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Exploring the factors which effect participation in exercise and physical activity in adults with multiple sclerosis.

THESIS – MSC RESEARCH
HUMAN & HEALTH SCIENCES
CHRISTINA WILKS

# **Acknowledgments**

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# **Abstract**

Reason: Although exercise has been shown to be beneficial for individuals with Multiple Sclerosis (MS), studies suggest that 80% of adults with MS do not reach the recommended guidelines for physical activity and exercise set by the department of health. This can lead to secondary conditions and progression of MS symptoms. The purpose of this research is to explore the reason why adults with MS do and do not meet the recommended physical activity and exercise guidelines.

Method: The researcher ran 4 focus groups to gain knowledge of the lived experiences of 18 individuals who either had MS or were speaking on behalf of an individual they cared for with MS. Individuals were approached at a Multiple Sclerosis Society branch. The data was transferred into transcriptions and then analysed using template analysis.

Results: The results showed 3 major emerging themes, these were personal barriers, social barriers and environmental barriers. These 3 themes linked with the Socio-Ecological Theory, developing elements of the model which could help future research develop physical activity and exercise interventions individuals reported that they didn't exercise for a number or reasons, the largest discussions were based around individuals suggesting: being scared of the risk of falling, not physically able to participate, need too much time for recovery and overcome by fatigue.

<u>Conclusion:</u> The research has limitations however it provided strong findings to suggest further research is needed to look at using the Socio Ecological Model to create behavior change in individual with MS to participate in Exercise and physical activity. Behaviour change models need to consider personal, social and environmental barriers.

**Keywords:** Multiple Sclerosis, MS, Social Support, Environment, Physical, Disability, Personal, Guidelines, Recommendations, Confidence, Self-efficacy, Socio-Ecological, Model.

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# **1 Introduction**

Multiple sclerosis (MS) is the most common chronic inflammatory disease affecting the central nervous system; it is unpredictable and often disabling. The National Health Service (2016) indicates that MS can start to affect adults mostly between 25 – 35 years of age. Health Line (2015) and the Multiple Sclerosis Trust (2015) suggest that 2.5 million people around the world have multiple sclerosis, with 2-3 women for every man. Generally, the prevalence appears to cluster further from the equator, the reasoning for this is unknown.

There are currently three types of MS, relapse remitting where the person with MS has remission periods, secondary progressive where a person with MS has little-to-non remission periods and primary progressive which doesn't have any remission periods at all (The Multiple Sclerosis Society, 2016) The type of MS is usually based around the pattern of symptoms and findings from a magnetic resonance imaging scan (Chataway, 2008).

Multiple sclerosis develops when the myelin sheath on the axon of a nerve fiber is damaged. Myelin sheath is a layer of myelin that insulates some of the nerve cells within the body. Myelin is made up of a white fatty chemical substance which surrounds the axon of a nerve cell- this forms an electrical insulating wall for when the nerves are sending electrical messages around the body (Haghighi, Lekman, Nilsson, Blomqvist, & Andersen, 2011). The production of myelin is called myelination which occurs around the fourteenth week of foetal development this is a crucial stage for ensuring the body's nerve cells work accordingly (Barkovich, 2000).

When a person has MS the body assumes the myelin sheath is a foreign body; it attacks and damages the myelin sheath leaving swelling and permanent damage leaving the nerve fibres exposed. The nerve fibres send messages around the body which creates movements and

responses (Franklin, 2002). Once the myelin sheath is damaged this can cause a fault in these messages being sent to the correct place due to damage and exposure of the nerve. This can cause blindness, difficulties with bladder control, muscular spasticity, extreme fatigue, and many other physical and psychological effects (Feinstein, Freeman, & Lo, 2015).

Currently in today's medical existence we are still trying to understand the cause of the disease to then be able to establish a cure, the disease is a lifelong progressive condition and can cause severe disability (Moccia et al., 2016). Current treatments such as: diet alterations, exercise, lifestyle modification, disease modifying therapies, medication, physiotherapy and complementary or alternative therapies have been trialed and tested to reduce the progression of symptoms and increase quality of life. Evidence from Paltamaa, Sjögren, Peurala, and Heinonen, (2012) suggests via a systematic review and meta-analysis there are small but significant improvement to walking balance and quality of life when using a physiotherapy intervention. They further concluded that there are many physiotherapy intervention studies including people with mild to moderate disability, and progression of the disease, but a limited number of studies for severe disability, and progression of the disease.

Exercise has been suggested to be beneficial through studies on exercise therapy interventions (Sa et al., 2014). Sa, et al., (2014) suggests through a systematic review of randomised control trials using 591 participants with 60.6% female and 39.4% male population, that using a variety of physical activity interventions, exercise is beneficial to health outcomes and increasing quality of life in MS sufferers and should be recommended for rehabilitation interventions for patients with MS. Straudi, Fanciullacci, Martinuzzi, Pavarelli, & Rossi et al. (2015) indicated through a randomised control trial, testing robot assisted gait training in progressive MS patients, that walking endurance and balance significantly improved with a difference in 2 points on the berg balance scale from post intervention to the 3 month follow up, including positive effects on depressions.

A meta-analysis of three different fatigue focused exercise interventions for people with MS by Asano and Finlayson, (2014) reported that education, medication and exercise all had an effect on reducing fatigue in people with MS; when exercise was involved there was a greater impact in reducing fatigue. They further indicate that people considering interventions for fatigue in MS should consider using education, exercise and medication together to aid fatigue management through a multidimensional approach. Although exercise has been highly suggested to be beneficial for people with multiple sclerosis in many ways Motl (2014) indicates that 80% of people with MS do not meet the recommended level of moderate to vigorous activity (The Department of Health, 2011). These findings are further supported by Neill, Belan, and Ried (2006) who suggest that although exercise is beneficial for people with MS, this population have exceptionally low levels of physical activity.

The National Institute for Health and Care Excellence, (NICE, 2016) suggests that people with MS should try to adhere to the government exercise guidelines where possible as people with MS should be encouraged to exercise, they further conclude that exercise and physical activity is beneficial and does not have harmful effects on their MS. The Department of Health, (2011) suggest that adults 19 plus years should take part in 150 minutes per week of moderate activity or 75 minutes of vigorous activity with two sessions per week of physical activity to improve muscular strength. Adults should reduce the amount of time they are sedentary. Adults ages 65 and over who are at risk of falls should also incorporate balance and coordination activities within physical activity. The Health Survey for England (2012) reported that via self-reporting methods in the UK only 67% of men and 55% of women aged 16 and over met the recommendations for aerobic activity with 26% of women and 19% of men being classed as inactive. Motl, McAuley, Sandroff and Hubbard, (2015) further support these suggestions as their study indicates that there were statistically significant differences in overall Godin leisure-time exercise questionnaire (GLTEQ), scores and rates of physical

activity in MS participants and control groups. They indicate that insufficient activity levels in the MS groups were at 58.0%, moderate activity levels were at 15.2%, and sufficient activity levels being at 26.8%. They further suggested that those with MS were 2.5 times more likely to report insufficient physical activity levels and 2.3 times less likely to report sufficient physical activity levels than the control groups. The study concluded that the majority of persons with MS are insufficiently physically active.

The researcher has explored the factors which effect participation in exercise and physical activity within adults with multiple sclerosis, to explain these, differences need to be explored. A study looking into the reasons surrounding exercise participation in adults with multiple sclerosis suggests, through a study using 52 participants, that overall there were associations with females who were unemployed and had a low quality of life and low physical activity levels. This could be the effect of the multiple sclerosis symptoms on the body and the body's ability to maintain a good standard quality of life including retaining employment. They further suggested that people with MS generally have lower walking speeds (Kahraman, Savci, Coskuner-Poyraz, Ozakbas, & Idiman, 2015). These findings suggest further research is needed to identify the personal reasoning why adults with multiple sclerosis are inactive. The next section of this research will explore further into the existing literature within this field using systematic methods to review the literature. A search involving multiple library and online searching strategies, (please see below) indicated that there are very limited number of studies surrounding the factors which effect participation in adults with multiple sclerosis.

# **2 Review of Literature**

## 2.1 Methods

#### 2.1.1 Design of the review:

The systematic process of the review was established using knowledge from Noyes, (2008). This included a systematic search of the English language literature, precise inclusion and exclusion criteria using a framework, the use of a critical appraisal tool and a thematic analysis constructed from the evidence tables which uses a narrative summary technique.

This systematic process is a well-established scientific method and has been used in a myriad of successful qualitative studies (Kitchenham, et al, 2010). The study follows the PRISMA (Preferred Reporting Items of Systematic reviews and Meta-Analyses. 2009 17b) checklist alongside systematics processes from Noyes, (2008) to ensure the highest quality review.

# 2.1.2 Search Methods:

The study has used the following search string to establish the results:

'((Facilitators) OR (Barriers) OR (factors) OR (participation) OR (correlates) OR (engagement)) AND ((physical activity) OR (sport) OR (exercise)) AND ((MS) OR (multiple sclerosis))'

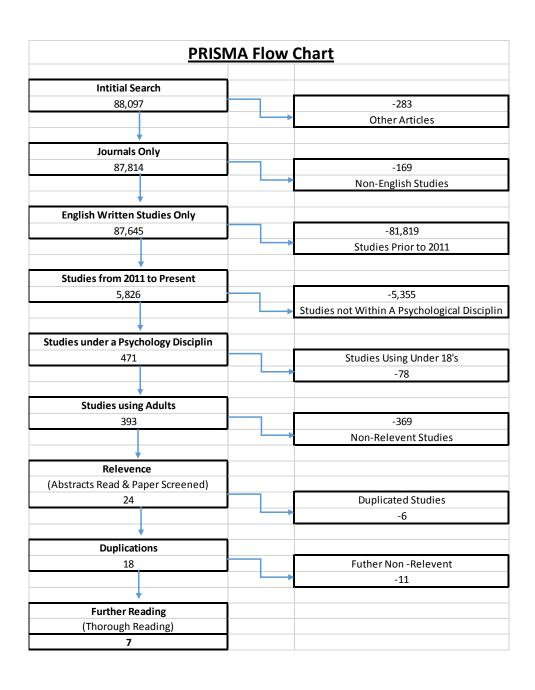
(Please see appendix for search string key words table)

The study used three electronic databases to find the articles for the review; these consist of CINAHL, PUBMED and SUMMON.

CINAHL proclaims to be the most widely used, respected research tools for nurses, students and allied health professionals around the world. PUBMED is a database consisting of over 25,000,000 citations for biomedical literature from medline, life science journals and online books. And finally SUMMON is a database used at the University of Huddersfield which comprises of the most relevant and fast accessing scholarly materials.

A precise inclusion and exclusion criteria was used to guide the articles found for the research, this ensured the articles found were the most appropriate to include in the findings. The study used PRISMA (Moher, Liberati, Tetzlaff, Altman, 2009) to demonstrate these findings.

Figure 1. Literature review PRSMA flow chart



# 2.1.3 Inclusion and Exclusion of Studies:

The initial search found over 88,000 studies, as this is such a high figure the review used the databases refinement process to filter the articles to find the most relevant considering validity and reliability. The database filtered down the results using the inclusion of journals only, English language studies only, studies from 2011 to present only which the review with 5,826 articles left to scrutinise, as this was still such a high figure with the majority seeming irrelevant the review then used inclusion of articles under a psychological discipline. The review used a psychological discipline to remove any articles that did not consider psychological aspects of participation or non-participation in exercise or physical activity, this option was available throughout all three databases. 471 studies remained; from this the database refinement was able to filter any studies which contained anyone under the age of 19 which resulted in 393 studies remaining, from this each title was read to remove any irrelevant studies. This then left the study with 24 articles, the abstracts were read and the rest of the papers screened, after removing any duplications and from further reading of those studies any further non-relevant articles the final figure of articles stood at 7.

The inclusion and exclusion criteria was chosen and used to try find the most accurate, valid reliable and up to date sources of information to conduct the review, each section of criteria was formed to potentially remove any pieces of data which were irrelevant to answering the aim and objectives of the review.

#### 2.1.4 Appraisal of the Articles:

The study used 6 quantitative studies and 1 qualitative study. The literature review used CASP a critical appraisal tool to critically appraise the qualitative article as it is a well-established method which is frequently used. The study had its limitations (Critical Appraisal Skills Program, 2014). The quantitative studies used were analysed and found to have high trustworthiness, credibility and to have significance in providing themes to answer the research question.

# 2.1.5 Data Analysis:

The review has used a thematic analysis, this method was chosen as it was the most appropriate categorising strategy for the data found giving the opportunity to discuss in detail any relationships and patterns between the factors found to affect participation in exercise and physical activity in adults with MS. Common themes have emerged from the summarised findings of the articles. These are: self-efficacy, fatigue, social support, disability status & walking impairment & symptom severity.

# 2.2 Results

From the 7 studies analysed the table below demonstrated the evidence found in each of the studies to discuss throughout the review.

Table 1, Literature review evidence table.

