajan et al., 1996 Sutherland et al 2001 Oken et al 2004 Romberg et al, 2005 Dettmerts et al 2009 Dalgas et al 2010 Velikonja et al 2010 McCullagh et al 2008 Stuifbergen et al 2006 Motl and McAuley 2009 Stroud and Minahan (2009) Motl et al 2010 Bombardier et al 2011  Solari et al 1999 Mostert and Kesselring 2002 Schulz et al 2004 McAuley et al 2007 Ahmadi et al 2010 Sabapathy et al 2010 Rasova et al 2006 Mutluay et al 2008 Motl et al 2008 Motl et al 2009 Turner et al 2009 Suh et al 2010	Exercise and physical activity improves QoL and mood in pwMS. Increased physical activity associated with higher QoL, self-esteem, less depression fatigue and pain.  <i>Limitations:</i> Included other studies other than RCTs. Did not account for demographic profile (e.g. age, gender types of MS) in studies.

<b>Author /Country</b>	<b>Aims</b>	<b>Reviewed studies included</b>		<b>Conclusion/ Limitations</b>
Andreasen et al 2011 Denmark	To determine the effect of exercise on fatigue in pwMS	Petajan et al., 1996 Romberg et al, 2005 Mostert and Kesselring 200 van den Berg 2006 Rasova et al 2006 Oken et al 2004 Schulz et al 2004 White et al 2004 Gutierrez et al 2005 Fragoso et al 2008 Geddes et al., 2009; Plow et al., 2009;Smith et al., 2009	Dodd et al, 2006 Newman et al 2007 Rampello et al, 2007 Cakt et al 2010 Dalgas et al 2010 Kileff et al 2005 Surakka et al 2004 Broach and Dattilo 2001 Roehrs and Karst 2004 McCullagh et al., 2008	Exercise has the potential to have a positive effect on fatigue in pwMS.  <i>Limitations:</i> The authors did not state how studies were analysed or the methodological rigor of the studies included in the review.
Ensari et al 2014 USA	To examine the effect of exercise training on depression	Ahmadi et al 2013 Cakit et al 2010 Dalgas et al 2010 Dettmers et al 2009 Romberg et al 2005 Skjerkhaek et al Briken et al 2014	Hebert et al 2011 Learmonth et al 2012 Oken et al. 2004 Petajan et al 1996 Schulz et al 2004 Sutherland et al 2001	Exercise training can lead to a small but statistically significant reduction in depression in pwMS.  <i>Limitations:</i> Authors did not state the clinical course of MS. Findings limited to pwMS who are mildly or moderately affected by MS
Pilutti et al., 2014 Canada	To quantify the rate of relapses and adverse events reported in RCTs of exercise training in pwMS.	Carter et al 2013 Doulatabad et al 213 Garrett et al 2013 Ahmadi et al 2010 Golzari et al., 2010 Cakit et al 2010 Geddes et al 2009 Dalgas et al 2009 Bjarnadottir et al 2007 Debolt and McCubbin 2004 Mostert and Kesselring2002 Schulz et al 2004 Harvey et al., 1999	Hebert et al 2011 Kargarfard et al 2012 Learmonth et al 2012 McCullagh et al 2008 Sosnoff et al 2014 Negahban et al 2013 Oken et al 2004 Petajan et al 1996 Romberg et al 2004 Tarakci et al 2013 van den berg 2006 Broekmans et al 2011 Nilsagard et al 2013	Exercise training is safe for pwMS. pwMS should be encouraged to engage in exercise as findings did not report an increase in relapse rates and adverse events over and above what is seen in the average population.  <i>Limitations:</i> relapse was self reported and not clinically verified. Findings limited to people who are mildly or moderately affected by MS.

## **Appendix 2b: Content and frequency of exercise and physical activity in people with MS**

<b>Author/Country</b>	<b>Study Aims</b>	<b>Setting/participants (Sex/age/years/type of MS)</b>	<b>Methods/Analysis (structure/unstruc- ctured activities)</b>	<b>Outcome Measures</b>	<b>Results</b>	<b>Limitations/Bias</b>
O'Hara, Desouza and Ide, 2000  United Kingdom	To gauge views and priorities of pwMS to inform design of self-care programme	Community dwelling 200 recruited, 136 pwMS started study (68% response rate) Age range 22-78 years (mean 50 years) Type of MS- RR (N=32, 47%), Other progressive (N=71, 53%). N=131 (96%) Round 2, N=126 (95%) Recruited through MS organisations	3 Rounds Delphi Study - Postal Questionnaire Round 1- List self care practice- Content Analysis Round 2- Rank categories- mean rank Round 3- Consensus- stability across rounds, Kendall coefficient of concordance $p<0.05$	Impact of MS on life- Likert rating scale	Consensus was not achieved, a wide range of self-care practices were reported, information used to develop self- management programmes	Authors did not state whether or not any disability and or functional scales were used in order to compare this study to others in the field.

<b>Author/Country</b>	<b>Study Aims</b>	<b>Setting/participants (Sex/age/years/type of MS)</b>	<b>Methods/Analysis (structure/unstructured activities)</b>	<b>Outcome Measures</b>	<b>Results</b>	<b>Limitations/Bias</b>
Einarsson et al., 2006  Sweden	To describe independence in personal and instrumental ADLs	Community 166pwMS Mean age $51 \pm 12$ yrs. N=118 (71%) women, N=48 (29%) men; RR,SP,PP Participants were chosen at random and stratified by age, gender and hospital from a database that included people who had met study inclusion criteria	Cross sectional study Structured Interviews	BI, Katz Extended ADL Index –personal and instrumental ADLs, Frenchay Activities Index Coherence Scale-coping strategy	52% independent in ADLs, 30% independent in instrumental ADL, 35% normal frequency of social/lifestyle activities. Difficulties with transportation, maintaining home, mobility and gardening were mentioned	Used structured interviews, which are restrictive. Did not state how the survey was developed or types of questions asked. The authors did not address participants' disability levels based on EDSS.

<b>Author/Country</b>	<b>Study Aims</b>	<b>Setting/participants (Sex/age/years/type of MS)</b>	<b>Methods/Analysis (structure/unstructured activities)</b>	<b>Outcome Measures</b>	<b>Results</b>	<b>Limitations/Bias</b>
Currie et al., 2009 Canada	To examine the types and amount of physical activity	Community N=108 pwMS Age 51 yrs (SD11.7) 74 Females/34 males Mean EDSS 3.5 (SD 2.9)	Cross Sectional Study – Questionnaire  Frequency counts, central tendency, Spearman rank correlation, independent t-test	EDSS	93.5% engage in PA at least once per week. 17.7% group classes, 63.9% self directed activity, 88% short bursts of moderate activity. As disability increased physical activity levels decrease.	Highly functional, restricted to small town in Canada, low response rate- 38.2%. Restricted the activities people reported. Not a comprehensive view of activities pwMS engaged in.. No mention of type of MS in sample
Weikert et al., 2011 USA	To find out most frequent types of physical activity in pwMS	Community 272pwMS (235 women/36 men), RRMS only	Postal questionnaire from data from a previous study- longitudinal study Frequency analysis, Descriptive statistics (mean and SD), and Chi Square tests SPSS	PDDS, Modifiable Activity Questionnaire (MAQ), Leisure Time Physical Activity (LTPA)	5 most common PA, walking (79%), bicycling (30%), gardening (44%), calisthenics (20%), weight training (34%)	Only looked at mobility disability using PDDS scale; Did not look at meaningful activity, reasons why. Limited to RRMS

Author/Country	Study Aims	Setting/participants (Sex/age/years/type of MS)	Methods/Analysis (structure/unstruc- ctured activities)	Outcome Measures	Results	Limitations/Bias
Motl, McAuley and Snook, 2005  USA	To compare physical activity levels of pwMS with other diseased and non-diseased population	13 studies with 2360 pwMS Type of MS- RR/PP	Meta-Analysis  Analysis: Effect size expressed as Cohen's d	Survey and Objective measures of physical activity	People with MS are inactive compared to healthy individuals but comparable with individuals with other long term conditions (ES=-0.60(95% CI=-0.44,-0.77).	Lack of information about the disease severity of participants hence it was difficult to compare these findings with other studies in pwMS. Also, the authors were not explicit about the methodological quality of the studies included in the review in either the methods or results section.
Sandroff et al 2012  USA	To compare physical activity levels in pwMS and healthy individuals	77 pwMS (66F/11M) and 77 aged, weight matched control. Mean age 47.3 for pwMS and 47 for control Recruited via MS society- RRMS ? other types of MS	Analysis: descriptive statistics	GLTEQ, IPAQ, MET, ActiGraph accelerometer. PDDS, MSWS-12	pwMS had reduced PA levels compared to healthier peers.	Accelerometer limits some forms of activities-e.g. swimming, all participants ambulant, more than half (63%) had RRMS

<b>Author/Country</b>	<b>Study Aims</b>	<b>Setting/participants (Sex/age/years/type of MS)</b>	<b>Methods/Analysis (structure/unstruc- tured activities)</b>	<b>Outcome Measures</b>	<b>Results</b>	<b>Limitations/Bias</b>
Rietberg et al 2014  Netherlands	To examine the quantity and patterns of physical activity in pwMS over a 24 hour period	43pwMS (30F/13M) and age gender matched control healthy individuals Mean age 48.7 pwMS recruited locally Type of MS, RR/SP/PP EDSS<6	Multi level analyses across the day (am, afternoon and pm)	24 Hour activity monitor – accelerometer	pwMS had lower levels of physical activity more notable in the morning and persisted throughout the day.	pwMS all ambulant, did not state the activities people were involved in, possible influence of the accelerometer on PA levels.
Kayes et al 2011a  New Zealand	To explore the impact of physical activity on health beliefs and illness behaviours	282pwMS (222F/ 60M) Age range 23-83 years Type of MS-RR,SP, B	Cross sectional survey using questionnaires	PADS-R, BHADP and MSSS and CFQ, GNDS.	pwMS were more likely to engage in household activities; mental fatigue influenced physical activity	Low response rate (38%). Sample recruited locally hence limiting the findings to wider MS populations.

<b>Author/Country</b>	<b>Study Aims</b>	<b>Setting/participants (Sex/age/years/type of MS)</b>	<b>Methods/Analysis (structure/unstructured activities)</b>	<b>Outcome Measures</b>	<b>Results</b>	<b>Limitations/Bias</b>
Beckerman et al 2010  Netherlands	To determine physical activity levels and factors related to physical activity behaviours	106pwMS (66F/40M) Age range 20-65 years Type of MS- RR, non-RR Median EDSS score 3	Cross sectional survey-questionnaires	SQUASH, EDSS, FSS, CES-D, EQ-5D	pwMS spend ~30hrs per week on activities with MET $\geq 2$ . Determinants of PA = disease severity, disability pension and caring for children	Authors did not measure changes in physical activity levels. More than half of study participants mildly affected by MS.
McAuley et al 2007  USA	To determine the effects of an efficacy enhancement programme on adherence and wellbeing	26pwMS (23F/3M)- 13 in standard care and 13 intervention group Mean age 43.46 years (7.6 SD) Type of MS- RR/SP/PP	RCT – Standard care and efficacy enhancement completed twice weekly over a period of 12 weeks.	EXSE, SWLS, SF-12,	Greater adherence noted with efficacy enhancement intervention	Small sample size, unclear how randomisation was done or whether or not blinding was done.
Motl et al 2011b  USA	To examine the effect of Internet intervention on physical activity.	54pwMS but analysis completed on (43F/5M), RRMS	RCT- intervention or Waitlist control group	GLTEQ, EXSE, PDDS, EDSS	Intervention group Increase in PA ( $p=0.01$ ), large increase over time ( $d=0.72$ ), increase in goal setting ( $p=0.001$ ) compared to the control group	No blinding of participants. Only people with RRMS and mildly affected by MS were included

## Appendix 2b: Exercise and physical activity: pwMS' perspective

<b>Author/Country</b>	<b>Study Aims</b>	<b>Participants (mild/mod/severe) Sex/age/years</b>	<b>Methods/Analysis (structure/ unstructured activities)</b>	<b>Outcome Measures</b>	<b>Results</b>	<b>Limitations/Bias</b>
Van der Linden et al., 2014  United Kingdom	To explore the feasibility, efficacy and experience of Pilates in pwMS who use w/c	15 pwMS (8 females/7 males) All SPMS, EDSS (7-8), all w/c users. Age- 31-65 (mean 51, SD 8)  12 weeks exercise program (1 drop out from group due to relapse) only 10 participated in Focus groups Recruited from local clinicians and MS groups  Location: Community day centres	Mixed methods- pre and post test design, followed by x2 FG 6 weeks post intervention Statistics: ANOVA, Wilcoxon Signed Rank test , Post-hoc tests for parametric tests to evaluate significant differences between sessions, p<0.05 Qualitative analysis- Inductive Framework analysis	Outcomes measures taken baseline, 6 and 12 weeks Sitting stability, (COPmax), Posture, Pain (VAS), Function (COPM), Fatigue (FSS), MSIS-29	Significant improvement COP (p=0.046), sitting posture (p=0.004), pain in shoulders and back (0.005), MSIS29(0.006) No significance on COPM Participants described benefits physical, psychological and social benefits, increased confidence in ADLs, enjoyment of classes	No rationale for mixed methods approach. No control, repeated measures could have a learning effect on participants. Hard to differentiate for this without control group. Transportation arranged/ cost paid for participants and classes free. Results limited only to people with SPMS

<b>Author/Country</b>	<b>Study Aims</b>	<b>Participants (mild/mod/severe) Sex/age/years</b>	<b>Methods/Analysis (structure/ unstructured activities)</b>	<b>Outcome Measures</b>	<b>Results</b>	<b>Limitations/Bias</b>
Learmonth et al., 2013  United Kingdom	To explore experiences and views of pwMS (moderately affected) on 12 week exercise program	14 pwMS (4Males/10 Females) Age range- 41-68 EDSS score 5-6.5 Recruited locally – classes held in community leisure centre	Mixed methods (Quant and Qual) Based on 12 week ex group program across two sites FG- x2 – semi-structured Analysis- thematic content analysis	MMSE over 24	Benefits of exercise groups- improvement in symptom, goal achievement, social support Barriers- knowledge of health and leisure professionals, MS symptoms	Findings limited to participants who were involved in exercise group. Did not report on the type of MS represented in the sample
Kayes et al., 2011 b)  New Zealand	To explore facilitators and barriers of engaging in physical activity	Community dwelling recruited through local MS societies 10 pwMS (7F/3M) Age range 34-53 Type of MS (RR, SP, chronic progressive)	Semi-structured interviews Analysis- informed by Grounded theory approach	GNDS	Beliefs about PA (e.g. fine line between benefit and harm/ negative impact of PA on MS) Emotional response (e.g. negative experiences of PA before and after MS) Role of fatigue in influencing decisions around physical activity	Small sample recruited purposively thus views and opinions might not be representative of the wider MS population.

<b>Author/Country</b>	<b>Study Aims</b>	<b>Participants (mild/mod/severe) Sex/age/years</b>	<b>Methods/Analysis (structure/ unstructured activities)</b>	<b>Outcome Measures</b>	<b>Results</b>	<b>Limitations/Bias</b>
Smith et al., 2011 New Zealand	To describe the experience of pwMS who engage in exercise	Community dwelling 9 pwMS (all women) (RR, SP, unknown) 28-70 yrs	Qualitative-interpretive description approach Inductive Thematic analysis		Improvement in activities of daily living and sleep	Experiences limited to only females
Smith et al., 2009 New Zealand	To explore the influence of 8 week exercise programme on fatigue	10 pwMS (8F/2M) Age range 32-61 Type of MS- All RRMS Location: PT gym Ex program- mainly structured exercises-aerobic- 1 hour, completed x3 times per week for 8 weeks.	Semi-structured in-depth interviews Analysis-Interpretive Description methodology Purposive sampling (MS society and PT clinic)	No EDSS score – stated all ambulant without aid for short distances.	Greater control over fatigue led to greater +ve outcomes-physical improvement and feelings. Lesser control led to negative feelings and physical deterioration.	All done in RRMS, all independently mobile
Plow, Resnik and Allen, 2009 USA	Identifying facilitators and barriers in PA behaviour	13pwMS ( 2M/11F) (RR,SP) 18-68 yrs (mean 45) Recruited following clinical trial through MS society	Qualitative- semi structured interviews – questions focused on experience of exercise program and beliefs about exercise Analytic induction-transcript and pt activity log	SF-36, Modified Fatigue Impact Scale, MS Functional Composite	pwMS differ in self-regulation skills, self efficacy and coping styles. Barriers include symptoms and environment. Facilitators – strong self regulation skills, confidence to overcome symptoms and positive coping styles.	Sample had previous involvement in clinical trial Small sample size Highly functional - all mobile

<b>Author/Country</b>	<b>Study Aims</b>	<b>Participants (mild/mod/severe) Sex/age/years</b>	<b>Methods/Analysis (structure/ unstructured activities)</b>	<b>Outcome Measures</b>	<b>Results</b>	<b>Limitations/Bias</b>
Dodd et al., 2006  Australia	To explore perceptions about exercise program with pwMS  10 week gym based progressive resistive exercise program	Community – gym setting (exercise protocol carried out by PT and fitness instructors)  9pwMS (7 females/2males) Age range 18-65 ( mean 45.6 years SD10.7)	Qualitative-interviews (5 at home and 4 in the group following end of group based program)  Semi-structured in-depth interviews	Disease step scale. MSIS-29 (Psychological and physical)	Physical, psychological and social benefits reported  Decrease in fatigue  Minor aches and pain. Motivation to complete – enjoyment/self determination /positive attitudes towards exercise	Small sample size  All participants mobile without aid  Not explicit about how data were analysed  No report of the types of MS in the sample
Borkoles et al., 2008  United Kingdom	To examine the lived experience of pwMS - related to exercise	7 (4 Females/3 Males) pwMS , active exercisers  Age- 34-65 (mean 47.1 yrs), EDSS 4-6  Recruited- Local MS centre in a region of the UK	Qualitative-Interpretative Phenomenological Analysis (IPA)  Semi-structured interviews		Functional limitations due to MS influenced ability to exercise, loss of spontaneous opportunity to exercise  Effect of previous exercise experience, environmental and social barriers to exercise	Small sample size, looked at meaning of exercise generally in sample who regularly engage in exercise and who were all ambulant.  Participants all mobile (EDSS 4-6) All causations

<b>Author/Country</b>	<b>Study Aims</b>	<b>Participants (mild/mod/severe) Sex/age/years</b>	<b>Methods/Analysis (structure/unstructured activities)</b>	<b>Outcome Measures</b>	<b>Results</b>	<b>Limitations/Bias</b>
Kasser (2009) USA	Explore meaning of exercise and motivational intent	Community setting-university gym 12 pwMS (10 females and 2 males)-RR,SP,PP) Age- 32-56 (average age 46.25) Functional level -mobile with or without device	Interviews Phenomenological-inductive approach Structured exercise program 2-3 per week, 1:1 supervised and group intervention Thematic analysis	Based on experience of attending exercise group/1:1 exercise sessions	Exercise to increase health and function, enhance self-efficacy, feelings of hope and optimism	The researcher led the exercise groups, recruited participants and conducted interviews. Participants already motivated to exercise
Dlugonski, Joyce and Motl, 2012 USA	To understand adoption and maintenance of PA in women with MS	Setting- Community living 11 women with RRMS Age- 18-64 Functional level- mobile without assistance Recruitment- participants listed on local database	Qualitative- x2 semi-structured Interviews Inductive coding approach Commented on both structured & unstructured PA	PDDS	Practical strategies to maintain physical activity were prioritising, schedule, social support, management of fatigue and pain	Small sample size, only used women,- limits transferability All participants had RRMS All mobile without assistance

**Abbreviations:** F- Female, M- Male, RR- Relapsing Remitting, SP- Secondary Progressive, PP- Primary Progressive, PA-physical activity  
PDDS- Patient Determined Disease Steps, MSIS- Multiple Sclerosis Impact Scale, EQ-5D- European quality of life scale, MSSS- MS Self-efficacy Scale, COP –Centre of pressure, COPM (The Canadian Occupational Performance Measure), PASIPD- Physical Activity Scale for Individuals with Physical Disabilities), SF-36- Short Form 36 , MSWS- MS Walking Scale , EXSE- Exercise Self- Efficacy Scale , SLIQ- Simple Lifestyle Indicator Questionnaire , BI- Barthel Index, MSQoL-54 ( MS quality of life), HLAQ- Historical Leisure Activity Questionnaire (HLAQ) , MAQ (modifiable Activity Questionnaire, GNDS- Guys Neurological Disability Scale, MET- Metabolic Equivalent, SQUASH- The Short Questionnaire to Assess Health-Enhancing Physical Activity, FSS- Fatigue Severity Scale, CES-D The Centre for Epidemiologic Studies Depression, GLTEQ- Godin Leisure-Time Exercise Questionnaire, EGS- Exercise Goal Setting Scale. Physical Activity Disability Survey-Revised (PADS-R) and Barriers to Health Promoting Activities for Disabled Persons Scale (BHADP) and MS Self-Efficacy Scale (MSSS) and Chalder Fatigue Questionnaire (CFQ). Disability was rated using the Guys Neurological Disability Scale (GNDS).

### **Appendix 3a: Ethics approval**



## **School of Health Sciences and Social Care**

School of Health Sciences and  
Social Care  
Brunel University,  
Uxbridge  
Middlesex UB8 3PH

**15 May 2012**

**Proposer:** Andrea Stennett

**Title:** A day in the life of people with Multiple Sclerosis

**Reference:** 12/4/PHD/04

### **Letter of Approval**

The School Research Ethics Committee has considered the amendments recently submitted by you in response to the Committee's earlier review of the above application.

The Chair, acting under delegated authority, is satisfied that the amendments accord with the decision of the Committee and has agreed that there is no objection on ethical grounds to the proposed study. Approval is given on the understanding that the conditions of approval set out below are followed:

- *The agreed protocol must be followed. Any changes to the protocol will require prior approval from the Committee.*

**NB:**

- Research Participant Information Sheets and (where relevant) flyers, posters, and consent forms should include a clear statement that research ethics approval has been obtained from the School of Health Sciences and Social Care Research Ethics Committee.
- The Research Participant Information Sheets should include a clear statement that queries should be directed, in the first instance, to the Supervisor (where relevant), or the researcher. Complaints, on the other hand, should be directed, in the first instance, to the Chair of the School Research Ethics Committee
- Approval to proceed with the study is granted subject to receipt by the Committee of satisfactory responses to any conditions that may appear above, in addition to any subsequent changes to the protocol.
- The School Research Ethics Committee reserves the right to sample and review documentation, including raw data, relevant to the study.

