

Impact case study (REF3)

Institution: Sheffield Hallam University		
Unit of Assessment: UOA24 - Sport and Exercise Sciences, Leisure and Tourism		
Title of case study: Improving Health Outcomes for People with Multiple Sclerosis through Exercise		
Period when the underpinning research was undertaken: March 2006 - May 2017		
Details of staff conducting the underpinning research from the submitting unit:		
Name(s):	Role(s) (e.g. job title):	Period(s) employed by submitting HEI:
Dr Anouska Carter	Principal Research Fellow	2005 - Present
Professor John Saxton	Principal Research Fellow	2000 - 2010
Liam Humphreys	Research Fellow	2009 - Present
Dr Nicola Snowdon	Senior Lecturer	2004 - Present
Dr Amanda Daley	Principal Research Fellow	2000 - 2006
Period when the claimed impact occurred: January 2014 - December 2020		
Is this case study continued from a case study submitted in 2014? No		

1. Summary of the impact

Exercise is critical for the self-management of Multiple Sclerosis (MS); however people with MS are less physically active than the general population. Sheffield Hallam research was the first pragmatic large-scale MS and exercise randomised control trial in the world. This has been able to inform best practice and support better adherence and access to tailored exercise provision. As a result, it has improved levels of activity, and subsequently the fitness, **quality of life** and **health outcomes** of people with MS. It has informed **NICE guidelines** for the management and treatment of MS and influenced the MS Society's **national strategy** for improving exercise provision. The research has also **shaped the practice** of health professionals, including MS clinicians, nurses and physiotherapists. It has informed exercise **referral pathways**, locally and nationally. The research has also resulted in a nationally run and **accredited exercise qualification** for neurological conditions, developing the practice of exercise professionals both in the UK and internationally.

2. Underpinning research

MS is a chronic unpredictable disease affecting the central nervous system. Approximately 130,000 people in the UK (2.3 million globally) are living with MS, with fatigue and pain often reported as the most disabling symptoms. Historically exercise was discouraged by health professionals, due to fatigue and symptom exacerbation. Currently there is no cure and better self-management is critical. While exercise offers a non-pharmacological approach to symptom management, people with MS experience barriers to exercise participation, resulting in low levels of physical activity (PA).

Previous research highlighted the need for robust evidence to influence clinical practice, plus specialist health professional training to improve access to tailored exercise advice for this clinical population. Sheffield Hallam research provided this evidence, required to inform clinical and professional practice, and facilitate pragmatic solutions to support long-term behaviour change.

Sheffield Hallam specialises in applied exercise and PA research with clinical populations, including MS. This expertise, alongside a strong history of collaboration with the MS neurology team at Sheffield Teaching Hospitals (STH), underpinned this research. Feasibility work, funded by STH, was led by Dr Amanda Daley and Dr Anouska Carter. The main trial, Exercise Interventions for MS (ExIMS), was designed and delivered by the SHU research team led by Professor John Saxton (clinical exercise specialist) and Dr Carter (exercise physiologist), and supported by Dr Daley (behaviour change), Liam Humphreys and Dr Nicola Snowdon. Support

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from external partners included Basil Sharrack, Consultant Neurologist at STH. A 3-year programme grant was provided by the MS Society (£197,000).

The feasibility work (30 participants) demonstrated that a pragmatically designed, tailored exercise intervention was safe and acceptable for people with mild to moderate MS, showing effective exercise progression, low rates of attrition and high compliance (**R1**). Feasibility data informed the methodology for the ExIMS randomised control trial (RCT) (**R2**).

ExIMS determined if a 12-week programme of supervised and home exercise was cost-effective and evoked improvements in PA levels and health outcomes, over 9-months follow-up. This incorporated evidence-based behaviour change techniques (BCTs; flexible goal-setting, action planning, self-monitoring and social support) to initiate and maintain behaviour change. A total of 120 people with MS were randomised to either an individually-tailored pragmatic exercise intervention or a usual care control group.