Journal	Qual/Quan	Sample	Design	Results	Themes	Limitations
(include						
country)						
1.	Qualitative	18	Observationally	Goal adjustment helped some of the	Self-efficacy.	Low sample size
Smith,		participants	analytic study	men stay more engaged in meaningful		
Fitzgerald &				activity despite fatigue.	Symptoms	Only
Whitehead.		18 Men				generalizable to
2015.				Perceived control has been linked to	Perceived	the male MS
				self-efficacy the study proposes that	risks	population
How fatigue				perceived control may influence		
influences				exercise experiences.	Perceived	
exercise					Outcome/	
participation				It is possible that the ability to readjust	Outcome	
in men with				goals is linked to self-efficacy and	Expectancy	
multiple				therefore should be considered by		
sclerosis.				health care professionals when	Social	
				considering behaviour change	Support	
New Zealand.				strategies in men with multiple		
				sclerosis.	Fatigue	

Journal	Qual/Quan	Sample	Design	Results	Themes	Limitations
(include			200.9	Trooping .		
country)						
2.	Quantitative	282	Cross sectional	Self-efficacy, mental fatigue and	Self-efficacy	Cross sectional-
Kayes,		participants	questionnaire	perceived barriers to physical activity		shouldn't be
Mcphearson,			design.	are potentially modifiable variables	Mental fatigue	used for testing
Schulter,		220 Women		which could be incorporated into		causal
Taylor, Leete		60 Men		interventions designed to improve	Perceived	relationship
& Kolt, 2011.				physical activity engagement.	barriers	
						More women
Exploring the				Multivariable stepwise regression	Health beliefs	than men as
facilitators				analysis found that greater self-		typical within the
and barriers				efficacy, greater reported mental		MS population
to				fatigue and lower number of perceived		
engagement				barriers to physical activity accounted		
in physical				for a significant proportion of variance		
activity for				in physical activity behaviour, over that		
people with				accounted for by illness related		
multiple				variables.		

sclerosis.						
				The results varied from a p values of		
New Zealand.				<0.001 to 0.04		
Journal	Qual/Quan	Sample	Design	Results	Themes	Limitations
(include						
country)						
3.	Quantitative	335	Online cross-	The study found that cognitive	Self-	Only able to
Plow,		randomly	sectional survey	problems and environmental barriers	management	explain 19% of
Finlayson,		selected		had the largest negative direct effect on		the variation in
Gunzler &		participants		participation.	Self-Efficacy	participation-
Heinmann.						need to consider
2015		Large		Self-management and self-efficacy	Environmenta	different
		multiple		might have an indirect effect on	I barriers	theoretical
Correlates of		sclerosis		participation via engagement in self-		frameworks.
participation		database		management behaviours.	Cognitive	
in meaningful					problems	Limited via its
activities		267 Women		The two groups with the highest level		cross sectional

among		68 Men		of guideline participation at 84.6% were	Stages of	approach.
people with				in social groups via religion / support.	change	Self-sectional
multiple						sample.
sclerosis.				P value of 0.01	Social	
					support	The
USA						generalizability
						was limited to the
						white middle
						class
						populations with
						multiple
						sclerosis.
Journal	Qual/Quan	Sample	Design	Results	Themes	Limitations
(include						
country)						
4.	Quantitative	46	Cross sectional	Bivariate correlated found that average	Self esteem	Convenience
Dlugonski &		participants	analysis	daily step count and social support		sampling
Motl				were significantly correlated to self-	Self-Efficacy	
2012		40 female	7 days	esteem.		Sampling bias as
		and 6 male	accelerometer &		Social	they could
Possible			Multiple	Multiple linear regression analysis	Support	already be
Antecedents		Recruited a	Questionnaires	indicated that only social support was a		motivated etc
and		convenience		significant predictor of self-esteem.	Quality of life	

consequence		sample from				Small sample
s of self-		a database		Bivariate correlation analysis further		size and
efficacy and		of people		indicated significant associations		relevantly all
self-esteem in		who noted		between self-esteem and physical and		were well
persons with		they		psychological domain of health related		educated.
multiple		wouldn't		quality of life.		
sclerosis:		mind				Mostly
preliminary		participating		Social support may be a variable to		Caucasian
evidence		in further		consider when making interventions		women.
from a cross		research.		and physical activity plans for a person		
sectional				with multiple sclerosis.		Self-efficacy and
analysis.						self-esteem
				P value of 0.01		measured
USA						signally however
						they are
						multidimensional
Journal	Qual/Quan	Sample	Design	Results	Themes	Limitations
(include						
country)						
5.	Quantitative	215 people	Multi-	Highlighted people with Ms have a risk	Outcome	Convenience
Chiu,			discriminant	of secondary conditions due to limited	Expectancy	sample was used
Fitzgerald,		185 women	analysis	physical activity, this can often lead to		to the study.
Strand,		30 men		difficulties in retaining employment-	Self-efficacy	

Muller,			Recruited	education in being physically active.		Completed
Brooks &			through NMSS		Expected	survey online
Chan. 2012.			and neurology	Suggested health promotions	benefits	without support
			clinic of a	interventions		
Motivational			university		Health risk	
and Volitional			teaching hospital	Stage of change varied throughout	perception	Potential sample
Variables			in the Midwest-	people with MS.		bias as people
Associated			USA.	P value of 0.01	Depression	reaching out to
with Stages						join and
of change for					Coping	participate in
exercise in					mechanisms	research may
multiple						already be in a
sclerosis: a						motivated
multi-						positive mind to
discriminant						do so.
analysis						
USA						
Journal	Qual/Quan	Sample	Design	Results	Themes	Limitations
(include						
country)						

6.	Quantitative	348 people	Online Survey	Participant's perceptions of	Self-efficacy	Study used more
		Northeast US		susceptibility to negative health		women than men
Kasser &			Emailed out to	outcomes were focused more on	Symptoms	although typical
Kosma, 2012		57 male	mailing list from	physical conditioning and functioning		within the Ms
		291 Female	the National	rather than on general health condition.	Disability	populations
Health Beliefs			Multiple		status	
and Physical			Sclerosis Society	The most important health benefit		Although results
activity				model predictor of physical activity	Perceived	were sought we
behaviour in				were self-efficacy and perceived	Barriers	believe that the
adults with				benefits of exercise. Even when they		reasons to or not
multiple				controlled for difference in disability	Knowledge	to exercise are
sclerosis				level outcome the results were the		multidimensional
				same.		not signal
USA						explanations.
				Individuals with MS believe they can		
				benefit from physical activity and		
				remain healthy even within the context		
				of their disease however they do		
				suggest that their disability level		
				influences their ability to maintain		
				physical activity levels.		
				Self-efficacy- modifiable factor &		

				should be considered in future health		
				promotion.		
				P value of 0.001		
Journal (include country)	Qual/Quan	Sample	Design	Results	Themes	Limitations
7.	Quantitative	269 People	Longitudinal	The study documented a significant	Disability	Limited
Motl, McAuley		223 Women	investigation	linear reduction in physical activity	status	generalizability
& Sandroff		46 Men		over a 2.5 year period of time in people		to those with
2013				with MS.	Walking	progressive
		Recruited via			impairment	multiple
Longitudinal		an		No changes in fatigue, depression and		sclerosis
changes in		advertiseme		pain	Symptoms	
physical		nt through				Physical activity
activity and		National		Self-reported changes were down to	Self-Efficacy	Changes are self-
its correlates		Multiple		changes in self-efficacy		reported
in relapsing		Sclerosis				
remitting		Society		P value ranges between 0.001 to 0.0001		
multiple		(NMSS)				
sclerosis						
USA						

The findings suggest that there is no singular cause of low participation in exercise and physical activity in adults with MS but more a multidimensional issue. Therefore it could be suggested that a multidimensional approach to getting adults with MS active would be an ideal intervention method. This links well with Bronfenbrenner's (1979) Socio-Ecological Theory of behaviour change. Peacock, et al, (2015) suggest that multidimensional approaches to interventions are more successful than a singular approach to an exercise and physical activity intervention in primary care. From the results the following themes emerged:

- Self-efficacy
- Social support
- Disability Status, Walking Impairment & Symptom Severity
- Fatigue

### 2.2.1 Self-Efficacy

Self-efficacy is the extent in which a person believes in their own ability to complete a task or reach goals (Matthews, et al. 2015). Self-efficacy was the strongest theme found in each study reviewed. Kayes et al., (2011) suggest through a quantitative study exploring the facilitators and barriers to engagement in physical activity for people with MS that self-efficacy is potentially a modifiable variable which could be incorporated into intervention designs to improve physical activity engagement, Kayes et al., (2011) used two self-efficacy scales, The general self-efficacy for multiple sclerosis scale (MSSS) and self-efficacy sale for chronic disease, both of these scales are fairly well established and developed and have been used in many multiple sclerosis related studies. Motl, McAuley and Sandroff, (2013) also support these suggestions as they found significant linear changes in self-reported and objective measures of self-efficacy using the 6 item exercise self-efficacy scale (EXSE). Kasser, and Kosma, (2012) state using a quantitative study using 348 participants that one of the most important health belief model

predictors of physical activity was self-efficacy using the 14 item scale, asking participants to report how confident they felt in certain physical activity situations rating each situation out of 100%, with 0% being no confidence at all and 100% being completely confident. They further suggested that future health promotion should focus on this modifiable factor; therefore low self-efficacy has an effect on participation levels in exercise and physical activity.

Self-efficacy has shown to be a major contributor towards successful levels of participation in exercise and physical activity in adults with MS. Self-efficacy in relation to exercise and physical activity participation links closely with other contributors such as social support and outcome expectations this is due to a building confidence when feeling social supported by others and having a social support network that works well for the individuals (Bonino., et al. 2016). Therefore those who have a higher self-efficacy are more likely to have higher participation levels in exercise and physical activity and be more motivated towards behavior change and making physical activity and exercise a ritual than those with lower self-efficacy. However within the studies it was apparent that although they all tested self-efficacy levels across a scale, each scale was different with not all of them being well established and developed models. For the scale to work each individual had to self-report these finding, therefore creating limitations as each person's perception of the scale and identifying how confident they are cannot be measured indefinitely.

Self-efficacy is an issue for individuals with MS as this is a progressive disease it is essential that individuals keep themselves moving and active as possible, it was identified people with lower self-efficacy are less likely to be active therefore it is important that self-efficacy is addressed as it may prevent people from participating in the exercise they require to stay fit and strong and to maintain a good to standard quality of life.

# 2.2.2 Social Support

Social support is the perception and actuality a person is being cared for, assisted and supported by others, and having a good social network, social support can come in many forms: emotional, tangible, intangible, companionship and informational (Motl, McAuley, & Snook, 2007). Plow, Finlayson, Gunzler and Heinemann (2015) suggest that a small group of men from one geographical region found strength and meaning at a group exercise class hosted by the multiple sclerosis society, they further discuss how they believe this is an example of a shift in attitude and behavior in men who previously preferred to exercise on their own to go at their own pace but yet found benefits in exercising now as a group. The results show that from those who report they participate in religious or spiritual activities or attend support groups or self-help meeting 84.6% of them are doing enough activity. This further supports social support as a variable to increase participation. Dlugonski and Motl, (2012) further supports these findings as they indicate that through a multiple linear aggressor analysis social support was the only significant predictor of self-esteem. Dlugonski and Motl, (2012) used a 6 item social provisions scale to establish their results which included the following levels of social support, "I have close relationships that provide me with a sense of emotional security and wellbeing", "There is someone I could to talk to about important decisions in my life". Which were rated between 1 to 4 with 1 being strongly disagree and 4 being strongly agree.

Mendonca,. et al (2014) suggest that social support is a vital factor to higher participation levels in exercise and physical activity. Plow, Finlayson, Gunzler and Heinemann (2015) supported these claims as their results showed the higher population of those who were attaining the recommended amount of exercise were the groups who were socially supported; they belong to either the category participates in religious or spiritual activities or goes to support groups or

self-help meetings. Dlugonski and Motl (2012) suggested that social support can boost self-efficacy and motivational traits and help people to attain exercise and physical activity goals, which is essential for getting individuals with multiple sclerosis to maintain regular physical activity levels with physical activity and exercise becoming a ritual.

#### 2.2.3 Physical Effects

Disability status, walking impairment and symptom severity are all physical conditions where the body is unable to function to complete such tasks like walking, standing, holding an object or completing general day to day tasks like showering or picking up the post. Chiu, et al,. (2012) suggests through a quantitative study using multi-discriminatory analysis which is a statistical technique used to reduce the differences between variables in order to classify them into wide themes or groups, that people with MS are vulnerable to secondary conditions which can affect their ability to obtain and retain employment and that this can have a negative effect on being physically active and participating in exercise, and current physical activity levels. Chiu, et al,. (2012) used a Minimal Record of Disability tool (MRD) to evaluate MS Symptoms and severity and the effect it has on overall quality of life. This scale was established in 1984 by the International Federation of Multiple Sclerosis Societies (Roullet,. Et al,. 1988). Kasser, and Kosma, (2012) suggest that disability level affects a person with MS by influencing their ability to maintain physical activity levels. This could be a perceived barrier and can be linked to outcome experiences and expectations.

Kasser, and Kosma, (2012) suggest that the disability severity in adults with MS can cause more barriers to exercise and people may become physically unable to participate in certain types of physical activity and exercise. However Dalgas and Stenager (2012) suggest that being physically active early on could potentially help reduce the deterioration of symptoms and

reduce the rate in which disability is apparent. Allar, Baek, and Taliaferro, (2014) suggests that to get people physically active with major disabilities, it is essential to construct an accessible inclusive environment where people can be socially active without feeling limited.

The severity of an individual's disability may make exercise and physical activity less accessible for them to perform in groups and social environments. It is essential we focus upon these areas to ensure individuals who are severely disabled due to MS are not excluded from activity sessions and socialising as this can worsen the development of symptoms of MS.

#### 2.2.4 Fatigue

Physical fatigue is a subjective and overwhelming feeling of tiredness, it is separate from weakness and fatigue can be alleviated through periods of rest. Fatigue can be both physical and mental. Smith, Fitzgerald and Whitehead, (2015) discuss in a qualitative study how, from 18 participants who struggle with mild to chronic fatigue, that from their findings using a web based survey, people with fatigue feel the need to adjust goals and preserve energy for other daily tasks rather than strenuous exercise to prevent suffering with chronic fatigue and to be able to achieve smaller energy consuming tasks. They further reported that 86% of the sample of participants reported fatigue to be a barrier sometime, often or routinely. However Kayes et al., (2011) suggested that mental fatigue is a modifiable variable and although a negative effect on mental fatigue can cause lack of participation and engagement in physical activity and exercise, it can also be used to change attitudes and behaviours to get people active.

Physical and mental fatigue within adults with MS can cause crippling tiredness and exhaustion without any signs or cause (MacAllister, et al., 2009). These symptoms have been shown to

have negative effects on participation in exercise and physical activity alongside the perceived risk of triggering fatigue.