A handwritten signature in black ink, appearing to read "D. Anderson - Ford".

David Anderson-Ford

Research Ethics Officer

**School of Health Sciences and Social Care**  
**Research Ethics Committee**

School of Health Sciences and  
Social Care  
Brunel University,  
Uxbridge

14 May 2013

Proposer: Andrea Stennett

Title: A day in the life of people with Multiple Sclerosis

Reference: 12/4/PHD/04

**APPROVAL OF AMENDMENT TO PROTOCOL**

The School Research Ethics Committee has considered the amendment to protocol recently submitted by you in relation to the addition of a fourth round with regard to the above study. Acting under delegated authority, the Chair is satisfied that there is no objection on ethical grounds to the amendment. Approval is given on the understanding that the conditions of approval set out below are followed:

- *The agreed protocol must be followed. Any changes to the protocol will require prior approval from the Committee.*

**Please note that:**

- Research participant information sheets and (where relevant) flyers, posters and consent forms, should include a clear statement that research ethics approval has been obtained from the School of Health Sciences and Social Care Research Ethics Committee.
- Approval to proceed with the study is granted subject to receipt by the Committee of satisfactory responses to any conditions that may appear above, in addition to any subsequent changes to the protocol.



**Dr Mary Pat Sullivan**

Chair, School Research Ethics Committee  
School of Health Sciences and Social Care

## Appendix 4



April 2012

Dear .....

I am a PhD research student at Brunel University and am recruiting for a study looking at exercise and physical activity in people with Multiple Sclerosis (MS).

My Clinical background is in the area of physiotherapy and over the years I have worked with people affected with MS in a variety of clinical settings. For example, inpatient, outpatient and community based settings. During this time I have seen the impact MS can have on peoples' functional abilities and also, the effects exercise and physical activities can have in managing the symptoms of the disease.

From previous research done in this area we are aware of the benefits of exercise and physical activities. However, research has also demonstrated that adherence to physical activities can be challenging especially for people with MS who are functionally impaired. Anecdotally we are aware that people with MS participate in a wide variety of activities. Therefore, the main aim of the first phase of this study is to capture the activities people with MS are involved in, irrespective of their level of function.

As part of this study, I would like to recruit people with MS who live in the community. The study has received ethical approval from Brunel University Ethics Committee, and details of supervisors of the study are included at the end of this letter.

The study itself will involve the completion of 3 Rounds of questionnaires. The 1<sup>st</sup> questionnaire should take approximately 20mins to complete.

The 2<sup>nd</sup> and 3<sup>rd</sup> Questionnaires should take approximately 15mins to complete. All volunteers will be given an information sheet explaining the study, covering issues of confidentiality and their rights to withdraw at any time.

In order to recruit volunteers, I would appreciate a chance to meet with centre members to explain the study and what it would involve. Also, I would also like to ask whether I might be able to organise some advertising of the study with you, such as on a notice board or in your centre newsletter.

I look forward to hearing from you, and would be delighted to come and meet with you to answer any questions you have. I enclose my telephone contact number and email address.

Yours sincerely

Andrea Stennett, PhD Student

School of Health Sciences and Social Care , Mary Seacole Building

Brunel University, Uxbridge, UB8 3PH

Tel: 01895268729

Email: [andrea.stennett@brunel.ac.uk](mailto:andrea.stennett@brunel.ac.uk)

### **Research Supervisors**

**Professor Lorraine De Souza  
Head of School and Professor  
Rehabilitation**

Mary Seacole Building,  
Brunel University Uxbridge, Middlesex  
Tel: 01895268755  
e-mail: [lorraine.desouza@brunel.ac.uk](mailto:lorraine.desouza@brunel.ac.uk)

**Dr. Meriel Norris  
Physiotherapy Lecturer**

Mary Seacole Building  
Brunel University  
Uxbridge, Middlesex  
Tel:01895268685  
e-mail: [meriel.norris@brunel.ac.uk](mailto:meriel.norris@brunel.ac.uk)

## **Appendix 5: Questions for Pilot Study May 2012**

1. How long did it take to complete the questionnaire?

---

2. Were the instructions clear?

---

3. Were the questions clear or ambiguous?

---

---

4. If so which question and why?

---

---

5. Did you object to answering any of the questions?

---

---

---

6. Was the layout of the questionnaire clear

---

---

---

7. Any other comments?

---

---

## **Appendix 6a**



Brunel University  
Mary Seacole Building  
PhD Room 111  
Uxbridge, Middlesex, UB8 3PH

Dear

### **Re: Brunel University Multiple Sclerosis Research**

Thank you for expressing an interest in the current research. In your research pack you will find 2 documents entitled Participants Information Sheet and Questionnaire booklet for Research Participants. Please read the Participants Information Sheet first before answering the questionnaire.

If you have any further questions please do not hesitate contact me on Tel: 01895268729 or email: [andrea.stennett@brunel.ac.uk](mailto:andrea.stennett@brunel.ac.uk).

Yours sincerely

Andrea Stennett MSc Neurorehabilitation, MCSP  
Physiotherapist & Lead Researcher  
Enhanced PhD Studentship  
Brunel University

## **Appendix 6b: Participant information sheet**



### **Research Participant Information Sheet**

**Research Title: 'A Day in the Life of people with Multiple Sclerosis: An Exercise and Physical Activity Study.'**

You are invited to take part in this research entitled: '**A Day in the life of people with Multiple Sclerosis**'. This is part of a Doctoral study led by Andrea Stennett, Physiotherapist, under the supervision of Professor Lorraine De Souza and Dr. Meriel Norris at Brunel University. Below is some information that covers why this research is being done and what it would involve should you decide to take part.

#### **1. What is the purpose of the Study?**

This research is designed to find out the types of exercise and physical activities people with multiple sclerosis are engaged in on a typical day. So far, we have learnt a lot about exercise but there are still gaps in our knowledge about peoples' priorities in this area. This is essential to help us establish physical activity and exercise guidelines for people with MS irrespective of their disability. That is, everyone, whether you think you are physically active or not can participate.

## **2. Who can take part?**

If you are over 18 years old, living in the community and have a diagnosis of Multiple Sclerosis, I would be interested in hearing from you. You will be asked to complete 3 Rounds of questionnaires over approximately 6 Months. We will be looking at a wide variety of activities so your level of disability should not prevent you from taking part.

## **3. What are the benefits of taking part?**

It is unlikely that there will be a direct benefit to you from this study. However, the results of this study will give us further insight into the levels of exercise and physical activities people with MS are involved in which will further inform and guide how clinicians prescribe exercises in the future. Results from this study will be submitted for publication, or presented at conferences, so that they can reach an audience of professionals as well as people with MS.

## **4. What will happen to me if I take part?**

Your participation in this study would involve providing us with information using a technique known as the Delphi Method. That is, using a series of questionnaires known as Rounds. For this study, we will be using **3 Rounds** to gain adequate knowledge about exercise and physical activity.

**Round 1:** This involves completing 2 questions regarding exercise and physical activities. You would then send the information back in paid self-addressed envelope. I will collate all the responses from all participants and then send you another questionnaire. We expect that the first questionnaire should take approximately 20mins to complete.

**Round 2:** After about 4 weeks, you will be asked to review the groups' responses and rank them in order of importance to you and then return the questionnaire in a self-addressed envelope. I will then collate the information and send it back to you. We expect that the 2<sup>nd</sup> questionnaire would take approximately 15mins to complete.

**Round 3 (Final):** After a further 4 weeks approximately, you will be asked to state whether or not you agree with the ranking of the other participants from Round 2. We anticipate that the 3<sup>rd</sup> questionnaire will take approximately 10mins to complete.

Your involvement in the Rounds will be confidential. All your answers will be anonymous to other participants. You will be provided with a self-addressed stamped envelope for all the Rounds of the study so you should not incur any expenses. If you have difficulty writing, then we can make alternative arrangements for you to give your responses by telephone.

## **5. Do I have to take part?**

Your participation is completely voluntary. This means that you can choose not to be involved, or if you start, you can choose to withdraw at anytime. If you decide not to participate, it will not affect any treatment, membership and or care that you are currently receiving. We believe that you can make a valuable contribution to the research in this area, as we do not know what activities people with MS do as part of their routine and how they prioritise these activities. Your insight and knowledge will help us to establish this foundation.

## **6. If I want to take part, what will happen next?**

If you decide to take part in this study, you can contact me, Andrea Stennett, by telephone 01895268729 or email on [andrea.stennett@brunel.ac.uk](mailto:andrea.stennett@brunel.ac.uk) and I will send you an information pack, or if you wish to have further information about the study. Also, you can collect a research pack from your local MS Therapy Centre. Please note, that participating in this study is completely voluntary. Therefore, by completing the questionnaires the researcher is led to believe that you consent to be in the study.

## **7. Will my taking part in this study be kept confidential?**

All the information that is collected about you during the course of the research will be kept strictly confidential. Because of the nature of the Delphi Method other participants will not be able to link you to any of your responses. I will be the only one to see your responses and other identifiable information. Any personal information will be kept securely in a locked cupboard in a pass code protected room at the university.

## **8. What will happen to the results of the study?**

The results from the research will be used as part of my Doctoral thesis. A report of the key findings will be sent to you at your request. The findings will be presented at academic and professional conferences and also published in academic journals. The findings and summary will be shared with members of the MS society. Anonymity and confidentiality will still be in place in all cases. Findings from this study will contribute to developing a better understanding of exercise priorities in people with

MS. This will help us to establish exercise guidelines specific for this population.

## **9. Who is organising and funding the research?**

This research is part of a Doctoral Study undertaken by Andrea Stennett. It is supported by - The Centre for Research and Rehabilitation (CRR) within the School of Health Sciences and Social Care at Brunel University and has gained Ethical Approval from the Ethics Committee at the school. If you have questions about the Ethics of this study please contact the Chair of the Ethics Committee, Simon Bradford ([simon.bradford@brunel.ac.uk](mailto:simon.bradford@brunel.ac.uk)).

### **Contact for further information about the research:**

Andrea Stennett, Telephone 01895268729

Email: [andrea.stennett@brunel.ac.uk](mailto:andrea.stennett@brunel.ac.uk)

### **Research Supervisors:**

Professor Lorraine DeSouza, Email: [lorraine.desouza@brunel.ac.uk](mailto:lorraine.desouza@brunel.ac.uk)

Dr. Meriel Norris, Email: [meriel.norris@brunel.ac.uk](mailto:meriel.norris@brunel.ac.uk)

### **Useful contact details for MS Society:**

**Website: [www.mssociety.org.uk](http://www.mssociety.org.uk)**

**MS Helpline – 0808 800 8000 (calls to this number are free)**

**Thank you for considering being part of this study.**

**Appendix 6c: Research booklet Round 1**

**Brunel Multiple Sclerosis Research**

**Questionnaire booklet for research participants**

This booklet contains a number of separate sections and scales. Please read the instructions at the beginning of each section carefully before completing it. Once you have finished please go back through your answers and make sure you have responded to each item.

You may find that some of the questionnaires appear to ask similar questions, we would be grateful, however, if you could answer all the questions. Leaving a few questions unanswered in any scale will limit the usefulness of the rest of the information in this scale and in others.

Please note that all of the information obtained from participants will be kept confidential. Only researchers working on the project will have access to this information. Also, by completing this questionnaire it is implied that you give your consent to participate in this study.

**NOW TURN THE PAGE OVER TO PROCEED WITH THE  
QUESTIONNAIRE**

## **SECTION A EXERCISE AND PHYSICAL ACTIVITY**

The following section contains questions that attempt to find out what exercise and physical activity you do on a 'typical day'. A typical day can be any day of your choice.

People use the term exercise and physical activity inter-changeably, so to help you we have defined what we mean by exercise and physical activity.

**Exercise:** involves planned repetitive bodily movements. For example, exercises involving aerobic, strength, flexibility and endurance training.

**Physical activity:** involves activity that is part of your daily life. For example, activities involving cooking, shopping and or climbing stairs.

Please only use the examples given above as a guide. You can list any exercise and or physical activity. Now, think back to a typical day in the last week and answer the questions below.

Question 1. List up to 10 exercises and physical activities you do on a typical day.

<b>10 exercises and physical activities you do on a typical day</b>
1.
2.
3.
4.

5.
6.
7.
8.
9.
10.

**Question 2.** List up to 5 reasons why you do these exercise and or physical activities.

<b>5 reasons why you do these activities</b>
1.

2.
3.
4.
5.

## **SECTION B ACTIVITIES OF DAILY LIVING**

### **PART 1: The Barthel ADL Scale**

B.1 This next section asks a standard set of questions to find out how peoples' daily activities may be affected. It is important that you answer ALL the questions even if you feel that some of them may be obvious or not applicable. Please **tick one box** in each section in the category that you feel is generally the most appropriate.

<b>Bathing</b>	Manage on your own?	
In a bath or shower, do you:	Need help getting in or out?	
	Need other help?	
	Never have a bath or shower?	
<i>Remember- tick one box only</i>	Need to be washed in bed?	
<b>Stairs</b>	Without help?	
Do you climb stairs at home:	With someone carrying your frame?	
	With someone encouraging you?	
	With physical help?	
<i>Remember – to tick one box only</i>	Not at all?	
	Don't have stairs?	
<b>Dressing</b>	Without any help?	
Do you get dressed:	Just with help with buttons?	
	With someone helping you most of the time?	
<i>Remember – to tick one box only</i>		
<b>Mobility</b>	Without any help apart from a frame?	

Do you walk indoors:  <i>Remember- tick one box only</i>	With one person watching over you?	
	With one person helping you?	
	With more than one person helping?	
	Not at all?	
	Or do you use a wheelchair independently (e.g. around corners)?	
<b>Transfer</b>  Do you move from bed to chair  <i>Remember- tick one box only</i>	On your own?	
	With a little help from one person?	
	With a lot of help from one person or more people?	
	Not at all?	
<b>Feeding</b>  Do you eat food:  <i>Remember- tick one box only</i>	Without any help?	
	With help cutting food or spreading butter?	
	With more help?	
<b>Toilet use</b>  Do you use the toilet or commode:  <i>Remember- tick one box only</i>	Without any help?	
	With some help but can do something?	
	With quite a lot of help?	

<b>Grooming</b>  Do you brush your hair and teeth, wash your face and shave:  <i>Remember- tick one box only</i>	Without help?	
	With help?	
<b>Bladder</b>  Are you incontinent of urine?  <i>Remember- tick one box only</i>	Never	
	Less than once a week	
	Less than once a day	
	More often	
	Or do you have a catheter managed for you?	
<b>Bowels</b>  Do you soil yourself  <i>Remember- tick one box only</i>	Never	
	Occasional accident	
	All the time	
	Or do you need someone to give you an enema?	

Were there any questions in The BARTHEL that did not apply to you? If yes write the title of the question below e.g. Bladder, and say why they didn't apply.

Were there any questions in The BARTHEL that you found confusing? If yes write the title of the question below.

**Section C**                    **The SF36 Health Survey**

**This scale comprises some questions about what you think about your health. Answer every question by marking the answer as indicated. If you are unsure about how to answer a question please give the best answer you can.**

1. In general would you say your health is:

*(Circle one number)*

Excellent ----- 1

Very good ----- 2

Good ----- 3

Fair ----- 4

Poor ----- 5

2. Compared to one year ago, how would you rate your health in general now?  
*(Circle one number)*

Much better than one year ago ----- 1  
Somewhat better now than one year ago ----- 2  
About the same as one year ago ----- 3  
Somewhat worse than one year ago ----- 4  
Much worse than one year ago ----- 5

3. The following items are about activities you might be doing during a typical day. Does your health now limit you in these activities? If so, how much?

**(Circle one number on each line)**

Activities	Yes, limited a lot	Yes limited a little	No, not limited at all
a. Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports	1	2	3
b. Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	1	2	3
c. Lifting or carrying groceries	1	2	3
d. Climbing several flights of stairs	1	2	3
e. Climbing one flight of stairs	1	2	3
f. Bending, kneeling, or stooping	1	2	3
g. Walking more than a mile	1	2	3

h. Walking half a mile	1	2	3
i. Walking one hundred yards	1	2	3
j. Bathing or dressing yourself	1	2	3

4. During the past four weeks, have you had any of the following problems with your work or other regular daily activities as a result of your physical health?

(Circle one number on each line)

	Yes	No
a. Cut down on the amount of time you spent on work or other activities	1	2
b. Accomplished less than you would like	1	2
c. Were limited in the kind of work or other activities	1	2
d. Had difficulty performing the work or other activities( for example, it took extra effort)	1	2

5. During the past four weeks, have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

(Circle one number on each line)

	Yes	NO
a. Cut down on the amount of time you spent on work or other activities	1	2
b. Accomplished less than you would like	1	2
c. Didn't do work or other activities as carefully as usual	1	2

6. During the past four weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbours or groups?  
*(Circle one number)*

Not at all -----1  
Slightly -----2  
Moderately -----3  
Quite a bit -----4  
Extremely -----5

7. How much bodily pain have you had during the past four weeks?  
*(Circle one number)*

None -----1  
Very mild -----2  
Mild -----3  
Moderate -----4  
Severe -----5  
Very severe -----6

8. During the past four weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?  
*(Circle one number)*

Not at all ----- 1

A little bit ----- 2

Moderately ----- 3

Quite a bit ----- 4

Extremely ----- 5

9. These questions are about how you feel and how things have been with you during the past four weeks. For each question, please give the one answer that comes closest to the way you have been feeling.  
How much of the time during the past four weeks-

**(Circle one number on each line)**

	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
a. Did you feel full of life?	1	2	3	4	5	6
b. Have you been a very nervous person	1	2	3	4	5	6

c. Have you felt so down in the dumps that nothing could cheer you up?	1	2	3	4	5	6
d. Have you felt calm and peaceful?	1	2	3	4	5	6
e. Did you have a lot of energy?	1	2	3	4	5	6
f. Have you felt downhearted and low?	1	2	3	4	5	6
g. Did you feel worn out?	1	2	3	4	5	6
h. Have you been a happy person?	1	2	3	4	5	6
i. Did you feel tired?	1	2	3	4	5	6

10. During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives etc)?

(Circle one number)

All of the time ----- 1

Most of the time ----- 2

Some of the time ----- 3

A little of the time ----- 4

None of the time ----- 5

11. How TRUE or FALSE is each of the following statements for you?

(Circle one number on each line)

	Definitely True	Mostly True	Don't know	Mostly False	Definitely False
a. I seem to get ill more easily than other people	1	2	3	4	5
b. I am as healthy as anybody I know	1	2	3	4	5
c. I expect my health to get worse	1	2	3	4	5
d. My health is excellent	1	2	3	4	5

#### **SECTION D     YOUR BACKGROUND INFORMATION**

Finally, we would be grateful if you could provide us with some background information about yourself and your MS. We need this information in order to check how representative our study sample is. We would like to remind you that this information will be treated with the strictest confidence and will be used for research purposes only. **Please fill in the details or circle the correct option where appropriate.**

## **Part 1: ABOUT YOU**

**1. Sex:** Male Female

**2. Date of birth:**

**3. Do you live?**

- |                           |                     |
|---------------------------|---------------------|
| By yourself               | Single, Never       |
| With husband/wife         | Married             |
| With Partner              | Separated           |
| With adult family members | Divorce             |
| With other adult/s        | Widowed             |
| With children<br>under 16 | Living with partner |

**5. What is your employment status?**

- Full time
- Part time
- Not currently working/retired
- Voluntary work

**6. If you're in full- time or part-time paid work, what is your job?  
(Please be specific)**

**7. If you are currently not working what was your previous full-time paid job?**

**8. What is your highest educational qualification?**

**9. Specifically, what educational qualifications do you have? (Please circle any options which apply)**

- a. CSE or GCSE (D, E, F, or G)
- b. O-level or GCSE (A, B, C)
- c. A-Level
- d. First Degree (e.g. BA, BSc)
- e. Higher Degree (eg. MA, MSc, PhD, postgraduate certificate)
- f. Other Qualifications (eg. City & Guilds, RSA/OCR/BTEC)
- g. No qualification
- h. Other (please describe)

## **Part 2: About your MS**

**10. Have you had a relapse (i.e. been ill because of your MS or had a worsening of symptoms for at least a day) within the last 6 months?**  
*(Please circle one option only).*

Yes                          No

**11. If you had a relapse within this time when was it?**

*(Please circle one option only)*

*within the last week*

*within the last month*

*2-3 months ago*

*4-6 months ago*

**12. How does MS affect your exercise and physical activities?**

*(Please circle one option only)*

*No effect at all*

*Slightly*

*Moderately*

*Severely*

**13. Please describe 5 MS symptoms, which affect you most with your exercise and physical activities.**

*(Please use the box below)*

5 MULTIPLE SCLEROSIS SYMPTOM	
1.	
2.	
3.	
4.	
5.	

**14. Please circle the type of MS you have been diagnosed with**

*(Circle one option only)*

*Benign*

*Primary Progressive*

*Secondary progressive*

*Relapsing Remitting*

*Not known*

**Mailing Address for Round 2 (write in space provided):**

**Would you like a copy of the main findings when the study has been completed? Please circle one option:**

**Yes                  No**

**Could you please go back and check you have answered all the questions in this booklet.**

**If completing this booklet has caused you any distress please contact MS Helpline on 0808 800 8000 which offers free professional advice and support. Calls to this number are free.**

**THANK YOU VERY MUCH FOR TAKING THE TIME TO COMPLETE AND RETURN THE QUESTIONNAIRE**

## Appendix 6d



Brunel University  
Mary Seacole Building, PhD Room 111  
Uxbridge, Middlesex, UB8 3PH

Name.....

Address.....

Date: ....

Dear....

Re: Brunel University Multiple Sclerosis Research

Four weeks ago a booklet was mailed to you seeking your views about exercise and physical activity.

Your involvement in this study is entirely voluntary but I wanted you to know that if you are still interested, there is still time for you to complete and return the booklet.

If you have already completed and returned this booklet, please accept our sincere thanks. If not, and you would still like to participate, we would appreciate it if you could return it by (date), as we would like to include your views in this study. If by chance you did not receive a booklet or it has been misplaced, please call me at 01895268729 and I can send you another one. Thank you for your assistance.

