



Developing and exploring the acceptability of a community-based exercise intervention for people with MS in Rotherham

The MS Active for Health Project

Report prepared by:

Liam Humphreys

**Sheffield
Hallam
University**

Centre for Sport
and Exercise
Science

Table of contents

1	Executive Summary	3
2	Introduction	5
2.1	Report Overview	5
2.2	The aim of the report	5
3	Background	5
3.1	Multiple Sclerosis	5
3.2	Exercise and Multiple Sclerosis	5
3.3	Exercising in Rotherham.....	6
3.4	The Project Approach.....	6
3.5	Definition of terms	6
4	Project 1: Developing a community based exercise intervention for people with MS in Rotherham	7
4.1	Aims:.....	7
4.2	Objectives:.....	7
4.3	Methods	7
4.4	Participants	7
4.4.1	<i>People with MS</i>	7
4.4.2	<i>Professionals</i>	8
4.5	Data Analysis.....	8
4.6	Findings	8
4.7	Recommendations for the development of a community based exercise programme for people with MS.	12
4.8	Conclusions.....	13
5	Project 2: Exploring the acceptability of a community-based exercise intervention for people with MS	15
5.1	Introduction.....	15
5.2	Aims of the evaluation	15
5.3	Objectives.....	15
5.4	Exercise programme overview.....	15
5.4.1	Functional Fitness.....	15
5.4.2	Mode of exercise.....	15

5.4.3	Intensity.....	16
5.4.4	Frequency and duration.....	16
5.5	Methods.....	16
5.5.1	Design.....	16
5.5.2	Procedures.....	16
5.5.3	Outcome measures.....	16
5.6	Data Analysis.....	17
5.7	Results.....	18
5.7.1	Referral to the exercise programme.....	18
5.7.2	Demographics.....	18
5.7.3	Reason for drop out.....	18
5.7.4	Attendance and attrition.....	19
5.7.5	Physical activity.....	19
5.7.6	Fatigue.....	19
5.7.7	Quality of life.....	19
5.7.8	Self-efficacy.....	19
5.7.9	Functional tests.....	19
5.7.10	Participant experience.....	20
6	Overall discussion and reflections.....	25
6.1	Outcome measures.....	25
6.2	Participant experience.....	26
6.3	Conclusions.....	26
7	Future recommendations.....	27
7.1	Public health.....	27
7.2	Leisure providers.....	27
8	Project dissemination.....	27
9	Acknowledgements.....	28
10	References.....	29

1 Executive Summary

Exercise has been shown to be a safe and effective strategy for management of multiple sclerosis (MS). The strength of the evidence has led to the development exercise guidelines for people with MS. Despite this people with MS are reported to be less active than the general population. There is a need for the development and piloting of community-based exercise programmes to provide people with MS with more opportunities to be physically active. This report presents the findings of the two-phase MS Active for Health project funded by the MS Society. The project ran from 2017-2018.

Scope of the report

The project consisted of two phases:

Phase 1: Development of a community-based exercise intervention for people with MS in Rotherham.

Health professionals and people with MS were consulted to support the development of a community-based exercise programme in Rotherham.

Phase 2: Explore the acceptability of a community-based intervention for people with MS.

A cohort of people with MS participated in the community-based exercise programme. The programme was evaluated to explore the acceptability of the programme and the impact on exercise levels, physical function, fatigue, self-efficacy and quality of life. The evaluation also explored the participant's experience of engaging in the programme.

Summary of findings

Phase 1

The findings suggested that a community-based exercise programme for people with MS would be supported by both health professionals and people with MS. Key components barriers for a successful community-based programme can be categorised into two main areas: delivery, and skills and education. Key delivery components included; social interaction, accessibility, tailored exercise, and stratification of exercise groups by level of MS-related disability. People with MS and health professionals stressed the importance of highly skilled and experienced instructors to lead the exercise programme.

Phase 2

The programme was promoted by a variety of sources (self-referral, physiotherapists, social media, newspaper adverts, and word of mouth). Generating referrals from health professionals such as consultants and nurse proved difficult. This was deemed to be because of a lack of capacity and time pressures of busy clinics. A total of ten people with MS agreed to join the programme. One individual decided not to attend due to difficulties travelling to the venue. The findings suggest that the format and content of the programme were acceptable for people with MS. The programme was well attended by the nine participants with a median attendance of nine sessions. Participants in the programme experienced a number of benefits including increased physical activity levels, improved total and physical fatigue, increased walking capacity, increased self-efficacy, and improved

perceived health. The improvement in the six minute walk test (6MWT) distance of 60 metres suggests that the group had clinically important changes in their function.

The findings from the participant experience compared well with phase one data. Participants felt the experienced instructors made them feel supported. The social environment created by the programme allowed the participants to feel more confident whilst exercising. Despite the positives participants also experienced increased levels of fatigue post-exercise. To help to recover participants would have to rest for the remainder of the day. It is possible that the increased fatigue experienced by participants is due to being deconditioned and will reduce as their fitness increases. Participants reported feeling embarrassed and intimidated at conventional exercise environments. The feelings of being judged, self-conscious and out of place were not overcome by participating in the programme.

Conclusion and recommendations

- The programme increased the number of exercise participants performed, increased their walking capacity, improved fatigue, and self-efficacy.
- The overwhelming positive was the social interaction of the exercise sessions. Participants felt the programme was a positive experience and felt supported throughout.
- More work is needed to generate an effective referral pathway from health professionals to the community. Improving communication between health professionals and leisure providers can help to resolve uncertainties in the referring patients.
- People with MS identified low confidence and embarrassment as barriers to using leisure facilities. Leisure providers should consider ways to make people with MS feel confident using their facilities.

2 Introduction

2.1 Report Overview

2.2 The aim of the report

This report presents the findings of the multiple sclerosis Rotherham Active for Health project. The report discusses the two phase process of the project with findings supported by empirical evidence. Key interpretations and recommendations highlighted to inform future design of community-based exercise opportunities for people with multiple sclerosis (MS) are provided.

The report provides the following:

- An overview of the project and the two phased approach to developing and piloting a community based exercise programme for people with MS.
- Findings from phase one and phase two projects.
- Recommendations for commissioners, practitioners, and the academic community working to promote health and wellbeing in people with MS.