The intervention significantly increased self-reported exercise behaviour, reduced fatigue and pain, and led to sustained enhancements in overall health-related quality of life and sub-domains (emotional wellbeing, social function) (**R3**). The exercise intervention was reported as cost-effective at the Quality-Adjusted Life Year (QALY) threshold currently accepted by the NHS for drug use (**R4**), providing a unique and effective method to implement progressive exercise rehabilitation within health care settings.

Qualitative research, conducted as part of the trial (**R5**), reported that people with MS experience a transition to sedentary behaviour following diagnosis, with lack of knowledge, low confidence and negative perceptions of exercise capabilities highlighted as common barriers. This is further compounded by a lack of MS-specific exercise advice in clinical and exercise settings:

"When I was diagnosed, I asked specifically if there was anything I could do to help myself, diet wise and exercise, and I was told there was nothing you could do whatsoever" (R5).

Access to and sustained involvement in exercise has been a persistent problem:

"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" (R5).

This research has provided the evidence needed to inform clinical and exercise professional practice and was the first robust, pragmatically designed RCT for exercise and MS in the world. ExIMS was one of only five studies included in the updated Cochrane review on MS, exercise and fatigue (Heine et al., 2015) and the only pragmatic trial to include BCTs. ExIMS was highly commended for an MS Society award for MS research of the year (2014).

3. References to the research

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- R1.** Carter, A. Daley, AJ. Kesterton, S. Woodroffe, N. Saxton JM. Sharrack, B. (2013). Pragmatic Exercise Intervention in People with Mild to Moderate Multiple Sclerosis: A Randomised Controlled Feasibility Study. *Contemporary Clinical Trials*. 35, 2: 40-7. <http://doi.org/10.1016/j.cct.2013.04.003>
- R2.** Saxton, JM. Carter, A. Daley, AJ. Snowdon, N. Woodroffe, MN. Petty, J. Roalfe, A. Tosh, J, Sharrack, B. (2013). Pragmatic Exercise Intervention for People with Multiple Sclerosis (ExIMS Trial): Study Protocol for a Randomised Controlled Trial. *Contemporary Clinical Trials*. 34, 2: 205-11. <http://doi.org/10.1016/j.cct.2012.10.011>
- R3.** Carter, A. Daley, AJ. Humphreys, L. Snowdon, N. Woodroffe, MN. Petty, J. Roalfe, A. Tosh, J. Sharrack, B. Saxton, JM. (2014). Pragmatic Intervention for Increasing Self-Directed Exercise Behaviour and Improving Important Health Outcomes in People with Multiple Sclerosis: A Randomised Controlled Trial. *Multiple Sclerosis Journal*. 20, 8: 1112-22. <http://doi.org/10.1177/1352458513519354>
- R4.** Tosh, J. Dixon, S. Carter, A. Daley, AJ. Petty, J. Roalfe, A. Sharrack, B. Saxton, JM. (2014). Cost Effectiveness of a Pragmatic Exercise Intervention (EXIMS) for People with

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Multiple Sclerosis: Economic Evaluation of a Randomised Controlled Trial. *Multiple Sclerosis Journal*. 20, 8, 1123-30. <http://doi.org/10.1177/1352458513515958>

- R5.** Crank, H. Carter, A. Humphreys, L. Snowdon, N. Daley, A.J. Woodroffe, N. Sharrack, B. Petty, J. Saxton, JM. (2017). Qualitative Investigation of Exercise Perceptions and Experiences in People with Multiple Sclerosis before, during, and after Participation in a Personally Tailored Exercise Program. *Archives of Physical Medicine and Rehabilitation*. 98, 12, 2520-25. <http://doi.org/10.1016/j.apmr.2017.05.022>

All articles underwent rigorous peer-review and are published in leading journals in the field.