Yours sincerely

Andrea Stennett

PhD Physiotherapy Student

**Appendix 7: Development of categories for exercise and physical activity in pwMS.**

<b>List of activities</b>	<b>Brief description of category</b>	<b>Category</b>
<ul style="list-style-type: none"> <li>• Washing and dressing</li> <li>• Shower</li> <li>• Shaving</li> <li>• Cleaning teeth</li> <li>• Eating and Feeding</li> </ul>	Activities done pertaining to and the maintaining of one's basic need.	<b>Self-Care Activities</b>
<ul style="list-style-type: none"> <li>• Cooking</li> <li>• Ironing</li> <li>• Laundry</li> <li>• Housework</li> <li>• Shopping</li> <li>• Making bed</li> <li>• Washing sink</li> </ul>	Activities involve working around the home and or activities to do for the running and general upkeep of the home.	<b>Domestic Activities</b>
<ul style="list-style-type: none"> <li>• Playing pool</li> <li>• Gardening</li> <li>• Listening to music</li> <li>• Tennis</li> <li>• Reading</li> <li>• Sport (TV &amp; play)</li> <li>• Visiting friends</li> <li>• Photography</li> <li>• Zumba</li> <li>• Sewing</li> </ul>	Activities done as recreational, fun, hobby, in spare time or just to pass time.	<b>Leisure activities</b>
<ul style="list-style-type: none"> <li>• Reflexology</li> <li>• Massage</li> <li>• Yoga</li> <li>• Pilates</li> <li>• Thai Chi</li> </ul>	Activities related to non-traditional forms of therapy.	<b>Unconventional Therapies</b>
<ul style="list-style-type: none"> <li>• Sort mail</li> <li>• Sort bills</li> <li>• Paperwork</li> </ul>	Activities done for administrative purposes	<b>Administrative activities</b>
<ul style="list-style-type: none"> <li>• UL ,LL, Neck ex.</li> <li>• Bed exs , chair exs</li> <li>• Abdominal exs</li> <li>• Floor based exs</li> <li>• Vestibulocular exs.</li> <li>• Pelvic Floor</li> </ul>	Any activity irrespective of the positioning done without the use of weights.	<b>Activities without the use of weights.</b>

List of activities	Brief description of category	Category
<ul style="list-style-type: none"> <li>Weights</li> <li>Theraband</li> <li>Press ups</li> <li>Tip toeing</li> </ul>	Any activity irrespective of the position done with the use of weights.	<b>Activities done with the use of weights</b>
<ul style="list-style-type: none"> <li>UL ,LL, Calf</li> <li>Stretches</li> </ul>	Activities done to stretch any muscle in the body.	<b>Stretches</b>
<ul style="list-style-type: none"> <li>Stairs</li> <li>Walking (in/out)</li> <li>Transfers (bed, chair, toilet)</li> <li>Pushing wheelchair</li> <li>Standing</li> </ul>	Activities described by participants as needed in order to get through or as part of their daily routine. <i>The term every life activity was taken directly from quotations made</i>	<b>Every Day life activities</b>
<ul style="list-style-type: none"> <li>Swimming</li> <li>Jogging</li> <li>Running</li> <li>Cycling</li> <li>Aerobics</li> </ul>	Activities done based on the enduring nature of the activity. These activities required participating over a certain distance or space in time	<b>Endurance</b>
<ul style="list-style-type: none"> <li>Picking up toys</li> <li>Family time</li> <li>Looking after children</li> <li>Running after children</li> </ul>	Activities that involved looking after or playing with children or grandchildren.	<b>Activities due to family roles</b>
<ul style="list-style-type: none"> <li>Playing with pets</li> <li>Taking dogs for walk</li> <li>Feeding pets</li> </ul>	Activities that involved feeding, playing with or taking pet/s out for walks)	<b>Activities due to being pet owners</b>
<ul style="list-style-type: none"> <li>Computer</li> <li>Phone</li> <li>Wii</li> <li>Move it for MS DVD</li> </ul>	Activities done with an electronic device.	<b>Activities done with technology</b>
<ul style="list-style-type: none"> <li>Powerplate/Vibrogram</li> <li>Exercise bike/Pedalling</li> <li>Rowing machine</li> <li>Gym ball</li> </ul>	Any external device or equipment needed to carry out a particular activity.	<b>Activities done with the use of equipment</b>
<ul style="list-style-type: none"> <li>Work related</li> <li>Voluntary</li> </ul>	Activities related to paid or voluntary employment	<b>Employment</b>

<b>List of activities</b>	<b>Brief description of category</b>	<b>Category</b>
<ul style="list-style-type: none"> <li>• Driving</li> <li>• Getting on and off bus</li> </ul>	Activities done to keep driving personal car or to keep using public (bus/taxi/tube/train) transportation	<b>Transportation</b>
<ul style="list-style-type: none"> <li>• Gym based</li> <li>• Hydrotherapy</li> </ul>	Activities done within the gym or outpatients settings. Can be done on land or in water.	<b>Activities done in different environment</b>
<ul style="list-style-type: none"> <li>• Physiotherapy</li> </ul>	Activities done by or with a physiotherapist	<b>Physiotherapy</b>

**Appendix 8a: The development of categories for the reasons why people with MS engage in exercise and physical activity.**

<b>Lists of Reasons why</b>	<b>Categories /description</b>	<b>Category</b>
<ul style="list-style-type: none"> <li>• Walking with or without walking aid</li> <li>• To keep mobile</li> </ul>	To keep mobile or to maintain mobility	<b>For Mobility</b>
<ul style="list-style-type: none"> <li>• Flexibility</li> </ul>	To maintain and or improve flexibility	<b>For Flexibility</b>
<ul style="list-style-type: none"> <li>• Pleasure</li> <li>• Mood</li> <li>• Anxiety</li> <li>• Relaxation</li> <li>• Wellbeing (physical and mental)</li> <li>• Hobby/leisure</li> <li>• Therapeutic</li> <li>• Attitude</li> <li>• Reduced stress</li> </ul>	To have fun or pleasure or done to improve or maintain a particular emotion.	<b>For Emotional Well being</b>
<ul style="list-style-type: none"> <li>• To ↑ ROM</li> <li>• Maintain strength/core strength</li> <li>• Improve or maintain balance</li> <li>• Feel stronger</li> <li>• To ↓ pain</li> <li>• To ↑ control of leg</li> <li>• To alter MS tone</li> <li>• To remind the brain</li> <li>• To ↓ atrophy</li> <li>• To keep hand working</li> <li>• To wake up legs</li> <li>• To ↓ spasms</li> <li>• To improve stamina</li> </ul>	To improve or maintain symptoms associated with MS	<b>To improve MS symptoms</b>
<ul style="list-style-type: none"> <li>• As part of work</li> <li>• To return to work</li> <li>• As part of voluntary work</li> <li>• Return to work</li> </ul>	To keep working or to be able to return to work	<b>For Employment</b>

<b>Lists of Reasons why</b>	<b>Categories /description</b>	<b>Category</b>
<ul style="list-style-type: none"> <li>• Live in 2 storey house</li> <li>• Stairs at work</li> <li>• Stairs to get to toilet</li> <li>• Use kneeler in the garden outdoor</li> <li>• Supermarket (using trolley)</li> <li>• Modification of environment</li> </ul>	<p>To be able to navigate the environment whether indoors or outdoors.</p> <p>To access different environments</p>	<b>Because of the Environment</b>
<ul style="list-style-type: none"> <li>• Part of daily activities</li> <li>• Necessity</li> <li>• Keep home tidy</li> </ul>	<p>To keep doing activities that are necessary and forms part of daily activities</p>	<b>Out of Necessity</b>
<ul style="list-style-type: none"> <li>• Driving to visit friends/families to maintain social life</li> <li>• Group exercise sessions</li> <li>• “Feel connected”</li> <li>• to feel apart of community</li> <li>• get out of the four walls to see people (reduced isolation)</li> </ul>	<p>To improve and or maintain social life both personally and with the wider community</p>	<b>For Social Reasons</b>
<ul style="list-style-type: none"> <li>• To keep home tidy</li> <li>• Provide food for the family</li> <li>• To help daughter with childcare</li> <li>• Role of wife</li> <li>• Responsibility as a mom</li> <li>• Activities done because I live alone</li> </ul>	<p>To keep home tidy or because of their role within the home and family.</p>	<b>Because of my role within home/family</b>
<ul style="list-style-type: none"> <li>• To keep active</li> <li>• To keep transferring</li> <li>• To maintain function</li> </ul>	<p>To keep mind and body active in order to carry out different tasks.</p>	<b>To keep Active</b>

<b>Lists of Reasons why</b>	<b>Categories /description</b>	<b>Category</b>
<ul style="list-style-type: none"> <li>• Independence (Shopping, cooking)</li> <li>• Ability</li> <li>• Challenge self</li> <li>• Choice</li> <li>• Because I can and I must</li> <li>• Confidence</li> </ul>	Independence and choice	<b>For Self-Reliance</b>
<ul style="list-style-type: none"> <li>• Advice given by physiotherapist</li> <li>• Advice given by physical trainer</li> <li>• Nagged</li> <li>• Advice given by neurologist</li> </ul>	Activities done because of advice given by health professional or family member, friend)	<b>Because of Advice given</b>
<ul style="list-style-type: none"> <li>• Cosmetics</li> <li>• To maintain weight /to stay slim</li> <li>• To feel better about self</li> <li>• Self esteem</li> <li>• Self worth</li> <li>• Sense of achievement</li> <li>• Pride</li> <li>• Motivation</li> </ul>	Activities as a way to improve appearance mind and body	<b>For Self-esteem</b>
<ul style="list-style-type: none"> <li>• Fear of deterioration</li> <li>• Combat MS</li> <li>• To live &gt;150 years</li> <li>• Normal life</li> <li>• Life before and after MS</li> <li>• Future</li> </ul>	<p>To live a normal life as possible and limit deterioration as much as possible.</p> <p>Also, to be able to increase life span.</p>	<b>Living with MS now and in the future</b>
<ul style="list-style-type: none"> <li>• Fitness</li> <li>• Be healthy</li> <li>• Increase cardiovascular</li> <li>• Circulation</li> </ul>	To be healthy and for cardiovascular fitness	<b>For Health and Fitness</b>

**Appendix 8b: Extract from the reasons why pwMS engaged in exercise and physical activity and the MS symptoms listed**

Reference	Reasons why	MS symptoms
R1004	<p>Necessary exercise coming from living in a house (<a href="#">necessity</a>), helps control pain (<a href="#">symptom management</a>)..</p> <p>Keeping active keeps mind off disabilities (<a href="#">mental attitude</a>)....</p> <p>Reassures children that I can live a normal life (<a href="#">Role within home/normality</a>)....</p>	Muscle spasms, pain, fatigue, vertigo, tremor...
R1 014 Commented on Barthel part A (bathing- do not need help from people but need to use grip rails same on toilet)	<p>Stairs need to for toilet and bed (<a href="#">environment/necessity</a>)...</p> <p>Walking around house to clean it and prepare food and drink (<a href="#">independence/necessity</a>)...</p> <p>Gym to try to ease pain in legs (<a href="#">Mx symptoms</a>) and try to stay as fit as possible (<a href="#">fitness</a>)...</p> <p>Driving to keep up a social life (<a href="#">social life</a>). Playing with kids keeping some sort of normality for them &amp; me (<a href="#">role within family</a>) linked also to <a href="#">normality</a> ....</p>	Fatigue.. Stiffness... Balance...Feet swelling...Numbness in hands and legs...
R1 019 Commented on Barthel (Part A mobility- indoors I sometimes use a stick but can manage without. Use furniture but not frame <i>( Interesting comment about "I miss the feeling of being physically tired" considering that most people with MS report fatigue as main</i>	<p>The physical activities are part of everyday life (<a href="#">everyday life</a>). I want to do as much as possible for myself although I rely on my husband to do quite a lot (<a href="#">maintain independence/ability/family support</a>).</p> <p>..Having played a lot of sport and had a very active job I miss the feeling of being physically tired (<a href="#">emotion</a>). The exercise bike is a way of increasing my heart rate (<a href="#">Health benefit/increase HR</a>).</p> <p>Pilates class I enjoy (<a href="#">enjoyment</a>) and I go with a friend so it is social as well (<a href="#">social</a>).</p> <p>I am not convinced my MS symptoms have got worse. I was diagnosed 15</p>	Right foot drags- the knock on effect of this is my real problem.... As a result of the above I fall over and balance is all over the place when I am vertical ( the foot and leg have not worked properly for 25 years. .. The inability to lift my right leg has made me nervous of tripping particularly on uneven surfaces which has further inhibited my ability to walk

<i>limiting factor of MS)</i>	months ago although I have had symptoms for 25 years but they got mixed up with result of car accident. My problem is walking but that maybe due to walking badly and having no treatment for 25 years	normally
R1 038 Commented on Barthel ( 2 <sup>nd</sup> part- "sometimes I use aids to help me that was not an option" ( <i>People speak about life before MS and life with MS- a sense that they want to hold on to the things they use to be able to do before MS. Sense of willing self/combating /defying MS</i> )	I do exercise to keep fit as being overweight causes me pain and I struggle to be active ( <i>fitness/weight management</i> )... I like to be active and it helps my brain to be active and thinking ( <i>keep brain active./aid thinking/Mx symptoms</i> )... I like to feel that I am living a normal life ( <i>normal</i> ) just with aches and pains which hinder me sometimes.. I enjoyed dancing before MS and still like to feel I can do the same things ( <i>how I see myself/sense of self/ability/future</i> )... I have to keep my weight down and increase mobility ( <i>weight management to manage symptom</i> )...	Numb feet/hands.. Tiredness/fatigue.. Webbed feet... Pains in legs... Burning legs...
R1052 Participant commented on Barthel ( Mobility- "do not use a frame-only walking stick for balance to go up steps in garden") ( <i>People mention stairs in a variety of ways- enable them to go upstairs/ part of work/get to the toilet- here stairs is not seen as a barrier but more as a facilitator to access other areas of home/work. ...Stairs to increase PA</i> )	To improve my flexibility ( <i>flexibility/Mx. Symptoms</i> ) and balance ( <i>mx symptom</i> ) ... ...to obtain household provisions ( <i>independence</i> ).. To keep home tidy ( <i>role within home/family</i> )... To provide food to eat ( <i>necessity/everyday activity</i> ).. ...to get to first floor of house ( <i>environment-must climb stairs/necessity/</i> )	Dropped right foot resulting from brain tumours, operation ..Constant tingling of both hands...since 1991 (Have to wear cotton gloves at night so that I can get to sleep... restricted movement in right leg making lifting leg together with dropped foot more difficult... Sensitivity to hot items eg. Hot plates... The dropped right foot in particular restricts greatly my mobility



Brunel University  
Mary Seacole Building, PhD Room 111  
Uxbridge, Middlesex, UB8 3PH

Dear

**Re: Brunel University Multiple Sclerosis Research**

Thank you for returning the first Round Questionnaire about the exercise and physical activities you do as part of your routine and also the reasons why you do these activities.

Enclosed you will find the second questionnaire. Please read the instructions before completing the questionnaire. Return of the questionnaire implies consent to participate.

Please return the questionnaire in the enclosed self addressed free post envelope or email your response to [andrea.stennett@brunel.ac.uk](mailto:andrea.stennett@brunel.ac.uk) by **5<sup>th</sup> February 2013**.

If you have any further questions please do not hesitate to contact me on Tel: 01895268729 or email: [andrea.stennett@brunel.ac.uk](mailto:andrea.stennett@brunel.ac.uk) .

Yours sincerely

Andrea Stennett

Physiotherapist & Lead Researcher

## **Appendix 9b**

### **Brunel Multiple Sclerosis Research**

#### **Questionnaire booklet for research participants**

In the previous questionnaire you were asked to list the exercise and physical activities you do on a ‘typical day’ and also the reasons why you did these activities. All the responses given by yourself and all the other study participants from around the United Kingdom were grouped based on their similarity and organised into categories, thereby creating this new questionnaire.

Please read the instructions carefully before completing it. Once you have finished please go back through your answers and make sure you are happy with your decisions.

Please note that all of the information obtained from participants will be kept confidential. Only researchers working on the project will have access to this information. Also, by completing this questionnaire it is implied that you give your consent to participate in this study.

**NOW TURN THE PAGE OVER TO PROCEED WITH THE  
QUESTIONNAIRE**

## **Question1: Categories for Exercise and Physical Activity**

There are 18 categories for exercise and physical activities listed on the next page, please look through each category and rank 10 which are important to you. Your most important category should be ranked 1. Your next most important category ranked 2 and continue ranking until number 10, your 10<sup>th</sup> most important category.

<b>Categories for Exercise and Physical Activity</b>	<b>Rank</b>
<b>Activities due to being pet owners</b> (e.g. feeding, playing with and or taking out for walks)	
<b>Leisure Activities</b> (e.g. gardening, reading, zumba, sports, visiting friends)	
<b>Every Day life Activities</b> (e.g. stairs, walking, pushing wheelchair, standing and transferring)	
<b>Activities without the use of weights</b> (e.g. upper and lower limbs exercises, bed, chair and floor exercises done without weights)	
<b>Activities to increase or maintain strength</b> (e.g. weights, press ups, tip toeing)	
<b>Self -care Activities</b> (e.g. washing & dressing, shaving, showering, eating, cleaning teeth)	
<b>Activities done with the use of Equipment</b> (e.g. treadmill, exercise bike, power-plate, vibrogram)	
<b>Unconventional Therapies</b> (e.g. yoga, pilates, tai chi, massage)	
<b>Endurance activities</b> (e.g. swimming, running, aerobics, cycling)	
<b>Activities done for administrative purposes</b> (e.g. sort mails/bills)	

Categories for Exercise and Physical Activity	Rank
<b>Activities due to being pet owners</b> (e.g. feeding, playing with and or taking out for walks)	
<b>Employment</b> (e.g. activities done as part of paid or voluntary work)	
<b>Physiotherapy</b> (e.g. activities done with or by a physiotherapist)	
<b>Activities done in different environment</b> (e.g. gym, pool)	
<b>Transportation</b> (e.g. to keep driving personal car/ to keep using public (bus/taxi) transportation)	
<b>Activities due to Family Roles</b> (e.g. spending time with family, looking after or playing with children/grandchildren)	
<b>Stretches</b> (e.g. activities done to stretch the upper and lower limbs)	
<b>Domestic Activities</b> (e.g. cooking, shopping, housework, laundry, making the bed, washing the sink)	
<b>Activities done with Technology</b> (e.g computer, phone, Wii, DVD)	

## Question 2: Categories for reasons why you do these activities

There are 15 categories listed for the reasons why you do the activities on a typical day. Please look through each category and rank 10 which are important to you. Your most important category should be ranked 1. Your next most important category ranked 2 and continue ranking until number 10, your 10<sup>th</sup> most important category.

Categories for reasons why you do these activities	Rank
<b>To improve MS symptoms</b> (e.g. to improve or maintain range of movement, strength, balance, reduce pain and alter muscle tone)	
<b>For Mobility</b> (e.g. to keep walking)	
<b>For Flexibility</b> (e.g. to maintain or improve flexibility)	
<b>For Emotional Wellbeing</b> (e.g. for pleasure, improve mood, reduce stress)	
<b>For Employment</b> (e.g. as part of paid or voluntary work or to keep working)	
<b>Because of the Environment</b> (e.g. stairs indoors or at work, or easy to do exercise in pool)	
<b>Out of Necessity</b> (e.g. need to because they are part of daily activities and everyday life)	
<b>For Social reasons</b> (e.g. to maintain a social life, provide a sense of belonging and to feel connected to community)	
<b>Because of my role within home/family</b> (e.g. to keep home tidy, provide food for family or part of role as a partner or parent)	
<b>To keep active</b> (e.g. to keep mind and body active, to maintain function and keep transferring)	
<b>Because of Advice given</b> (e.g. by health professional or personal trainer)	
<b>For Self-Reliance</b> (e.g. to maintain ones' independence and choice)	
<b>For self esteem</b> (e.g. to manage weight, feel better, sense of achievement, self-worth)	
<b>For Health &amp; Fitness</b> (e.g. to be healthy and for	

Categories for reasons why you do these activities	Rank
cardiovascular fitness)	
<b>Living with MS now and in the future</b> (e.g. to limit deterioration, to combat MS, to keep doing the things I could do before MS.	

**Please insert Name and Mailing Address for Round 3 (write in space provided):**

**Could you please go back and check you have answered all the questions in this booklet.**

**THANK YOU VERY MUCH FOR TAKING THE TIME TO COMPLETE AND RETURN THE QUESTIONNAIRE**

**Appendix 10 a**



Brunel University

Mary Seacole Building, PhD Room 111

Uxbridge, Middlesex, UB8 3PH

Dear

**Re: Brunel University Multiple Sclerosis Research**

Thank you for participating in the study 'Exercise and Physical Activity in people with MS'.

As you may remember, this study consists of three Rounds. In the previous Round (Round 2) you were asked to rank 10 categories for exercise and physical activities and also the reasons why you did these activities in order of importance to you.

Enclosed you will find **Round 3** which is the final questionnaire.

Please return the completed questionnaire in the enclosed self addressed free post envelope by **10th April 2013**.

If you have any further questions please do not hesitate to contact me on Tel: 01895268729 or email: [andrea.stennett@brunel.ac.uk](mailto:andrea.stennett@brunel.ac.uk) .

Yours sincerely

Andrea Stennett

Physiotherapist & Lead Researcher

## **Brunel Multiple Sclerosis Research**

### **Questionnaire booklet for research participants**

In the previous questionnaire you were asked to rank 10 categories for exercise and physical activities and also the reasons why you did these activities in order of importance to you.

All the responses given by yourself and all the other study participants from around the United Kingdom were organised revealing the groups' **top 10** choice. The information received was used to create this new questionnaire.

Please read the instructions carefully before completing this final questionnaire. Once you have finished please go back through your answers and make sure you are happy with your decisions.

Please note that all the information obtained from participants will be kept confidential. Only researchers working on the project will have access to this information. Also, by completing this questionnaire it is implied that you have given your consent to participate in this study.

**NOW TURN THE PAGE OVER TO PROCEED WITH THE  
QUESTIONNAIRE**

## Question1: Categories for Exercise and Physical Activity

The top 10 categories for exercise and physical activities are listed on the next page.

Please look through each category and rank your most important category as 1. Your next most important category ranked 2 and continue ranking until number 10, your 10<sup>th</sup> most important category.

Categories for Exercise and Physical Activity	Rank
<b>Leisure Activities</b> (e.g. gardening, reading, zumba, sports, visiting friends)	
<b>Every Day life Activities</b> (e.g. stairs, walking, pushing wheelchair, standing and transferring)	
<b>Activities without the use of weights</b> (e.g. upper and lower limbs exercises, bed, chair and floor exercises done without weights)	
<b>Self -care Activities</b> (e.g. washing & dressing, shaving, showering, eating, cleaning teeth)	
<b>Physiotherapy</b> (e.g. activities done with or by a physiotherapist)	
<b>Transportation</b> (e.g. to keep driving personal car/ to keep using public (bus/taxi) transportation)	
<b>Activities due to Family Roles</b> (e.g. spending time with family, looking after or playing with children/grandchildren)	
<b>Stretches</b> (e.g. activities done to stretch the upper and lower limbs)	
<b>Domestic Activities</b> (e.g. cooking, shopping, housework, laundry, making the bed, washing the sink)	
<b>Activities done with Technology</b> (e.g computer, phone, Wii, DVD)	

Do you agree or disagree with the top 10 categories listed above? **Please tick one box below:**

Agree  Disagree:

If you disagree please state in space below which activity/activities should have been included that is not currently represented in the list above.

