

Impact case study (REF3b)

Institution: Oxford Brookes University
Unit of Assessment: 3 - Allied Health Professions, Dentistry, Nursing and Pharmacy
Title of case study: Improving access to exercise for people with neurological conditions
<p>1. Summary of the impact (indicative maximum 100 words)</p> <p>The pioneering research carried out by Brookes' Movement Science Group (under the umbrella of the Centre for Rehabilitation) into the barriers and benefits of safe community led exercise for people with long-term neurological conditions, has significantly improved quality of life for many sufferers. Their research has raised awareness amongst healthcare and fitness professionals, and led to specific measures being put in place to facilitate and encourage exercise. These measures include the development of: clinical exercise and rehabilitation units, web-based physical activity support system, national occupational standards, and the only level 4 accredited exercise training course in the UK. The research has also led to the establishment of a registered charity that aims to increase exercise participation of people with long-term neurological conditions across the UK.</p>
<p>2. Underpinning research (indicative maximum 500 words)</p> <p>The research and impacts reported here originate from the work of the interdisciplinary Movement Science Group (MSG) based within the Centre for Rehabilitation at Oxford Brookes University (Brookes) from 2005 to the present. The Brookes Movement Science Group is principally comprised of Prof. Helen Dawes, Dr. Johnathan Collett, Dr. Patrick Esser. Since its inception the following have also contributed: Charlotte Elsworth (PhD student from Birmingham), Ken Howells (Brookes), Derick Wade (Brookes & Oxford), Charlotte Winward (PhD student & Physiotherapist), Meredith Newman (PhD student), Andy Meaney (CLEAR unit director, Brookes), James Bateman (CLEAR unit staff, Brookes) and Elizabeth Buckingham (user steering group).</p> <p>The work of the MSG has addressed the provision of exercise for people with neurological conditions, by providing evidence in support of both appropriate content and safe community delivery exercise interventions, evaluating systems for delivery and identifying barriers and facilitators to physical activity. The research has taken the form of experimental studies investigating the mechanisms of benefit alongside effect of clinical trials, incorporating both quantitative and qualitative methods, and falls into two broad themes:</p> <p>Community delivery</p> <p>People with neurological conditions approached the MSG and asked them to develop a system to support their safe participation in exercise and physical activity, as they felt isolated and unable to exercise in their local community. This was largely due to the lack of training of fitness professionals to support people with neurological conditions; a lack of knowledge of appropriate exercises and a lack of appropriate facilities. Dawes, Wade and Esser undertook the first study for the Long-term Neurological Conditions Research Initiative (LTNC), Policy Research Programme, Department of Health to develop and evaluate a physical activity support system (PASS) for people with neurological conditions (Grant no. 0530006, 2005-8). This confirmed that there was no appropriate cheap delivery model for community exercising for neurological conditions [1]. The study demonstrated that people with long-term neurological conditions can safely exercise in community gyms when supported and achieve similar attendance to standard exercise referral schemes [2] and then provided insight on how to deliver and support it [3].</p> <p>Exercise Content</p> <p>The evidence for the beneficial effects of exercise is overwhelming and increasing activity levels is now an important part of government health policy. The group undertook pioneering research on exercise for people with neurological conditions. Specifically, Dawes investigated treadmill walking exercise for people with Multiple Sclerosis (pwMS) and demonstrated that aerobic treadmill training is feasible and well tolerated. Improving walking speed and endurance and did not increase fatigue [4].</p> <p>Concerns over fatigue and exacerbating MS symptoms have, in the past, led to exercise being discouraged in people with MS. Dawes, Collett and Wade further investigated exercise 'dose' for pwMS in a study funded by the MS society (Grant no. 840/06, 2007-9). The study was the first to look at high intensity exercise 'doses' in people with MS and found that all intensities improved</p>

mobility and leg power. However the results indicated that greater benefit may be associated with higher-intensity exercise, and although this may be less well tolerated, it did not cause exacerbations [5].

3. References to the research (indicative maximum of six references)

1. Elsworth, C., Dawes, H., Sackley, C., Soundy, A., Howells, K., Wade, D., Hilton-Jones, D., Freebody, J. and Izadi, H. (2009). *A study of perceived facilitators to physical activity in neurological conditions*. International Journal of Therapy and Rehabilitation, 16 (1), 17-24. <http://www.lacliniquedusport.com/wordpress/wp-content/uploads/2011/07/Elsworth-2009-Percieved-facilitators-to-pa-in-Neuro-conditions.pdf>
Izadi; Department of Mathematical Sciences, Oxford Brookes University
Sackley; School of Population Sciences, University of Birmingham
Soundy; School of Health Sciences, University of Birmingham
Hilton-Jones and Freebody; Department of Clinical Neurology, University of Oxford
2. C. Elsworth, C. Winward, C. Sackley, C. Meek, J. Freebody, P. Esser, H. Izadi, A. Soundy, K. Barker, D. Hilton-Jones, C. M. Lowe, S. Paget, M. Tims, R. Parnell, S. Patel, D. Wade and H. Dawes, (2011), *Supported community exercise in people with long-term neurological conditions: a phase II randomized controlled trial*, Clinical Rehabilitation, 25 (7), 588-598 DOI: 10.1177/0269215510392076
Meek & Patel; Primary Care Clinical Sciences, School of Health and Population Sciences, University of Birmingham.
Barker & Minns-Lowe; Physiotherapy Research Unit, Nuffield Orthopaedic Centre, Oxford
Paget & Parnell; Department of Clinical Neurology, University of Oxford