3 Background

3.1 Multiple Sclerosis

Multiple Sclerosis (MS) is a chronic condition that affects the central nervous system[1]. It is a complex condition with many consequences including impaired muscle strength, mood, fatigue, and mobility [2]. All these impact on a person's quality of life following diagnosis. In the United Kingdom it is estimated that more than 126,000 people are living with MS[3]. Symptoms often start in a person's 20s or 30s making MS the most common cause of disability in young to middle-aged adults in the developing world [4]. The high incidence rates and longitudinal nature of the condition have a large economic impact on the health care system, people with MS, and their families [5]. Treatments are now able to better manage the condition (disease modifying therapies) but there is no cure and the fundamental cause is unknown [6]. Therefore, symptom management and maintenance of function is crucial. Exercise is increasingly being considered as a means of supporting people with MS to better manage their condition[7].

3.2 Exercise and Multiple Sclerosis

Exercise has been shown to be a safe and effective treatment strategy for people with MS[8]. A Cochrane review on 'exercise therapy for Multiple Sclerosis' [9] concluded that exercise is beneficial for people with MS after identifying nine randomised controlled trials of high quality. Further research has followed demonstrating the beneficial effects of exercise on fatigue[10], fitness[11], walking mobility[12] and general quality of life [13] for people with mild-to-moderate disability. The research team, from Sheffield Hallam University, previously developed a trial to determine if an exercise therapy intervention could improve health outcomes in people with mild-to-moderate MS disability compared to usual care [14]. The trial recruited 120 people with MS and was shown to be feasible with improved self-reported exercise behaviour, reduced fatigue, and sustained enhancement of health related quality of life[15]. The strength of collective evidence has led to

consensus statements specifying exercise as one of the most important interventions for the management of MS[16] yet people with MS are reported to be less physically active than the general population [17]. This leaves people with MS susceptible to secondary conditions such as obesity, diabetes, and heart disease [18]. People with MS cite information on lifestyle factors (exercise and diet) as a higher priority than pharmaceutical information [19]. The contrast between evidence demonstrating that exercise is beneficial and the low activity levels of people with MS highlights a need for programmes to support this population to be more active.

Latimer-Cheung and colleagues developed exercise guidelines for people with MS in 2013[20]. These provide exercise prescription guidelines for people with MS and an evidence based platform for exercise professionals to base community exercise programmes. The guidelines state that adults with MS should engage in at least 30 minutes of moderate intensity aerobic activity two times per week and strength training of major muscle groups two times per week. Even though formal exercise guidelines have been developed for people with mild-to-moderate MS, exercise options remain limited. There is a need for the development and piloting of community based exercise trials for people with mild-to moderate MS disability.

3.3 Exercising in Rotherham

Exercise and other health behaviours are influenced by social characteristics such as age, gender, and ethnicity. Individuals living in areas of deprivation are more likely to be physically inactive and have a long term condition. Rotherham is ranked 52nd most deprived district, within the 16% most deprived districts in England[21]. For people living in Rotherham individuals are less likely to participate in exercise compared to those nationally [22]. This combined with the fact people with MS are less active than the general population makes providing exercise opportunities for people with MS in Rotherham a priority.

3.4 The Project Approach

The overall research aim was to design, deliver and evaluate a tailored community exercise programme for people with MS in Rotherham. In order to achieve this, the research was split into two phases:

Phase 1: Developing a community-based exercise intervention for people with MS

Health professional and people with MS were consulted to support the development of a community based exercise programme in Rotherham.

Phase 2: Exploring the acceptability of a community -based exercise intervention for people with MS

A cohort of people with MS participated in the community-based exercise programme. The programme was evaluated to explore the impact of the programme on participant's exercise levels, physical function, fatigue, and quality of life along with their experiences of being involved in the programmes.

3.5 Definition of terms

For the purpose of this report exercise has been defined as a planned structured activity designed to improve fitness and health. In this context, exercise is distinguished from physical activity which is defined as including activities of daily living such as household jobs, walking the dog, and manual labour[23].

4 Project 1: Developing a community based exercise intervention for people with MS in Rotherham

The purpose of this qualitative study was to explore the views of people with MS and health professionals with regards to a community-based exercise programme. The research questions directing the study included: 1) What are the key components needed to create a model of community exercise for people with MS? 2) What are the needs and preferences for a future exercise programme?

4.1 Aims:

1. To explore the views of people with MS and health care professionals regarding community-based exercise for people with MS.
2. To identify important content and key components of a community-based exercise intervention.
3. To develop a community-based exercise intervention for people with MS based on patient and health care professionals preferences and priorities for implementation and delivery.

4.2 Objectives:

1. To find out what support people with MS would like as part of a community-based exercise intervention and how it should be delivered.
2. To explore the views of health-care professionals regarding implementation and delivery of a community-based exercise intervention for people with MS.
3. To design an exercise intervention to be delivered in the community.
4. To develop support materials to supplement programme content.

4.3 Methods

The project adopted a qualitative design involving one-to-one semi-structured interviews and discussion groups with health professionals and people with MS. Semi-structured interview guides were used to provide evidence-based structure, yet remain flexible, allowing time for the participant to discuss topics that naturally emerge through conversation and which are important to them. The interviews were led by an experienced researcher, lasted between 30-to-60 minutes and all participants provided informed written consent prior to involvement. Focus groups were led by a researcher trained in facilitating group discussions. As per the interviews a semi-structured focus group guide was used. This helped focus the conversation whilst allowing the discussion to flow.

4.4 Participants

To meet the aim of the study two groups of participants were consulted; people with MS and health professionals.

4.4.1 *People with MS*

People with MS (n=11) were purposively recruited with level of MS (EDSS 1.0 – 6.5; mild-to-moderate MS) being the targeted strategy. MS nurses recommended eligible people for the study. Individuals that declared interest were contacted by a member of the research team. Participants

were also recruited from community centres such as; Neuro Therapy Centre, and the local MS Centre. Characteristics of people with MS are displayed in Table 1.