### **Question 2: Categories for reasons why you do these activities**

The top 10 categories for the reasons why you do these activities are listed on the next page.

Please look through each category and rank your most important category as 1. Your next most important category ranked 2 and continue ranking until number 10, your 10<sup>th</sup> most important category.

<b>Categories for reasons why you do these activities</b>	<b>Rank</b>
<b>To improve MS symptoms</b> (e.g. to improve or maintain range of movement, strength, balance, reduce pain and alter muscle tone)	
<b>For Mobility</b> (e.g. to keep walking)	
<b>For Flexibility</b> (e.g. to maintain or improve flexibility)	
<b>For Emotional Wellbeing</b> (e.g. for pleasure, improve mood, reduce stress)	
<b>Out of Necessity</b> (e.g. need to because they are part of daily activities and everyday life)	
<b>For Social reasons</b> (e.g. to maintain a social life, provide a sense of belonging and to feel connected to community)	
<b>To keep active</b> (e.g. to keep mind and body active, to	

maintain function and keep transferring)	
<b>For Self-Reliance</b> (e.g. to maintain ones' independence and choice)	
<b>For self esteem</b> (e.g. to manage weight, feel better, sense of achievement, self-worth)	
<b>Living with MS now and in the future</b> (e.g. to limit deterioration, to combat MS, to keep doing the things I could do before MS)	

Do you agree or disagree with the top 10 categories listed above? **Please tick one box below:**

Agree  Disagree:

If you disagree please state in space below which activity/activities should have been included that is not currently represented in the list above.

**Please insert Name and Mailing Address if you have changed your mailing address (write in space provided):**

**Could you please go back and check you have answered all the questions in this booklet.**

**THANK YOU VERY MUCH FOR TAKING THE TIME TO COMPLETE AND RETURN THE QUESTIONNAIRE.**

**If you have further questions please do not hesitate to contact me on telephone: 01895268729 or email: [andrea.stennett@brunel.ac.uk](mailto:andrea.stennett@brunel.ac.uk)**

**Appendix 11 a**



Brunel University  
Mary Seacole Building, PhD Room 111  
Uxbridge, Middlesex, UB8 3PH  
Dear

**Re: Brunel University Multiple Sclerosis Research**

Thank you for participating and staying engaged in the study 'Exercise and Physical Activity in people with MS'. Enclosed you will find **the results** from all the people with MS who replied to Round 3, highlighting how the group prioritize exercise and physical activity. We would really appreciate knowing whether you agree or disagree with the overall groups' results. Therefore, this offers you an opportunity to have your say about the results.

The information from this study will help to shape how healthcare professionals design exercise and physical activity programmes in the future.

Please return the completed booklet in the enclosed **self addressed free post envelope by 23<sup>rd</sup> May 2013**. You do not have to put a stamp on the envelope.

If you have any further questions please do not hesitate to contact me on Tel: 01895268729 or email: [andrea.stennett@brunel.ac.uk](mailto:andrea.stennett@brunel.ac.uk).

Yours sincerely

Andrea Stennett  
Physiotherapist & Lead Researcher

## **Brunel Multiple Sclerosis Research**

### **Results of the study**

All the responses given by yourself and all the other study participants from around the United Kingdom have been analysed. The results of the groups' top 10 choice in order of their ranking are enclosed.

Please look through the results and have your say about the groups' ranking. Once you have finished please go back through your answers and make sure you are happy with your decisions.

Please note that all of the information obtained from participants will be kept confidential. Only researchers working on the project will have access to this information. Also, by completing this questionnaire it is implied that you give your consent to participate in this study.

**NOW TURN THE PAGE OVER TO PROCEED**

## Categories for Exercise and Physical Activity

Below are the results of the groups' top 10 categories for exercise and physical activity in ranked order. The most important category ranked as 1 and the least important as 10.

Do you agree or disagree with the order of the categories listed?

**Please tick one box:** Agree  Disagree

If you ticked agree please continue to **page 3**.

However, if you ticked disagree please re-rank in space provided below.

Rank	Categories for Exercise and Physical Activity	Re-Rank
1	<b>Self -care Activities</b> (e.g. washing & dressing, shaving, showering, eating, cleaning teeth)	
2	<b>Every Day life Activities</b> (e.g. stairs, walking, pushing wheelchair, standing and transferring)	
3	<b>Domestic Activities</b> (e.g. cooking, shopping, housework, laundry, making the bed, washing the sink)	
4	<b>Transportation</b> (e.g. driving personal car/ to keep using public (bus/taxi) transportation)	
5	<b>Leisure Activities</b> (e.g. gardening, reading, zumba, sports, visiting friends)	
6	<b>Activities due to Family Roles</b> (e.g. spending time with family, looking after or playing with children/grandchildren)	
7	<b>Stretches</b> (e.g. activities done to stretch the upper and lower limbs)	
8	<b>Physiotherapy</b> (e.g. activities done with or by a physiotherapist)	
9	<b>Activities without the use of weights</b> (e.g. upper and lower limbs exercises, bed, chair and floor exercises done without weights)	
10	<b>Activities done with Technology</b> (e.g. computer, phone, Wii, DVD)	

## **Categories for reasons why you do these activities**

Below are the results of the groups' top 10 categories for the reasons why you engage in exercise and physical activity in ranked order. The most important category ranked as 1 and the least important as 10.

Do you agree or disagree with the order of the categories listed?

**Please tick one box:** Agree  Disagree

If you disagree please re-rank in space provided below.

<b>Rank</b>	<b>Categories for reasons why you do these activities</b>	<b>Re-Rank</b>
<b>1</b>	<b>To improve MS symptoms</b> (e.g. to improve or maintain range of movement, strength, balance, reduce pain and alter muscle tone)	
<b>2</b>	<b>Out of Necessity</b> (e.g. need to because they are part of daily activities and everyday life)	
<b>3</b>	<b>To keep active</b> (e.g. to keep mind and body active, to maintain function and keep transferring)	
<b>4</b>	<b>For Mobility</b> (e.g. to keep walking if am able to)	
<b>5</b>	<b>Living with MS now and in the future</b> (e.g. to limit deterioration, to combat MS, to keep doing the things I could do before MS)	
<b>6</b>	<b>For Self-Reliance</b> (e.g. to maintain ones' independence and choice)	
<b>7</b>	<b>For Emotional Wellbeing</b> (e.g. for pleasure, improve mood, reduce stress)	
<b>8</b>	<b>For self esteem</b> (e.g. to manage weight, feel better, sense of achievement, self-worth)	
<b>9</b>	<b>For Flexibility</b> (e.g. to maintain or improve flexibility)	
<b>10</b>	<b>For Social reasons</b> (e.g. to maintain a social life, provide a sense of belonging and to feel connected to community)	

**Please insert Name and Mailing Address if you have changed your mailing address (write in space provided):**

**THANK YOU VERY MUCH FOR TAKING THE TIME TO COMPLETE AND STAYING ENAGED IN THE STUDY.**

**If you have further questions please do not hesitate to contact me on telephone: 01895268729 or email: [andrea.stennett@brunel.ac.uk](mailto:andrea.stennett@brunel.ac.uk)**

## Appendix 12a

### The Frequency of MS Symptoms reported by study participants (n=101)

50 listed MS symptoms identified by the group

<b>MS symptoms</b>	<b>Frequency</b>
Fatigue	63
Poor balance	45
Weak lower limbs	30
Weak upper limbs	21
Difficulty walking	21
Bladder	18
Spasm	18
Pain	16
Muscle stiffness	16
Visual impairment	15
Tremor	14
Drop foot	12
Co-ordination	10
Spasticity	8
Standing up	8
Loss of mobility	8
Sensitivity to heat	7
Memory impairment	7
Numbness	7
Limb not working	7
Tingling upper limb	6
Reduced sensation	6
Dizziness	6
Writing	5
Falls	5
Cognitive impairment	5
Weakness core muscles	4
Low mood/irritability	3
Paralysis	3
Confidence	3
Bowel	3
Need assistance with exercise	2
On/off floor	2
Poor concentration	2
Poor circulation	2
Slurred speech	2
Muscle wasting	2
Appearance	1
Deformity	1
Muscle cramp	1
Word retrieval	1
Sleep disturbance	1
Difficulty with bed mobility	1
Difficulty carrying groceries	1
Cannot run	1
Rely on muscle memory	1
Anxiety	1
Unable to go outdoor independently	1
Difficulty with transfers	1
Reduced muscle tone	1

## Appendix 12b

### MS Symptoms in grouped categories

50 listed MS symptoms in to 27 categories

<b>MS Symptom</b>	<b>Categorised frequency</b>
Fatigue	63
Weakness <ul style="list-style-type: none"> <li>• Upper limb (30)</li> <li>• Lower limb (21)</li> <li>• Core (4)</li> <li>• Paralysis (3)</li> </ul>	58
Mobility <ul style="list-style-type: none"> <li>• Difficulty walking (21)</li> <li>• Loss of mobility (8)</li> <li>• Limb not working (7)</li> <li>• Cannot run (1)</li> <li>• Drop foot (12)</li> </ul>	49
Poor Balance	45
Tonal Changes <ul style="list-style-type: none"> <li>• Reduced tone (1)</li> <li>• Spasticity (8)</li> <li>• MS stiffness (16)</li> </ul>	25
Sensory Changes <ul style="list-style-type: none"> <li>• Numbness (7)</li> <li>• Tingling upper limb (6)</li> <li>• Reduced sensation (6)</li> </ul>	19
Bladder	18
Spasm	18
Pain	16
Visual impairment	15
Cognitive changes <ul style="list-style-type: none"> <li>• Word retrieval (1)</li> <li>• Memory impairment (7)</li> <li>• Cognitive impairment (5)</li> <li>• Poor concentration (2)</li> </ul>	15
Tremor	14
Co-ordination	10
Transfers <ul style="list-style-type: none"> <li>• Standing up (8)</li> <li>• Bed mobility (1)</li> <li>• Transfers (1)</li> </ul>	10
Falls <ul style="list-style-type: none"> <li>• Falls (5)</li> <li>• On and off floor (2)</li> </ul>	7

<b>MS Symptom</b>	<b>Categorised frequency</b>
Sensitivity to heat	7
Dizziness	6
Writing	5
Appearance <ul style="list-style-type: none"> <li>• Muscle wasting (2)</li> <li>• Appearance (1)</li> <li>• Deformity (1)</li> </ul>	4
Mood <ul style="list-style-type: none"> <li>• Anxiety (1)</li> <li>• Low mood/Irritability (3)</li> </ul>	4
Confidence <ul style="list-style-type: none"> <li>• Confidence (3)</li> <li>• Unable to go outdoor (1)</li> </ul>	4
Bowel	3
Poor circulation	2
Slurred speech	2
Muscle Cramp	1
Sleep disturbance	1
Other: Difficulty carrying grocery (1) Need assistance with exercise (2)	3

### **Appendix 13: Example of adjusting for ties Round 2**

Scoring of categories and adjustment of tied categories

Category selected	Score	Example tied rank	Example of adjustments Score
1	10	1	10
2	<b>9</b>	<b>2</b>	<b>(9+8/2)= 8.5</b>
3	<b>8</b>	<b>2</b>	<b>8.5</b>
4	7	4	7
5	6	5	6
6	5	6	5
7	4	7	4
8	3	8	3
9	2	9	2
10	1	10	1

**School of Health Sciences and Social Care**  
**Research Ethics Committee**

School of Health Sciences and  
Social Care  
Brunel University,

**26 September 2013**

Proposer: Andrea Stennett – PhD Student

Title: Experiences of community dwelling people with Multiple Sclerosis  
on their participation in a Delphi study exploring physical activity: a  
qualitative study

Reference: 13/08/PHD/04

**LETTER OF APPROVAL**

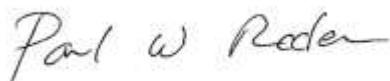
The School Research Ethics Committee has considered the amendments recently submitted by you in response to the Committee's earlier review of the above application.

The Chair, acting under delegated authority, is satisfied that the amendments accord with the decision of the Committee and has agreed that there is no objection on ethical grounds to the proposed study. Approval is given on the understanding that the conditions of approval set out below are followed:

- *The agreed protocol must be followed. Any changes to the protocol will require prior approval from the Committee.*

**Please note that:**

- Research Participant Information Sheets and (where relevant) flyers, posters, and consent forms should include a clear statement that research ethics approval has been obtained from the School of Health Sciences and Social Care Research Ethics Committee.
- The Research Participant Information Sheets should include a clear statement that queries should be directed, in the first instance, to the Supervisor (where relevant), or the researcher. Complaints, on the other hand, should be directed, in the first instance, to the Chair of the School Research Ethics Committee
- Approval to proceed with the study is granted subject to receipt by the Committee of satisfactory responses to any conditions that may appear above, in addition to any subsequent changes to the protocol.
- The School Research Ethics Committee reserves the right to sample and review documentation, including raw data, relevant to the study.



**Paul Roden**

Deputy Research Ethics Officer

**Appendix 15 a**



Mary Seacole Building, PhD Room 111

Uxbridge, Middlesex, UB8 3PH

Dear

**Re: Experiences of community dwelling people with Multiple Sclerosis on their participation in a Delphi study exploring physical activity: a qualitative study**

Thank you for your ongoing support to the current research looking at physical activity in people with Multiple Sclerosis.

The first study you were involved in looked at the activities you prioritised during a typical day and the reasons why you undertake them. Now, you are invited to take part in the second phase of this research which is designed to find out your views about the physical activities identified and prioritised from the previous study.

In your research pack you will find two documents entitled Participant Information Sheet and Consent Form. Please read the participants information sheet first to find out more about this study.

If you have any further questions please do not hesitate to contact me on Tel: 01895268729 or email: [andrea.stennett@brunel.ac.uk](mailto:andrea.stennett@brunel.ac.uk).

Yours sincerely

Andrea Stennett

PhD Research Student



## **Research Participant Information Sheet**

**Research Title: Experiences of community dwelling people with Multiple Sclerosis on their participation in a Delphi study exploring physical activity: a qualitative study**

You are invited to take part in the above mentioned research. You are being approached because you were involved in a previous study entitled: A day in the life of people with Multiple Sclerosis: an exercise and physical activity study.

These studies will form part of a Doctoral thesis led by Andrea Stennett, PhD student, under the supervision of Professor Lorraine De Souza and Dr. Meriel Norris at Brunel University. Below you will find some information that covers why this current study is being done and what it would involve should you decide to take part.

### **1. What is the purpose of the Study?**

This study is designed to gain a deeper understanding of the findings from the previous study you were involved in entitled: A day in the life of people with MS. The findings from this study identified the top 10 activities people with MS prioritise and the reasons why they prioritise the activities in order of importance. Therefore, the next step is to gain

your views and opinions about the top 10 chosen activities and reasons why people with MS engage in these activities.

## **2. Who can take part?**

If you are over 18 years old, able to communicate clearly in English, live in the community with multiple sclerosis and have completed the previous study entitled: A day in the life of people with Multiple Sclerosis: an exercise and physical activity study, I would be interested in hearing from you.

## **3. What are the benefits of taking part?**

It is unlikely that there will be a direct benefit to you from this study. However, the results of this study may provide further insight into the prioritised activities people with MS are involved in, which may further inform and guide how clinicians prescribe exercises in the future. Results from this study will be submitted for publication, or presented at conferences, so that they can reach an audience of professionals as well as people with MS.

## **4. What will happen to me if I take part?**

You will be asked to attend a **one off** interview to discuss your views and opinions about the findings from the previous study. There are no right or wrong answers; we are only interested in your views and opinions. The interview will be led by myself, Andrea Stennett and should last approximately 60 minutes. The timing is flexible should you require a break during the interview.

The interview will take place at a mutually agreed location and time that is safe, quiet and convenient to you. You will be offered venue options for example, the local MS therapy centre or at your home. If you decide to

meet at the MS therapy centre, I will contact the centre manager and make the necessary arrangements.

Please be aware that the information you provide during the interview will be recorded using an audiotape as well as a note pad. This will be done to ensure that I capture what you say and represent the information accurately.

## **5. Do I have to take part?**

Your participation is completely voluntary. This means that you can choose not to be involved, or if you start the interview, you can choose to withdraw at anytime. If you decide not to participate, it will not affect any treatment, membership and or care that you are currently receiving. Also, should you decide to participate in the study you do not need to answer all the questions posed by the researcher during the interview.

## **6. If I want to take part, what will happen next?**

If you decide to take part in this study, you can contact me, Andrea Stennett, by telephone 01895268729 or email on [andrea.stennett@brunel.ac.uk](mailto:andrea.stennett@brunel.ac.uk) to discuss a convenient time and location for the interview to take place. Also, if you have further questions about the study this could be clarified at this time. Please note, that participating in this study is completely voluntary. Therefore, following the telephone conversation if you are happy to participate then you will be asked to sign the consent form which can be found in the research pack.

## **7. Will my taking part in this study be kept confidential?**

All the information that is collected about you during the course of the research will be kept strictly confidential. However, due to professional codes of conduct there are limits to confidentiality, which includes disclosure of any information to the relevant personnel about potential harm to yourself or other vulnerable groups. Should this situation arise you would be encouraged to seek assistance or support from the relevant authorities. Additionally, if in the unlikely event information disclosed throughout the interview suggests harm to a third party (e.g. children or other vulnerable adults), I reserve the right to disclose the information to my supervisory team at the university. This may also involve informing third party services.

Also, in line with ensuring confidentiality, any personal information will be kept securely in a locked cupboard in a pass code protected room at the university.

The researcher will transcribe the interview and all notes kept in a secure location. No one will be able to link your responses to you, as any identifiable information will be coded. All audio recording will be erased once the data has been transcribed and analysed.

## **8. What will happen to the results of the study?**

The results from the research will be used as part of my Doctoral thesis. A report of the key findings will be sent to you at your request. Your mailing address will be retained for this purpose only.

The findings will be presented at academic and professional conferences and also published in academic journals. The findings and summary will be shared with members of the MS society. Anonymity and confidentiality will still be in place in all cases. Findings from this study may contribute to developing a better understanding of exercise priorities in people with MS.

## **9. Who is organising and funding the research?**

This research is part of a Doctoral Study undertaken by Andrea Stennett. It is supported by - The Centre for Research and Rehabilitation (CRR) within the School of Health Sciences and Social Care at Brunel University and has gained Ethical Approval from the Ethics Committee at the school. If you have questions about the Ethics of this study please contact the Chair of the Ethics Committee, Dr. Elizabeth Cassidy ([elizabeth.cassidy@brunel.ac.uk](mailto:elizabeth.cassidy@brunel.ac.uk)).

## **Contact for further information about the research:**

Andrea Stennett, Telephone 01895268729

Email: [andrea.stennett@brunel.ac.uk](mailto:andrea.stennett@brunel.ac.uk)

## **Research Supervisors:**

Professor Lorraine DeSouza, Email: [lorraine.desouza@brunel.ac.uk](mailto:lorraine.desouza@brunel.ac.uk)

Dr. Meriel Norris, Email: [meriel.norris@brunel.ac.uk](mailto:meriel.norris@brunel.ac.uk)

## **Useful contact details for MS Society:**

**Website:** [www.mssociety.org.uk](http://www.mssociety.org.uk)

**MS Helpline – 0808 800 8000 (calls to this number are free)**

**Thank you for considering being part of this study.**

## Appendix 15 c



Title: Experiences of community dwelling people with Multiple Sclerosis on their participation in a Delphi study exploring physical activity: a qualitative study

### CONSENT FORM

*Please complete the whole of this sheet*

*Please tick the appropriate box*

YES    NO

Have you read the Research Participant Information Sheet?

Have you had an opportunity to ask questions and discuss this study?

Have you received satisfactory answers to all your questions?

Who have you spoken to?

Do you understand that you will not be referred to by name in any report concerning the study?

Do you understand that you are free to withdraw from the study:

- at any time?
- without having to give a reason for withdrawing?
- without affecting your future treatment or care?

I agree to my interview being recorded.

I agree to the use of non-attributable direct quotes when the study is written up or published.

Do you agree to take part in this study?

**Signature of Research Participant:**

Date:

Name in capitals:

Witness statement

I am satisfied that the above-named has given informed consent.

Witnessed by:

Date:

Name in capitals:

Researcher name:	Signature:
Supervisor name:	Signature:

## **Appendix 15 d**



### **School of Health Sciences and Social Care**

Research Ethics Committee

#### **RESEARCH ETHICS RISK ASSESSMENT AND MANAGEMENT**

This form should be used to support the assessment of risks associated with your research project and their mitigation. It should be completed for **every** research project that involves human participation. It **must** be submitted as an attachment to the Research Ethics Application Form and discussed with your supervisor.

Prior to completion, if there is any aspect of the risks or risk management process associated with your proposed research that you feel unsure about then it is **your responsibility** (as the researcher) to seek further guidance from your supervisor.

**For Completion by the Researcher:**

Identified Risks	Likelihood	Potential Impact/Outcome	Risk Management/Mitigating Factors
Identify the risks/hazards present	High/Medium/Low	Who might be harmed and how?	Evaluate the risks and decide on the precautions, e.g.: Health & Safety
Home visits	Low	Physical injury to researcher by travelling in unknown areas	<ul style="list-style-type: none"> <li>• Plan journey ahead of time</li> <li>• Ask participant about transportation route</li> <li>• Carry personal alarm</li> <li>• Inform colleagues and supervisors about location and time of interview.</li> <li>• On completion of interview email/telephone supervisors and colleagues</li> <li>• Conduct interviews during the day and within day light hours.</li> </ul>
Disclosure of risk to self and or other vulnerable person	Low	Participant: <ul style="list-style-type: none"> <li>• Emotional distress from disclosing the event</li> </ul>	<ul style="list-style-type: none"> <li>• Inform participants of limits to confidentiality in Participant Information Sheet</li> <li>• At time of disclosure, cease interview</li> <li>• Have identified person to pass on details of the event</li> </ul>

## **Topic Guide**

**Research Title:** The meaning of exercise and physical activity for people living in the community with Multiple Sclerosis: exploration of a Delphi Study

### **Introduction**

- Thank interviewee for taking part in the study
- Introduce self, length of interview, confidentiality, check consent form, reiterate the right to withdraw from the study.
- Explain the purpose of the interview
  - ❖ To explore your views on the results of the Delphi study, specifically to gain some understanding about why particular activities and the reasons why they were selected.