#### 2.2.5 Other Potential Themes

Health beliefs, education and knowledge is the understanding of the physiological aspects and health related aspects in relation to exercise and physical activity a person may have, these beliefs may have formed from potentially correct or incorrect information. Kasser and Kosma, (2012) suggest that in their quantitative study using 348 participants the participants had very varied health beliefs and understandings, their perception of negative health outcomes were linked with the association of inactivity- this was more focus towards physical conditioning rather than the health benefits.

Kasser, and Kosma, (2012) showed that the limited knowledge that some adults have surrounding physical activity and exercise, they discussed the negative associations with being inactive were more focused towards a visual perception of physical activity and exercise as opposed to health related goals and achievements gained through knowledge. They further suggest that through correcting educational beliefs surrounding exercise and physical activity this can encourage more people to be physically active. If people were made more aware the health risks that inactivity impact on the body and the government guidelines on recommendation for the type and amounts of exercise, they may feel the need to seek further physical forms of activity (Doring, Pfueller, Paul, & Dorr, 2012). Especially when in relation to adults with MS, Doring, Pfueller, Paul, and Dorr, (2012) suggest that exercise is beneficial in reducing relapses and can be beneficial to alleviating symptoms.

It is recommended that adults with MS are given the adequate advice on exercise and physical activity guidelines and are given the right advice on how to prolong a good quality of life and

prevent any further deterioration from sedentary behaviors (Short,. et al, 2016). One way of addressing this issue could be when at the stage of the diagnosis of MS, GP's and Health Specialists should provide this adequate information at the time and provide each individual with further information to refer to, such as the NICE Guidelines (National Institute for Health Care Excellence, 2016).

Environmental barriers could consist of a variation of environmental factors such as the weather, transport, facilities, cost, accessibility, crime rates and the outdoor environment. Plow, Finlayson, Gunzler and Heinemann (2015) used 335 randomly selected participants to complete a cross-sectional survey. The data analysis found that environmental factors had one of the largest negative direct effects on participation in exercise or physical activity, these factors consisted of transport, health care services and obtaining information. They further suggest that potential strategies to overcome this could be social support and teaching skills to utilise the community resources. It is essential for adults with MS to overcome any environmental barriers where possible but for some, the barrier is not being able to physically access buildings, stairwells and facilities to take part is social sessions and environments, this then has an impact of social support due to individuals not being able to join and utilise social sessions and environments. The Quantitative studies within the review focused mostly on the physical barriers rather than environmental and external forces which affect participation.

Previous studies by Humpel, Owen and Leslie (2002) and Dijkstra, Jaarsma, Dekker and Geertzen, (2014) both suggest that environmental factors are key to low participation levels in adults, factors such as limited time, resources, transport and costs from their perception limited the opportunities available to them to be physically active. Plow, Finlayson, Gunzler and Heinemann (2015) linked these suggestions with social support recommending that for future

interventions it would be beneficial to consider overcoming environmental facts with social support. However Aghaei, Karbandi, Gorji, Golkhatmi, and Alizadeh, (2016) suggest that social support is a central issue and once sought social support this could alleviate environmental barriers and concerns.

However the literature review findings has shown that using quantitative methods to establish causes of low participation cannot get to the route of the problem, more just outline the areas to look into. Therefore future research would need to consider qualitative methods to explore the reasons why individuals with MS do, or do not participate in exercise and physical activity. (Hammersley, 1990). The themes that were indicated through the review were interchangeable and could be used alongside each other to explore these factors further and to create an intervention. It seemed apparent that there was no singular cause of low participation and that it requires a multidimensional intervention to try increase activity. However, self-efficacy seemed to have a central position when relating to other factors and contributors to inactivity. These findings from the literature review link with the Socio-Ecological Model with multiple areas of cause and effect.

### 2.2.6 Literature Review Findings Link to the Socio-Ecological Theory

The findings from the review have shown a consistent link with one another showing each barrier to participation cannot solely be fixed on its own. From the literature review the studies have measured a number of outcomes in relation to barriers which could affect participation levels in adults with MS, the results from the studies highlights that there wasn't one singular cause of inactivity in individuals with MS, but more of a multidimensional barrier, however it appears that previous quantitative methods of research have focused more on physical factors. Therefore it would require multiple contributing factors when addressing participations levels with adults with MS and when considering behavior change to participate in regular physical

activity and exercise. Therefore any future research would benefit from looking at multidimensional interventions, this links with the Socio-Ecological Model, which is a model used to show how external and internal forces can alter our behaviors.

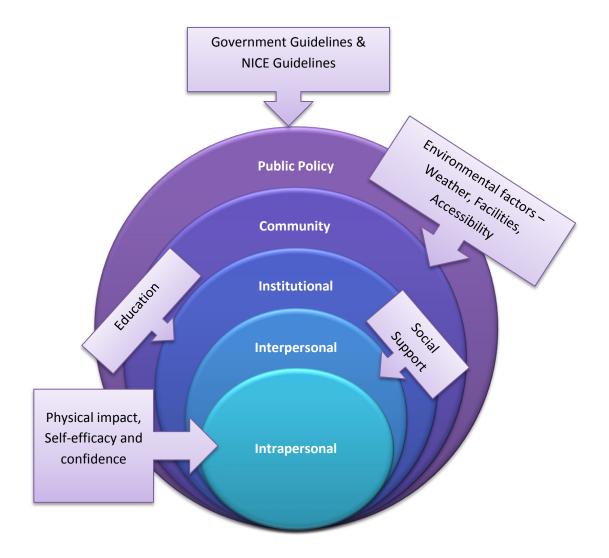
# 2.3 Socio-Ecological Theory

The Socio-Ecological Theory was developed by Urie Bronfenbrenner in 1979, the theory suggests that there is not one singular cause of behavior change, the multidimensional cause must be analysed to establish a successful method of creating interventions to help reduce an issue (Bredahl, Særvoll, Kirkelund, Sjøgaard, & Andersen, 2015). The theory recognises the interwoven relationships that exist between individuals and their environment, and that although they have individual responsibility the environmental factors may also have an effect.

For example, an Individual can have really high self-efficacy which is a contributing factor to maintaining regular physical activity and exercise levels which lies at a intrapersonal level, however if this individual also lived in the middle of nowhere without any form of transport or local, accessible sporting facilities which lies at community level or social support which lies at interpersonal level then the individual is unlikely to maintain physical activity and exercise levels.

The theory uses a model constructed with 5 categories or themes which address the issue, these are: Individual, Interpersonal, organizational, community & public policy. The most effective method of change through the model is to address each area (McLeroy, Steckler, Bibeau & Glanz, 1988).

Figure 2, Socio-Ecological Model.



(Barton, Ullah, Bergin, Mitasova & Sarjoughian, 2012)

Intrapersonal- Personality, Attitudes, Behaviors, History of the individual, skill

Interpersonal – Social Support, friendship networks, social media, family, friends

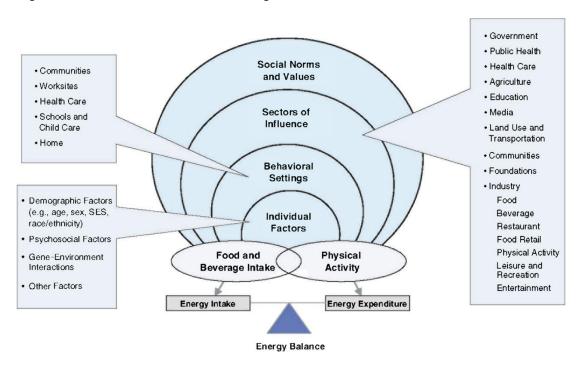
Institutional- Institutional rules and regulations both formal and informal

Community- Relationships among organizations both formal and informal

Public Policy- Local/state/national laws and policies (Mehtälä, Sääkslahti, Inkinen & Poskiparta, 2014)

The Socio-Ecological Theory has been used in many physical activity related studies; Mehtälä, Sääkslahti, Inkinen and Poskiparta, (2014) conducted a systematic review of 23 studies that looked at Socio-Ecological Theory based physical activity interventions in childcare ranging between 2 days to 12 months in length of intervention period. 14 of the 23 studies showed increased levels in physical activity levels and a reduction in sedentary behavior when using the Socioc-Ecological model approach to an intervention, adapting the environment, their education, their support systems with structured sessions and activities to exhaust each of the 5 sections to the model. Although the findings were modest they insist on a more intense program approach using a more structured approach using longer time frames to asses each area, as the majority of children within the setting were still not reaching their recommended guidelines of physical activity levels. Another study by Hill., et al (2013) explored the pre-determinants of pre diabetes and type 2 diabetes the below diagram explains how they categorised each element of the Socio-Ecological Model.

Figure 3, Elements of the Socio-Ecological Model.



The model shows how it categoriesed each element (Hill., et al, 2013). Hill., et al (2013) suggested that previous methods of using a medical model to explain behavior to promote diabetes prevention hadn't worked as well as previously expected however the Socio-Ecological Model they have adapted for pre-determinants of diabetes has more of a tailored approach considering both social and environmental factors. The American Diabetes Association, (2016) has recognized that they need the association between social and environmental factors in the development of obesity and type 2 diabetes. These results are promoting a multidimensional model when considering behavior change in relations to nutrition and physical activity; this could also reflect inactivity in adults with MS.

O'Donoghue, Perchoux, Mensah, Lakerveld, Ploeg, and Bernaards, (2016) analysed the effectiveness of the Socio-Ecological Model through a systematic review of 74 observational studies. The studies used a Socio-Ecological approach to categorise the correlates of sedentary behavior in adults aged 18 to 65 years. The results showed a trend towards increased amounts

of leisure screen time in those married or cohabiting. They suggested that people who had children had less total sitting time. Several environmental correlates were also identified including proximity of green space, neighborhood walkability and safety and weather. However, it appears through extensive searches through online databases that there are a limited number of studies using the Socio-Ecological Theory in relation to physical activity and exercise interventions with adults with a neurological disease.

The literature review has highlighted the possibility that the Socio-Ecological Model could be used to promote behavior change indicating a multidimensional model is required for adapting behaviours to participate in regular exercise and physical activity; this includes physical, environmental and psychological, especially in those with neurological conditions such as multiple sclerosis. At an intrapersonal level, the researcher identified through the review themes such as educational beliefs and self-efficacy, this highlighted the barriers which an individual may perceive, and how knowledge may inhibit someone's desire to be healthier if they are unaware of the damages and secondary effects they are causing by being inactive.

Further findings from the literature review suggests that individuals preferred to exercise in groups rather than on their own, the findings suggest that exercising and being physically active in groups has a positive effect on participation levels, this also linked in with the community level of the Socio-Ecological Model (Plow, Finlayson, Gunzler and Heinemann, 2015). At the community level of the Socio-Ecological Theory experiences with exercise and health professionals have an effect on individuals take up and adherence to physical activity and exercise. Negative experiences or inadequate or incorrect advice from professionals may impact an individual's mind set to uptake or maintain healthy behaviours.

## 2.3.1 Strengths and limitations of the studies

The 7 studies from the literature review all sought the appropriate ethical approval. Each study showed high statistical significance when using quantitative methods. However they do have their limitations; the 7 studies originated from USA and New Zealand, this may make the data less generalisable to populations that are outside of these countries. Kayes et al., (2011) suggested that their research strength was that they had a higher female to male population within their study as this was typical within the MS population. Dlugonski and Motl, (2012) mentioned several limitations, firstly using a convenience sample group, this may cause potential sample bias as the group could have already been motivated to become physically active to offer their participation in the research therefore limiting the results.

## 2.3.2 Qualitative Vs Quantitative

Both qualitative and quantitative studies have limitations generally with the main one being that the studies are heavily dependent upon the skill and experience of the researcher/s. However within qualitative studies rigor is difficult to explain and it can be complex and time consuming when presenting the findings as these have to be interpreted by the researcher dependent upon their philosophical background. However quantitative studies also have weaknesses as the data may not be robust enough to explain complex issues and it may be difficult to understand the context of a phenomenon. Previous research that requires explanations of participation in exercise and physical activity has been more successful using qualitative methods for finding complex answers (Hammersley, 1990).

The finding from the literature review used 6 quantitative studies and 1 qualitative study, the findings were difficult to comprehend as they used quantitative methods therefore highlighting potential barriers but not identifying the reason why this is a barrier. For example one study looked at social support as an aspect of participation rates in adults with MS, but as it used

quantitative methods the study could then not go into any more details with the participants as to why social support was an issue to them which influenced their participation levels in exercise and physical activity. If the studies were to be repeated using quantitative methods the findings may have being different and would have offered a more in depth discussion and reasoning to the outcomes. It is essential that as a researcher they choose the best method for acquiring the data needed to answer the research question however it is questionable that when using quantitative methods to establish people's perceptions and confidence and self-efficacy that important information and a truer understanding can be missed. Creswell, (2014) suggests that qualitative research is beneficial for working out how to explain the unknown of people's behavior, thoughts and feelings as quantitative methods aren't as successful for providing evident results. There is a lack of research using the Socio-Ecological Model on exercise and physical activity participation in adults; this further suggests limited research with the Socio-Ecological Model in participation interventions in adults with long term conditions (Linke, Robinson, & Pekmezi, 2014).

### 2.3.3 Implications to Practice

The aim of this literature review was to research the existing literature surrounding participation in exercise and physical activity in adults with multiple sclerosis. For future research it would be beneficial to include studies with those who are less mobile or have sever multiple sclerosis symptoms. The results from the literature review indicated that self-efficacy was the main emerging theme; therefore future studies, interventions, individuals and health professionals need to consider and support adults with MS in building their self-efficacy as this will have an impact on participation levels in physical activity and exercise.