Table 1: Characteristics of the participants

Characteristics
Gender: Females 9 (82%) Males 2 (18%)
Age (y): 48.9 ±14.03
EDSS: 3.1 (1.0-6.5)

4.4.2 Professionals

Professionals (n=12) were approached and recruited via the Royal Hallamshire Hospital, Sheffield Department of Neurology and community centres such as Neuro Therapy Centre. This included; consultants (n=2), nurses (n=3), physiotherapists (n=5), and rehabilitation specialists (n=2). Characteristics of professionals are displayed in Table 2.

Table 2 Characteristics of professionals

Characteristics
Gender: Female 11 (92%) Male 1 (8%)
Age (y): 45±12.6

4.5 Data Analysis

Framework Analysis (FA) was used to analyse the data generated from focus groups and interviews. FA is an effective approach for analysing rich data in pragmatic health services research[24]. The approach consists of five inter-connected, but distinct stages for analysis: familiarisation, identifying a thematic framework, indexing, charting, mapping, and interpretation. The unique aspect of this methodology is the latter stage where associations between themes are made and related to the research objectives. Process notes are made between each stage and are referred to throughout, thus increasing the transparency and quality of the data. NVivo Version 14 data analysis software was used as a tool to facilitate the framework analysis as this has been found to be a valid and reliable tool, which enhances the transparency of the data analysis procedure[25].

4.6 Findings

Results are displayed according to key themes and sub themes that arose in line with the framework analysis technique[26]. Key themes were:

1. Health professionals' and patients' views about exercise for people with MS.
2. Effects of MS on ability to exercise.
3. Key components of a new community-based exercise programme for people with MS.

Theme 1: health professionals' and people with MS' views about exercise for people with MS

- There was a strong feeling that, with exceptions for those with more severe MS, exercise is a safe and essential part of disease management. All the professionals interviewed felt that exercise was good for people with MS, for managing the condition and preventing other comorbidities. Professionals also supported the idea of a community-based exercise programme.
- Patients agreed that exercise is helpful for the management of their condition. One patient stated that they did not feel any positive reactions from exercise but stressed that it was still important.
- Some health professionals focused less on whether a person with MS should exercise and more on how intensive the exercise should be. They voiced the prospect of exercise having positive effects beyond the ability to manage MS symptoms. They discussed the possibility that exercising at a high enough intensity can have an effect on neurogenesis by improving brain-derived neurotrophic factor.

"But I think also just for management of the primary symptoms, um, you know, so particularly motor control, strength, sensory and proprioceptive awareness exercises I think is really positive for all of those, um, primary problems that people with MS might experience. Um, but then also in terms of preventing onset of comorbidities as well, you know, someone's had their diagnosis at 30, what we don't want is because they become sedentary, maybe their BMI gets high but by the time they're in the mid-50s, they've also got Type II diabetes"

"Well I think it, it, it lifts you. It lifts your spirits as well. I feel a lot better when I've been out and done some, some exercise."

"I was supposed to feel better the next morning, but that never happened! I used to get rid of all my energy doing the exercise class and knock out the next day as well, but it was kind of worth it."

"They exercise at an intensity high enough for them, as compared to their prior, they can somehow start, um, getting their brain-derived neurotrophic factor, it will drive all these BDNF [Brain-derived neurotrophic factor] and GDNF [glial cell line-derived neurotrophic factor] and start to actually, um, bring those back into the blood system and, and working better for them and minimise the progress."

"You know, if you don't push them enough, they're not going to improve."

Theme 2: Effects of MS on ability to exercise

- Health professionals and people with MS mentioned a range of symptoms that affected a patient's ability to exercise, including both physical and psychological effects. Physical effects included balance issues, fatigue and bladder control.
- Psychological effects included fear, depression and low confidence. Fears manifested in different ways, fear of seeing people with higher disability than themselves and fear of making symptoms worse.

"I have issues with balance and I do have some weakness which is worst on the left and have had hyperreflexia although apparently that's now diminishing."

"It's like you've run into a wall and then I feel personally that it's like I'm walking through water or treacle or whatever."

"The one thing we're probably too polite to mention is your bladder, which in some people that is just the most horrendous symptom, no bladder control at all."

"I'm just frightened of getting really tired or whether I'm frightened that actually through exercising I might make myself have a relapse which I don't think that's true."

"I do sometimes find it quite upsetting when I go to hospital and obviously when you're sat in a waiting room, you don't know that them people have got the same condition as you, but it is quite upsetting to think that might be me 10 years, 15 years down the line."

"You're supposed to be depressed if you've got MS."

Theme 3: Key components of a new community-based exercise programme for people with MS.

Health professionals and people with MS highlighted many potential areas that would need to be addressed in a future exercise programme.

1. Skilled instructors, preferably physiotherapists

- People with MS described trust and respect for the knowledge of physiotherapists, but apprehension about the skills and knowledge of exercise professionals.
- Some health professionals felt that not all people with MS require the support of physiotherapists.

"All sorts of very basic things, but done in a very, very skilled way and which gave me, well, I've always had respect for physios, but by golly I've got more respect for them now."

"Do try to get the advice of a proper neuro, neuro physiotherapist in order to work out what's the right exercise for you."

"I'm very reluctant to join a gym or anything like that without having somebody that's got expertise and knows a bit about the condition so that I don't sort of overdo it and trigger anything."

"I think people who are showing minimal symptoms, they don't, to me now they don't need the physiotherapist instigating."

"There's a point where they, they don't need that professional input. If they can just get into the habit and lifestyle includes exercise."

2. Stratification of exercise groups

- Health professionals and people with MS unanimously felt that any exercise groups for this population would need to be stratified by level of impairment. Health professionals felt that a group of mixed disabilities would be difficult to manage.
- People with MS stated that they would not attend a class with mixed levels of impairment because seeing a person with higher disability would frighten them.

"If you've got, you know, a huge variance in terms of physical ability, then it's going to be difficult. So no I think despite some of the concerns and drawbacks with a stratified system, I think it's probably a reality for this population group."

"What I would absolutely hate would be to go to a class where there were people who were more visibly, um, limited, have, you know, with limited functionality than I have because that would serve no purpose other than to terrify me."

3. Accessibility

- Accessibility of any exercise group was highlighted as a key barrier.