### **Background and context - Exploration of terms**

As you will remember, this study asked people with MS about their physical activity in a typical day.

#### **What does the term exercise and physical activity mean to you?**

- ❖ Can you think of some examples of exercise
- ❖ Can you think of some examples of physical activity
- ❖ What influenced that understanding?  
e.g. The study, living with MS, physiotherapist, media, activity classes?
- ❖ How do you understand the relationship between physical activity and exercise?

#### **How did you interpret the idea of a typical day?**

- ❖ Were there important things missed?
- ❖ How stable do you think the idea of a typical day is for you?

### **Exploration of Delphi Results**

#### **a) For Activities** (*Cue cards with the results for activities will be placed in front of the participant to assist with recall*)

These cards show the top 10 physical activities that were selected by 70 people with MS and the order in which the group prioritised them.

Please take some time to look though the cards

**What are your thoughts on the physical activities selected?**

- ❖ Are there any you would change?
- ❖ Which?
- ❖ Why?
- ❖ Any surprises?
- ❖ Any missing?

**What are your thoughts on the order presented?**

- ❖ Are there any you would change?
- ❖ Which?
- ❖ Why?
- ❖ Any surprises?

**In the study I asked about a typical day. How stable is this list for you over a longer period?**

**b) For Reasons why** (*Cue cards with the results for the reasons why will be placed in front of the participant to assist with recall*)

These cards show the top 10 reasons why physical activities were selected by the group and the order in which they were prioritised.

Please take some time to look through the cards

**What are your thoughts on the reasons why these physical activities were selected?**

- ❖ Are there any you would change?
- ❖ Which?
- ❖ Why?
- ❖ Any surprises?
- ❖ Any missing?

**What are your thoughts on the order presented?**

- ❖ Are there any you would change?
- ❖ Which?
- ❖ Why?
- ❖ Any surprises?

**Once again thinking about the typical day issue, how stable is this list for you over a longer period of time?**

### **Exploring the experience of participating in the Delphi Study**

**Could you tell me what it was like doing the different questionnaires as part of this study?**

- Time taken between Rounds?
- Format
- Number and type of questions
- How long did the questionnaire take you to complete?
- Did you discuss your answer with anyone?
- What kept you involved until the end of the study?

### **Closing**

- Thinking about the findings overall from the study, what would be your key message to physiotherapists.
- Is there anything that you expected to talk about that we haven't discussed that you would like to raise?
- Do you have any questions for me?

**Thank participant and close**

## **Appendix 15f: Cue Cards**

### **Top 10 categories for Exercise and Physical Activity**

#### **# 1: Self-Care Activities**

Description of category

(e.g. washing and dressing, shaving, showering, cleaning teeth)

#### **#2: Every day life Activities**

Description of category

( e.g. stairs, walking, pushing wheelchair, standing and transferring)

#### **#3: Domestic Activities**

Description of category

(e.g. cooking, shopping, housework, laundry, making the bed, washing the sink)

#### **#4: Transportation**

Description of category

(e.g. driving personal car/to keep using public ( bus/taxi) transportation

#### **#5: Leisure Activities**

Description of category

(e.g. gardening, reading, zumba, sports, visiting friend)

## **#6: Activities due to family roles**

Description of category

*(e.g. spending time with family, looking after or playing with children/grandchildren)*

## **#7. Stretches**

Description of category

*(e.g activities done to stretch the upper and lower limbs)*

## **#8. Physiotherapy**

Description of category

*(e.g. activities done with or by a physiotherapist)*

## **#9. Activities without the use of weights**

Description of category

*( e.g. upper and lower limb exercises, bed, chair and floor exercises done without weights)*

## **#10: Activities done with Technology**

Description of category

*(e.g. computer, phone, Wii, DVD )*

## **Top 10 categories for the reasons why**

### **#1: To improve MS symptoms**

#### Description of category

*(e.g. to improve or maintain range of movement, strength, balance, reduce pain and alter muscle tone)*

### **#2: Out of Necessity**

#### Description of Category

*(e.g. need to because they are part of daily activities and everyday life)*

### **#3: To keep active**

#### Description of category

*(e.g. to keep mind &body active, to maintain function and keep transferring)*

### **#4: For Mobility**

#### Description of category

*(e.g. to keep walking if am able to)*

### **#5: Living with MS now and in the future**

#### Descriptive of category

*(e.g. limit deterioration, combat MS, keep doing the things I could do before MS)*

## **#6: For Self-Reliance**

Description of category

(e.g. to maintain ones' independence and choice)

## **#7: For Emotional Wellbeing**

Descriptive of category

(e.g. for pleasure, improve mood, reduce stress)

## **#8: For self esteem**

Description of category

(e.g. to manage weight, feel better, sense of achievement, self worth)

## **#9: For Flexibility**

Description of category

(e.g. to maintain or improve flexibility)

## **#10: For social reasons**

Description of category

(e.g. to maintain a social life, provide a sense of belonging and to feel connected to community).

## **Appendix 15g: Reflexivity Study 2**

### **Vignette 1: Reflexivity**

As a novice researcher, the first set of interviews were done adhering closely to the topic guide, however as I became familiar with the interview questions, I found that I would delve more in-depth. I felt free to move off script, explore ideas and thoughts as they occurred during the interviews. The more interviews I did the more confident I became. Kvale and Brinkmann (2009) described this as “transition from novice to skilful researcher”. This transition just happened. I actually surprised myself... It happened spontaneously as oppose to the first interview where in retrospect I missed opportunities to explore some thoughts/ideas in depth. (Research Journal, October 2013).

### **Vignette 2: Data Analysis- Familiarisation phase**

This stage of the data analysis was quite lengthy because I was quite keen to ensure that I had a sense of what people were reporting. The difficultly or the challenge this stage posed was knowing when to move forward to the next stage of the analysis. The diagram (see chapter 6) showing the stages involved in framework analysis gives a good example of the iterative process in the analysis but the key especially for novice researchers is to know when to move forward to the next stage and having the confidence to know that it is ok to move up and down each stage of analysis (Spencer et al., 2009).

Another interesting point, which I reflected on, was the impact re-listening to the interviews and reading the transcripts had on me. I felt as though I was transported back to the moment in time when the interviews were carried out. This was particularly remarkable being new to the field of qualitative research. I was amazed that the same emotions resurfaced by re-listening to the interviews as I did while sitting with the interviewee. For example, when someone made a point that was very

funny, I found myself laughing or when someone was making a point about a sad event, I also found myself being moved emotionally by what was said. These emotions occurred despite the lapse of months between the interview and the analysis phase (Research Journal, March 2014).

### **Vignette 3- what is this really about?**

The mapping and interpretation stage of the analysis was very challenging and the stage where I doubted myself. To help me through this phase I reflected and pondered on a number of questions:

- What is this study really about?
- What are the research questions? Am I answering the research questions?
- Am I representing participants' views accurately... am I doing justice to the data?
- Am I making things up?

I remembered sitting at my desk at the University one Friday morning desperate to speak to someone about what the findings from the study and the stage I was at; i.e. interpreting. The analysis was in the final stages, which was a lonely place... I felt I was immersed deeply into the data and needed to talk. I needed to share my thoughts with someone to see whether or not they made some sort of sense.

That morning I met a colleague who patiently took the time to hear my thoughts and some of the challenges I was facing. I explained that one of my challenge was knowing whether or not I was staying true to the data and I was not imposing my physiotherapist head on what participants were telling me... I felt that the study participants had trusted me with valuable information and I wanted to represent their views and opinions as best I could.

I felt a huge sense of responsibility to ensure that I was doing justice to what people discussed in the interview. The participants (pwMS) were very happy for the study overall- as one said "*I feel people (GP, health ministers, physiotherapists, public, even other pwMS) needed to understand more about people living with MS because of the variability of the disease*".

For me, coming from a quantitative background I found myself initially trying to find an answer to the research question. That was how I have been socialised from my undergraduate training and also in life. My friends called me the 'problem solver'. I always tried to explain things away... however the challenge was I could not find an answer, because peoples' views were shaped by their own social context, living with the disease, age, stage of life and personal circumstances. All of which made it impossible to find an answer to any question I might have. There were some similarities as well as notable differences in the views and opinions of some participants but where would I begin?

Having discussed my dilemma with my colleague, I felt like a heavy load was lifted off my shoulders. She could empathise as she had recently completed a PhD and used a qualitative approach, albeit a different type of data analysis. She explained that she went through a similar phase and that it was ok to feel stretched, uncomfortable and challenged during the analysis stage... she said that these feelings would suggest that I was staying true to the data because I cared about the data which ethically meant I wanted to do due justice to the data. I could identify with what she was saying as I do care and wanted to help this group of people and also help other health professionals understand MS (Research Journal, April, 2014).

#### **Vignette 4 - Learning and doing framework analysis- Study 2**

The data analysis process demonstrated the concept of learning and doing. That is, learning about framework analysis and doing it all at the same time. I felt very uncomfortable during this process... actually a more accurate description would be a 'roller coaster of emotions'. I was genuinely eager to start the analysis because I wanted to hear participants' views. The deeper I went into the analysis this sense of foreboding crept in, this feeling of needing to know that you are on the right track. During this phase, I found discussions with my supervisors and peer support useful tools/ strategies. For example, there was another PhD student doing framework analysis so we would discuss the process even though we were researching different areas.

I used Ritchie and Lewis as my guide... it never left my side. I would read and re-read.. I also found articles using framework to see how they went about the analysis. I quickly learnt that the data analysis was not a linear process. We read it that way but it was like going from point A to point B, then to point A again, to point B, to point C, then to point A. This led to the diagram illustrated in chapter 6 (see Figure 6.3), which demonstrates this iterative process between the stages of analysis (Research Journal, May, 2014)

## **Appendix 15h: Developing a conceptual framework study 2 (Draft)**

### **1. Background/Demographic information**

- 1.1 Age
- 1.2 Sex
- 1.3 Functional Level
- 1.4 Impact of MS on activity
- 1.5 Occupation/Employment Status
- 1.6 Type of MS
- 1.7 Other

### **2 Meaning of Exercise**

- 2.1 Movement (organised (leads to health fitness and strength), keep mvt, puffy, repetitive, supportive)
- 2.2 Conscious activity/focused/set/intentional)
- 2.3 Demanding (intensity/work/extra/challenging/creates conflict/can't do)
- 2.4 Feelings (feel good factor, sense of achievement), Boring (-ve)
- 2.5 Activities done with health professionals (+/- equipment)
- 2.6 Supports daily routine/efficient
- 2.7 Location of activity (gym/home/outdoors)
- 2.8 Consequences and Benefits of exercise
- 2.9 Other issues

### **3 Meaning of Physical Activity**

- 3.1 Any movement (you do/ choose to do/purposeful/practical movement/Chore\*/)
- 3.2 Daily activity (Normal/day to day/part of daily life/how we live life)
- 3.3 Feelings (mundane, fun, irrespective of feeling, feel good factor)
- 3.4 Social element (beyond impairment and function to participation)
- 3.5 Reason and benefit of physical activity
- 3.6 Physical type activities (will not focus on these as they are similar to those listed in study 1)
- 3.7 Other

## **4 Relationship between exercise and physical activity**

- 4.1 Similarities (overlap/no difference/what's in a word, Incidental/accidental activities, time of day)
- 4.2 Differences (no relationship)
- 4.3 Conscious versus unconscious activities (just do it/routine)
- 4.4 Energy expenditure (Discipline required)
- 4.5 Other

## **5 Influencing Factors for exercise and physical activity**

- 5.1 Preference and Choice (Fun, Age)
- 5.2 MS (before & or after dx/MS related symptoms/Experience of living with MS)
- 5.3 Professional input (Attending MS therapy Centre /PT)
- 5.4 Circumstances
- 5.5 Personal belief & desire (motto/do something/desire to be fit)
- 5.6 Prior education (Primary and or high school)
- 5.7 Better than doing nothing
- 5.8 Other (being involved in the study)

## **6 Views about the top 10 chosen activities**

- 6.1 Views about top 10 activities (chosen, order, missing, surprises, overlap)
- 6.2 Anchor activities (stretches, PT & act without weights supporting top 6)
- 6.3 Identity (Separation of self from other pwMS & general population)
- 6.4 Variability of activities (Strength in diversity/Incidental, desirable vs necessary, vital, human versus non-human)
- 6.5 Priorities depends on (age/personal choice, stage of disease, ability, energy demands/circumstances/lifestyle/perception of ex and PA)
- 6.6 Relevant for life with MS (Not always about fitness  
(Freedom/access/fun/pleasure/family), Routine of life, connectivity, aid normal life (physical/social))
- 6.7 Other

## **7 Views about the top 10 reason why**

- 7.1 Views about the reasons why (Chosen, missing, surprises, overlap, order, ideal versus reality, personal belief, age, stage of disease)
- 7.2 Motivation for exercise and PA (sense of achievement/management weight)
- 7.3 Conflict between physical and emotional
- 7.4 Coping strategy (part of living with MS, Rule and challenge MS, Control& wellbeing)
- 7.5 Normal life (how to live in the normal world)
- 7.6 Road map for MS journey (vital, identity of self, objectives, resilience)
- 7.7 Organisation and Planning
- 7.8 Participation
- 7.9 Other

## **8 Understanding of a typical day**

- 8.1 Activities over a week
- 8.2 Difficult to describe
- 8.3 Energy levels
- 8.4 Normalcy
- 8.5 Practical things to keep living /Routine activities/same
- 8.6 Priorities changes in a typical day
- 8.7 Typical day depends on circumstances
- 8.8 Typical day depends on feelings
- 8.9 Variety
- 8.10 Other

## **9 Sense of loss**

- 9.1 Loss of activity
- 9.2 Loss of employment
- 9.3 Loss of energy
- 9.4 Loss of family and or friends
- 9.5 Loss of identity
- 9.6 Loss of independence
- 9.7 Compromise and reconciliation

9.8 Other

## **10 Role of Support**

- 10.1 Exercise Class
- 10.2 Family and friends
- 10.3 Health professionals
- 10.4 MS therapy centre
- 10.5 Other

## **11 Risk and Safety**

- 11.1 Conflict between PT and pt
- 11.2 Falls
- 11.3 Other

## **Addendum**

### **12 Methodological Considerations**

- 12.1 Administration of the Delphi
- 12.2 Anonymity
- 12.3 Band wagon effect
- 12.4 Change mind about ranking
- 12.5 Honest response
- 12.6 Interpretation of the categories
- 12.7 Iterative process of the Delphi
- 12.8 Level of importance attached to the categories
- 12.9 Reasons for staying engaged/What kept u engaged
- 12.10 Timeframe of the study/ time complete questionnaire
- 12.11 Use of questionnaires
- 12.12 Interpretation of typical day
- 12.13 Moving cue cards (comparing interview prompts to questionnaire)
- 12.14 Other (memory)

### **13 Experience of Being involved in the study**

- 13.1 Benefit pwMS
- 13.2 Awareness ( self before and after MS/of study findings)
- 13.3 Positive (habit forming, interesting, pleased about study, valued)
- 13.4 Having a voice through the study
- 13.5 Focus mind on something else/ study focused attention
- 13.6 Need for more MS research
- 13.7 Outcome
- 13.8 Provided opportunity
- 13.9 Understanding MS (personally and others)
- 13.10 Other

### **14 Message to Physiotherapist**

- 14.1 Get the balance right/time constraints/discipline
- 14.2 Empathise/sense of humour/intuitive/know ouch limit/encourage
- 14.3 Think of the individual / rapport with pt
- 14.4 Explain what you are doing and why
- 14.5 Listen
- 14.6 Make activity fun / Realistic and doable programs/incorp. Act. Daily life
- 14.7 Have resources available to support pwMS post discharge
- 14.8 Other

### **15 Message to Neurologist**

### **16 Message to pwMS**

### **17 Perceptions about the state of the Healthcare system**

- 17.1 State of Physiotherapy (access/loss of PT/Loss of MDT/Waiting times)
- 17.2 Location of Care (hospital/community (classes, self mx, patient centred care, holistic/Continuity of care in the community))
- 17.3 Financial Constraints (don't want to be a burden on healthcare)
- 17.4 Cope with HS (Isolated, give up or stay engaged-through research)

### **18. Other (Life history of MS)**

## Appendix 15i: Example of interview extract and labeling

*Study 2: Interview transcript.*

**Meaning of PA**

D: For me it's, more than to.. have.. I can't do any exercise without help. So, Jane (wife) and I manage to do a bit.. everyday, when we are dressing, its ah... physical activity and ah... movement that I wouldn't normally have.

I: ok

D: Because, I have no active movement. Any movement, it's passive, in other words is done by somebody else. Because I don't have any movement of any, no voluntary movement anyway. I believe in physiotherapy because hydrotherapy once a week and physiotherapy once a week. Those help me to maintain. ammm... mobility, limited passive mobility of my limbs. Which is important because if you loose that, you can't even really get dressed. So by definition you probably, astoundingly bed ridden.

I: So, what the physio does or the hydrotherapy, would you classify that as exercise or as physical activity?

D: both

I: Both

D: its as a... a social element as well.

I: ok. So, then what do you think makes physical activity physical activity as oppose to exercise. Do you draw a distinction between the two?

D: Not really, because, my level of disability, only draws a blurr with those distinctions. I can't... If I can't move, I can't actually participate in physical activity. But if you extend that into socialising I can.. but that's sort of a grey area really isn't?

I: hummm...

D: (sipping coffee with wife feeding..).

I: so for you then, ammm.. so you've mentioned that you are involved in physiotherapy and involved in hydrotherapy. What else are you involved in?

D: Really, the remainder it is, I would put under the social category.

I: For example?

D: For example, I just want to sort of make this, ammm.. distinction.. that if you are like me, in other words quadriplegic, then you have two options. You can continue to live in the abled body world and try to participate in as many.. social and wait... yeah... social activities,

**Social Element**

**Relationship ex+PA**

**linked to social element**

**Social**

**Participation**

*unable to do ex by self*

*movement that I ...*

*type 3 achieves benefits of PA*

*reason for ...*

*Hydro + ex & PA*

*4.2 3.6 7.5  
No difference bw r/r*

*EX PA  
Social*

*7.5 5.3*

133 I: is there? (laughing)  
134 I: So, so you said your physio does passive movements to keep your  
135 limbs flexible.  
136 D: yeah.. yeah..  
137 I: you said because those are necessary for your self-care/personal  
138 care and you link that as being able to take part in, amm.. daily  
139 activity.  
140 D: yeah.  
141 I: anything else?

8.6 [8.2]  
Loss of  
Achilles  
(7.2) (5.2)

2.7  
6.3

142 D: amm... Yeah.. I think that If I..it's worth re-stating the fact that, if I  
143 didn't have physiotherapy, the amount of way my physique  
144 generally has so atrophied, the muscle loss all those things which  
145 can be a bit demoralising when you are use to being a runner. I  
146 wanna go for a run!.. u know.. I want to go for a run.. but I think  
147 running for me was always the way, of maintaining a level of  
148 physical fitness.. that makes you feel good. And physiotherapy,  
149 comes a close second to that. When I am having physiotherapy, I am  
150 running or metaphorically I am doing all the things that I really  
151 would do if I was abled body. And my physios relates to that..  
152 and...does that make sense? I am not sure if any of this is making  
153 sense.

154 I: yes you are. So, what I hear you saying is before when you could  
155 run you associated that with physical fitness so now, amm... you have  
156 physiotherapy you can participate in self care activities , you engage  
157 in social..amm.. activities as well. So, because you associated  
158 running with physical fitness, what do you associate like your self-  
159 care with now or do you get the same ...this may be a trick  
160 question..

161 D: the buzz?

162 I: yeah..

8.2 [6.3] [8.1]  
Loss of  
Achilles  
+ Compulsive  
+ recompulsive

163 D: no because the buzz is chemical ...and based on physical.. or  
164 that's my..that's my opinion.. but it is ammm..yeah.. it's the nearest  
165 I can get. If I don't do physio for a week, I am probably a bit more  
166 grumpy than I would normally be, because I need that.. in the same  
167 way that I needed to run... I had this strange compulsion. I use to  
168 work shifts... and it allowed me a lot of time to run.. I guess I was a  
169 bit compulsive.. And I am a little bit like way about my

Reasons for PT

Identify self → Runner (h+) → MS (vni)

Replacement of  
Activities  
Running → feel good (Buzz)  
PT (dream ) running

Running → the Buzz  
PT

7.5 Participation  
7.2  
Role & Challenge  
MS  
Normal life

60 going to the cinema, going for coffee and meeting friends, all of  
61 those things..which is what we do (pointing at his wife). But if you  
62 are at your limitation, and allow your physical limitations to dictate  
63 to you what you do; you then become a disabled person.. always  
64 unable to participate in the able bodied world.

Social activities world  
Don't be limited  
by physical  
impairment.

7.5  
7.2  
Role & challenge  
MS  
Participation  
8.1  
7.6

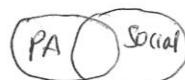
70 I: and so, going to the cinema, that's apart of activity for you?  
71 D: yeah, that's just an example, yeah.. I think really.. if you think of it  
72 in able bodied terms, Jane and I, we participate in virtually  
73 everything. What we used to do..u..know.. you go out for a meal, you  
74 go out for coffee, you maybe go out and see play or something.. we  
75 do all of that. But I can't do that, without my wife. I rely 110% on  
76 her.

Compare life now to  
past → made a decision  
Participation in  
able bodied  
world  
Cinema  
Coffee  
Dinner  
Dependence on  
others → family support

7.2B  
Relationship  
ex PA 7.5

77 I: So then, does that make you view exercise and physical activity in  
78 a different way then?  
79 D: Partly, because, when I go for hydrotherapy, I know the people  
80 there. We have a laugh and a joke, so that's social. We pull each  
81 others legs (laughing), and have a bit of fun and the same as  
82 yesterday afternoon, the physio comes round.. and we know her  
83 socially as well. So, that's an hour of physiotherapy, but coffee and  
84 fun as well. So the two things mere intermingle as well. Does that, I  
85 don't know...does that make sense?

support → other people  
social → PT



(4.2)

86 I: So exercise and physical activity overlaps for you.

87 D: yeah.

88 I: amm.... and what do you think influenced your understanding of  
89 exercise and physical activity?

5.2  
Influence of  
deficit + PA  
8.2  
SENSE  
LOSS  
B.6  
B.3

90 D: amm..I think that's a gradual process. Because with MS over the  
91 last 10 years, when I was first diagnosed 10 years ago, very slowly  
92 and gradually, it's an insidious, amm.. deterioration, which forces  
93 you to compromise gradually, year by year! Ammm..in..amm... in  
94 ah...compromising what you want to do and what you can do. For  
95 instance, I was a very active runner. I was a pilot, both things that I  
96 cannot do anymore, but I can reconcile that to a certain extent.