# 2.3.4 The Gap in Literature

This literature review has suggested a gap in the literature as there is limited research available in relation to barriers and facilitators for physical activity and exercise in adults with MS, It is beneficial that future studies consider using multidimensional research and interventions to asses and explore further a myriad of barriers and methods to overcome these rather than targeting a singular issue as there is no singular cause for inactivity. Further to this, the review has suggested that further studies need to consider the different types of social support offered, whether a person's health beliefs are based on fact or fiction and the variation between the different environmental factors. Future studies need to consider qualitative methods of research to establish the reasoning behind individuals barriers and perceptions of exercise and physical activity.

#### 2.3.5 Strengths and limitations of the literature review

This literature review has multiple strengths, the review has used a systematic method of analysis which is a well-established and developed methods. The review also used evidence tables as an analysis technique to avoid over sumarising the data when in discussion. Although there is a myriad of strengths to the literature review there is also many limitations; when producing the studies through the databases the review used the databases own filtering systems to reduce the amount of studies following the PRISMA format. This in effect could have removed relevant articles which could have been considered and included within the research. This also applies for the inclusion of a 'psychological discipline only' filter as this may have removed more science based quantitative but relevant studies.

This review was needed to try and establish the causes of inactivity in adults with MS. Hopefully information from these findings could help and inform future researchers of ways to consider

targeting inactivity in adults with MS. As this element of the research is a literature review and not a study of direct data the results and findings from the studies may have misinterpreted with the perception of the researchers own beliefs and physiological position. Each study used different scales and techniques for data analysis therefore this could be seen as a limitation as when compared next to one another they may be considering different aspects of the measured data.

# 2.4 Literature Review Conclusion

The major barriers to participations in exercise and physical activity in adults with MS that have been evident from the literature review findings are: self-efficacy, fatigue, social Support and disability status, walking impairment & symptom severity. Each of the themes can be linked together through the Socio-Ecological Theory and have a multidimensional effect on one another. Therefore for future research it would be beneficial to consider using the Socio-Ecological Model in future studies.

### 3 Research Methodology

#### 3.1 Philosophical position

The realist ontology in the assumption that there are real world objectives apart from our perceptions- an objective reality (Angen, 2000). The subtle realist position, which is the researcher's ontological belief, is that we can assume there is an objective reality which can be found, seen or measured, however we assume we can only find the reality from our own perspective (Guba and Lincoln, 1994).

The subjectivist epistemology shows that the researcher has as understanding that as a researcher we cannot separate our self fully from having a personal version or reality of the world and that this could influence the research in some way although it may be minor. This study has focused on using a qualitative method of data collection - focus groups. This could have led to the participants involved feeling the need to conform to what they believe the researcher may have wanted as an outcome, due to the position or knowledge base of the researcher, as opposed to their own raw beliefs and thoughts (Guba and Lincoln, 1994). The researcher accepts that although such beliefs and personal understanding could influence the researchers perception of what the participants may verbalise, and what the participants answer in relations to the research questions, as they may feel the need to conform to what they believe is the correct answer rather than a truer representation. We cannot separate our self from what we already know as what we know if only our perception of reality. The researcher may also be considered to influence the perception and objectivity of the research and previous studies may have influenced ideas and perceptions of this field. The study uses reflexivity to ensure these issues are minimised and to prevent any researcher bias (Hammersley, 1990).

#### 3.2 Qualitative research

Qualitative research links well with the subtle realist approach, the researcher's ontological belief is that there is an objective which can be found, seen or measured. A qualitative approach gives the researcher the opportunity to get to know deep down causes, feelings, ideas, knowing and seeing through the participant eyes (Hammersley 1990). This form of approach is for researching the cause of an issue.

As previous research in the field has not been successful and mostly uses quantitative methods, we need to consider using qualitative research methods for this piece of research and for future

research also. It is essential that a qualitative method is used to ensure the research targets the discovery of the cause and perceptions of barriers and gages an understanding of how the individuals feel mentally and physically toward participation in exercise and physical activity.

#### 3.3 Method

A subtle realist philosophy was used to explore and investigate the factors why adults with MS did or did not participate in exercise and physical activity. Utilising the subtle realist approach the researcher established the research question as it used qualitative methods of understanding the researchers positioning and assumptions of the world around them in accordance with collecting the most appropriate information to answer the research question (Pawson, 2014). The aim of the study is to explore the factors which effect participation in exercise and physical activity in adults with multiple sclerosis.

### 3.4 Ethics

Full ethical approval was sought from the School of Human and Health Sciences Research Ethics Panel prior to any research taking part. Signed information sheets (Appendix 1) and consent forms (Appendix 2) were compulsory for anyone who was willing to take part, it also contained information explaining to participants that they have the right to withdraw from the research at any point (Please see appendix 3, for confirmation of full ethical approval).

To ensure anonymity throughout the transcriptions the participant's names have not been written within the transcripts, alternatively they have had an alphabetical letter presented, this also applies to throughout the written research to avoid being referred to by name. As the topic of conversation may cause an emotional response the committee member for the multiple sclerosis society branch was on hand to offer emotional support for group members and to be

able to refer them to the appropriate resources if needed. It was vocalised to all potential participants that it wasn't mandatory to participate, and it was the individuals' choice to participate; It was reiterated thoroughly that participants could withdraw from the research at any point to prevent coercion.

The researcher followed The Data Protection Act, (1998) strictly adhering to University policies regarding data storage. Paper copies of data with identifiable information on participants such as contact details forms, interview transcripts and consent forms have been locked securely in the researcher's supervisors University office desk drawer. The University regulations state that research data has to be kept for a period of 5 years. The media data will be kept on a portable memory stick which will be kept alongside the paper form data in a locked drawer by the researchers' supervisor. The entire process of data collection and analysis has been completed by the researcher only. There has been no transfer of personal data. The research did not require access to any other personal data such as medical records.

#### 3.5 Recruitment Process

The participants were recruited through a branch of the 'multiple sclerosis society'. Initially the researcher contacted a main lead, at a branch of the Multiple Sclerosis Society, to arrange a date in which we could meet to discuss participant requirements for the research. Through utilising this method, the main lead suggested to meet the researcher at a coffee group the Multiple Sclerosis Society host, thus allowing the researcher to meet multiple contacts from the MS society branch. The main member of the Multiple Sclerosis Society committee suggested a few groups they ran to approach to see if anyone would like to participate within the research, prior to approaching the groups they also sent out a flyer (Appendix 4) across the Multiple

Sclerosis Society Huddersfield network to see if anyone who doesn't normally attend the groups was interested in coming for the purposes of the research.

Participants had to show a willingness to be involved and to come forward to be considered as a participant for the research. Once they showed an interest to participate in the research the research details were thoroughly explained verbally and then reiterated in the form of an information sheet (Appendix 1) for them to sign a copy and keep. Participants were also asked to sign an informed consent form (Appendix 2) prior to any research taking part, the researcher expressed strongly if they did not want to participate prior or throughout the research they are free to leave at any point.

This study used exclusion and inclusion criteria, please see the table below.

Table 2, Inclusion and exclusion criteria.

Inclusion	Exclusion
People ages 19 and	People ages under
over	19
People who attend	People who do not
the MS society's	attend the MS
network of groups	society's network of
	groups
People with MS or	People who have no
career/parent of	link to MS
someone with MS	

#### 3.6 Participants

The research required the participants to be adults aged 19 and above with Multiple Sclerosis, or someone who could speak on behalf of an individual who matched these criteria, if so they must be a parent or career. Below is a table with the characteristics of the participants of the research. All data from the table has been self-reported by the participants via a basic information questionnaire. The data has shown an average age of 64. The research group self-reported an average a total of 4 hours of exercise per week however they all have different understandings of what was classed as physical activity and exercise, as some believed twiddling fingers and toes whilst watching TV to prevent the feeling of pins and needles was exercise and others went swimming and walking as much as possible. The research findings suggest that 4 people have relapsing remitting MS, 6 people with secondary progressive multiple sclerosis and 8 people who either didn't know their type of MS or were speaking on behalf of someone who has/had MS.

Table 3, Population breakdown.

Ages	Gender	Ethnicity	Place of Birth	Type of MS	Hours of PA per Week
36	F	British	Bradford	RR	3.5
57	F	British	Rumford	2P	1.5
66	F	British	England	N/A	3.5
55	F	British	Huddersfield	N/A	1
61	F	Mixed	Bradford	2P	1
44	F	British	Huddersfield	N/A	3
38	F	British	Crawley	2P	15
75	F	British	London	N/A	20
81	М	British	Huddersfield	N/A	1
71	F	British	Huddersfield	N/A	4

67	F	British	Wakefield	N/A	3	
67	F	British	Essex	N/A	1	
57	M	British	Stourbridge	2P	4	
58	F	British	Leeds	RR	2	
67	F	British	Huddersfield	RR	0.5	
63	F	British	Huddersfield	2P	3	
67	F	British	Bradford	2P	2	
48	F	British	London	RR	3	

#### 3.7 Data Collection

The data was collected via four different focus groups. The researcher was responsible for introducing and guiding the focus groups conversation using an interview guide to prevent bias (please see appendix 5 for a copy of the interview guide). Each focus group was recorded then transcribed anonymously to protect the participant's identity.

This research has facilitated focus groups to retrieve raw data as this method was been shown to be beneficial and insightful for engaging in groups and discussing topics (Stewart & Shamdasani, 2015). Focus groups have been found to open up complex issues among participants, with the researcher having the ability to ensure the emphasis in on answering the research question through questions of their own or prompts. Focus groups have also been found beneficial in prompting ideas or comments from other participants (Abrams, Wang, Song & Galindo-Gonzalez, 2015).

Each participant was asked to fill out a short basic information questionnaire to establish ages and gender, this would help when referring back to a singular comment or comments made to give background on the buildup of that character.

### 3.8 Data Analysis

After the focus group data was transcribed the study used template analysis to analyze the data. Template analysis is a method of thematic qualitative analysis founded by Nigel King (Cassell, & Symon, 2004) template analysis uses the option to include a priori themes, these could compile of previous hypothesis or themes evident from previous literature. These themes can be used, removed or adapted throughout the analysis. The themes are used to construct a template the template will develop when considering different transcriptions from each focus group. The final template should be able to fit each transcription from the focus groups.

Using a literature review carried out prior to the research its established 4 priori themes:

- Self-efficacy
- Social support
- Disability Status, Walking Impairment & Symptom Severity
- Fatigue

This is the final template created – Please see below for the process of developing the final template.

Figure 4, Template 4.

# Template 4

#### 2. Social Support and Networks 1. Personal Development 1.1 Physical Limitations 2.1 Enjoyment in exercising in 1.1.1 Symptom severity 1.1.2 Symptom management 2.2 Feeling isolated from social 1.1.3 Beneficial physical results networks 1.1.4 Physical limitations 2.3 Lack of social support from 1.1.5 Fatigue individuals 1.1.5.1 Physical fatigue 2.4 Promoting inclusion for others 1.1.5.2 Need for recovery 2.5 Avoiding groups with time individuals with the same 1.2 Fear of negative impact condition 1.2.1 Individuals perceived risks 3 The Importance of a safe environment 1.2.2 Risk/fear of falling 3.1 Weather 1.2.3 Negative physical results 3.1.1 Temperature 1.2.4 Lack of confidence 3.1.2 Wet Surfaces 1.2.5 Self-efficacy 3.2 Specialist classes 1.2.6 Personal negative 1.3 Sense of accomplishment 3.2.1 Lack of specialist classes 1.3.1 The determination to 3.2.2 Lack of specialist staff achieve 3.2.3 Class not fit for purpose 1.3.2 Personal preference 3.3 Too Expensive 1.3.3 Reward and Sense of achievement 3.4 Time available to the individual 1.3.4 response to exercise 3.5 Accessibility to Facilities 1.4 In-adequate exercise knowledge 3.5.1 Limited accessibility 1.4.1.1 Advised to exercise 1.4.1.2 Not advised on 3.6 Facilities exercise 3.6.1 Not able to use facilities 1.4.1.3 advised for at all physiotherapy 1.4.1.4 Advised to decrease 3.7 Flooring exertion

3.7.1 uneven flooring

3.7.2 Slippery flooring

(Please see individual copies of template development in appendix 6)

1.4.1.5 self-sought

knowledge

This table explains the stages of development using template analysis (Cassell, & Symon, 2004) Table 4, Template development log.

Stages of template analysis	Implementation	Rigor	Example
Setting pre-defined	To distinguish		Priori themes emerged:
codes	through the use of		Self-efficacy
	a literature review		Fatigue
	the priori themes		Health beliefs, education &
			knowledge
			Environmental factors
			Social support
			Disability status, walking
			impairment & symptom
			severity
Data collection	The focus groups	Reflective	"group 2- very forthcoming,
	were recorded and	summary from	they were eager to provide
	transcribed	each group.	information to support the
	verbatim following	(Please see	research and were happy to
	the university's	appendix for this	express and feelings and
	policies and data	summary)	emotions"
	protection act		
Creating the initial	After reading	Asked a	Please see appendix for
template	through 2	supervisor for	template development
	transcripts an	feedback	

	initial template		
	was made		
Developing the final	Using the Initial	Kept copies of	Please see appendix for
template	template, and	each template to	template development
tomplate		·	template development
	applying it to the	show progression	
	existing 2	and development	
	transcriptions to		
	develop the		
	template further		
Using the final	using the final	Asked a	Please see appendix for
Template	template again	supervisor for	template development
	over all text in	feedback	
	transcriptions to		
	ensure data has		
	been fairly		
	analyzed		
Collation	Collated themes	Asked a	Please see appendix for
	and categories	supervisor for	template development
	with links to Socio-	feedback	
	Ecological Theory		

This study used template analysis as it was beneficial in analyzing the raw data from the focus groups and transcriptions; the template is beneficial for aiding and guiding the discussion and fairly considers all sections of data (Brooks, McCluskey, Turley, & King, 2015).