"I have to say, if I had to travel more than 15 minutes in the car to get there, I don't think I'd bother"

"It has to be local. It has to be easy, it has to be accessible"

4. Social interaction

- Although people with MS (n=2) stated the desire to exercise alone or one-to-one with an appropriately trained instructor, most participants stated the need for social interaction.

"Quite often I feel isolated because you tend to lead a sheltered life when you've got MS."

"Now that social side you can't beat is vital and special yeah. Getting people together and the sociable part of exercise is vital."

5. Tailored to the individual

- Although group based exercise was stated as the preferred option people with MS and health professionals discussed the need for exercise programmes to be tailored to a person's needs.

"I think there's never a one size fits all solution is there so it'll be more tailored to the individual"

4.7 Recommendations for the development of a community based exercise programme for people with MS.

The purpose of this study was to identify the key components needed to design a community based exercise programme for people with MS. Exercise in people with MS is a clinical and public health concern (26). People with MS are not engaging in sufficient exercise and are subsequently missing out of opportunities to manage MS and its consequences. Findings presented above suggest that a community-based exercise programme would be supported by both health professionals and people with MS. Professionals discussed the effects exercise can have on MS symptoms and reducing risk of co-morbidities. Previous research has highlighted that healthcare professionals play a key role in changing behaviours of people with chronic conditions (27).

Participants with MS felt that the social side of exercise was vital, consistent with previous research (28) (29) (30). Once diagnosed, people with MS can feel isolated; providing them with an opportunity to get out of the house and meet other people in a friendly and supporting environment was desired. Nevertheless, the group dynamics of an exercise class would need to be carefully managed. Many people with MS felt anxious that being in a group with people with higher levels of impairment would simply make them feel dejected because of the progressive nature of the condition, so a stratified approach to an exercise group would need to be applied. This idea was supported by health professionals who felt that without stratification the classes would be unmanageable.

Collectively, the findings of the current study, highlight the need for community-based exercise for MS and the key components that are required. A summary of the key issues can be organised into two main areas: delivery, and skills and education. Figure 1 illustrates the proposed community design resulting from the discussions in phase one. The MS Guidelines have been incorporated into the programme[27].

In the present study, people with MS indicated that they did not trust the skill and knowledge levels of exercise professionals in the fitness industry. The importance of quality instructors is supported by previous qualitative research (28). Health professionals also voiced apprehension about people with MS exercising under the supervision of exercise professionals. Both groups felt that people with MS should be seen by a physiotherapist, although several health professionals felt there are no reasons people with mild-to-moderate MS should not be seen by exercise professionals in community exercise facilities. This view is shared by researchers who suggest the needs of people with MS can be met by fitness instructors in gyms providing a non-medical environment for exercise participation (32). Although access to physiotherapy services are most desired by people with MS availability and accessibility of services are limited[28]. An alternative is to develop a model in which exercise professionals work closely with health professionals (including physiotherapists)[29]. For the phase two project exercise professionals will be used but will have access and contact with neuro physiotherapists to provide advice if needed.

Ultimately, there is a need for the development of a fitness industry qualification for neurological conditions. Currently exercise professionals train to become GP referral qualified and can then specialise in specific long term conditions such as Cardiac Rehabilitation, Stroke, Diabetes, and

Cancer. Following the discussions with people with MS and with health professionals there is scope for the development of a qualification in this area. With all the research now available for exercise for people with MS and other neurological conditions such as Parkinson's disease (39) exercise is now being advocated as an essential means to manage neurological conditions. The fitness industry needs to be better prepared to meet rising demand and respond to growing evidence to effectively support people with MS to be more physically active.

4.8 Conclusions

The current study provides further understanding of barriers and enablers to exercise for people with MS. Exercise is now accepted as safe and beneficial for people with mild-to-moderate MS but there is a need to build on research findings and increase the accessibility to exercise for this population. Future community programmes should consider working more closely with local exercise providers, increasing knowledge and skills of fitness professionals, and providing people with MS with practical support to help exercise and physical activity be part of their everyday lives.

Delivery
<ul style="list-style-type: none"> • Accessible location. <ul style="list-style-type: none"> • Accessible for cars, parking, bus routes. • Space in rooms, easy access to facilities. • Sociable environment. <ul style="list-style-type: none"> • Allow opportunities for social interaction. • Need for stratification of exercise groups. <ul style="list-style-type: none"> • Stratify by level of impairment. • Exercise programmes tailored to individuals. <ul style="list-style-type: none"> • Assess participants' needs and adapt recommendations accordingly. • Participants preferred functional exercise options. • Links with neuro-physiotherapist. <ul style="list-style-type: none"> • Provide referral links for people with MS interested in physical activity. • Neuro-physiotherapist can provide support and guidance to exercise professional.
Skills and Education
<ul style="list-style-type: none"> • Skills and knowledge of exercise professionals. <ul style="list-style-type: none"> • Link with neuro-physiotherapist to gain knowledge and support. • Trust and over reliance of physiotherapists. <ul style="list-style-type: none"> • Health professionals need to be confident in recommending physical activity to people with MS. • Future development of an exercise professional's qualification for neurological conditions.
Frequency
<ul style="list-style-type: none"> • Two times per week. • Aerobic and strength activities can be done on the same day. • Have a rest day between exercise sessions.
Intensity
<ul style="list-style-type: none"> • Exercise at a moderate intensity. <ul style="list-style-type: none"> • 11-14 on the RPE scale. • Can talk but not sing during activity. • Strength training should aims for 10-15 repetitions for each set.
Time
<ul style="list-style-type: none"> • Build exercise up to at least 30 minutes of aerobic activity. • Gradually build to 2 sets of 10-15 repetitions of each exercise.
Type
<p>There are many options for exercise for people with MS.</p> <ul style="list-style-type: none"> • Gym based exercise, circuit training, aquatic exercise, free weights, Suspension training and calisthenics are all suitable options. • A range of options would be beneficial to provide the tailored approach preferred by people with MS.