MS → gradual loss  
function ↓  
compromise

(Loss of Activity)  
(Running)  
(Pilot Identity)

Reconcile? Come to terms  
with loss

Interview D.M

Sinduj 2

Printed 28/03/14  
→ filled in gaps by re-checking transcript

A	B	C	D	E	F
1 : interview SB  Age = 60 Impact of MS on Exercise and Physical activity = Moderately affected Sex = Female Type of MS = Primary Progressive	A: 2.1 Activities done with Health professional  Goes to physio once per week... Does ball and floor exercises with physio (24)	B: 2.2 Any movement of the body  Movement that keeps her mobile and build muscles(2-36)	C: 2.3 Consciously intentional activities something else... activities you don't do every day (17-18)	D: 2.4 Consequences and benefits of doing exercise  Has foot pedal cycle at home, despite convenience of exercise equipment at home, does not do exercises (24-28)	E: 2.5 Demanding activities you don't do everyday (17-18)  Requires effort (49-50)
2 : interview C.G  Age = 53 Impact of MS on Exercise and Physical activity = Moderately affected Sex = Male Type of MS = Primary Progressive	MS therapy Centre(55)  Use exercise equipment... but because spends most of the day in a room in the house, activity revolves around getting up from chair and going to look(104-110)	Aerobic activity to get heart going so prevent sedentary life.  Move fast to get out of breath to improve overall healthy lifestyle for over all health (84-89)...  Gym type and core activities definitely exercises (102-103)	Continued activity done in the gym (80)  Focused activity using equipment, may involve walking (30)	No comment  Deliberate activity (50)	Activities contained now, unable to run, can't swim because don't like walking barefoot and also getting into the pool and needing the too (72-76)
3 : interview K.M  Age = 65 Impact of MS on Exercise and Physical activity = Moderately affected Sex = Female Type of MS = Unsigned	Did not mention anything in this column. Takes a holistic view to exercise and PA, does not use equipment or engage in exercise with physio (52)	Any movement is exercise does not have to be specific. Any movement forms part of daily life, like cooking(30-34)  Other people view exercise as going to gym, jogging... that is specific but any movement that involves the body is exercise(36-39)	No comment	No comment	NO COMMENCE
4 : interview B.W  Age = 63 Impact of MS on Exercise and Physical activity = Mildly affected Sex = Female Type of MS = Unsigned	Did not mention anything here	Not just any movement but movement in an organised way, ones that strengthen the core ms (77-78)	Organised movement(78)  Can put into daily routine (87-89). Like this fact about exercised(89)	Do exercises because of previous back problems associated with poor posture  Exercises does not take long ~10mins.  Recently tried putting exercises into daily routine and think this is good to do (81-89)	NO COMMENCE
5		Movement that keeps you fit and moving (122-125)	Can pace self if tired (127-130)	Exercises done to strengthen core muscles (81)	

	A	B	C	D	E	F
	A : 2.1 Activities done with health professional	B : 2.2 Any movement of the body	C : 2.3 Conscious / Intentional activities	D : 2.4 Consequences and benefits of doing exercise	E : 2.5 Demanding activities	F
1 5 : Interviewee T.S	Exercises done at MS centre (77-79)	A number of things mainly walking (90-96)	No comment	Exercise is a utility to prevent muscle loss so that when u need those muscles they are there and functioning.	Had home exercise in the past but unable to do them (79-80)	
	Age = 55 Impact of MS on Exercise and affected Sex = Female Type of MS = Secondary Progressive			You do more exercise when it is fun, exercise now is not the same (99-105)		
6 6 : INTERVIEW C.W	Does exercise class at MS therapy Centre with physio (28)	Cause breathlessness example, exercise class, yoga tai chi (28-39)	Focused activity for a period of time (23-24)	Maintains general fitness (72)	<i>Exercise - challenging and exhausting but end (28-34) separate activity done at a family not around to get place + quiet.</i>	
	Age = 47 Impact of MS on Exercise and affected Sex = Female Type of MS = Secondary Progressive	Not everyone sees those activities as exercise but for me it is quite challenging. Love the challenge (32-34)	Stair climbing is hard work, it is exercise but don't consciously think of it as exercise (62-66) good quotation			
7 7 : Interview V.S	Did not mention anything here	moving specific muscles that you don't usually move in your daily routine (75-74)	Exercise is a set routine e.g. Mr. Motivator (50-51, 59-60, 68-69)	Can't exercise every day due to fatigue (65-66)	Find exercises challenging even the mildest exercises (112), my body rebels but by emptying dishwasher which is gentle movement relaxes muscles (120-133)	
	Age = 47 Impact of MS on Exercise and affected Sex = Female Type of MS = Relapsing Remitting	These muscles then can be used in every day life routine to make it easier (75-79)				
8 8 : Interview D.M	Has physio once per week, does hydrotherapy (37)	Exercise is like keep fit activities or gym work (177-179)				
	Age = 52 Impact of MS on Exercise and affected Sex = Male	Unable to move upper or lower limb, for him exercise is done passively (29-34)	No comment here	Passive movements done to maintain some level of functioning e.g. getting dressed. Without it I would be bedridden (31-36)	Unable to do any movement by self so depend on others for movement, gets some during washing and dressing but all passively (24-31)	
9 9 : Interview with A. F	Goes to exercise class at MS therapy centre...use motor med and has stretching still not enough (40-594-596)	Keeps moving for as long as possible to delay getting into a wheelchair (42-47, 503-504)	Think about what you are doing and how you are going to do it without falling over (72-73).	Without exercise I would be in a wheelchair because I am heading that way (44-47).		
	Age = 58 Impact of MS on Exercise and affected Sex = Female Type of MS = Primary Progressive	Specific type of activity (126-127)	Exercise you have to concentrate to do e.g. lifting leg when walking (81-87)	Exercise makes you more efficient in daily life (61-62)		
10	Use the info learnt at the center at home (426-430)		Hip hitching helps when my leg goes numb-ex helps with walking (81-87)	Hip hitching helps when my leg goes numb-ex helps with walking (81-87)		
			Want to keep going for as long as possible (503)			

SA  
2

A	B	C	D	E	F
10 : interview P.J Age = 70 Impact of MS on Exercise and affected Sex = Male Type of MS = Unassigned	A : 2.1 Activities done with Health professionals Does not have physio and does not do any formal exercise	B : 2.2 Any movement of the body Any movement, e.g swimming, walking, cycling, lifting weights, going to the gym, exercise most of your body (52-54,58-61,93-94) Movement that is hardwork (74-75)	C : 2.3 Conscious / intentional activities Choosing and activity and doing more of it (103-105)	D : 2.4 Consequences and benefits of doing exercise No comment	E : 2.5 Demanding activities Swimming is exercise because it is hard work (52-75), doing more of an activity that you choose to do (94-105) ex. is lifting weights (206-208)
11 : Interview data Not S.F Age = 71 Impact of MS on Exercise and affected Sex = Male Type of MS = Unassigned	Does not have physio and does not do any formal exercises	No comment here	No comment	No comment	Don't do any exercise would measure 2/10 and that would be active (34-37) Exercise is work (89)
12 : interview R.A Age = 71 Physical activity = Unassigned Sex = Female Type of MS = Unassigned	Goes bowling, does it in a wheelchair (103)	Movement that keeps you fit and keeps you moving to combat the symptoms of normally do during your daily MS (52-62)	Doing things you would not normally do during your daily activities (177-179)	Not only makes you fit but gives you the feel good factor (139-142,146)-150)	Ex is doing things you don't normally do (177-179) Ex is activity you repeat for a certain time (253-266)
13 : interview S.O Age = 72 Impact of MS on Exercise and affected Sex = Female Type of MS = Unassigned	Does exercises prescribed by physios in bed and wheelchair (57)	Repeated activity but even moving during cooking because it involves bending, stretching, more than just sitting and doing nothing(186-188,221,109-1010,1044-1048) Movement that you don't usually do in daily activities, but because you exercise it makes daily activities easier(481-493)	Activities that you have to concentrate on and do it separately (33-35, 57-61)	Without exercise you go downhill and not other with self which does not help you (850-856)	Ex is activity you repeat for a certain time (253-266)
14		Aware of the need to do exercise to strengthen back; about 100 per day but don't do it because it causes me pain (45-54)	Activities that you have to concentrate on and do it with transferring from wc(58-60)	Physio ms tightening ex will help do (30)	Any movement that she cannot do (30)
		Do muscle tightening exercises in bed as shown by physio(57-58)	Can consciously do daily activities lifting saucerpan x10 (86-90)	Aware of the need to do exercise to strengthen back; about 100 per day but don't do it because it causes me pain (45-54)	

3

**Appendix 15k: Examples of Mapping and Interpretation**

**Name: 7 Views top 10 reasons why\7.1 Conflict between physical and emotional**

**Description: Dilemmas experience// which to tackle first the physical or the emotional**

<b>Participants</b>	<b>Key Dimensions</b>	<b>What are they really saying</b>
■	Physical and emotional linked-inter-related  Influence of physical and emotional visa versa	Inter-relatedness of Physical and emotional states of being  The effect of exercise on physical and emotion states  Personal belief
■	Importance of maintaining self esteem; +ve links with emotional and physical	Inter-relatedness of Physical and emotional states of being  The effect of exercise on physical and emotion states  Personal belief
■	Impact of depression -ve on physical  Dilemma of what to tackle first- emotional/physical  +ve effects of exercise on depression   Ability to do self-care is linked with independence, self-esteem and confidence.  Transportation linked with independence, confidence and self-esteem	The effect of exercise on physical and emotion states  Personal belief  Dilemma with pwMS but also has clinical implications- what do you tackle first? Physical/emotional   Identity/ Linked with chart 6   Identity/ Linked with chart 6
■	-ve effects of depression and	The effect of exercise on physical and

<b>Participants</b>	<b>Key Dimensions</b>	<b>What are they really saying</b>
	<p>impact on physical activity</p> <p>Priority then for reasons would be based on personal circumstances- if depressed prioritised emotions first</p> <p>Set Routine</p>	<p>emotion states</p> <p>Personal belief</p> <p>Prioritised based on personal circumstances-? linked with chart 6</p> <p>Coping strategy</p>
█	Notes the importance of self-esteem	Personal belief
█	<p>-ve impact of stress on the physical self</p> <p>what to treat first?</p> <p>Physical/emotional ? answer is - both</p>	<p>Effect of exercise on physical and emotional states</p> <p>Personal belief</p>
█	<p>-ve influence of anxiety on exercise and physical activity</p> <p>Which to tackle first?</p>	<p>Impact of negative emotions on physical</p> <p>Dilemma- which one to treat?</p>
█	Link of family support to +ve emotional states- self esteem and emotional wellbeing	+ve emotional states also dependent on support structure
█	Link between physical and emotion	Effect/influence of exercise on physical and emotional states
█	Self-reliance and mobility helps self-esteem	Inter-relatedness of exercise and physical activity on the physical and emotional states

Appendix 15k: Examples of Mapping and Interpretation

Name: **7 Views top 10 reasons why|7.2 Coping strategy**

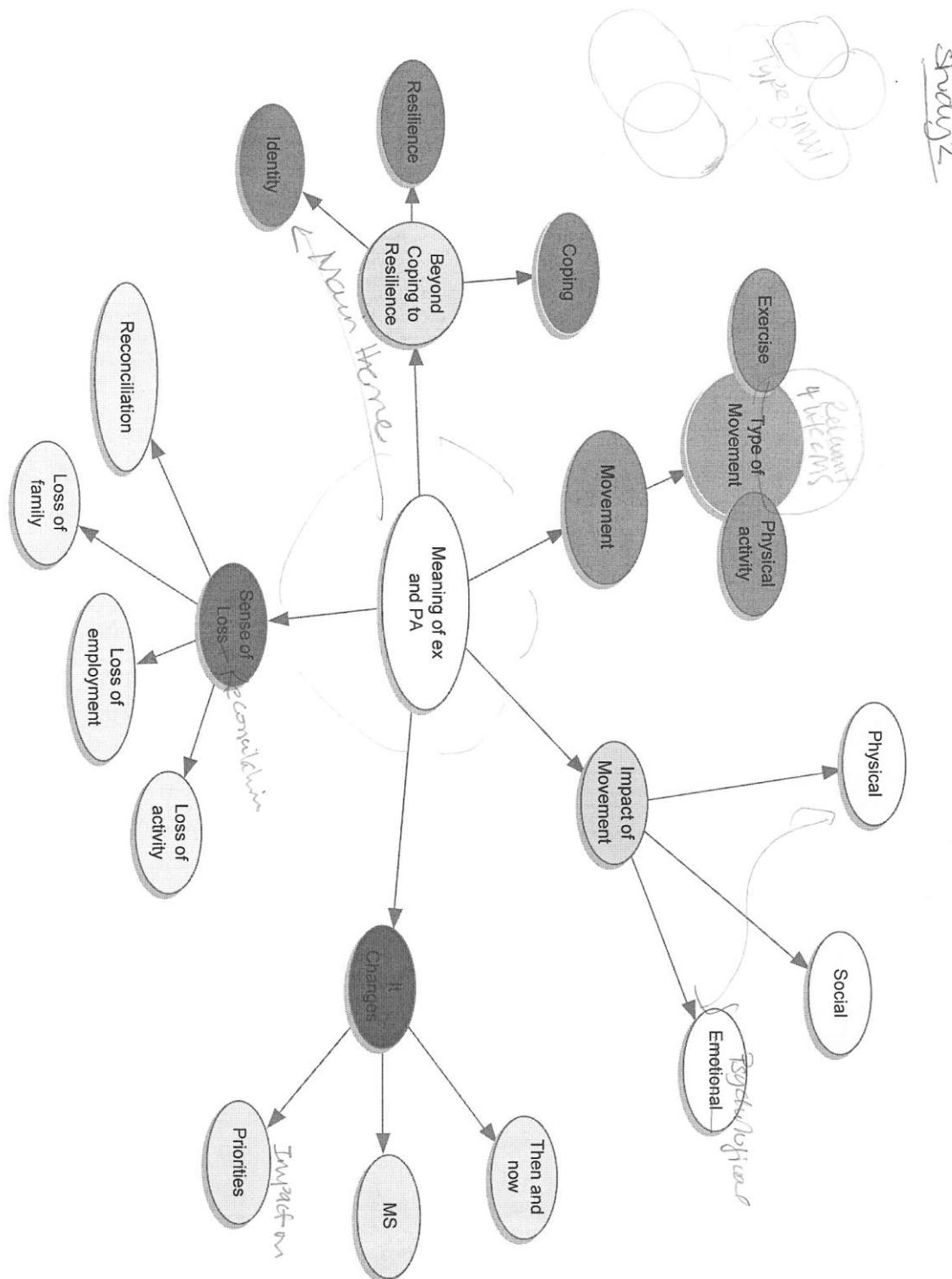
Description: **Part of living with MS, Rule and Challenge MS, Control and wellbeing, normal life ( how to live in the normal world....acceptance of MS**

<b>Participants</b>	<b>Key Dimensions</b>	<b>What are they really saying?</b>
■	Engage in activities that combat both MS and age	Coping Road map with MS – personal mx of disease
■	Determination to keep mobile/ maintain functional level and mx symptoms through exercise Uncertainty about the future-aging with MS and disease progression Top 10 reflects objectives to maintain above	Coping Road map with MS – Uncertainty with aging- personal mx of disease – engaging in exercise
■	Engage in exercise and physical activity to limit deterioration- personal choice Motivation is to keep active to prevent loss of further activities	Personal choice- link with chart 6 Coping Road map- personal mx of disease
■	Survived marriage breakdown through personal independence- support of family Top 10 keeps you going despite physical limitation Set Routine- provides structure for activities – without routine notice depression Flexibility helps to control symptoms Fatigue- experience of living with MS	Self-determination to survive- for kids – a reason to survive? Identity/coping Road map –personal emotional strength & support / personal mx of MS  Linked to chart 6- energy expenditure.

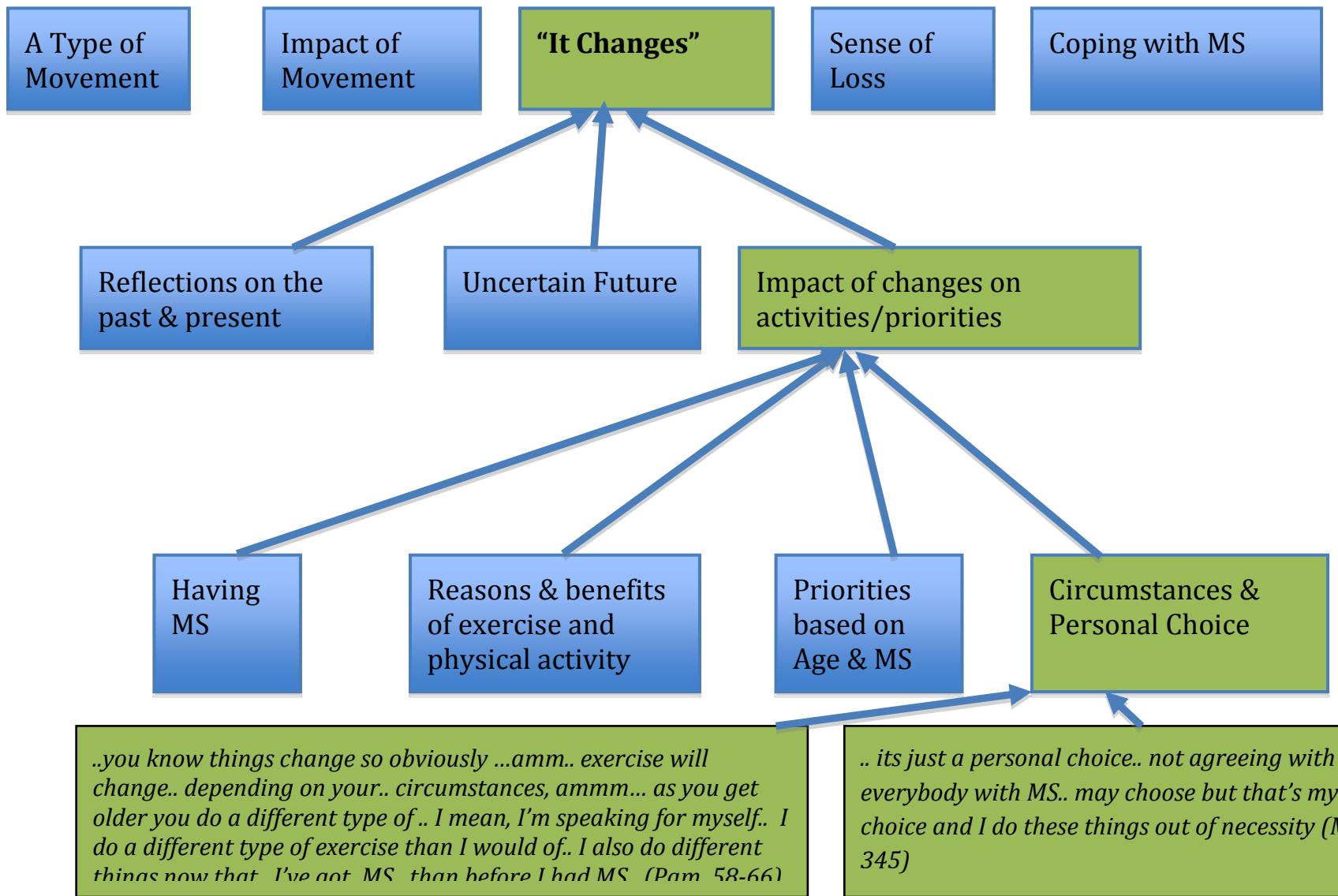
<b>Participants</b>	<b>Key Dimensions</b>	<b>What are they really saying?</b>
■	Living in an able bodied world-not being disabled by it Keep dreaming Role of using communication tool-coping in normal world	Coping Road map with MS Connectivity
■	Ex- limits deterioration	Coping Road map with MS
■	Ex inadvertently improve MS symptoms- don't consciously do activities to improve MS symptoms Be active rather than depending on others to do things for you..	Road map/coping Call to be self-reliant- personal advice from pwMS
■	Accepted MS – “incurable disease” life wrapped around it- allow personal limitation to limit things that he would like to do Personal belief- so different compared to ■ and both accept MS but the response to MS is very different	Accepted the disease “Given up- mentally” Personal belief- response to belief
■	“This is me” – identity Self-care linked with independence, self image and personal dignity	Road map- not allowing to define who you really are at your core- the person not the disease
■	Exercise to maintain independence and limit deterioration Top 10 provides a reference for the reasons why to exercise/head knowledge- after that follows another stage where you engage because of the experience of exercise Stair climbing is good ex but don't necessarily do it for exercise- do it because of purpose – loo is upstairs Think about activities around home as exercise- because exhausting and keep active	Coping – personal belief about mx of MS Road Map- personal knowledge  Life with MS much more than fitness- link with chart 6 Perception of meaning of exercise and physical activity
■	Fatigue- keep exercising to maintain ms- activity gauge Get balance right- pacing	Coping /Road map with MS Personal mx of MS- pacing/fatigue /Knowledge of living

<b>Participants</b>	<b>Key Dimensions</b>	<b>What are they really saying?</b>
	Once PA is in place family functions normally Personal advice about fatigue-pacing “Everything is about how I cope”	with MS /experts of living with MS
■	Fatigue & rest in afternoon	Road map/coping/knowledge of living with the disease
■	Ex- done with carers to improve pain- not balance/strength	Coping/ knowledge of living with MS
■	Top 10 important to live a normal life	Road map
■	Self-reliance number 1 because it is personally vital and don't want it to be taken away Do ex to keep life going and to be normal in a normal world Top 10 reflect living with MS	Linked with physical and emotional Coping/Road map/normal Road map with MS /relevant for life with MS/ link with chart 6

## Appendix 15k: Worked example of Mapping and Interpretation stage



## Appendix 15l: Development of themes in the analytic process- Interviews with pwMS



**Appendix 16a**

School of Health Sciences and Social Care

**Research Ethics Committee**

School of Health Sciences and  
Social Care  
Brunel University,  
Uxbridge  
Middlesex UB8 3PH  
Telephone: +44 (0)1895 274000  
30 October 2013

Proposer: Andrea Stennett

Title: Physiotherapists' perceptions of physical activity as described by people living in the community with Multiple Sclerosis: reflections on a Delphi study

Reference: 14/09/PHD/01

**LETTER OF APPROVAL**

The School Research Ethics Committee has considered the amendments recently submitted by you in response to the Committee's earlier review of the above application.