#### 3.9 Trustworthiness

Using guidance from Guba (1981) the study has considered the following to pursue the completion of a trustworthy study:

Credibility- O'Connor, (2011) suggests that credibility is the assessment of how congruent the findings are with reality. The researcher has used well established research methods, experienced early familiarity with the culture of participants by carrying our prior research at undergraduate level, attended frequent debriefing sessions, used a reflective commentary, and has some experience of the research including an undergraduate degree, and with the use of previous research and a literature review section to support this study the researcher has examined previous research findings within this field.

Transferability- The findings of the research can be transferred or applied to other situations to provide an outline regarding exercise and physical activity participation in adults with multiple sclerosis (Guba, 1981).

### 3.10 Reflexivity

Reflexivity is the reflective tool of looking back at work from a different position, and reflecting on practice (Archer, 2010). Reflexivity achieves study quality and rigor as the researcher's philosophical position being a subtle realist it is essential to provide reflexivity.

The study has used a myriad of forms of reflexivity, mainly by attending supervisions with Dr Kiara Lewis the main supervisor for the research, her feedback has prompted further analysis and revisions of methods, questions and sections of the research in which have been adapted and amended by the researcher over time to fulfill the purpose of the research to the highest quality. Another method of reflexivity used throughout the data collection was the reflective

summaries made from each focus group held (Focus Group Summaries can be found in Appendix 7).

# **4 Results and Discussion**

#### 4.1 Aim of the investigation

The aim of this research was to explore the factors which effect exercise and physical activity participation in adults with multiple sclerosis.

This chapter will include a critical analysis and discussion of the data found within this research.

The discussion will consider all philosophical and theory based links and will thoroughly consider themes evident from the findings.

The research established 3 emerging themes these being personal development, social support and networks and the importance of a safe environment.

#### 4.2 Theme 1 - Personal Development

Personal development has been broken down into multiple sub categories: Physical limitations, fear of negative impact, sense of accomplishment, and inadequate exercise knowledge. All of these categories are personal, psychological and physical factors which have been suggested to have the highest impact on participation in exercise and physical activity in adults with multiple sclerosis. These factors all link within the Socio-Ecological Theory to the intrapersonal element which has a central point of the Socio-Ecological Model (Golden & Earp, 2012). Personal development links within the realist ontology as participants understand that what is their reality is only their perspective of it, and others may have different beliefs and perceptions from their own lives and experiences (Guba, and Lincoln, 1994).



Figure 5, Personal development.

### 4.2.1 Physical limitation

Results from the focus groups suggested that participants with MS were underactive as being physically limited and challenged contributed towards participation levels, again this was broken down into sub categories: Symptom severity, symptom management, beneficial physical results, physical limitations and fatigue.

# Symptom severity

The participants from the focus groups suggested that the severity of their symptoms reduced their ability to maintain regular physical activity and exercise.

C: The effort of walking because I have to watch my feet because I don't know where my left leg is at any point in time so when I walk I have to watch I can't go for a nice walk in the country with a view because I watching down, looking at the my feet the whole time.

J: I've found that now I can't even go around the supermarket it's just too much to do and walk around I did try, erm, to go around and, err, I had to go sit down by the door and wait while my husband had to put everything through the checkout so you know it's very limiting is this condition you can't do even the things that you enjoy.

The above quotes suggest that every day activity and tasks are very difficult to go about and therefore this can lead to a reduction in physical activity and exercise levels as some find it difficult to walk and overs can't do shopping themselves. The loss of ability to maintain daily tasks such as shopping, going for a walk, watering the plants in the garden and so on can have quite a substantial effect on the amount of daily exercise and recommended daily step count an individual should maintain, without considering additional exercise is also required beyond general daily physical activity levels (Department of Health, 2011).

F: I think it's very much a case of if you don't use it you lose it. And even if there's things you can do now which you used to be able to do like I used to be able to do proper stood up yoga, but there's no way that I'd be able to do that now because I've got balance problems so it's about trying to adapt it and chair yoga for example or walking if you used to run, not me I never used to run, you know doing, doing what you can and trying to keep your muscles strong.

Although the phrase "If you don't use it you lose it" seems to be a popular, and commonly used within this particular Multiple Sclerosis Society branch, overall activity levels of those with

Multiple Sclerosis are exceptionally low with 80% of individuals not reaching the recommended guidelines (Motl, 2014). The phrase shows participants are aware that keeping their bodies moving is essential to keep their bodies functioning to the highest capacity it can, maintaining a standard of quality of life. However some individuals are still unable to carry out additional exercise and activities such as yoga due to the physical limitations that the MS symptoms are causing them, therefore an alternative option is to research further into medication and treatment to reduce the severity of symptoms.

#### Symptom management

The participants discussed a number of physical symptoms...

K: I find it essential, I think for me and I can only talk from a personal experience, that if I didn't do exercise my body would not work it, I, once id left it, and then I came back too it, it would not work or operate in the same way. So actually I need to do it it's to maintain, erm, my ability.

This suggests that participants have a consistent approach of using exercise and physical activity where possible as a technique and tool to ensure the body does not cease, reduce movement and physical ability or increase in symptom severity. Therefore this can be suggested that the participants believe that exercise and physical activity is essential for symptom management and ensuring the body doesn't start to deteriorate. Although participants are worried about their symptoms deteriorating and developing and feel that physical activity and exercise can help them they are still not maintaining the recommended guidelines. This could suggest that they don't feel the need to exercise outweighs the negative impact and inability to participate in physical activity and exercise.

#### Beneficial physical results & Physical limitations

Some of the participants within the focus groups suggested how physical activity and exercise lead to them having a breakthrough with their symptoms reducing and gaining feeling back within their legs motivated them further.

K: At the minute, erm, I've had quite, erm, a breakthrough, erm, in my recover in that, erm, I can actually feel my muscles hurting like mad. Because I am pushing them that hard that they really hurt and I haven't had that for nearly four years. So that it's self even though it's bloody painful its really enjoyable because I can feel that something positive is happening.

The benefits mentioned in the above comment suggests that exercise and physical activity has been beneficial to the individual in helping the feeling return to her legs and leg muscles, this particular participant of the research lost full use of her legs suddenly 2 years ago as a symptom of MS this dramatically reduced her ability to maintain physical activity levels, however the results of fighting back against MS symptoms and having the determination and self-efficacy.to carry on and achieve has given the participant a better quality of life, it is a monumental achievement.

#### Fatigue – Physical Fatigue

Participants within the focus groups expressed how they struggle with fatigue and thus limiting their ability to partake and maintain physical activity and exercise levels.

C: Can I just say I find it very difficult if, to come out for anything because when I get fatigue it it's like I'm falling off the end of a cliff and there's no predicting it so I can go all day and do a lot of hot activity and be absolutely fine and set off across a car park and whom! I just need to sit down and you know since that it make it very, very difficult to plan what I do in a day, and also I find that when we went on holiday with my sister in

law and husband they go out for a walk along some rock paths and there's some rocky bits and they walk down and there was a bench and its fine they all set off err and they left me there I couldn't get up the slope so I, I was quite a few minutes before they even noticed, they'd just abandoned me and with this place I just didn't have the balance to get over the rocks yeah I looked at them and then it was like Everest you know erm so yeah you know it's just impossible.

This suggests that fatigue is extremely limiting when it comes to physical activity and exercise. Fatigue can take over the body not allowing an individual to complete daily task or activities due to extreme and sudden exhaustion. In turn this effects physical activity levels as it can cause a negative outlook in relation to exercise, physical activity and exhaustion, as dependent upon how severe and how long it can take to overcome the feeling of fatigue individuals with MS are more likely to avoid physical activity and exercise and feeling so exhausted, if they relate this to a negative outcome such as fatigue thus creating a negative association with being active.

W: Sometimes we've have people turn up to the chair yoga and the physical effort of getting there, (NAME) I'm thinking of particular who drives herself and then has to feel her way around the car get her wheelchair out, a hoist, put the boot down which is the biggest problem having to actually reaching up to have to pull it down getting it into the car as well and sometime she gets as far as the car park and you go out and say (NAME) are you coming in n she says she can't get out of the car she's got to go home it's just shattered, getting this far she's made the effort to come and then that's it she like I'm going home you know are you safe to drive, yes I'll sit for ten minutes and then ill pull myself together and drive back home and her partner will come out and see her at the other end but just the thought of doing that is just too much for her.

The issues raise within the above quote suggest that on some individuals with MS do not have the physical ability to travel to and from and attend exercise and physical activity sessions and activities due to fatigue and that merely getting themselves there which may be easy for an adult without MS or disability can be an extreme challenge for an adult with MS. This may also implement issues for others who are severely affected by fatigue who may not be able to get out of the house or out of a chair, this the limits many forms of activity and for some this can mean they are bed ridden without the adequate support from others in getting up and out.

#### Need for recovery time

Throughout discussion within the focus groups it became evident that adults with MS required more time now than prior to being diagnosed with MS to recover from exercise, physical activity and fatigue.

K: I, the only negative I have is that I don't have enough time in a day, erm, I know the benefits, to me of exercising, erm, but I can only exercise for a short period of time and then I'll need to be able to recover and I don't give myself enough recovery time. Erm, and since having MS I have to have recovery time whereas before I never did.

K: Where's my car going to be, am I going to be able to get back to my car, am I going to be tired, too tired to drive home and what going to happen when I get home and I have two children to look after so actually it's not about the exercise it's about the everything else, the bigger picture.

H: When I get home, I'm a widow and I live on my own and I want to do things there as well so were talking about physical activity but I need to factor in gardening and factor in that sort of thing well, and think how much that takes and how much energy, and okay I've got a cleaner but I do my gardening and it's a decent size so actually I don't know how much time you do exercise to count digging or sweeping or you know if it snows id move the snot you know that almost cripples me the other winter just digging out so there is those other things, the do count.

J: Well, listening to everyone else it seems I become very negative on this subject and erm I use dot walk when I was working I used to walk miles and err I suppose I've just got used to not being able to do but I can't walk very far even on a flat surface without needing to sit on a wall or a bench and stop and I can stop and lean and rest standing so it it's just negative it's just I can't do that.

It is evident in the above comments that MS is effecting not just participation in physical activity and exercise but how physically active an individual with MS can be within their home environments and their limitation to what everyday tasks they used to be able to carry out. This can not only be physically straining to an individual but it can also affect a personal and mental outlook too, often causing depression in people who have sudden physical limitations (Kneebone, Dunmore, & Evans, 2003). This links with the Socio-Ecological Theory as although being house bound is the physical effect and this is caused by a physical aspect of having MS this also can have a mental effect and this in turn could affect self-efficacy, confidence and social networks. This reiterates the need for having a multidimensional approach to exercise and physical activity interventions for adults with MS as this could potentially have more of an impact on an individual than a single focus intervention (Barton, Ullah, Bergin, Mitasova & Sarjoughian, 2012).

### 4.2.2 Fear of negative impact

Individuals discussed how they are scared of a negative impact on their bodies from being physically active or participating in an exercise classes, they discussed elements such as the risk and fear of falling and excessive fatigue. Participants feel there could be a potential risk to their MS symptom development. Having a lack of confidence and self-efficacy is causing individuals to be worried by over exerting themselves from minimal tasks therefore they feel that taking part in physical activity and exercise isn't possible to sustain an ability to carry out the rest of the day. All these perceptions and fears of a negative impact will interfere with an individual's way of thinking in relation to priorities of being physically active and the element of being physically active will no longer be a priority as individuals develop into finding methods to protect themselves which would be to avoid such activity. Participants are trying to avoid the risk and although that may being how the individuals cope with the perceived risk, they are unaware that they are potentially causing themselves more health risks and development of secondary symptoms and conditions by being inactive, these risks are a lot bigger than the risks involved with being active and participating in exercise (Peterson, Cho & Finlayson, 2007). The fear of a negative impact links closely with the education and knowledge of the participants, and the environmental factors that oppose MS sufferers, this links with the community and intrapersonal elements of the Socio-Ecological Model.

# Risk and fears of falling

Individuals within the focus groups reveled how scared they are of falling over and the impact this could have on their bodies as a result of a fall.

H: Mmy thing is actually the fear of falling, so at the swimming pool it's slippery and I can't right myself so I'm fine at walking around but walking on slippery is not good, I have a, I've fallen

over, I've fallen in Japan I've fallen over in Turkey I can list the countries that I've fallen over in and I really don't want to fall over again but if I'm going to keep on exercising I'm going to end up falling over when I'm walking, that's what I done like it's a constant fear of falling. The above comment highlights that the participants feel that when they exercise they are confident that they will fall over as opposed to being confident in their strength an ability to prevent falling or overcome the result of a fall. This induces major risks to these individuals as if they reduce their activity because they feel they will fall they will inevitably increase sedentary behavior are more likely to have a loss in balance and walking ability if they become inactive (Hubbard, Motl, & Manns, 2015).

From one of the focus groups, individuals discussed about how the fear of falling was 'scary' and if they could guarantee they would not fall over, they would enjoy going swimming.

C: Yeah but I used to you know quite often walk three or four miles and I can't do that anymore erm although apart form that I'm reasonably active as I'm still working a bit and I'd really like to go swimming but the changing rooms terrify me, erm because I think I'll fall. Because I have no balance, err so if I could you know I'd prefer to go swimming because it's really good exercise and you don't get hot. And you've got to avoid getting hot and that's the problem. You know so anything that needs and aerobic type of activity is fine but I find it very difficult err, so yeah it's okay, swimming would be okay if I could find somewhere I could negotiate the changing rooms.

D: "oh and the sides of the swimming pool just walking."

C: "just walking around the sides is quite scary isn't it?"

K: "yeah."

C: "if you haven't got any balance."

K: "that's what's stopped me from swimming."

This highlights the need for individuals to have support in these environments to be able to partake in the activities they enjoy.

J: I think it's not so much risk as fear, these places are risk assessed and are safe but we are frightened that we might fall they aren't places that are safe we will fail ourselves and fall and uneven surfaces that are fine for everyone else and are not unsafe are not good for us, steps are not good all these sorts of things that just go over an ordinary persons head. But for us their like mountains like you've said aren't they.