Figure 1: Recommendations from qualitative analysis

5 Project 2: Exploring the acceptability of a community-based exercise intervention for people with MS

5.1 Introduction

The previous chapter described the development of a community based exercise programme for people with MS in Rotherham. This chapter presents a proof-of-concept study that was carried out to explore the acceptability of the programme. The results are presented and implications for future development are discussed.

In health care we often jump from knowledge of a situation to solutions bypassing important steps such as ideating, prototyping, iterating, and monitoring [30]. The aim of phase 1 was to engage people with MS and health professionals to understand underlying problems and what matters most to them in terms of becoming more active. We then designed a prototype community exercise programme based on the findings obtained. The results of the first iteration of testing the mode are presented here.

5.2 Aims of the evaluation

Explore the acceptability of a community based exercise programme for people with MS.

5.3 Objectives

1. Explore acceptability of the mode of delivery of the intervention.
2. Explore the acceptability of completing a range of potential outcome measures for use in the future.
3. Develop a refined exercise programme model.

5.4 Exercise programme overview

The exercise programme was designed using the qualitative findings from phase one of this project. The programme was designed to be accessible, sociable and include functional exercises tailored to the individual's needs. The programme was delivered in a community based facility that had ample parking and accessible entrances. Following is a summary of the exercise sessions including deliverers, mode intensity, duration, and frequency.

5.4.1 Functional Fitness

The exercise sessions were delivered by Functional Fitness. Functional Fitness are a team of exercise specialists with experience of delivering exercise programmes for people with health conditions including cancer, stroke, COPD, falls prevention, and mental health.

5.4.2 Mode of exercise

The programme was a circuit-based class that offered aerobic, strength, and balance exercises. Aerobic exercises included walking, cycling, and arm cranking. Strength exercises included wall press-ups, squats, sit-to-stand, lift-to-press and balance and core exercise. All exercises could be adapted to each individual's ability. Equipment used for the sessions included suspension trainers (TRX), ViPRs for increasing load to movements, therabands, and light dumbbells.

5.4.3 Intensity

Participants were instructed to complete exercises at a low-to-moderate level depending on how they were feeling that day. Participants were encouraged to work at 12-14 on the Borg rating of perceived exertion scale. Each station lasted for 30-60 seconds with participants encouraged to aim for 10-15 repetitions of strength exercises. Throughout the session participants were encouraged to rest if required.

5.4.4 Frequency and duration

Sessions were once a week for ten weeks on a Monday afternoon at a community facility. The sessions were run by two instructors to ensure participant safety. Participants were encouraged to engage in one self-directed exercise session in the leisure time although this was not recorded. Social time was incorporated at the end of the sessions to allow people to chat with tea or coffee provided.

5.5 Methods

5.5.1 Design

A proof-of-concept study was conducted to assess whether the intervention had the potential to be applied in practice. A mixed methods approach was used, whereby both qualitative and quantitative data were collected and analysed. The evaluation was independent to the delivery of the exercise programme.

5.5.2 Procedures

Data was collected from service users using a questionnaire booklet at baseline and post intervention (12 weeks). Demographic information including age, gender, employment status, disability level, and postcode were collected at baseline only. Disability level was measured using the patient determined disease steps (PDDS) which requires a patient to self-report their disability level. The scale ranges from 0 (normal) to 8 (bedridden). The programme targeted people with mild to moderate MS related disability therefore the maximum score for participation was 6 (bilateral support). All participants were interviewed at the end of the programme.

5.5.3 Outcome measures

A range of outcome measures were selected to best capture the important outcomes the impact of the programme on the physical activity levels and health of participants. Details of these are provided below.

Levels of physical activity

Physical activity was assessed using the self-administered short form of the International PA Questionnaire (IPAQ)[31]. This version contains 9 items relating to activity level over the last seven days and refers to the number of days and time spent doing PA at either moderate or vigorous intensity. The questionnaire includes additional questions on time spent walking and sitting. The median values of total MET minutes were calculated and compared. A MET is a unit of energy expenditure with resting energy expenditure is defined as 1 MET and moderate intensity walking defined as 4-5 METS. The MS guidelines recommend approximately 150-300 MET minutes per week.

Quality of life

The EuroQol index (EQ-5D-5L) and the EuroQol Visual Analogue Scale (EQ-VAS) are widely implemented measures of health status and health-related quality of life respectively. The EQ-5D-5L index assesses a person's health state across five dimensions (self-care, mobility, anxiety/depression, usual activities and pain/ discomfort). The EQ-VAS is measured on a continuous scale from 0 to 100 (with 100 representing full health). Individuals are asked how they would rate their health on that day; with higher scores representing better health.

Fatigue

The Modified Fatigue Impact Scale (MFIS) was used to measure perceived fatigue. The MFIS is designed specifically for conditions like MS and consists of 21 statements that describe how fatigue may affect a person.

Exercise Self-efficacy

Self-efficacy is defined as a person's belief in their ability to successfully perform a given behaviour [34]. Research has documented the linear relationship between exercise and self-efficacy in people with MS [35]. Exercise self-efficacy was measured using the exercise self-efficacy scale which asks participants to score how confident they are (on a scale of 0-to-100%) in being active in particular situations.

Six minute walk test

Functional exercise capacity was assessed using the six minute walk test (6MWT). The test was carried out to a standardised protocol[32]. The 6MWT is a test that is easy to administer in a community setting. It has been used to measure exercise tolerance exercise tolerance of people with a variety of different health conditions[33] including MS [15].

Grip strength

Grip strength was used as a measure of strength as it has related to mobility outcomes and is easy to use in both clinical and community settings[34]. Grip strength was measured using a handheld dynamometer. The average of two measurements were calculated for each hand.

5.6 Data Analysis

Statistical analysis was performed using SPSS (version 24). Due to small sample size statistical tests are considered exploratory. The results will be presented as medians and minimum and maximum values unless specified. Due to the small sample size (n=9) non-parametric statistics (Wilcoxon signed rank test) were used to evaluate baseline and post-test values for each outcome. The a priori significance level for all statistics was set at $P \leq 0.05$. To determine relative magnitude of change we also calculated the effect sizes (r) using the z-score (Z). Effect sizes are presented to highlight the meaningfulness in the differences between the results (28). Cohen d classified effect sizes as small ($d = 0.2$), medium ($d = 0.5$), and large ($d \geq 0.8$) (29).