The Chair, acting under delegated authority, is satisfied that the amendments accord with the decision of the Committee and has agreed that there is no objection on ethical grounds to the proposed study. Approval is given on the understanding that the conditions of approval set out below are followed:

- *The Participant Information Sheet should be amended as indicated in the attached version provided by the School REC.*
- *The agreed protocol must be followed. Any changes to the protocol will require prior approval from the Committee.*

**Please note that:**

- Research Participant Information Sheets and (where relevant) flyers, posters, and consent forms should include a clear statement that research ethics approval has been obtained from the School of Health Sciences and Social Care Research Ethics Committee.
- The Research Participant Information Sheets should include a clear statement that queries should be directed, in the first instance, to the Supervisor (where relevant), or the researcher. Complaints, on the other hand, should be directed, in the first instance, to the Chair of the School Research Ethics Committee
- Approval to proceed with the study is granted subject to receipt by the Committee of satisfactory responses to any conditions that may appear above, in addition to any subsequent changes to the protocol.
- The School Research Ethics Committee reserves the right to sample and review documentation, including raw data, relevant to the study.

*Elizabeth Cassidy*

Dr Elizabeth Cassidy

Chair, School Research Ethics Committee

School of Health Sciences and Social Care

## Appendix 16b: Research and Development approval- NHS



Please reply to: Research & Development Office  
Stoke Mandeville Hospital  
Mandeville Road  
Aylesbury

Telephone: 01296 316259  
Fax:  
E-mail: denise.watson@buckshealthcare.nhs.uk

Ms Andrea Stennett  
School of Health Sciences & Social Care  
Mary Seacole Building  
Brunel University  
Uxbridge  
UB8 3PH

25 November 2013

Dear Ms Stennett

ID: RXQ/577      **Physiotherapists perceptions of physical activity as described by people living in the community with Multiple Sclerosis: reflections on a Delphi Study.**

I am pleased to confirm that all local governance checks are now complete for the above study which meets Trust requirements for full Trust Registration and indemnity. Please let us know the actual start and end dates of the project and of any changes to the research team.

The Research office requests that you keep us informed of how the study is progressing.

Should you have any queries please contact the R&D office quoting the Trust ID number. May we wish you well with your project.

Yours sincerely

A handwritten signature in blue ink, appearing to read "Denise Watson".

Denise Watson  
**Trust Research & Innovation Manager**

## Appendix 17 a



**Title: Physiotherapists' perceptions of physical activity as described by people living in the community with Multiple Sclerosis (MS): reflections on a Delphi study.**

### CONSENT FORM

<i>The participant should complete the whole of this sheet</i>		
<i>Please tick the appropriate box</i>		
	YES	NO
Have you read the Research Participant Information Sheet?	<input type="checkbox"/>	<input type="checkbox"/>
Have you had an opportunity to ask questions and discuss this study?	<input type="checkbox"/>	<input type="checkbox"/>
Have you received satisfactory answers to all your questions?	<input type="checkbox"/>	<input type="checkbox"/>
Who have you spoken to?		
Do you understand that you will not be referred to by name in any report concerning the study?	<input type="checkbox"/>	<input type="checkbox"/>
Do you understand that you are free to withdraw from the study:		
at any time?	<input type="checkbox"/>	<input type="checkbox"/>
without having to give a reason for withdrawing?	<input type="checkbox"/>	<input type="checkbox"/>
without affecting your ACPIN membership? If applicable	<input type="checkbox"/>	<input type="checkbox"/>
I agree to my interview being recorded.	<input type="checkbox"/>	<input type="checkbox"/>
I agree to the use of non-attributable direct quotes when the study is written up or published.	<input type="checkbox"/>	<input type="checkbox"/>
Do you agree to take part in this study?	<input type="checkbox"/>	<input type="checkbox"/>
<b>Signature of Research Participant:</b>		
Date:		
Name in capitals:		
Researcher name:	Signature:	
Supervisor name:	Signature:	

## **Appendix 17b**



### **Research Participant Information Sheet**

**Research Title: Physiotherapists' perceptions of physical activity as described by people living in the community with Multiple Sclerosis: reflections on a Delphi study.**

You are invited to take part in this research entitled: '**Physiotherapists' perceptions of physical activity as described by people living in the community with Multiple Sclerosis (MS): reflections on a Delphi study**'. This research is part of a series of studies that will form part of a Doctoral thesis led by Andrea Stennett, Physiotherapist, under the supervision of Professor Lorraine De Souza and Dr. Meriel Norris at Brunel University. Below you will find some information that covers why this current study is being done and what it would involve should you decide to take part.

#### **1. What is the purpose of the Study?**

A series of studies were designed to gain insight into activities people with MS undertake as part of their daily routine and to use the knowledge gained to explore your views about working in the community with people with MS.

The first study in this series used a four Round Delphi methodology to identify the top 10 prioritised activities and the top 10 reasons why people with MS living in the community engage in these activities. Now we would like to share these findings with you, to find out your views and whether they are relevant and applicable to physiotherapists working in the community.

## **2. Who can take part?**

If you are a physiotherapist working at band 6level and upwards and have experience working in the community with people living with Multiple Sclerosis, I would be interested in hearing from you.

## **3. What are the benefits of taking part?**

There will be no direct benefit to you from participating in the study. However, the results of this study will provide further insight into the prioritised activities people with MS are engaged in, which may further inform and guide how we design our interventions. Results from this study will be submitted for publication, or presented at conferences, so that they can reach an audience of professionals as well as people with MS.

#### **4. What will happen to me if I take part?**

You will be asked to attend **one** focus group to discuss your views and opinions about the findings from the Delphi Study involving people with MS living in the community. There are no right or wrong answers; we are only interested in your views and opinions. The focus group will be led by myself, Andrea Stennett and should last approximately 120 minutes. I will also have another colleague who will help with note taking. The focus group will be held in London. As there is no direct funding associated with this study the researcher will not be able to reimburse you for any additional expenses travelling to and from the focus group.

The information you provide during the focus group will be recorded using an audiotape as well as a note pad. This will be done to ensure that I accurately record and represent the discussions from the focus group.

#### **5. Do I have to take part?**

Your participation is completely voluntary. This means that you can choose not to be involved, or if you start, you can choose to withdraw at anytime. Please note that should you decide to withdraw after the focus group has started it would be difficult to remove your comments from the data set. Nevertheless, withdrawing from the study, will not affect you in anyway. We believe that you can make a valuable contribution to the research in the area of exercise and physical activity in people with MS. Your insight and knowledge may help us to establish this foundation.

## **6. If I want to take part, what will happen next?**

If you decide to take part in this study, you can contact me, Andrea Stennett, by telephone 01895268729 or email on [andrea.stennett@brunel.ac.uk](mailto:andrea.stennett@brunel.ac.uk). Also, if you have further questions about the study this could be clarified at this time. Please note, that participating in this study is completely voluntary. Therefore, if you are happy to participate then you will be asked to sign the consent form, which can be found in the research pack.

## **7. Will my taking part in this study be kept confidential?**

All the information that is collected about you during the course of the research will be kept strictly confidential. Participants are advised not to share the outcome of the focus group in other settings to maintain your confidentiality. The researcher cannot guarantee complete confidentiality however, participants will be asked to agree not to share the information discussed in the focus group with others outside the group.

The lead researcher will transcribe the discussions from the focus group and all notes will be kept in a secure location. No one will be able to link your responses to you, as identifiable information will be coded. My supervisors and I will be the only ones to see your responses and other identifiable information. Any personal information will be kept securely in a locked cupboard in a pass code protected room at the university.

## **8. What will happen to the results of the study?**

The results from the research will be used as part of my Doctoral thesis. A report of the key findings will be sent to you at your request. The findings will be presented at academic and professional conferences and also published in academic journals. Anonymity and confidentiality will still be in place in all cases. Findings from this study will contribute to developing a better understanding of physical activity in people with MS.

## **9. Who is organising and funding the research?**

This research is part of a Doctoral Study undertaken by Andrea Stennett. It is supported by - The Centre for Research and Rehabilitation (CRR) within the School of Health Sciences and Social Care at Brunel University and has gained Research Ethics Approval from the Research Ethics Committee at the school. If you have any concerns about the conduct of this study, please contact the Chair of the Research Ethics Committee, Dr. Elizabeth Cassidy ([elizabeth.cassidy @brunel.ac.uk](mailto:elizabeth.cassidy@brunel.ac.uk)).

### **Contact for further information about the research:**

Andrea Stennett, Telephone 01895268729

Email: [andrea.stennett@brunel.ac.uk](mailto:andrea.stennett@brunel.ac.uk)

### **Research Supervisors:**

Professor Lorraine DeSouza, Email: [lorraine.desouza@brunel.ac.uk](mailto:lorraine.desouza@brunel.ac.uk)

Dr. Meriel Norris, Email: [meriel.norris@brunel.ac.uk](mailto:meriel.norris@brunel.ac.uk)

**Thank you for considering being part of this study.**

## **Appendix 17c: Topic Guide**

**Research Title: Physiotherapists' perceptions of physical activity as described by people living in the community with Multiple Sclerosis: reflections on a Delphi study.**

### **Introduction**

- Thank participants for taking part in the study
- Introduce self, length of focus group, confidentiality, check consent form, and reiterate the right to withdraw from the study.
- Introduction of participants using an ice breaker task

### **Background and context - Exploration of terms**

Provide a brief background to participants about Study 1 (A day in the life of people with MS). Explain the purpose and aims of the present study.

### **Explain the purpose of the focus group**

- ❖ To explore your views about the results of the Delphi study
- ❖ To explore your views about how relevant these findings are to your current practice.
- ❖ Explain that I am not looking for consensus rather looking for views and opinions and that there are no right or wrong answers.

### **Explore participants understanding of Physical Activity**

**Tell me about what you understand by the term exercise and physical activity?**

*(do activity using post-it to allow participants 2 mins to think individually about the question and then ask them to share their thoughts).*

- ❖ (if there is silence)-*You may find this difficult, so, it might be helpful to start by giving examples of what you consider as physical activity, or by talking about why it we might find it difficult to define or explain.*

### **Explore what influenced that understanding**

e.g. undergraduate training, post grad, courses, literature etc..

### **Explore how participants understand the relationship between physical activity and exercise**

- ❖ In relation to experiences of working with people with MS
- ❖ In relation to themselves

### **Explore how participants distinguish between the two terms when designing interventions**

- ❖ Do you make a distinction between physical activity and exercise when working with people with MS?

## **Exploration of Delphi Results**

### **c) Content and Prioritisation of Activity List (x2 sets of *cue cards with the results for activities will be placed in front of the group*)**

These cards show the top 10 physical activities that were selected by 70 people with MS and the order in which the group prioritised them.

Please take some time to look though the cards

### **Explore participants' views about the physical activities selected**

- ❖ Are there any surprises?
- ❖ Which?
- ❖ Why?
- ❖ Any missing?

### **Explore participants' views about the order presented**

- ❖ Any surprises regarding the order?
- ❖ Which?
- ❖ Why?

## **Reflecting on the prioritised activities in relation to Clinical Practice**

Reflecting on your experience of working with people with MS

- ❖ Is this new information?

Looking at the prioritised list, are these the activities you would use in current practice?

- ❖ If yes, which ones do you use? Explore underlying clinical reasoning
- ❖ If no, why not? explore underlying clinical reasoning
- ❖ Tell me about how you used this activity by giving an example from clinical practice

Having seen their priorities would these findings influence the way you approach your clients?

- ❖ If yes, how?
- ❖ If no why not?

### **d) Reasons for prioritising activities (2 sets of cue cards with the results for the reasons why will be placed in front of the group)**

These cards show the top 10 reasons why physical activities were selected by the group and the order in which they were prioritised.

Please take some time to look through the cards

**Explore participants' views about the reasons given by people with MS for selecting these activities above others.**

- ❖ Are there any surprises?
- ❖ Which?
- ❖ Why?
- ❖ Any missing?

**Explore participants' views about the order in which these activities were prioritised**

- ❖ Any surprises with the order?
- ❖ Which?
- ❖ Why?

**Reflecting on the overall Delphi results in relation to Clinical Practice**

**Now that you have a sense for what people with MS prioritise and why they prioritise these activities, would these findings influence your practice?**

- If yes, how?
- If no, why not?
- Do they affirm what you already do?
- If yes in what way?
- Tell me about how this may change your practice by giving an example from clinical practice.

**Closing**

- Summarise the main themes from the group discussions
- Is there anything else you would like to share or anything that you hoped to talk about today that we have not discussed?
- Do you have any questions for me?

**Thank participants and close**

## **Appendix 17d: Developing a conceptual framework for Study 3 (Final)**

### **1. Background and Demographic information**

- 1.1 Age
- 1.2 Sex
- 1.3 Band/post
- 1.4 Location
- 1.5 Other

### **2. The meaning of exercise as described by physiotherapist**

- 2.1 Outcome (benefits and consequences/ performance related)
- 2.2 Choice of activity
- 2.3 Demanding activities (challenging )
- 2.4 Focused activities ( targeted, specific)
- 2.5 Formal exercises (gym based ..text book related )
- 2.6 Incorporate/Supports into daily routine ++
- 2.7 Individual (perception of ex and PA, stage of disease, public versus pt)
- 2.8 Sports
- 2.9 Types of exercises
- 2.10 Other

### **3. The meaning of Physical Activity as described by physiotherapist**

- 3.1 Can count as exercise
- 3.2 Demands of the task ( less intensive than ex)
- 3.3 Feelings associated with PA
- 3.4 PA is anything
- 3.5 Part of daily life
- 3.6 Types of PA
- 3.7 Other (outcome based)

### **4. Relationship between exercise and PA**

- 4.1 Difficult to differentiate
- 4.2 Ex and PA are different
- 4.3 Ex and PA are similar (overlap)
- 4.4 Other (perception of ex and PA )

### **5. Influencing Factors for ex and PA**

- 5.1 Based on the individual (pt/public/stage of disease, person centred)
- 5.2 Experience of working environment (link to daily routine/self mx)
- 5.3 Government initiatives
- 5.4 Lack of resources
- 5.5 Media and general language usage ++
- 5.6 Training
- 5.7 Other (feelings, bored. fun)

**6. Physio views and opinions of the results 10 ex and PA practices in pwMS (through physio lens)**

- 6.1 Attitudes towards the top 10 (reassuring, +ve/-ve/ interesting/ group dynamics , missing, surprises)
- 6.2 Functional bias
- 6.3 Impact of cognition
- 6.4 Joint working with other health professionals
- 6.5 Participation
- 6.6 Priorities depend on... (role in family, age, individual, choice, fun, variability of the disease)
- 6.7 Reflect pwMS seen in clinical setting
- 6.8 Self initiation
- 6.9 Supporting activities (stretches, physio, act without weights)
- 6.10 Top 10 more about people priorities than ex and PA
- 6.11 What do pwMS really want versus what clinicians think is best
- 6.12 Other (limitations/strength of study, shifts in therapy mx over the years)

**7. Phyios views about the reasons why**

- 7.1 Attitudes towards the top 10 reasons why (+ve/-ve, missing, surprises)
- 7.2 Impact of cognition
- 7.3 Impairment based
- 7.4 Participation
- 7.5 Patient centeredness
- 7.6 Psychological versus physical
- 7.7 Reflects justification for why physios prescribe ex
- 7.8 What do pwMS really mean
- 7.9 Other (pwMS experts)

**8. Clinical Implications of the top 10 activities**

- 8.1 Clinical dilemma of managing activities and fatigue
- 8.2 Experience of working with pwMS
- 8.3 In line with what therapists want to achieve
- 8.4 Reflects or aids goal setting
- 8.5 Shifts in therapy management over the years.. more functionally based
- 8.6 What study highlights versus clinical practice
- 8.7 Other

**9. Clinical implications for the top 10 reasons why**

- 9.1 Are physios loosing autonomy?
- 9.2 Clinical relevance
- 9.3 Joint working with other Health professionals
- 9.4 Priorities is the main driver for activities
- 9.5 Provides structure to goal setting
- 9.6 PT should still drive for exercise and challenge
- 9.7 Shifts in therapy mx .. functional.. person centeredness
- 9.8 Other

## Appendix 17e: Examples of Focus Groups extracts and labelling stage of data analysis

<p>Shady3</p> <p>VN850074</p> <p><b>2.1</b></p> <p>146 147 R B Yeah increasing ... 148 149 R B Yeah. 150</p> <p><b>2.3</b></p> <p>151 R B ... and pushing yourself ... and that it has to be challenging to be advantageous.</p> <p><b>2.4</b></p> <p>154 R C I guess that it's more of a defined ... like a defined something, it's a defined activity. So like it might be swimming or I don't know going to the gym ... that might be considered more exercise based activity.</p> <p><b>2.4</b></p> <p>159 R B It's targeted.</p> <p><b>2.1</b></p> <p>160 Fac It's targeted okay. 161 162 R Z Yeah. 163</p> <p><b>2.4</b> <b>2.1</b></p> <p>164 R B Whether it's targeting a specific muscle group or whether it's targeting your general fitness, cardiovascular fitness.</p> <p><b>2.7</b></p> <p>165 R C It's maybe more sort of particular activities for different people. So it's quite individual. So what one person considers to be exercise somebody else might not.</p> <p><b>2.1</b></p> <p>166 Fac Right. Yeah okay. And can you throw out some examples of what you think exercise ... just an example of what you think exercise is.</p> <p><b>2.7</b></p> <p>167 R C I put down things like going swimming, going to the gym.</p> <p><b>2.7</b> <b>5.1</b></p> <p>168 R B I suppose it depends if you're thinking of patients or general public.</p> <p><b>2.7</b> <b>5.1</b></p> <p>169 Fac Right so if you're thinking of general public you might view it in a different way from if you're thinking of patients?</p> <p><b>2.7</b> <b>5.1</b></p> <p>170 R B Yeah, because if I'm thinking of ... if I think of exercise for myself for example I'd think of running or you know doing interval training or something. Whereas patients ... I'm just thinking of you know lower level patients, trying to get them ... a way of them exercising might be different ... you know they might not be able to</p>	<p>challenging - to gain benefit</p> <p>Defined activity</p> <p>Targeted</p> <p>Target &lt; MGP fitness Benefit</p> <p>Individually - shaped means (prephim)</p> <p>Examples swimming / gym</p> <p>Type depends on whether pt/general public</p> <p>Type of ex depends Rx pt/general public</p>
--	---

Study3

VN850074

196 run, so thinking ... swimming might be an option  
197 for them or ...

2.7

5.1

R B Or walking.

2.7

5.1

R B ... just walking, yeah.

203 Fac So are you saying then that when you think of  
204 exercise and physio- ... well exercise ... you .. it  
205 depends on who you're referring to? So it could  
206 be ...

2.7

5.1

R B Like some patients we see might say you know  
209 after a stroke for example, and you know they're  
210 not doing much at all, so you sort of recommend  
211 ... you know not just us as physios, I think OTs  
212 would as well, you know to say 'Just start off by  
213 increasing the amount you're walking because it's  
214 good exercise for generally everything' so just  
215 walking would be about exercise for them,  
216 whereas ...

perception of PT/  
general public or  
stage of disease

218 Fac Uhuh okay.

4.1

4.3

2.7  
different voice C

R I found it quite difficult to separate out exercise  
220 and physical activity. I sometimes lump them  
221 together. So ... because for some people  
222 physical activity ... exercise is a type of physical  
223 activity ... and physical activity can be a type of  
224 exercise depending on how you use it. So like  
225 the points about exercising implies that you're  
226 going to get better at it or do more of it ... or it's  
227 going to become easier ... whereas a physical  
228 activity is more the statement of what, an  
229 exercise is more the what you do with the what, if  
230 that makes sense. So swimming is a physical  
231 activity, but if you use swimming as an exercise  
232 you would expect that something about that  
233 activity would change. So it might be that you  
234 could swim longer or that it would take you less  
235 effort or something like that. Or like the  
236 hoovering I put down as a physical activity, so  
237 you could use hovering as an exercise to do it for  
238 longer or for it not to be so difficult or .. so I don't  
239 know whether ...

Difficult to separate  
means  
Blurring of meaning  
Exercise → do more to  
get better /  
either /  
What you do is what  
PA → what

Talk about ex based  
on outcome of  
the activity.

Can count as  
ex

242 Fac Yeah ...

243

244 2.1  
3.1

R C ... that's only my sort of ...

Study 3

VN850074

- 246 R B And I think some people distinguish ... some  
247 different people might say their work is quite physical,  
248 therefore they consider that to be their exercise in  
249 the day, whereas I see the definition more like  
250 you said (?) the exercise is something you are  
251 doing specifically for the gain, the physical gain ...  
252 so I don't think ... so that I would see their work,  
253 sort of a strenuous job, as being more a physical  
254 activity than exercise.
- 255
- 256 Fac Right. So it's almost like there's a blurring ...  
257 what you're saying there might be a blurring  
258 between the two, but the end might be different.  
259
- 260 R Agreement  
261 Different uhuh.  
262
- 263 Fac ... in terms of what you're wanting to experience.  
264 R Yes.  
265
- 266 Meaning of PA
- 267 Fac So some examples of physical activities .. so  
268 you've mentioned hoovering and what else ...  
269
- 270 R C Things like walking the dog, walking to the shops,  
271 carrying the shopping.  
272
- 273 R B As it's maybe a less intensive form of exercise  
274 (inaudible)
- 275
- 276 Fac If it helps you, the literature isn't very clear ...  
277
- 278 (laughter)
- 279
- 280 Fac ... and it lumps you know ... depending on what  
281 you read it talks about physical activity and then  
282 you're talking about exercise ... and vice versa.  
283 And so you know when we're designing it we had  
284 to use ... instead of using physical activity we just  
285 had to say 'exercise and physical activity'  
286 because they mean different things to different  
287 people. Okay, so thinking about your day to day  
288 interactions with people with MS, do you ... when  
289 you're designing your interventions, do you use  
290 these words interchangeably or not? Do you  
291 consider that this is exercise or this is physical  
292 activity or not?  
293
- 294 R CJ I suppose if I'd given a patient ... say if I've given  
295 someone some exercises to do ... you know a
- Demands of an activity  
Exercise - not pt driven  
Physical gain
- There is an overlap  
but end product /  
outcome different
- Examples of PA
- PA - less intensive  
than ex
- Do you use these  
words interchangeably

5.3 5.2

346 and enforce that actually government guidelines  
 347 still apply to them as much as they do to ... you  
 348 know in terms of the five (inaudible) exercise, and  
 349 trying to think how they can incorporate that.