The above commend raises just how big of an issue environmental factors can be to individuals with MS. To prevent individuals reducing activity due to the fear of the risk of falling it is essential that gyms and sport centers learn to have more of an inclusive practice, and offered services helping people getting around changing rooms and around the pool edges and steps. It would be essential for places to offer this service to help individuals around and in and out of the pools with adequate non slip flooring and walking aids and hoists if required to get individuals with MS away from feeling worried and scared are more into the enjoyment of the activity. The comments made in relation to being scared of falling indicate how individuals within the focus groups have low confidence and self-efficacy, this links to the intrapersonal element of the Socio Ecological model; Individuals need to consider behaviour change as they are preventing themselves for taking part in activities which they enjoy.

#### Personal negative

Individuals within the focus groups suggested how MS has negatively impacted their bodies and their ability to participate in exercise and physical activity.

K: I've had to learn that so it's, it's not negative about exercising its negative about the effect the MS has on my body it's that I've had to change how I come at stuff and go about things that, that's for me the negative as its learning, I feel like I'm a toddler you know, because, because I've been in this position for 4 years so I've learn enough as a 4 year old with this and it's just so conflicting because I'm not 4 clearly but actually I'm learning my body as a 4 year old would be and I've got a 2 year old and I can see what she's learning to do and my body can't yet do that. And it's trying but I can't yet do that.

J: It even puts me off holidays it puts me off not exercising puts me off entertainment things you know if I'm going to have to walk a long way to get to a theatre if I can't be dropped off quite near all these sorts of things because I know I can't do the walking And it's, it's not nice really.

For some individuals with MS the above comments illustrate that they have to adapt their life and their routines and adjust where possible to be able to carry out simple daily tasks. They have had to alter their lifestyles and their priorities due to what effects they have had from MS symptoms; this has not just limited them physically but also had a large impact on their confidence and self-efficacy at the intrapersonal level of the Socio-Ecological Model. It is essential individuals have social support from others to overcome these barriers within their homes and have help where required from external organisations, councils and from the NHS.

#### 4.2.3 Sense of accomplishment

Participants from the focus groups suggested that feeling a sense of accomplishment from exercising drives them to maintain exercise and physical activity levels. Once an individual see's the benefits from being physically active and exercising regularly then this could boost their

confidence and self-efficacy (Rigby, Domenech, Thornton, Tedman, & Young, 2003). For the individuals to change their ways and perceptions they need to make the benefits of exercising outweigh the risks. This could be approached by further education to the individuals on what could happen to the body if they do not maintain exercise and physical activity levels. However, for some they have their own personal physical activity and exercise goals and accomplishments and have found their own way of participating in exercise and physical activity and maintaining these levels.

#### Response to exercise

The below comment from a participants of the focus group below shows how determined the individual is to achieve physical milestones and overcome issues relating to MS symptoms and barriers.

K: At the minute, erm, I've had quite erm, a break through erm, in my recovery in that erm, I can actually feel my muscles hurting like mad. Because I am pushing them that hard that they really hurt and I haven't had that for nearly four years. So that it's self even though it's bloody painful its really enjoyable because I can feel that something positive is happening.

The above participant has shown how they have the determination to achieve physical goals using physical activity and exercise to strengthen and regain feeling in their legs. This individual has outweighed the risks from being active to the risk of being inactive and is using it to reinforce their motivation, This relates to the intrapersonal elements of the Socio-Ecological Model, Individuals who have a positive experience from taking part in regular physical activity are more likely to have a build in confidence and self-efficacy and a better perception of expected outcome from being active. It would be essential for health care specialist,

physiotherapists and doctors to track individual's progress and achievements with them as a motivational tool.

#### 4.2.4 Inadequate exercise knowledge

When carrying out the focus groups it was alarming how many individuals said they did not know the recommended guidelines for being physically active and that when they were diagnosed with MS they were not educated upon how important it was to maintain activity levels an exercise, and still aim to meet these guidelines. However this is a major conflicting factor as the NICE guidelines (National Institute for Health Care Excellence, 2016) suggest that individuals with MS should still carry out the recommended weekly physical activity and exercise levels as this is beneficial to health and will not have a negative impact on an individual's MS. They conclude in areas of their publications for health professionals to promote activity although it is clear within this branch from the Multiple Sclerosis Society that these individuals who have been diagnosed by neurologists and doctors and have regular appointments with health specialist are not aware of the required knowledge the government is advising health professionals to pass on. Education is a big part of the Socio-Ecological Theory and if individuals aren't aware of how good or bad being active or inactive may be and the impact it could have on their bodies they will not be aware of how important it may be to implement physical activity and exercise into their daily routine.

#### Not advised on exercise

The below comment demonstrates one individuals experience on exercise advice from the GP/specialist.

H: Well no one has ever advised me anything I had one major attack many years ago which left me not walking all in the space of one week and I did the physio after that but as soon as I could walk up and down corridors they sort of signed me off and left me with some exercises which I can do and since then I've done what I want

It is staggering how out of the 18 individuals who participated within the focus groups not one of them when being referred or speaking on behalf of an individual who has been referred was given the adequate knowledge and recommendation to maintain or take up exercise and physical activity. Many studies have shown how exercise is beneficial to individuals with MS including the NICE Guidelines. Institute for Health Care Excellence, 2016) who published documents that express how exercise and physical activity does not have any negative effects on MS and that it is essential that people keep and maintain the exercise and physical activity quidelines.

#### Advised to decrease exertion levels

Within one of the focus groups one of the participants declared that they had been asked by the occupation health nurse to slow things down and to reduce exertive exercise.

K: Every week, 3 hours or so I go out about once per week and really sort of push it to the limit and really suffer for it, yeah the Temperature goes up the symptoms appear erm yeah the afterwards, eughh, but I love it, just go out n push myself to the limit

T: "So do you feel the even though there is obviously consequences as such for pushing yourself that bit further do you feel that more benefits than there is negatives from the consequences?"

K: "Erm no not necessarily my occupational health nurse seems to think that I'm sort of accelerating my detrition because yeah she's trying to get me to learn when to stop and erm take a rest"

This comment raises concerns as this piece of advice could be damaging for some individuals who then feel they have to reduce activity to being sedentary, or stop doing something they enjoy which could also reduce an individual's social support and network. This contradicts the government guidelines and recommendations of practice for health care specialists. The NICE Guidelines (National Institute for Health Care Excellence, 2016) suggest that exercise and physical activity is not harmful to an individual's MS and it is essential for health care professionals to pass on guidance around the activity guidelines.

### 4.3 Theme 2 - Social Support and Networks

Social support and social networks are one of the biggest contributors to being creating behavior change and making new rituals to become physically active and participate in regular exercise (George, et al, 2013). Social support is the support an individual's feels from family, friends, colleagues, support groups or health specialists to achieve in a personal area of development. Social support links into the interpersonal section of the Socio-Ecological Theory, this element of the theory has to be addressed with the intrapersonal element of the model to be able to carry on to the next stages and create a behavior change (Barton, Ullah, Bergin, Mitasova & Sarjoughian, 2012).

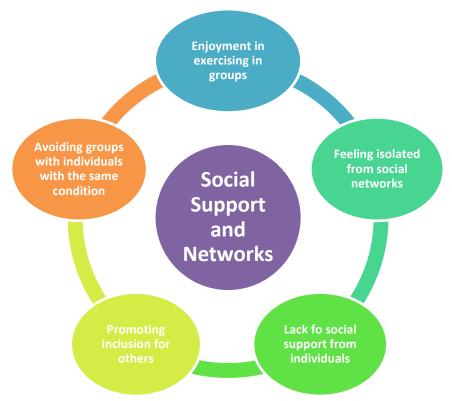


Figure 6, Social support and networks.

### 4.3.1 Enjoyment in exercise in groups

Below are comments from participants of the focus groups, they suggest they feel more comfortable and more likely to maintain activity in socially supported groups.

K: My trike helps because before I used to go up n into the moors and you know all the places on my own but of course you wake up in the morning and think, ahh, I can't be bothered today where as if its organised and there's ten of you turning up to do the same thing you push yourself.

C: "it's a social thing meeting people and the their expecting you you're more likely to keep going aren't you, but that's not a specific thing that an everyone thing"

M: I think it's good they all meet together because they can talk about things like you know you might come in and say ohh you know I've had a bad day or something and other people can say what they've done.

The above comments have suggested how individuals from the focus groups feel comforted by having others there in which they can speak to about how they feel and someone who can equally support them, however this may be seen as a limitation to the research as the individuals approached for the focus groups are already within support groups and a support network has already been established, it is likely they have social support and enjoy social groups as opposed to preferring to be on their own or out of larger social groups.

### 4.3.2 Feeling isolated from social networks

Some individuals from the focus groups suggested how their MS has limited their ability to be part of a social network.

K: Erm for me I think we were talking about it the other day weren't we that I. I have to do everything on my own, I have to keep the motivation to exercise every day and it's a personal motivation theirs no social anything to do with my exercise because I am so slow and I can only do such a little amount that erm it's a very isolating, for me. Erm cos I can't access the gym cos I can't even get in the dam building so it has to well be at my own house and all that sort of stuff so actually for me that for me I walked, I used to pack a 80 litre rug sack and go on 3 day hikes through the, the Scottish hills and just pitch a tent then in the middle of nowhere because you can up there and that's what we used to do, and that was amazing and I'd love to be able to you know hit all the Monroe's again I know I'm never going to get to that point but I, but it's a social element that, going away with some friends, that sort of thing. I miss that.

H: "I'm aware of my friends they've gone off and done something, and I know why they haven't invited me because I can't get up a hill again".

This can effect individuals confidence and self-efficacy and could potentially lead to them feeling socially secluded, It is essential to overcome these barriers that we address the intrapersonal and interpersonal elements of the Socio-Ecological Model, Health specialists and social networks need to help others who are more physically limited and have to exercise from home come together where possible, this could be via social media, email, Skype. Future research should consider using social media as a form of social support as Cavallo, et al, (2012) found through a random control trial that using Facebook as an physical activity intervention methods can be successful in increasing an individual's social support and confidence if used correctly.

### 4.3.3 Lack of social support from individuals

Some of the individuals from the focus group expressed how others don't understand how their symptoms affect them as the injury and damage is not visible from the outside.

J: I have had relatives that have sort of said to me oh you have some free time you ought to get out more, try harder and erm really that just puts me the other way I just makes me think no, go away, no and you know so, so gentle encouragement could be helpful but being told you need to do more this you need to try harder it's just not constructive.

Situations like these can damage people's confidence and put them off being physically active and can cause people to feel socially excluded as they can feel others just do not understand, such situations can give individuals a negative association with socialising where physical activity and exercise is involved. It is essential for family members, partners, children and health specialists to understand how important it is to not give reasons for an individual with MS to have negative associations with being physically active and exercising within their social

networks and structures. This issue fit within both the intrapersonal and interpersonal element of the Socio-Ecological Model.

#### 4.3.4 Promoting inclusion for others

Individuals from the focus group have set up chair based yoga sessions within the Multiple Sclerosis Society branch to get people active and to try get people in social groups and away from being and feeling socially excluded.

W: Like the chair yoga, you couldn't even do the social side of things because you couldn't meet anyone and that's why we set it up wasn't it to get people not just for the yoga its self which is also beneficial but also to get people out, if they couldn't come to this or didn't fancy the coffee, it just to get together and I mean you do get different people coming don't you so it's a social aspect as well it gives people the opportunity to come out and talk to one another and have a coffee do whatever.

This is beneficial for individuals with MS to help them feel understood and to give others the confidence on the type of activity they will be taking part in is inclusive for all as this has been set up by people with MS that fully understand the personal effect of the condition This concept of classes built by the Multiple Sclerosis Society address' both interpersonal and community levels of the Socio-Ecological Model.

### 4.3.5 Avoiding groups with individuals with the same condition

One participant of the focus groups who was speaking on behalf of her son raised a really valid perception.

W: Well you get to see other people's condition and I think sometime people get frightened and put off they don't like you know and aren't comfortable, my son is not a member of the MS society and my husband is the same as soon as we saw somebody who we found had MS he was really, really upset by the, their condition because then he was worried that his son was going to then get the same, you know be the same where as some people feel, they come and see wheelchairs and very disabled people and that puts them off but then you've got to think well not everyone gets like that, is, and it's you don't have to do something so the social aspect is nearly as big issue for some people as the physical exercise themselves. Because they don't actually have to come to the chair yoga they can just come and sit and have a natter.

The above comment is important for others to remember as some individuals may be scared and worried about how their MS will develop and this may cause them to avoid social support from MS networks. This can affect exercise and physical activity participation levels as if individuals are unable to join in mainstream classes, sport or gyms but then are avoiding specialised classes and groups this may leave them socially excluded. Health care specialists and family members must encourage individuals with MS to seek social support where required to prevent individuals becoming socially excluded. However if an individual can still take part in mainstream sports, exercise and physical activity and this is something they enjoy, it is essential they carry out such activity maintain the recommended physical activity guidelines.

#### 4.4 Theme 3 - The importance of a safe environment

Environmental factors are usually one of the biggest contributing factors to low participation levels in adults it is essential that people feel safe and secure in a comforting environment to succeed in behavior change (Vanner, Block, Christodoulou, Horowitz & Krupp, 2008).

Environmental factors link with the community element of the Socio-Ecological Theory, consisting of costs, accessibility, inclusivity, weather, flooring, steps, and transport.



Figure 7, The importance of a safe environment.

### 4.4.1 Weather

Participants from the focus groups suggest how weather can have an impact on their symptoms and this in turn has an impact on their ability to take part in physical activity and exercise.

LL: "yeah I'm affected by the weather like this rubbish weather, everyone different I like it when it's really hot but others that makes them act out. But I like it when it really hot. What do you like?"