Framework analysis was used to analyse the qualitative data [24]. NVivo Version 14 data analysis software was used as a tool to facilitate the framework analysis [25].

5.7 Results

5.7.1 Referral to the exercise programme

In the interviews and focus group participants discussed how they accessed the programme. In total 20 participants were referred to the programme. Participants learned of the programme from a variety of sources such as Facebook, from a friend, advertisement in paper, and advertisement in GP surgery. Three of the participants were referred to the project from a health professional (physiotherapist).

"I had individual physio then they referred me to this."

"I saw it in the local paper. I thought I have nothing to lose just come and if I don't like I don't come back. And I love it, absolutely love it."

"My wife went to the doctors and she heard about it."

5.7.2 Demographics

In total, ten (50%) participants enrolled on to the project and completed baseline measures. One participant dropped out before completing any exercise sessions and has therefore been omitted from the analysis. Descriptive characteristics of the 9 remaining participants are summarised in table 3. The median PDDS score was 5 which means most participants required some use of walking aids (e.g. cane).

Table 3: Demographics

Variable	Baseline Mean (SD) Median (minimum and maximum value)
Gender (M/F)	3/6
Age (y)	Mean: 55.2 (8) Median: 57 (44-66)
PDDS	Mean: 3.9 (1.7) Median: 5 (1 - 5)

5.7.3 Reason for drop out

One participant dropped out of the project before completing any exercise sessions. The participant agreed to do an telephone interview at the end of the programme. The only reason for not attending the sessions was inability to travel. This confirms the importance of accessibility which was a theme identified in phase 1.

"Literally getting there that is the only thing that holds me back."

"If there was something within walking distance of my home I would be there. Probably everyday if I could"

5.7.4 Attendance and attrition

The programme offered a maximum of ten exercise sessions (one session per week for 10 weeks). The median attendance was 9 (7 - 10 sessions) sessions. This suggests the sessions were well attended. Four participants attended all 10 sessions, seven sessions was the lowest level of attendance (n=3).

5.7.5 Physical activity

Compared to baseline, participants undertook physical activity on more days of the week after the programme (baseline median = 2 days per week; follow up median = 4 days per week). As seen in table 4, median weekly physical activity levels increased from 132 MET minutes at baseline to 231 MET minutes of exercise post intervention. The result was not statically significant and had a small effect size ($r = 0.3$).

5.7.6 Fatigue

As shown in table 4, median total MFIS improved from 48 at baseline to 45 at follow up. Total MFIS was not significant and showed a small effect size ($r = 0.4$). Physical fatigue was significantly lower after the programme with a moderate effect size ($P < 0.025$; $r = 0.5$).

5.7.7 Quality of life

Quality of life, measured using the median visual analogue scores (VAS) increased from 50 to 70 after the programme. Changes in quality of life were not significant and had a small effect size ($r = 0.4$).

5.7.8 Self-efficacy

Self-efficacy improved from 11.25 at baseline to 40 at follow up. The result was not statistically significant and had a small effect size ($r = 0.2$).

5.7.9 Functional tests

The median distances for the 6MWT test were significantly improved more at follow up with a moderate effect size ($P < 0.012$; $r = 0.6$). Participant grip strength increased in the right hands from baseline to follow up with a small effect size ($r = 0.2$). Left hand grip strength had a negligible reduction in the median with a very small effect size ($r = 0.1$).

Table 4: Outcome measures

Measure	Baseline		Follow up		P	Effect size <i>r</i>
	Median (Minimum and maximum values)	N	Median (Minimum and maximum values)	N		
Physical activity						
IPAQ	132 MET minutes (0 - 693)	9	231 MET minutes (0 - 1440)	9	0.208	0.3
Fatigue						
Physical	28 (14 - 31)	9	20 (12 - 28)	9	0.025	0.5
Cognitive	19 (0 - 28)	9	20 (0-28)	9	0.528	0.1
Psychological	4 (2 - 7)	9	4 (2 - 7)	9	0.348	0.2
Total MFIS	48 (32 - 64)	9	45 (14 - 53)	9	0.086	0.4
Quality of Life						
VAS	50 (30 - 80)	9	70 (55-70)	9	0.096	0.4
Self-efficacy						
Exercise self-efficacy scale	11.25 (0 - 56.3)	9	40 (0 - 70)	9	0.374	0.2
Functional tests						
6MWT	440 metres (80 - 780)	9	520 metres (240 - 810)	9	0.012	0.6
Grip strength (right hand)	23.5 (19.5 - 43.25)	9	25 (16.5 - 40.3)	9	0.326	0.2
Grip strength (left hand)	18.8 (8.75 - 40.25)	9	18.5 (12.5 - 42.5)	9	0.017	0.1

5.7.10 Participant experience

Table 5 represents the main themes and sub themes derived from the qualitative interviews with the participants following the programme. Participants discussed positives and negatives to participating in the programme. The themes highlight the difficulties people with MS face when trying to increase the amount of physical activity they do. People with MS often enjoy physical activity and the social interaction but are affected by their condition both physically and psychologically.

Table 5: Participant experience qualitative themes

Main themes	Sub themes
Experiences of the programme	Social interaction Exercise sessions and structure Instructors
Effects of MS	Lack of confidence Impact of exercise (positive and negative) Coping with embarrassment

Theme one: Experience of the programme

Social interaction

- Social interaction was an important factor for the participants. All participants discussed the importance of making friends, and having an opportunity to talk with people in similar positions.
- Each participant spoke of the importance of everyone there having a common bond; the group developed a sense of comradery.
- The social interaction was discussed as a way to overcome their embarrassment. Participants didn't feel judged within the group because they can all relate to each other.
- Participants discussed the significant benefits to being in a group situation in terms of improving mental health and helping them cope with having MS.

"It's good to know that there are a lot of other people in similar position."

"We all look stupid, but we're stupid together."

"Doing it on my own I find it boring. In a group you have people such as [participant name] because he pushes himself it makes you push yourself. I mean he is amazing, If he can do that then I can do it."