Incorporate Government  
guidelines

350

351 Fac So then do you think that these initiatives have  
 352 brought the whole idea of exercise and physical  
 353 activity to the forefront of your brain ... or have  
 354 you always distinguished between exercise and  
 355 physical activity. I guess what I'm asking is what  
 356 influenced how you view exercise and physical  
 357 activity.

358

359 R Well I think ... well for me pers- ... I think it  
 360 depends a little bit on your sort of working  
 361 environment, your team set-up and also you sort  
 362 of mentioned about sort of goals, things like that.  
 363 If you're thinking in a more functional sense and  
 364 considering the whole sort of holistic picture of  
 365 the individual you're wanting to just generally  
 366 increase their activity, I think that ...

Working Environment

Team set up

Goals

Holistic picture

Influence  
Meaningful  
Exercise

5.2

27

367 R Agreement  
 368 Definitely yeah.

5.2 2.6

369

370 R And also you know sort of trying to embed it into  
 371 something that they do every day as a way to  
 372 keep them doing it, sustain it, rather than you  
 373 know ... like I've worked here for sort of 7 ... 6  
 374 years now, so I've seen a few patients over time.  
 375 And you see that they stop doing exercise  
 376 programmes, they get bored with them ... I get  
 377 bored if I do exercise – I get bored with doing the  
 378 same thing. So you do start to once you've been  
 379 seeing people for longer start to think hang on,  
 380 you've got to try and make it a bit more relevant,  
 381 a bit more exciting, a bit more meaningful, a bit  
 382 more ... if you really are going to help people to  
 383 build exercise and physical activity into their  
 384 every day ... I mean I still think specific exercises  
 385 are useful for certain things ...

incorporate into  
daily activity  
make it relevant  
exciting  
meaningful  
sustain

5.2 5.7

386

5.7 2.2

387

2.6

388

5.1 4.4

389

Person  
Centredness

390

391

392

393

394

395

And certain individuals.

\* Specific or one  
use for

ex-individuals  
ex-focus  
others  
nightmare  
perception  
of the  
individual.

ex-individuals  
ex-focus  
others  
nightmare  
perception  
of the  
individual.

ex-individuals  
ex-focus  
others  
nightmare  
perception  
of the  
individual.

[5.5]

296

297

298

[5.2]

299

300

301

302

303

304

305

306

307

308

309

310

311

312

313

314

315

316

317

318

R

Becky

[5.5]

[5.2]

[2.6]

[3.5]

R

CJ

[5.3] [2.6]

327

328

329

330

331

332

333

334

335

336

337

338

339

340

341

342

343

344

345

sheet of targeted home exercises to target either like specific strengthening work, then I would use the word 'exercise' – here are your exercises. But more with sort of ... we've been doing lots of ... partly to do with where we're working and looking at goals, we've sort of changed ... well I've certainly changed a bit more to consider physical activity and to reinforce to patients that the physical things you do every day can be a form of exercise, so that they try ... because some patients that I've found when you mention the word 'exercise' they go 'Oh my God, you're going to tell me I've got to join the gym' and to them it seems 'How can I go from doing nothing to ... there's a physio telling me to do exercise?' So ... I probably spend more time talking about the physical things you do every day, to keep going with those and try and increase those to then ... so that would be more things like walking the dog, going to the shops, going up the stairs ...

use of word of  
change - depending  
on working environment  
+ goal setting'

Shift in choice words  
from ex to PA in  
Clinical practice  
(Shift is dependent  
on patient's view/  
PT experience)

Or even that putting ... you know saying to them when you're doing your washing, technically you're doing a squat every time you're doing your washing, so making sure you're not getting someone else to do it because it's a bit difficult, try and do that activity, because that's part of your exercise, but you're not having to think about 'Oh I'm doing my physical exercises'.

linking ex to daily routines

And whether that sort of joins in with you know these initiatives of ... you know general health initiatives about you know people getting off a bus the stop earlier ... you know there's been a lot about that hasn't there? So whether it's just we're sort of including some of those things in what we would say, or whether ...

Links to government initiatives - Active transport  
Spills over into clinical practice

(sound of door opening/closing)

R B Yeah. And I think that's something I've tried to ...

Fac Thank you.

R ... or I've tried highlight to ... because a lot of people I think that we see ... you know some of them just have never done exercise generally for fitness, for health before they got the diagnosis of MS, so it is quite alien for them. But then to try

Ex - quite  
alien for  
some people

**Chart 9- Clinical implications for the top 10 reasons why**

	A	B	C	D	E
	9.1 Are physios loosing autonomy?	9.2 Clinical relevance	9.3 Joint working with other HP	9.4 Priorities is the main driver for activities	
1	<b>FG1 -</b> <b>5 Community neuro</b> <b>physio (NHS) out of</b> <b>London</b> <b>band 6-7</b> <b>Age- 29-38</b> <b>All Females</b>	The results will challenge autonomy of the profession because not totally physio (C.1714-1741)	General agreement that the top 10 relevant to practice (All, 1162-1164) Top 10 affirms what they already do in their practice (All,1188-1190) Shifts in practice making ex more functional (CJ,1191-1198) Study confirms what I do in clinics- that is reassuring ( M,1294-1300) provides a useful tool especially with complex patients in goal setting (B,1307-1317)	Top 10 reflects what is meaningful, relevant to the individual but physios need to make the link, keep ex fun-life already hard (CJ, 1166-1185;M 1178-1179)	
2	<b>FG2- 4 Community</b> <b>neuro physio within</b> <b>London (NHS)</b> <b>All band 6</b> <b>Age- 26-50</b> <b>All Females</b>	In my head it doesn't work- stretches on spasticity, reflecting on story researcher told about study 2 participant relaxing with domestic activities (J,1302-1317)- need MS specific outcome measures (C,1323-1339);J,1341-1348)	The study will influence goal setting and Rx, personal priorities (C,1600-1604; L,1609-1625; J,1631-1640;L,1642-1650)) Reflections on a pt who unrealistic about his goal (M,1652-1659) important to link priorities with how to achieve them ( L,1661-1670;M1665-1672)	Results highlight MDT working and support (M,1767-1776)	The study will influence goal setting and Rx, personal priorities (C,1600-1604; L,1609-1625)
3	<b>FG3- 5 Community</b> <b>MS specific Physio</b> <b>(MS Charity) -</b> <b>Outside London</b> <b>Age -30-57</b> <b>Band 5-8</b> <b>3 Females &amp; 2 Males</b>	Made us reflect on making activities fun (C,1210-1220)	Study highlights the need to work jointly with Psych support due to the complexity of life and MS ..therapy should be a combined approach ( L, 1264-1284)	Made us reflect on patient priorities (A,1207-1208) Interesting to see what they consider activities and incorporate more into practice ( J, 1222-1229)	
4					

**Appendix 17f: Examples of charting stage**

## Chart 9 - Clinical implications for the top 10 reasons why

F	G	H	I
<b>9.5 Provides structure to goal setting</b> Provides a useful tool especially with complex patients in goal setting (B,1307-1317). Agreed I like the use of the categories because we assume we know but we don't know what people priorities are ( CJ, 1321-1328; B, 1328)	<b>9.6 PT should still drive for exercise and challenge</b> Physios still need to push the ex boundaries ..make it physically challenging..even if it is PA make it challenging (CJ,1235-1250) but have to get the balance right (B,1252)	<b>9.7 Shifts in therapy mx .. functional.. person centeredness</b> Shifts in practice making ex more functional (CJ,1191-1198) Physios need to guide physioS to make the link between the activity and purpose of the activity because some struggle to make that link(B, 1200-1213; CJ,1215-1223) Personally I struggle with loads of ex..tend to go for a few (1225-1229) With pushing boundaries of ex it goes back to knowing the individual pacing (CJ,1254-1259; B 1257) Reflects person centeredness (ZJ, 1302-1305)	<b>9.8 Other</b> FAQ - Did you get a clear sense for what they felt physio was? Did you stratify to see impact of functional abilities on results? Where did you recruit? England only?
Cue cards can help structure goal setting and help focus Rx(J,14881505;L,1508-1514) The study will influence goal setting and Rx, personal priorities,person centred care (C,1600-1604; L,1609-1625;J,1631-1640))	The study will influence goal setting and Rx, personal priorities,person centred care (C,1600-1604; L,1609-1625;J,1631-1640)) Reflections on a pt who unrealistic about his goal (M,1652-1659) important to link priorities with how to achieve them ( L,1661-1670;M1665-1672)	The study will influence goal setting and Rx, personal priorities,person centred care (C,1600-1604; L,1609-1625;J,1631-1640)) Reflections on a pt who unrealistic about his goal (M,1652-1659) important to link priorities with how to achieve them ( L,1661-1670;M1665-1672)	FAQ - Did you get a clear sense for what they felt physio was? Did you stratify to see impact of functional abilities on results? Where did you recruit? England only?
Shifts in therapy to more a functional approach and incorporating ex into daily life (L,1231-1237)			

## Chart 2 - The meaning of exercise as described by Physiotherapists

F	G	H	I	J
<b>2.5 Formal exercises</b>	<b>2.6 Incorporate/Supports into daily routine</b>	<b>2.7 Individual perception of ex</b>	<b>2.8 Sports</b>	<b>2.9 Types of exercises</b>
(B,318-325) or link to daily activities outside home e.g public transport (CJ,327-333) Incorporating ex into daily activities will sustain it (CJ,370-385;B,387)	(B) 487-493	Felt uncomfortable to differentiate because of the link with and attempts to incorporate into daily routine in the community (C, 249-253)	Meaning shaped by individual perception (170-173), 222-240 It depends on whether talking about sport or general public or self choose activity on level of function (182-201;208-215)  Individual prep-(B) 246-249	Defined activity e.g swimming (154-159) Swimming and gym (179-180)
Formal ex-gym,running, sport (J,161-165)	Formal ex-gym,running , sport (J,161-165)	Ex is a targeted activity that requires routine and practice (J,282-291) Agreed you don't just do ex it is for a purpose/goal oriented (C, 301-309) eg. Text book, bridging ex, rolling,squats C J) C282-299	strengthening and fitness Sport activity to improve performance (C, 216-221)	

## **Appendix 17g Study 3- Mapping and Interpretation for Meaning of Exercise- Chart 2**

### **2.1 Outcome**

Description: based on the benefits of exercise..what it does

<b>Focus Groups</b>	<b>Key Dimensions</b>	<b>Themes</b>
FG1	Leads to fitness, increase HR, change in physical ability	Outcome directed
FG2	Done for a particular reason Increase strength, fitness, requires practice, purpose and goal oriented	Outcome directed
FG3	Leads to fitness, strength, goal oriented , improves performance	Outcome directed

2.2 Choice of activity- decision made to join it to 2.7 because it reflects more about the individual.

### **2.3 Demanding Activities**

Description: meanings associated with the demands of the activity

<b>Focus Groups</b>	<b>Key Dimensions</b>	<b>Themes</b>
FG1	Challenging	Nature of the activity
FG2	Requires routine and practice	Nature of the activity
FG3	Challenging	Nature of the activity

### **2.4 Focused activity**

Description: Activities described as focused, specific or targeted, formal activities, sports

Decision made 2.5 and 2.8 was merged with 2.4

<b>Focus Groups</b>	<b>Key Dimensions</b>	<b>Themes</b>
FG1	Focused, defined, targeted activities	Nature of activity
FG2	Targeted and specific	Nature of activity
FG3	Specific, done outside normal routine, formal , sports	Nature of activity

## **2.6 Supports daily routine**

Description: activities that are incorporated into daily activities or support daily activities.

<b>Focus Groups</b>	<b>Key Dimensions</b>	<b>Themes</b>
<b>FG1</b>	Links ex into daily activities – one way to sustain it	Nature of activity
<b>FG2</b>	Felt uncomfortable to separate ex and PA because of links to daily activities	Feelings associated with Ex
<b>FG3</b>	No comment	

## **2.7 Individual (perception of ex, public versus pt)**

Description: definition is dependent on whether related to pt or Public

<b>Focus Groups</b>	<b>Key Dimensions</b>	<b>Themes</b>
<b>FG1</b>	Meaning shaped by individual Depends on pt or public	Nature of activity / perception of individual
<b>FG2</b>	No comment	
<b>FG3</b>	No Comment	

## **2.9 Types of exercise**

<b>Focus Groups</b>	<b>Key Dimensions</b>	<b>Themes</b>
<b>FG1</b>	Swimming and gym	Type of activities
<b>FG2</b>	Text book ex, squatting, bridging, rolling	Types of activities
<b>FG3</b>	Sports, strengthening ex	Types of activities

## Mapping and Interpretation for the meaning of PA -Chart 3

### 3.1 Can count as exercise

Description: activities that count as exercise

Focus Groups	Key Dimensions	Themes
FG1	Can count as exercise Outcome is different	Nature of the activity Outcome directed
FG2	pwMS don't realise they are ex when engaged in PA	Nature of the activity
FG3	No comment	

### 3.2 Demands of the tasks

Description: activities that are demanding

Focus Groups	Key Dimensions	Themes
FG1	Less intensive than exercise	Nature of activity
FG2	Movement where effort is required	Nature of the activity
FG3	No comment	

### 3.3 Feelings Associated with PA

Focus Groups	Key Dimensions	Themes
FG1	No comment	
FG2	Fun activities	Feelings
FG3	No comment	

### 3.4 PA is anything

Description: any activity –links with 3.7 outcome directed

Focus Groups	Key Dimensions	Themes
FG1	No Comment	
FG2	A number of different activities /increase HR	Nature of the activity /Outcome directed
FG3	Different types of activities	Nature of the activity

### **3.5 Part of daily life**

<b>Focus Group</b>	<b>Key Dimensions</b>	<b>Themes</b>
<b>FG1</b>	Part of daily activity	Nature of activity
<b>FG2</b>	Don't realise they are engaging in ex	Nature of activity
<b>FG3</b>	No comment	

### **3.6 Types of Physical Activity**

<b>Focus Groups</b>	<b>Key Dimensions</b>	<b>Themes</b>
<b>FG1</b>	Swimming, hovering, walking dog, shopping, carrying shopping	Types of PA
<b>FG2</b>	Sit to stand, walking, washing, ironing, dressing, cooking	Types of PA
<b>FG3</b>	No comment	Types of PA

3.7 Other- decision made to merge the comment under 3.4 as they reflect the meaning of 3.4

## **Appendix 17g: Study 3- Clinical Application**

### **Chart 9- Clinical Implications for the reasons why**

#### **9.2 Clinical relevance**

<b>Focus Group</b>	<b>Key Dimensions</b>	<b>Themes</b>
<b>FG1</b>	Relevant to clinical practice  Affirms what we do  Cue cards useful tool to aid goal setting	Reflects clinical practice  Further considerations (Cue cards)
<b>FG2</b>	In my head it doesn't work – stretches and spasticity  Demonstrates the importance of pt priorities  Highlights short bursts of interventions  Cue cards- useful tool help decision making process with such a variable condition  Results applicable to other LTC	Further considerations (Challenges how we work)  Reflect clinical practice  Further considerations (useful tool)
<b>FG3</b>	Make us reflect on make activities fun	Further considerations (fun)

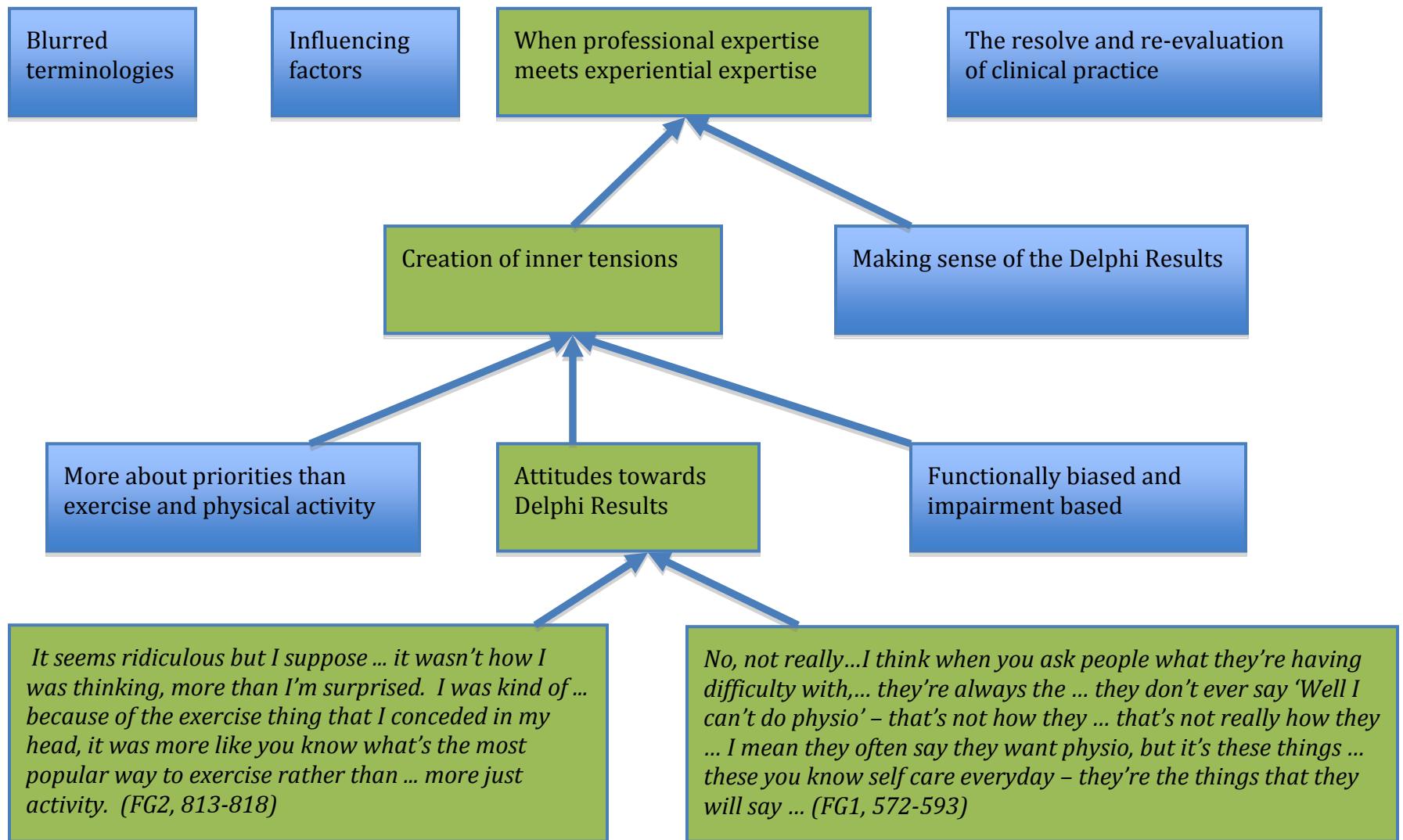
### 9.3 Joint working with other Health Professionals

Focus Groups	Key Dimensions	Themes
FG1	No comment	
FG2	Results highlights need for MDT working	Affirms current practice /Further consideration
FG3	Highlights need to MDT working	Affirms current practice/ Further consideration

### 9.4 Priorities is the main driver for activities

Focus Group	Key Dimensions	Themes
FG1	Reflects what is meaningful to the individual  Physios positioned to make the link between ex and PA  Make ex fun	Patient centeredness  Further considerations
FG2	Influence how goal setting is done – linking to priorities	Further considerations
FG3	Reflect on pt priorities – need to incorporate into practice	Further considerations

## Appendix 17h: Development of the themes in the analytic process- Focus Groups with physiotherapists



## **Appendix 17i: Reflexivity Study 3: Challenges with Focus Groups**

Overall, the groups went well, however each group had its own challenge. The first group was based within the NHS. As such, the major challenge was to satisfy the requirements for the local research and development department to avoid delaying the study. This was done in good time and without any changes to the University approved ethics paperwork. The major challenge for the second group was finding a location that was convenient for all the participants. This resulted in the loss of two participants who initially registered interest in the study. The major challenge for the third group was ensuring that all participants were reliably informed of the relevant research ethics issues and that consent was gained for participation. This was essential as the focus group was held during the weekly team meeting, therefore the researcher could not assume consent.

Another big challenge for the researcher was the foreboding thoughts about attendance on the day. The literature recommends 6-12 participants to a group (Morgan and Krueger, 1998; Holloway and Wheeler, 2010). Whilst these numbers are ideal, the reality is participants do sometimes cancel and decisions need to be made about whether to go ahead with the groups. Participants from two focus groups (FG1 and FG3) cancelled prior to the day and on the day of the focus group. Following the cancellations I decided to go ahead with the focus groups despite the low numbers. The numbers within each focus group did not meet the recommendations suggested by Morgan and Krueger, in and by themselves but collectively across three groups I had a total of 14 participants whose views were represented in the study. This was an advantage as I managed to recruit participants from the NHS as well as the charity based MS Therapy Centres. This was one of the strengths of the study as the Delphi Study included pwMS who were either treated by physiotherapist within the NHS or at a MS Therapy centre. Therefore it was valuable to have the views from both represented in the focus groups (Research Journal, February 2014)

### **Reflexivity: Data Analysis Study 3**

The levels of anxieties differed between Studies 2 and 3. One reason for this was that in Study 2, I was learning and doing framework analysis at the same time whereas in Study 3, I knew what needed to be done and progressed through the different stages of the analysis. However, whereas with Study 2 I had transcribed the data, in Study 3 I had to listen more to the focus groups to get a feel for them. However, I felt more at ease with the analysis process... One lingering thought though was whether I was interpreting participants' views accurately... for example, in Study 3 I felt professionals described physical activity less compared to participants in Study 2. During the charting phase, some of the charts for the groups were scant as such I kept revisiting the focus group transcripts to ensure I did not miss any information during the labelling stage. These participants were physiotherapists and that posed an additional pressure to ensure that I was presenting their views accurately.

With a background in physiotherapy I struggled initially to place myself as a researcher and not as a physiotherapist. My supervisors advised early on in PhD process to take my physiotherapy hat off!

Eventually by doing this, a number of things became apparent. For example, listening and re-listening to the focus groups I suddenly realised that participants were apprehensive to challenge the results of the top 10 this was more noticeable when the researcher asked participants to state whether they felt anything was missing from the top 10... some physiotherapists felt it was not their place to say what was missing if it was the groups' (pwMS') decision... this was an interesting concept and I reflected on that... it raised a big question about whether there is a place for healthcare professionals to challenge patients' choice... big debate.... Nevertheless, finding my place in the role as a researcher brought some clarity to the analytic process (Research Journal, July, 2014).