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3. Winward and LIFE group, (2011), *Supporting community-based exercise in long-term neurological conditions: experience from the Long-term Individual Fitness Enablement (LIFE) project*, Clinical rehabilitation, 25 (7), 579-87, DOI: 10.1177/0269215510392075.
LIFE Group is collaborative group research group including: Charlotte Winward, Charlotte Elsworth, Cath Sackley, Charmaine Meek, Jane Freebody, Patrick Esser, Andy Soundy, Karen Barker, David Hilton Jones, Catherine Minns Lowe, Sandra Paget, Martin Tims, R. Parnell, Smitaa Patel, Derick Wade and Helen Dawes
4. M. van den Berg, H. Dawes, D. T. Wade, M. Newman, J. Burridge, H. Izadi and C. M. Sackley, (2006), *Treadmill training for individuals with multiple sclerosis: a pilot randomised trial*, Journal of Neurology Neurosurgery and Psychiatry, 77 (4), 531-533, DOI: 10.1136/jnnp.2005.064410' van den Berg, University of Birmingham; Burridge, University of Southampton.
5. J. Collett, H. Dawes, A. Meaney, C. Sackley, K. Barker, D. Wade, H. Izardi, J. Bateman, J. Duda and E. Buckingham, (2011), *Exercise for multiple sclerosis: a single-blind randomized trial comparing three exercise intensities*, Multiple Sclerosis Journal, 17 (5), 594-603. DOI: 10.1177/1352458510391836. Duda; School of Sport and Exercise Sciences, University of Birmingham

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4. Details of the impact (indicative maximum 750 words)

The Long-Term Neurological Conditions Research Initiative (LTNC) research initiative produced essential evidence about how effective and affordable services should be designed. The LTNC initiative was designed to provide the evidence base for policy-making in the Department of Health [6]. The research from the LTNC initiative has directly impacted service delivery. For example, the Cornwall and Isle of Scilly Primary Care Trust (PCT) commissioned 'RENEW' an exercise delivery program based on the research. As producers of the underpinning research, the MSG were requested to audit the service in 2011, finding a trend towards reduced clinical service use in those taking part in the system [6]. Consequently the MSG has also been requested to audit the Oxfordshire community Physical Activity Care Pathway for individuals with and without disabilities [7]

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In response to the need at a local level, the Clinical Exercise And Rehabilitation Unit (CLEAR) was created at Brookes in 2005 to facilitate exercise for people who require a higher level of supervision due to their medical condition. The significance of this impact is demonstrated by the fact that in 2012 there were 3000 total clinic attendances. Patients referred to the unit have reported improved health and attributed it directly to the exercises they have undertaken under CLEAR supervision. One CLEAR unit client said: "*The progression I have made in six weeks has been quite remarkable – noticed by friends and family. Importantly I feel more confident and capable in my physical abilities.*" Another CLEAR client said "*If it wasn't for James' [CLEAR staff] dedication I wouldn't have improved and be able to walk...as much as I now can. CLEAR has been life changing for me, more than anyone will ever know*" [8].

The unit has also impacted on the practice of healthcare providers (GPs and physiotherapists), who now refer their patients from Oxfordshire and as far as Gloucester and Cheltenham. The unit also runs camps for children in the school holidays, including the Oxford dyspraxia group and the Oxfordshire paediatric physiotherapy service.

Having established a working model of delivery at a local level the success of the CLEAR unit has led to the establishment of the CLEAR Trust a registered charity which aims to;

- Advance the treatment and care of children and adults with long-term movement disorders and neurological disabilities, through the provision of affordable sustainable exercise and rehabilitation facilities and equipment,
- Support research and education in movement science and movement optimisation. [9]

Supported by the community physiotherapy service and sports partnership, Satellite CLEARs have been set up in the Thames Valley to support both adults and children with neurological conditions at two sites, with plans to expand to a further three sites in 2013/14 [9].

The unit employs a mutually beneficial arrangement whereby clients are supported to exercise by exercise and health trainees, an average of twenty per annum, which include a proportion of visiting students and practitioners.