4. Details of the impact

Sheffield Hallam research has influenced **national best practice** (NICE Guidelines, 2014) and significantly **enhanced quality of life** for people with MS. It has enabled them to benefit from bespoke exercise guidance from health care professionals in clinical settings. Specifically the research led to the development of an exercise **referral pathway**, and the upskilling of exercise specialists in neurological conditions through the UK's first nationally accessible level 4 **training course**. By 2020 the findings of ExIMS had **improved services** for the c.5,000 MS patients supported by health professionals at Sheffield Teaching Hospitals, 150 of whom have directly benefitted from exercise referrals. Approximately 100 national and international exercise professionals have undergone the training programme. This work has in turn provided evidence to Sport England for a future national roll-out of the programme.

NICE Guidelines and MS Society National Strategy

R3 and **R4** informed the NICE Guidelines *Multiple Sclerosis in Adults: Treatment and Management* (2014) (**E1**). Previously exercise only had a minor mention but, in this, exercise and behaviour change became core to the non-pharmacological management of fatigue. These guidelines influence the support provided by health practitioners across the UK and the 130,000 people with MS that they care for. NICE also influences international practice through widespread adoption of their guidelines by international health organisations, ministries and government agencies.

The new emphasis on exercise in the guidelines and a specific prioritisation for implementation also led, in 2016, to the development of a NICE Quality Standard for MS, supporting people with mobility issues and fatigue to remain physically active (**E2**).

The ExIMS research programme enabled the development of strong regional and national relationship with the MS Society. Sheffield Hallam's expertise supported the National MS Society's aim to improve services for people with MS, by contributing to their 'Models of Excellence' programme as an independent expert on physical activity (**E6**). This has been a key strand for delivering their 'Together to Beat MS' five-year strategy.

Improving Exercise Provision for People with MS

Although exercise was from 2014 being recommended for people with MS, there remained two main barriers to them accessing this: i) an inadequacy of exercise referral provision (formal mechanisms for medical professionals to refer patients to a fitness programme with an appropriately trained exercise practitioner) for people with neurological conditions and, ii) a lack of suitably trained exercise professionals. Sport England confirm:

"There was a significant gap in exercise referral schemes for people with neurological conditions. There was no industry recognised training for leisure service staff to support work with people with a neurological condition. This lack of training means people living with these conditions report being referred to leisure services under weight management or other programmes not tailored to their needs". (**E10**)

The ExIMS research informed a series of collaborative projects, supported by organisation such as the MS Society and Sport England, that began to address these gaps. These included HEIF Fellowship 2017 (**E7**), Active for Health Rotherham 2017-2019 (**E8**, **E9**), MS Society Tasters 2018, and Sport England's MS Access to Exercise 2018-19 (**E10**, **E11**).

The HEIF Fellowship project enabled SHU to build strategic relationships with industry partners involved in the exercise referral pathway for people with MS. MS Access to Exercise then provided

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the evidence needed to demonstrate the demand for a neurology specific qualification to our partners (**E4**). This directly resulted in the creation in 2019 of the first nationally available level 4 neurological fitness qualification, developed by the Wright Foundation (UK brand leader in exercise referral and specialist populations exercise qualifications) and accredited by CIMSPA (professional development body for the UK's sport and physical activity sector).

The Active for Health Rotherham and MS Access to Exercise projects also enabled the Sheffield Hallam research team to design, evaluate and implement exercise tasters and referral pathways for people with MS. This has enabled more people with MS to access tailored exercise advice through improvements in exercise referral, both locally and nationally, as a result of the research and evaluation evidence collected. These referrals have already enabled 150 people with MS to gain better access to tailored exercise advice.

In addition the level 4 neurological fitness training has been provided to over 100 exercise professionals in the UK. There has also been international uptake, with students from the United Arab Emirates. (**E4**, **E9** and **E11**).

This work is now providing the evidence to Sport England for national roll-out of an improved exercise referral pathway. Training of exercise professionals both nationally and internationally is also ongoing. Combined, these two interventions are enhancing access to and standards of exercise provision for people with neurological conditions.

Improving Clinical and Health Professional Practice

ExIMS has resulted in enhanced clinical and health professional practice on exercise for the treatment and management of MS, both nationally and internationally.