"It's great to have a social group and you're talking and telling people and they are like oh yeah I had that. It is just having that knowledge and talking about things you don't talk about with people in general. So, it's just that knowledge that there are other people there. We hoping we are all just going to meet up for a coffee."

"It gave me confidence to do a different type of exercise but knowing that there was people around that weren't going to criticise me."

Exercise session and structure

- The participants discussed how they looked forward to coming to the programme each week. This is supported by the records that show that all participants attended regularly.
- Tailoring the sessions based on participants' needs was identified as important. This ensures that participants are challenged but are not pushed too hard.
- The type of exercises and activities were enjoyable to the participants but were different from what they expected. Participants enjoyed the variability of the exercises and the way exercises could be adapted to suit their ability.
- The community location of the programme was a positive. Participants discussed how they would not want to go a hospital setting.
- Participants discussed how 10-12 weeks for a programme is not enough. Following the programme they still did not feel able to join a conventional gym environment and would be unlikely to exercise regularly in their home. Participants would prefer to attend a regular class and would be willing to supplement.

"The good thing is he can tailor it so he can make it harder for you. Make it different for everyone's ability. So you're not all doing the same thing."

"There is different levels to each exercise. Some of us are not very stable so we have to sit down. I couldn't stand up for all those things we were doing today."

"It has been I different type of exercise to what I thought we'd be doing. I thought it would be like a treadmill the bike like you do when you go to physio. I thought it would just be basically like physio stuff."

"You can stand on a treadmill or exercise bike as long as you want but you're not build any core strength just burning calories. We were doing more functional moving. "

"Doing exercise this way I could feel how it was working and feel why I was doing it."

"Rather than going to Rotherham hospital which is a nightmare to park."

Instructors

- The participants were very pleased with the instructors who ran the programme. Participants were looking for an instructor to be friendly, approachable, knowledgeable, experienced, and empathetic.
- Having knowledge of MS was important attribute for the instructor. This gave participants confidence.
- The instructor's ability to adapt was identified as an important factor. MS is a variable condition with no two people the same. The instructors being flexible and learning from the participants was important.

"You need the comradery and you need the instructor because I just end up doing my own thing and you need someone to tell you "come on put a bit more effort in". "

"[Name of instructor] is so good, he explains things well and he doesn't make you feel embarrassed or intimidated and that is half the battle."

"He explained why and what it is you are doing. He didn't just say right get on and do that. he explained it."

"Good instructors adapt to the situation they don't just say this is what we are doing. You can't do that with MS without even looking at them."

"I think also [name of instructor] has learnt from us. Everybody is different so it must be hard to tailor it meet everyone's needs."

Theme 2: Effects of MS

Lack of confidence

- Participant's confidence was a key barrier in their ability to be physically active.
- Most participants discussed how their confidence has increased as a result of the programme.
- Participants discussed how they were apprehensive at the start of the programme because they did not think they would be able to complete the exercises.

"When I first saw it I was like oh god I won't be able to do that."

"Yeah I was like horrified when he showed us. He pulled straps and was like I we are going to do this. I was like ha no way."

"I was like well that's me hitting the floor."

"Because you can do it at you own speed. Yeah when you first come here you worry that he is going to make everyone do the same."

Impact of the exercise

- Participants discussed how they had benefitted from the programme. Some felt they had benefitted physically including walking better and further. The programme improved strength and balance.
- Participants also discussed how they felt exhausted as a result of the exercise. Participants would have to factor the exercise into their day to allow themselves the energy to engage. They would then go home and have to lie down for the afternoon.
- Participants discussed how this management of fatigue is a constant aspect of their life. Because of their fatigue they have to plan all parts of their life to ensure they have enough energy.

"Some people can do exercise better than others. The walking for me that's the hardest thing. I can do all the others but walking up and down I have really got to stretch myself to make my legs stretch out. Otherwise I am shuffling. Which is a positive that I have learnt, lift your foot put your heel down."

"It has taught me to walk straight and tall whereas before I was that scared you are always staring at your feet."

"I was laid out the next day but I came back and I thought if I can't do it I can't do it but I want to be incorporated in it."

"I have felt that I can do more rather than less. So I have been on trips out whereas I would have been reluctant to do it before."

"Yes, a couple of days after the missus would say my walking was a little bit better and I had a bit more strength."

"Every week you went you felt you could do a bit more or you felt like you could do a bit less depending on whether you are on a up or down cycle."

"I rested before I went to the sessions so I had got that energy to use. And then I would come straight home and I would be laid down."

"I have to plan it into the day but I am getting really good at doing that."

"Yes, after the sessions I would say to the missus I am not going to be doing very much now. She'd know that I had used up my energy and would need more help in the evening. During it as well was quite tiring."

Coping with embarrassment

- Linked with lack of confidence; embarrassment is a key barrier to activity for people with MS. Participants discussed how they would not go to conventional gyms because of they feel embarrassed.
- Participants said they could all go to an exercise class but they would feel intimidated because they can't do what others, without MS, in the class can do. Some participants discussed how they are stand out in conventional exercise opportunities.
- Participants felt that the programme allowed them to exercise in a setting that was non judgement

"It gave me confidence to do a different type of exercise but knowing that there was people around that weren't going to criticise me."

"I wouldn't have gone to a conventional gym but you don't feel intimidated."

"We're not normal"

"No we're not. We look like the walking dead don't we."

"You just feel intimidated."

6 Overall discussion and reflections

In this section, the programme will be discussed in light of the findings from the quantitative and qualitative data presented in the previous sections. The aim of this project was to develop and explore the acceptability of a community based exercise programme for people with MS. Phase one identified a number of key components that would need to be included to implement a successful programme. These fit under the categories delivery, skills and education. The exercise programme included social time, an accessible location, tailored exercise sessions, and links to a neuro physiotherapist. The sessions were led by experience instructors, and the intensity of the sessions was aligned with evidence based exercise guidelines for people with MS[20].