To widen the impact further, based on the MSG research that provided the first evidence of the need for specific training of fitness professionals, it was realised that in order to facilitate impact at a national level, two key things were required; a National Occupational Standard (NOS) and an accredited training course. MSG research was presented to the Register of Exercise Professionals (REPs) to make a case for the development of a course and the NOS written by Dawes and endorsed by Skills Active [10]. REPs were sufficiently convinced of the need and expertise in the group, that they agreed to work with the researchers to develop the 'Exercise Prescription for Long-Term Neurological Conditions' course in 2011 [11]. It is the only level 4 accredited course (20 Level M CATS points) in the UK for healthcare and fitness professionals who are required to deliver exercise to people with a range of long-term neurological conditions [12]. Since 2011, 36 people all over the UK have completed the course, some sponsored by MS Society [13]. Dawes has incorporated the research findings into invited articles and training workshops as part of a specialist registrar course (Nottingham) to medical students (London) and Physiotherapists (New Zealand).

A key finding of the research was that people with long-term neurological conditions should be enabled and empowered to manage their exercise according to their wishes and in response the PASS system of informing and empowering people to achieve a physically active lifestyle was developed. The PASS handbook [14] contains information to empower people with neurological conditions to exercise and participate in physical activity in the community. 4000 printed booklets have been distributed since 2009, with 2000 funded by the MS society [13] and it is available on the group's website, which since September 2011 to July 31st 2013 has had 8534 unique on-line viewings and the booklet downloaded 688 times. MSG research has been extensively incorporated into resources for exercise delivery in neurological conditions including a neurological and neuromuscular chapter for Churchill Livingstone in their Exercise Physiology in Special Populations title.

In addition the researchers have undertaken a variety of activities to ensure that research findings reach relevant practitioners and patients. This has included speaking at events for practitioners such as the Association of Chartered Physiotherapists interested in neurology (ACPIN) group, Oxford Universities Hospital (OUH), NZ national physiotherapy conference, MS Frontiers conference 2009, REPs National Convention (Birmingham, 22 Sept 2011) Birmingham, Physiotherapy UK National conference (Liverpool, 10 October 2012), reaching an estimated 1200 professionals face to face. They have also reached out to professionals through print media including Dawes' report in the REPs journal [15] (Jan, 2012) that is distributed to 35,000 exercise professionals. Collett's report on exercise 'dose' in pwMS for the Wayahead newsletter [16], which is produced quarterly by the MS trust for nurses and health professionals who work with pwMS. (Jan 2009).

They have also been able to meet with approximately 700 patients and work with them through attending meetings of local groups including Parkinsons UK, MS Society [13], Stroke Association, and Huntingdon's Disease Association, therefore ensuring that the message about the possibilities of safe and beneficial exercise is heard by the potential beneficiaries themselves.

Sources to corroborate the impact (indicative maximum of 10 references)

6. http://www.ltnc.org.uk/download_files/final%20reports/ALMO_for_web.pdf
7. Deborah Matthews (2011) 'Refresh and re-invigorate your patients with gentle exercise' Primary Health Care. 21, 6, 28-30, DOI: 10.7748/phc2011.07.21.6.28.c8605. A Report on the success of the RENEW programme in Cornwall and Isles of Scilly.
8. CLEAR website: <http://www.shs.brookes.ac.uk/clear>, including testimonials from patients and practitioners: <http://www.shs.brookes.ac.uk/clear/testimonials>
9. CLEAR Trust website; <http://cleartrust.org.uk/>
10. National Occupational Standard; http://www.skillsactive.com/images/stories/PDF/D522_LTNC_mapping_toolkit.pdf
11. Course handbook for the REPS accredited course 'exercise prescription for long-term neurological conditions' available at; http://www.shs.brookes.ac.uk/images/pdfs/courses/postgraduate/short-courses/p16511_exercise-prescription-for-neurological-long-term-conditions.pdf
12. Corroborative statement author 1, formerly REPs advisory panel. Available on request.
13. Corroborative statement author 2, National Lead – Physiotherapy, MS society. Available on request.
14. <http://www.shs.brookes.ac.uk/lifepass/pass/images/PASS%20Handbook.pdf>
15. Dawes, H. (2012) *Working with Neurological Conditions*, REPS Journal, January 2012, pages 23-25 <http://content.yudu.com/A1qkok/REPs/resources/index.htm?referrerUrl=> REPS Journal is a practitioner magazine.
16. Collett, J. (2009) *Investigating safe and effective exercise for people with MS* Way Ahead Newsletter, January 2009, Volume 13, part 1 http://www.mstrust.org.uk/professionals/information/wayahead/articles/13012009_04.jsp
 The Wayahead Newsletter is the specialist MS practitioner newsletter produced by MS Trust