The strength of evidence provided by ExIMS has directly influenced the technical and applied knowledge of health practitioners in South Yorkshire and led to significant changes in practice:

"This research was also incorporated in our departmental guidelines at STH on the management of multiple sclerosis and in national guidelines produced by NICE, as well those promoted by the UK MS Society and MS Trust (the UK's leading MS charities)... leading to changes nationally in the use of exercise to manage symptoms." (Clinician at STH) (**E3**).

The provision of the first nationally available accredited course for exercise professionals (**E4**) has enabled GPs and other health professionals to refer patients to an exercise professional with experience in neurology, through the exercise referral scheme:

"It gives you confidence because safety is a big one. You want to know instructors are using evidence-based practice. The qualification gives you a lot of that confidence." (MS Specialist Nurse, Chester)

Findings from our clinical trials, and subsequent patient experience studies, have been disseminated at regional and national events organised for health professionals working with people with MS. Dr Carter was an invited speaker at both the national Physiotherapy UK conference (attended by over 1100 physiotherapists from across the world), and the British Association of Sport and Exercise Science conference. Internationally, our research has been published by Academic Press as a book chapter on exercise for MS, aimed at healthcare professionals worldwide (**E5**), presenting the role of non-pharmacological treatment for MS.

Improving Health Outcomes for People with MS

During our research and community work, a total of 300 people with MS have received direct benefit (150 in the trials, including post-study interventions with the control groups, and 150 from the subsequent implementation). In addition, the influence of our impact programme has gone on to benefit many more, through the better advice and support now provided by health professionals and exercise specialists across the UK. Benefits from exercise for these patients include improvements in cardiovascular fitness, reduced fatigue, pain and enhanced quality of life.

ExIMS qualitative research provided contextual impact evidence:

"I feel as though I'm less fatigued. I don't have as many floppy days. I still get the odd one, but nowhere near like it was" and *"I do find simple things like turning over in bed, which*

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isn't a very easy task, and picking things up off the floor without collapsing; things of that nature are a lot easier.” (R5)

Benefits also extended to family members, with people with MS more able to participate in family activities: *“I try harder. My little boy will be surprised when I say yeah, alright I'll go swimming or yeah OK let's go for a walk, and he'll think oh, that doesn't sound quite right.” (R5)*

The project and its findings have therefore enhanced the health of individuals, as well as exercise practitioners' competence, and therefore confidence, in recommending and delivering tailored exercise interventions.

5. Sources to corroborate the impact

- E1.** National Institute for Health and Care Excellence (2014). *Multiple Sclerosis: Management of Multiple Sclerosis in Primary and Secondary Care* (pp. 317, 335-6, 382-3, 593, 609). <https://www.nice.org.uk/guidance/cg186/evidence/full-guideline-pdf-193254305>
- E2.** National Institute for Health and Care Excellence (2016). *Multiple Sclerosis: Quality Standard*, Quality Statement 4: Physical Activity. <https://www.nice.org.uk/guidance/qs108/resources/multiple-sclerosis-pdf-75545244362437>
- E3.** Testimonial from Consultant Neurologist STH
- E4.** Testimonial from Associate Consultant, Wright Foundation
- E5.** Exercise in the Treatment of Multiple Sclerosis: Pragmatic Exercise Intervention in People with Mild to Moderate Multiple Sclerosis - The ExIMS Project. <https://doi.org/10.1016/B978-0-12-805298-3.00018-9>
- E6.** Final Report - Models of Excellence Literature Reviews: Physical Activity in People with MS, MS Society
- E7.** Final Report - HEIF Fellowship: Exercise for People with Neurological Conditions (HEIF)
- E8.** Final Report - MS Active for Health Rotherham: Developing and Exploring the Acceptability of a Community based Exercise Referral Intervention for People with MS in Rotherham, MS Society
- E9.** Testimonial - Active for Health Rotherham from Stakeholder Engagement Manager, MS Society
- E10.** Interim Report - MS Access to Exercise, Sport England
- E11.** Testimonial - MS Access to Exercise from MCSP, Centre Director - Neuro Therapy Centre