The findings from the evaluation suggest that the format and content of the community based exercise programme for people with MS is acceptable to the study population. High attendance (median 9 sessions) and positive post programme discussions provided evidence of acceptability. In total 20 participants were referred to the programme. Patients were referred from a variety of sources (self-referral, health professionals, social media, newspaper adverts, and word of mouth). A variety of sources were utilised to maximum accessibility to the project. However referrals from health care professionals were difficult to generate. Time pressures of a busy clinic might mean that referral to an exercise programme is a low priority for health professionals, resulting in missed opportunities to refer patients. Referral into an exercise programme is dependent on a health professional starting a discussion with the patient, then completing, signing, and sending a form [35]. Additionally, health professionals often have concerns about patient safety when referring into a community based exercise programme[36]. Further work to develop communication and integration between health care professionals and the fitness and wellness industry is required[30]. Promotion of the programme, or inviting health professionals to visit the sessions might help to develop trust and initiate referrals.

6.1 Outcome measures

Quantitative measures from this programme suggest that the programme could benefit participants' health and wellbeing. Questionnaire completion rates suggest that the measures were acceptable to participants, 100% of questionnaires were completed suggesting they were not too burdensome for the participants. The small sample size limits the strength of the evidence presented here, nevertheless all outcomes did improve for most measures. This provides preliminary evidence that the exercise programme is safe and effective in improving the physical, psychological and social wellbeing of people with MS. Previous research also supports the role of exercise in increasing fitness and improving fatigue and QoL in people with mild-to-moderate disability from MS [37]. Participants experienced a range of benefits from the programme, including increased exercise levels, self-efficacy, and walking distance, reduced physical and total fatigue, and improvements in quality of life. People with MS consider walking to be as the most important bodily function[38].

When the 6MWT is used a standard is required for determining if a real change has occurred this is defined as the Minimal Clinically Important Difference (MCID) [39]. An improvement of 54 meters has been the value most commonly used as the least change 6MWT that results in clinically important change[40]. In other conditions it has been reported as 14 - 35.4 metres [39]. In MS specifically it has been reported as 22 metres [38]. The median difference in 6MWT in the

programme was 60 metres suggesting that this group had clinically important changes in their function and supports the use of 6MWT in future community based programmes.

Self-efficacy has an important role in increasing exercise levels in people with MS[41]. Self-efficacy is defined as a person's belief that they can perform a given behaviour[42]. Research has documented the linear relationship between self-efficacy and objective physical activity in people with MS[41]. Once a person with MS believes they are able to exercise they are more likely to engage in the behaviour.

6.2 Participant experience

The qualitative aspect of the study allows us to more fully understand the participant's experience of participating in the programme. The findings from the qualitative data compare well with the phase one data. Accessibility, qualified instructors, group interaction and exercise tailored to the individual were all valued components of the programme. As reported in previous research [43], participants felt that having experienced instructors supervising the exercise allowed them to feel more confident and supported. All participants discussed how they struggle with low confidence especially in an exercise environment. Feelings of embarrassment are a barrier for people with MS to engage in community-based exercise. Participants feel intimidated and judged when they go to conventional fitness environments. Participants felt comfortable and supported in the environment created by the programme. Social support and enjoyment is an important determinant of exercise behaviour in people with MS [44]. Previous research demonstrated that group based exercises eliminate feelings of isolation and loneliness[43]. This was replicated in participants in this programme. The social environment created by the programme allowed the participants to feel more confident and supported whilst exercising. A potential issue is the short term nature of the programme. The programme was designed to be 10 weeks. At the completion of the programme the participants reported that they still did not feel confident to exercise in conventional exercise environments. The issues of feeling self-conscious, judged, and out of place were not overcome by participating in the programme. This suggests that people with MS require a group based exercise programme of indefinite length to facilitate long term exercise adoption.

Despite the positive experiences, participants also experienced high levels of fatigue post exercise. To help manage their fatigue participants discussed how they had to rest for the remainder of the day following the session therefore effecting completion of usual daily activities. Detrimental effects such as post exercise fatigue has been reported in previous research [45]. In the past people with MS have been advised not to exercise to preserve energy [46]. MS fatigue is aggravated by deconditioning and disuse, excessive fatigue combined with low levels of fitness leads to reduced levels of activities of daily living[47]. It is therefore possible that the increased fatigue experienced post exercise will reduce as the participant's fitness levels increase.

6.3 Conclusions

The programme increased the amount of exercise participants performed and improved QoL, fatigue, walking distance, and self-efficacy. Participants thought the programme was a positive experience but initially felt apprehensive about their ability to complete the exercise sessions. The overwhelming positive of the programme was the social interaction. Allowing people to exercise in a safe, supportive environment removed several barriers to exercise participation. More work is needed to develop a simple referral pathway for this population. Exercise is a safe and effective

strategy for managing MS. The aim now is to make exercise opportunities easily accessible for people with MS.

7 Future recommendations

Although there has been great progression in the area of exercise for people with MS, there is still a lack of quality evidence implementing the findings into practice.

7.1 Public health

- The MS Active for Health pilot provides preliminary evidence of the benefit of an exercise programme, such as the one presented in this report for people with MS and serves as the foundation to develop larger evidence based public health initiatives.
- Integrated referral models would need to be implemented with health professional engagement to ensure patient referral.
- The programme was designed with the input of health professionals and people with MS. The model suggested here could act as a blueprint for community based providers to use as a starting point for a community based programme for this population.
- More work is needed to initiate referrals from health professionals. Education about referral processes increases the likelihood of appropriate patient referral. This should be incorporated into the design of new services.
- Communication between HCPs and leisure providers can help resolve uncertainties in the referral process.

7.2 Leisure providers

- Practitioners delivering exercise training should be appropriately qualified. Level 4 qualifications are an appropriate bench mark for delivering exercise to people with complex healthcare needs.
- Exercise professionals should design their programmes so that there are opportunities for participants to socialise.
- People with MS identified low confidence and embarrassment as barriers to using leisure facilities. Leisure providers should consider ways to make people with MS feel confident using their facilities.

8 Project dissemination

Findings from this project will form part of a PhD thesis by evaluation lead Liam Humphreys. The findings are projected to be disseminated further including:

- Presentation of results at international research conferences (e.g., MS Frontiers, ECTRIMS, International Society for Physical Activity and Health).
- Publication of findings in academic journals (to be confirmed).

- Social media engagement and other media outlets (e.g., Sheffield Hallam University press releases, The Conversation).

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