L: I like it not too hot and not too cold so, so spring and autumn time's summers are too hot and winters are too cold. But as for exercises but yeah when you do them you know you may feel shattered but it keeps you going and I'm glad that I do it because it keeps us, us more active doing exercises.

Although it effects individuals differently, this could be an essential factor in tailoring activity's to individuals with MS and ensuring that physical activity and classes are held indoor away from the impact of weather in a temperature controlled environment to prevent flare up of symptoms from the individuals.

#### 4.4.2 Specialist classes

Some participants from the focus groups suggested how there is a lack of specialist classes available.

L: It's finding them and getting the information you need you know it's too special it's through word of mouth for a special one and nobody tells you oh yes there are one here and one there, so it's hard to win with them if you can't find them.

Others went on to discuss how when they have been to specialist classes and inclusive gyms and they do not offer specialist staff members to teach individuals on use of equipment and teach the classes.

H: I was actually looking through the different people who are available as coaches and so on at the sports center they've got their little CV's up on the wall but none of them have got a specialism that's remotely close to what I would want because I'd like to have them talk me through the appropriate thing they've got in the gyms that I can't just work out for myself. And no I don't see any of those as having the appropriate training.

Individuals have suggested they felt uncomfortable with not having staff members who are specialised in or trained in understanding MS as they are worried that they may have an instructor who is inappropriate for the class and does not fully understand their physical and mental boundaries. This is a major factor which can effect participation as this could make people socially excluded from trying social activity and could therefore have a negative impact on participation in exercise and physical activity levels.

Others have suggested they have been to specialist classes where they have struggled to keep up as it was not fit for the purpose in which it was advertised as a fully inclusive class.

K: Well yeah. When I was first diagnosed I was referred on to the, oh god what is it? Is it the PALS scheme or something? Yeah, so basically the doctor sends you down to the sports centre and you get cheaper courses and exercise classes. I went on the classes and the classes it was a completely inaccessible class it was just that somebody had decided that it was accessible but it wasn't just for people with accessibility issues or people with mobility issues or any specific issues because there were folks from the sports centre coming to do it on their lunch hour it was just one of the courses they said you could access, so, but I did the PALS thing for a couple of months but then I just dropped it off.

K: I was disappointed, I was disappointed that they had put this out there as something which was easy to do and accessible and really it wasn't so I wasn't disappointed in the exercise class its self, the expectation was that it would be okay and it wasn't.

J: Not all the people who run these classes not all for them appreciate full just how much it does take it out of someone with MS or other conditions that arte similar I went to agua aerobics a couple of times and it was just so exhausting it's all go and all

knees kick and all whoo, and it's just not for people with MS and they don't you know they try to sort of push you and you know getting their in itself you've pushed yourself on some occasions.

These experiences can put others off exercising and maintaining group physical activity classes in mainstream environments. This can have a major impact on participation levels as it can have a negative impact on people confidence and self-efficacy. This affects individuals at a community level of the Socio-Ecological Model; however with any negative experiences from community level this can also impact the intrapersonal level damaging self-efficacy and confidence. This in turn can then affect an individual's social outlook causing individuals to then be socially excluded and overall reducing physical activity and exercise participation levels (Hill, et al, 2013).

#### 4.4.3 Too expensive

Some of the individuals from the focus groups suggested how it was too expensive to find and get to and from specialist classes, as specialist classes tended to cost more and be lee frequent and harder to find.

J: Cost is everything's very expensive, you join a gym and you can't go so you feel you've wasted your money and for some people they are not able to get themselves there they have to get a taxi, erm, there and back that that adding to it all isn't it, erm, erm, and sometime so if people have ere r a limiting condition like MS and you're not able to work moneys not there so that's, that's makes it more difficult.

For some individuals the impact of MS on the body may have forced individuals to seize working and terminate employment, which may have depleted funds which supported transport, living costs, physical activity and exercise classes, and social elements. Therefore specialist classes which cost more than mainstream classes may not be an option. For some who are physically

unable to drive due to their MS symptoms of eyesight or other bodily controls transport costs have to be factored in which may not be an simple as a quick bus ride from one town to another, it may require specialist transport with specialist tools and hoists to help individuals be seated with the vehicle (Shier, Graham & Jones, 2009). All of these considerations need to me made when thinking about costs as it can soon add up.

#### 4.4.4 Accessibility to general facilities

As previously mentioned the cost and accessibility to sport centers and social classes may be a major barrier to participation in exercise and physical activity in adults with MS however so can the accessibility of general facilities such as parks, shopping centers, supermarkets etc, these are all every day places in which most individuals can easily access which is a great was to build daily physical activity levels and increasing step counts but for some individuals with MS it can be near to impossible to maintain such daily tasks as these places can be quite inaccessible.

K: I think I use to just take it for granted that I used to play county netball and I used to walk for miles and it was not something that needed thought or planning other than how much gear was I going to take or that sort of thing and now everything has to be thought about as it's not just about the physical activity it's about where's the nearest toilet, how far away is the door,, where's my car going to be, am I going to be able to get back to my car

C: "if it's anything slippery, even walking one of the reasons I find err walking is if it's on the pavement it's okay, but if the grounds uneven it takes a lot of effort."

This is a major contributing factor to physical activity levels in individuals with MS as everyday tasks become something that feels like an impossible task to achieve as inaccessible facilities can mean that doing the shopping or walking to the shop or park is no longer possible.

#### 4.5 Model summary

The findings from the research suggest that personal, social and environmental factors and the main caused of inactivity and low participation rates in physical activity and exercise in adults with MS. Below is a 3 element model that can be used to explain the findings of this research and potentially development an intervention to address participation levels and inactivity in physical activity and exercise in adults with MS. This also links into the Socio-Ecological Theory, using intrapersonal, interpersonal and community elements of the model.

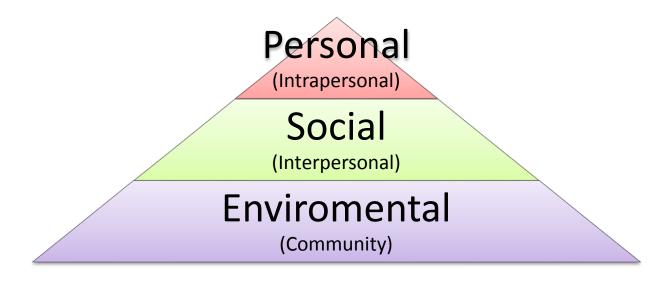


Figure 8, Wellbeing pyramid.

The pyramid represents the building blocks with what is required to be achieved by the individual be able to complete the next stage. The environmental factors that need to be achieved would require individuals to feel comfortable with their surrounding feeling safe and secure, with accessible facilities and transport with or without support. Once the environmental factors are achieved for the individuals they would move on to the next stage. The next stage would be social support, this would include trusting of exercise and physical activity specialists, having social and friendship networks, support from friends and family, social media groups or support groups, When individuals feel socially supported it would then move onto the last stage,

personal. Personal includes the management of symptoms, confidence and self-efficacy, knowledge and motivation. Some aspects from each area may knock the model in and out of sync and cause individuals to start over, the model can be affected by external forces causing individuals to reduce or take up physical activity and exercise. However this model is a strong tool for teaching others what needs to change. In an ideal world if environmental factors are all in sync for the individual, ie they have access to facilities and can access transport easily at a low affordable cost we can build up the social support ie, joining clubs and fitness groups to gain the social aspect or having a gym partner. Once social support is gained individuals can then work on the personal factors ie, building confidence and awareness of their own physical can mental ability. This tool can aid exercise and physical activity intervention methods for addressing participation rates in physical activity and exercise in adults with MS.

#### 4.6 The strongest themes

The literature review established self-efficacy as the main theme and barrier to participation in exercise and physical activity in adults with MS, However within the research the results from the focus group established physical, social and environmental are the main themes, with self-efficacy and confidence running throughout each of the three main themes. This change in results from one study to another may be caused by the qualitative approach taken in the research compared to a quantitative heavy literature review with 6 of the 7 articles of a quantitative approach. As previous research using quantitative methods has suggested a difficulty in explaining and exploring the barriers and factors which have affected participation rates in physical activity and exercise, it is essential that future research considers qualitative methods like this research to find and discover a deeper understanding of inactivity.

Within the study it was essential to use qualitative methods to gain the knowledge from individuals affected by MS to answer the research question, 'Exploring the factors which effect

participation in exercise and physical activity in adults with multiple sclerosis'. Qualitative factors let individuals participate in the focus groups opening up with their thoughts and feelings which explain in depth causes of their low participation rates in exercise and physical activity.

#### 4.7 Strengths and limitations of the research

The study had many strengths and limitations. Firstly, the sample group of participants coming forward to take part in the research was a strength of the research, as individuals attended rather than being chosen. Each of the groups consisted of individuals with MS or speaking on behalf of an individual with MS thus reaching the target audience. However the sample size was a limitation with only 18 individuals participating.

Another limitation of the sample was that all the individuals already attended a social support group at the Multiple Sclerosis Society therefore this could raise the issue that there could be bias with the social support outcome as the individuals already had social support and preferred social support hence they were at the group. The researcher had taken part in pre reading and previous research in the field of MS and exercise and physical activity although combining a strength with a wealth of knowledge in this field, this could also be considered a limitation as the research may have found it difficult to separate themselves from their views and beliefs therefore effecting their philosophical position.

The study used Template Analysis for the data analysis this which although could be seen as a strength of a systematic method to analyse data giving a good grasp of the perspective of the individuals it could also be a limitation and could potentially cause over genrealisation of the results, this could also have been affected as I am a novice researcher. Another limitation of the research is the philosophical position of the researcher. I have acknowledged that although I am aware of a reality I cannot remove myself from my perception of reality and when considering

the meaning of individuals comments this research may have been steered by my perceptions and understandings although I have given what I believe is the truest reflection of the results. One issue that arose from the focus groups the lack of understanding from participants of what was classed as physical activity and exercise; this could have impacted individual's perceptions and understanding when answering the research question. As an exercise science specialist leading the focus groups participants may have felt a need to conform to what they believed would be the researcher's ideal answers when answering questions and as in a group rather than individual interview they may not have opened up as much as they would have like to.

#### 4.8 Implications to practice & future research

Inactivity is a major issue within adults with MS with 80% of individuals with MS not meeting the required guidelines, Inactivity in individuals with MS has been show to causes further health risks and the development of secondary conditions, and hence we need to address these issues (Motl, 2014). The research has highlighted the barriers for adults with MS to participate in physical activity and exercise are: personal factors, social factors and environmental factors. To overcome these barriers individuals with MS, health specialist and supporting family need to consider using the Socio-Ecological Model adapting it to the individuals needs as done above for the participants in the focus groups. It is essential for health specialists and professionals to consider educating individuals with MS and especially when diagnosed on the exercise and physical activity guidelines to provide individuals with the correct information to develop positive activity habits as opposed to having negative activity due to being uneducated. From the results of the research it appears that this element of education is being missed by health specialists and professionals and contradicting the government guidelines and NICE guidelines (Department of Health, 2014) (National Institute for Health Care Excellence, 2016). Future research needs to consider the use of the Socio-Ecological Model and the education of individuals affected by multiple sclerosis in relation to physical activity and exercise.

### **5 Conclusion**

The exploration of the lived experiences of adults with multiple sclerosis in relation to exercise and physical activity concludes that the three main barriers to participation in exercise and physical activity in adults with MS are: Personal, consisting of physical symptoms of MS and limitations of movement and energy as fatigue is overpowering, lack of education and the fear and risk of falling and developing secondary injuries. Social, this consists of having social groups which are accessible with others with the same condition as this will help individuals build confidence in their own ability. However, it was identified that some individuals avoid groups with others participating with the same condition as they don't want to see people with severe development of the disease as this worries them about their own symptom and disease management and progression. Finally, environmental, this theme consists of accessibility to facilities, having MS specific classes available and reducing the costs for individuals with MS as they have reduced working hours or may have been forced to retire or quit due to their condition. Future research needs to establish Socio-Ecological Model structured interventions considering the 3 main emerging themes from this research. Wide scale research is required to ensure the findings are generalisable to the MS population.

Individuals with MS need to educate themselves on the benefits of exercise and physical activity and how beneficial being active is in preventing secondary conditions. Individuals with MS, family members and carers should consider potential future elements that could affect their physical activity and exercise participation rates and develop ways and methods of keeping active to prevent a negative impact on their disease management.

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# **7 Appendices**

Appendix 1. Participant Information Sheet



# Factors Influencing Participation in Exercise and Physical Activity in Adults with Multiple Sclerosis

#### **Focus Group**

#### INFORMATION SHEET

You are being invited to take part in this study.

Before you decide to take part it is important that you understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with me if you wish.

Please do not hesitate to ask if there is anything that is not clear or if you would like more information.

#### What is the study about?

The purpose of this study is to explore the reason in which adults with multiple sclerosis do or don't participate in physical activity and exercise.

#### Why I have been approached?

You have been asked to participate because you currently participate in the voluntary support group for adults with multiple sclerosis.

#### Do I have to take part?

It is your decision whether or not you take part. If you decide to take part you will be asked to sign a consent form, and you will be free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect you.

#### What will I need to do?

If you agree to take part in the research we will run a focus group of 6-10 people (who already participate in the support group prior to the focus group) which will last 30 to 45 minute; this entails an open conversation between the members of the focus group expressing their experiences and thoughts freely. The conversation will be tape recorded. Participants are needed to be as honest as possible. The researcher and Joanna Wilkins will be present throughout the focus group.

#### Will my identity be disclosed?

All information disclosed within the interview will be kept confidential, except where legal obligations would necessitate disclosure by the researchers to appropriate personnel.

#### What will happen to the information?

During the focus group the participants will be asked open questions allowing them to discuss the topic between themselves this shall be recorded. All information collected from you during this research will be kept secure and any identifying material, such as names will be removed in order to ensure anonymity. The information collected shall be transcribed anonymously. It is anticipated that the research may, at some point, be published in a journal or report. However, should this happen, your anonymity will be ensured, although it may be necessary to use your words in the presentation of the findings and your permission for this is included in the consent form.

#### Who can I contact for further information?

If you require any further information about the research, please contact me on:

Miss Christina Wilks
christina.wilks@hud.ac.uk | 07528142052

Or contact my supervisors:

Dr Kiara Lewis

kiara.lewis@hud.ac.uk | 01484 473218

Mr Matthew Haines

m.haines@hud.ac.uk | 01484 472701

Appendix 2. Participant Consei



#### **CONSENT FORM**

**Title of Research Project:** Factors Influencing Participation in Exercise and Physical Activity in Adults with Multiple Sclerosis

It is important that you read, understand and sign the consent form. Your contribution to this research is entirely voluntary and you are not obliged in any way to participate, if you require any further details please contact your researcher.

Participant may be quoted verbatim within the dissertation, any future platform presentation publications of the research results.	s or	
I have been fully informed of the nature and aims of this research		
I consent to taking part in it		
I understand that I have the right to withdraw from the research at any time		
without giving any reason		
I give permission for my words to be quoted (by use of pseudonym)		
I understand that the information collected will be kept in secure conditions		
for a period of five years at the University of Huddersfield		
I understand that no person other than the researcher/s and facilitator/s will		
have access to the information provided.		
I understand that my identity will be protected by the use of pseudonym in the		
report and that no written information that could lead to my being identified will		

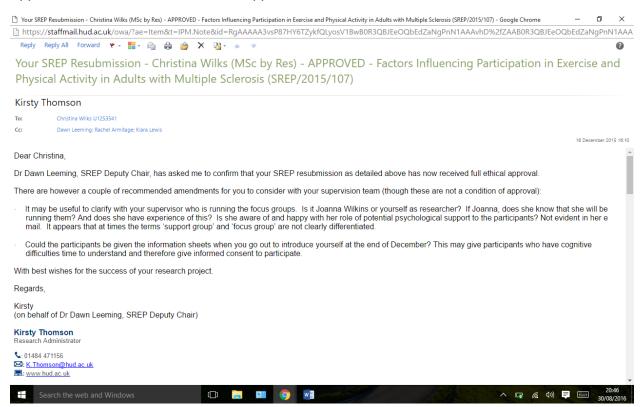
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If you are satisfied that you understand the information and are happy to take part in this project please put a tick in the box aligned to each sentence and print and sign below.

Signature of Participant:	Signature of Researcher:
Print:	Print:
Date:	Date:

(One copy to be retained by Participant / one copy to be retained by Researcher)

# Appendix 3. Confirmation of Ethical Approval



# <u>Important</u>

# Please help towards multiple sclerosis research!

Hi, I'm Christina Wilks and I am from the university Huddersfield. For my masters in research I am studying the reasons why people with multiple sclerosis do or don't exercise. I shall be running focus groups after each of the following sessions:

Tues 26th January - High Park - Bradley - 2 - 4pm (Focus group @ 3:30pm)

Weds 27th January - Sandy Mount – chair based YOGA -1 - 2pm (Focus group @ 2pm)

Weds 3rd February - Sandy Mount - chair based YOGA -1 - 2pm (Focus group @ 2pm)

Focus groups are an open group conversation guided by myself by the odd question here or there, the conversation shall be recorded.

There are not right or wrong answers, positive or negative.

Parents/Carers may also take part.

If you would like to participate within my research please attend one of the sessions to do so, I shall attend with the appropriate paper work ready to fill out to give confirmation to take part and to be recorded.

For any questions please feel free to contact me at <a href="mailto:cmwilks1@hotmail.com">cmwilks1@hotmail.com</a>

Thank you!

Appendix 5. Interview Guide

#### **Interview Guide**

#### Welcome:

Good evening and thank you for welcoming me into your session. Thank you for taking the time to talk with me about my research topic. My name is Christina Wilks and I am from the University of Huddersfield. I am currently studying masters by research in public health.

The main part of my research is to find out what you like about exercise and physical activity and what you don't, and the reasons for participating or not. This hopefully will then give me the information I need for my research which I can pass on to hopefully enhance availability and support for adults with multiple sclerosis to partake in physical activity and exercise.

I shall be attending several support groups over the next few weeks to try accumulate enough information for my research by doing focus groups. I chose to approach this support group as it already aims at speaking with others with multiple sclerosis about own experiences.

There are no wrong answers, I am relying on people being as honest as possible to make the information I get from the groups to be accurate and a truer reflection. Please feel free to share your experiences with me.

As this is an investigation negative comments surrounding the topic are as welcome and positive ones as these sometime can be the most helpful. Please respect others views and opinions although they may be different as we all have all had different experiences.

I shall be recording the conversation purely for my own benefit as I don't want to miss any of your comments as they are extremely valuable to my research. People often say very helpful things within discussions and I can't write fast enough to get them all down. Please do try not to speak over each other as it makes it difficult to listen through.

Well, let's get started. I have given our name stickers to help me remember who is who. To let me find out some more about you all can we go around the group and tell me your name, the area you are from and something exciting about yourself.

. . .

Fantastic, it is great to get to know you all, I hope you all feel relaxed and ready to discuss...

#### Main Questions:

- How often do you participate in exercise and physical activity? (give examples of each)
- How do you feel about exercise and physical activity?
- What do you enjoy about taking part in exercise and physical activity?
- What do you dislike about taking part in exercise and physical activity?
- If you could change anything about exercise and physical activity what would it be?
- Since being diagnosed with multiple sclerosis how has this if at all altered your thoughts and attitude towards exercise and physical activity?
- Since being diagnosed with multiple sclerosis have you been advised on the amount of physical activity and exercise to partake and how do you feel about this?
- How do you feel about the accessibility to partake in exercise and physical activity?
   (Further explain environmental factors)
- How do you feel about participating in exercise and physical activity on your own and with others?
- Can you please express any negative or positive experiences being physically active or exercising?

#### **Probes:**

- Please explain further?
- What were your thoughts when..?
- How did you feel about this?
- Why is that?

#### **Ending Question:**

Has anyone got any further information or experiences they would like to share?

Thank you for your time, that's the end of the recording.

# Appendix 6. Templates

- 1. Self-efficacy
- 2. Social support
- 2.1 Exercising in groups
  - 3. Environment
- 3.1 Weather
- 3.2 Specialist classes
- 3.3 Cost
  - 4. Knowledge
- 4.1 Advised to exercise
- 4.2 Not advised on exercise
  - 5. physical
    - 5.1 Symptom severity
- 6. Fatigue

- 1. Self-efficacy
  - 1.1 negative response
  - 1.2 determination
  - 1.3 personal preference
  - 1.4
- 2. Social support
  - 2.1 Exercising in groups
  - 2.2 Feeling isolated
  - 2.3 Social exclusion
- 3. Environment
- 3.1 Weather
- 3.2 Specialist classes
  - 3.2.1 Lack of specialist classes
  - 3.2.2 Lack of specialist staff
- 3.3 Cost
- 3.4 Time
- 3.5 Accessibility
- 3.6 Facilities
  - 4. Knowledge
- 4.1 Advised to exercise
- 4.2 Not advised on exercise

- 5. Physical
  - 5.1 Symptom severity
  - 5.2 Symptom management
  - 5.3 Beneficial results
  - 5.4 Recovery time
- 6. Fatigue
  - 6.1 Physical
  - 6.2 Time management
- 7. Perceived risks
  - 7.1 risk of falling

- 1. Self-efficacy
  - 1.1 negative response
  - 1.2 determination
  - 1.3 personal preference
  - 1.4 sense of achievement
  - 1.5 lack of confidence
- 2. Social support
  - 2.1 Exercising in groups
  - 2.2 Feeling isolated
  - 2.3 Social exclusion
  - 2.4 Lack of social support
  - 2.5 Promoting inclusion
  - Avoid groups with the same condition
- 3. Environment
  - 3.1 Weather
  - 3.2 Specialist classes
    - 3.2.1 Lack of specialist classes
    - 3.2.2 Lack of specialist staff
    - 3.2.3 Class not fit for purpose
  - 3.3 Cost
  - 3.4 Time
  - 3.5 Accessibility
    - 3.5.1 Limited accessibility
  - 3.6 Facilities
    - 3.6.1 Not able to use facilities

- 3.7 Flooring
- 3.7.1 uneven flooring
- 3.7.2 Slippery Flooring
- 4. Knowledge
  - 4.1 Advised to exercise
  - 4.2 Not advised on exercise
  - 4.3 advised for physiotherapy
  - 4.4 Advised to decrease exertion
  - 4.5 self-sought knowledge
- 5. Physical
  - 5.1 Symptom severity
  - 5.2 Symptom management
  - 5.3 Beneficial results
  - 5.4 Recovery time
  - 5.5 Negative effects
  - 5.6 Physical limitations
- 6. Fatigue
  - 6.1 Physical
  - 6.2 Time management
- 7. Perceived risks
  - 7.1 Risk/fear of falling
- 8. psychologically
  - 8.1 mental benefits

- 1. Personal Development
  - 1.1 Physical Limitations
    - 1.1.1 Symptom severity
    - 1.1.2 Symptom management
    - 1.1.3 Beneficial physical results
    - 1.1.4 Physical limitations
    - 1.1.5 Fatigue
      - 1.1.5.1 Physical fatigue
      - 1.1.5.2 Need for recovery time
  - 1.2 Fear of negative impact
    - 1.2.1 Individuals perceived risks
    - 1.2.2 Risk/fear of falling
    - 1.2.3 Negative physical results
    - 1.2.4 Lack of confidence
    - 1.2.5 Self-efficacy
    - 1.2.6 Personal negative
  - 1.3 Sense of accomplishment
    - 1.3.1 The determination to achieve
    - 1.3.2 Personal preference
    - 1.3.3 Reward and Sense of achievement
    - 1.3.4 response to exercise
  - 1.4 In-adequate exercise knowledge
    - 1.4.1.1 Advised to exercise
    - 1.4.1.2 Not advised on exercise
    - 1.4.1.3 advised for physiotherapy
    - 1.4.1.4 Advised to decrease exertion
    - 1.4.1.5 self-sought knowledge
- Social Support and Networks
  - Enjoyment in exercising in groups
  - 2.2 Feeling isolated from social networks
  - Lack of social support from individuals
  - 2.4 Promoting inclusion for others

- Avoiding groups with individuals with the same condition
- 3 The Importance of a safe environment
  - 3.1 Weather
    - 3.1.1 Temperature
    - 3.1.2 Wet Surfaces
  - 3.2 Specialist classes
    - 3.2.1 Lack of specialist classes
    - 3.2.2 Lack of specialist staff
    - 3.2.3 Class not fit for purpose
  - 3.3 Too Expensive
  - 3.4 Time available to the individual
  - 3.5 Accessibility to Facilities
    - 3.5.1 Limited accessibility
  - 3.6 Facilities
    - 3.6.1 Not able to use facilities
  - at all
  - 3.7 Flooring
    - 3.7.1 uneven flooring
    - 3.7.2 Slippery flooring

#### Appendix 7. Reflective Summaries

Focus Group 1 – 26/01/2016 – 3pm

Environment: High Park, Public House, Bradley, Public environment slight back ground noise and the odd disruption throughout recording. Recording quality sometimes compromised.

Did the session follow the plan: the session followed the plan it sometimes was a little off topic when people got discussing, however the questions followed well and lead people back to topical discussion when required.

Engagement: The group seemed thoroughly engaged initially it was led by a few of the individuals however this then over the first 5 to 10 minutes boosted everyone else's confidence in discussion and got some great points from what was discussed.

Feedback: after the session the group were really grateful for the experience to to have had a voice in this piece of research and some said how they haven't spoken about some things and aspect of MS before and it was nice to air these views and get off their chest how fed up the can sometime feel.

Emotional: Everyone in the group was fine to carry out the focus group, although it is a personal subject and topic area to each of the individuals they did not become emotional more passionate about supporting one another.

Focus Group 2 – 26/01/2016 – 7:30pm

Environment: High Park, Public House, Bradley, Public environment slight back ground noise and the odd disruption throughout recording.

Did the session follow the plan: The session became a little off topic at times but the interview guide brought the conversation back on topic.

Engagement: Each individual was thoroughly involved within the conversation and was really eager to contribute any forms of knowledge, experiences and feelings surrounding each question.

Feedback: Each individual gave really positive feedback and was willing to meet again if I required any more information to help towards my research, they were very positive that this form of research could help them and others in their position to understand how beneficial exercise can be.

Emotional: Everyone in the group was fine to carry out the focus group, although it is a personal subject and topic area to each of the individuals they did not become emotional more passionate about overcoming the barriers MS presents.

Focus Group 3 – 27/01/2016 – 2pm

Environment: Sandy Mount Nursing Home Cafe, Public environment slight back ground noise and the odd disruption throughout recording.

Did the session follow the plan: Yes, the session followed plan.

Engagement: Some were really engaged and happy to help and contribute towards the research where as some were a little rude and thought it was a bit of a laugh and didn't take

seriously the purpose of the research, they started their own conversations throughout the recording however some contributed a lot and has a myriad of good suggestions.

Feedback: The people who were engaged and enjoyed the session apologised for others who disrupted the session from time to time.

Emotional: Everyone in the group was fine to carry out the focus group, although it is a personal subject and topic area to each of the individuals they did not become emotional more passionate about overcoming the barriers MS presents.

Focus Group 4 – 28/01/2016 – 1:30pm

Environment: Dalton Community Centre, Public environment slight back ground noise.

Did the session follow the plan: Yes, the session followed plan.

Engagement: Everyone who took part was thoroughly engaged, one individual had to leave for transport reasons towards the end of the recording but made her apologies.

Feedback: Everyone in the group contributed towards the research with some good comments.

Emotional: Everyone in the group was fine to carry out the focus group, although it is a personal subject and topic area to each of the individuals they did not become emotional more passionate about overcoming the barriers MS presents.