Title. Long-term Individual Fitness Enablement (LIFE) study

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Executive Summary of Research Findings

People with neurological and neuromuscular disorders are interested in increasing their participation in regular physical activity, thus providing access to the health benefits from exercise participation experienced by people without disease. The study aimed to use complex intervention trial methodology developed by the Medical Research Council, to work with service users to model a physical activity support system (PASS) to enable individuals to participate in exercise in community leisure centres.

Our initial focus group questionnaire and community mobility Phase I studies found low levels of physical activity in people with long-term neurological conditions (LTNC). People with LTNC expressed a desire to have the opportunity to be physically active. But they reported physical, environmental and social barriers to participating within community leisure centres and a lack of NHS support for ongoing exercise. When asked to contemplate exercising using community facilities, 30% of people in our sample stated they would be happier to exercise at home if supported, however the majority (60%) stated a preference to exercise in a community facility with people and ideally with people with some form of disability rather than with non disabled people. The most requested physical activities by this group were those involving walking, stretching and swimming. Community facilities are available for people to exercise in their locality; however during pilot testing we found variability in the ability of community centres in Oxfordshire to meet the needs of people with LTNC. Inclusive Fitness Initiative Centres met the exercise needs of people with LTNC, but there are areas in the UK where when there are no local IFI centres. These facilities would need to be evaluated for adequate access, equipment and appropriately skilled staff on an individual basis. The exercise environment is extremely important to the success of achieving a physically active

lifestyle for people with LTNC; staff attitudes, skills and appropriate facilities were highlighted as extremely important for successful use of community centres in both our Phase I studies and in our exit poll of participants of the Phase II study.

From our Phase I pilot work we developed a method for supporting exercise in community facilities. We set out to enable people with LTNC to develop and control their own exercise programme to suit their personal needs with the support of an information booklet, a community Register of Exercise Professionals (REPs) level three or above Fitness Professional and the support of a health professional (physiotherapist). The initial appointment in the community centre was arranged by the physiotherapist who introduced the patient to the community facility and fitness professional. The exercise prescription provided by the Fitness Professional was directed by the participant with the Health Professional providing support. In our Phase II RCT evaluation we found that people with LTNC were able to safely and effectively exercise in community fitness centres. Participants achieved comparable adherence (44%) over the 12 week trial to other exercise referral schemes in the same facilities with 30% of participants continuing to exercise at the end of the 12 week intervention. Provisional data from the trial demonstrated a positive effect of community exercise on body function, health and wellbeing measures, supporting the implementation of a Phase III trial.

Background

Adults with neurological conditions have low levels of participation in leisure time physical activities, perceive themselves as isolated and have high rates of secondary complications from inactivity [1,2]. Some people receive short periods of hospital-based rehabilitation but there is minimal initiation or maintenance of community activity [3,4]. Participation in regular exercise provides health and social benefits for all [1,2,5-10] and evidence suggests that attaining a physically active lifestyle benefits mobility, health and wellbeing and reduces the impact of disease and health care costs in people with long-term neurological conditions (LTNC) [11-13] .

In order to achieve regular ongoing physical activity people need to be able to integrate physical activity into their everyday lives. Community exercise facilities are available in most localities in the UK and, whilst considering the concerns of people with neurological conditions[14 15,16 17-19], they remain an attractive resource for supporting exercise for all.

The 2006 National Institute of Clinical Excellence (NICE) Public Health Intervention Guidance urges commissioners, practitioners and policy makers to provide exercise referral schemes that help to prevent or improve individual health conditions which fall outside the overarching advice to achieve 30 minutes moderate activity on at least five days a week. The importance and case for enabling individuals with neurological conditions to achieve active lifestyles is clear [14.] This research set out to explore exercise provision in people with LTNC.

The aims of the study were as follows:

PHASE I INVESTIGATIONS

Aim1. To identify and explore the experiences, views and beliefs of people with neurological and neuromuscular disease regarding participation in physical activities / therapeutic exercises and preferences for service delivery.

Aim 2. To determine community mobility in individuals with a range of neurological conditions

Aim 3. To determine whether physical activity delivered with a physical activity provision support system (PAPSS) is feasible and able to change individual physiological and psycho/social variables

PHASE II INVESTIGATIONS

Aim 4. To determine the need for a trial to determine whether a physical activity provision support system is effective and cost-effective in improving activity levels for neurological patients compared with waiting list control patients and to inform the design of such a trial.

Definitions of physical activity

Physical Activity: Is a broad term that encompasses anything that involves movement, from participating in sport, to washing up.

Exercise: Is when physical activity is planned and structured and targets one or more aspects of fitness. Exercise may be therapeutic and targeted to improve different aspects of human fitness including muscle strength,

power, speed, endurance, cardiovascular fitness, balance, flexibility and so to benefit general health and wellbeing. Certain diseases such as osteoporosis, cancer, high blood pressure, heart disease and stroke, and body systems including the immune system and mental health have been shown to benefit from specific exercise interventions and physical activity.

Community mobility: In this study community mobility was defined as the level of daily walking measured over a 7 day period. Physical requirements associated with community mobility
are complex and include dimensions such as distance, time, ambient conditions (eg, light level, weather conditions), terrain characteristics, physical load, attentional demands, postural transitions, and traffic levels. These dimensions represent the external demands that have to
be met for an individual to be mobile within a particular environment.

About the study

The study was carried out in two regions in England: Birmingham and Oxford. The focus of our research was people with Neurological Conditions. The research had four main stages:

1. Focus groups with people with a range of neurological conditions
2. Evaluation of community mobility levels
3. Initial pilot single case evaluation of the developed physical activity support system
4. Phase II study to investigate the need for a Phase III trial to investigate physical activity in people with LTNC

The research took place between January 2007 and December 2009 and was carried out by researchers at the School Life Sciences (Oxford Brookes

University) and in partnership with the Departments of Nursing and Physiotherapy and Primary Care and Clinical Sciences (University of Birmingham). It was funded by the Department of Health as part of the Research and Development Initiative on Long Term Neurological Conditions with further support from the NIHR and the University of Birmingham.

Findings for study AIMS

Findings: AIM 1

To identify and explore the experiences, views and beliefs of people with neurological and neuromuscular disease regarding participation in physical activities / therapeutic exercises and preferences for service delivery. Participants were recruited from local support groups for neurological and neuromuscular conditions in the community. Four condition specific focus groups were run with 24 people with muscular dystrophy, multiple sclerosis, motor neurone disease and Parkinson's disease. The questionnaire was given to 115 individuals with a range of neurological conditions.

Method

Support groups for people with progressive neurological conditions in Oxfordshire, UK were contacted by post and phone, and asked to invite their members to contribute to focus groups to discuss physical activity. There was no upper age limit and people with any level of functional ability were invited. Following ethical approval from the University Research Ethics Committee, 24 individuals (mean age (SD): 54 (25) years) with various neurological conditions - muscular dystrophy (n=5), multiple sclerosis (n=7) motor neurone disease (n=6) and Parkinson's disease (n=6) - gave formal

consent to take part in a group discussion. All participants had partners who acted as carers and 22 individuals brought them to the focus group. At the beginning of each focus group session, group facilitators explained the purpose of the study being to discuss issues relating to perceived barriers and facilitators to taking part in physical activity. Groups also discussed current levels of activity and the difficulties in changing behaviour. Notes taken by the three researchers during focus group sessions were analysed using a note-based approach according to the procedures of Kruger [23]. Independent note analysis by the researchers provided identification of major themes; these were then reviewed and refined to three themes (see next paragraph) by consensus. Following the analysis a questionnaire was developed using the themes that emerged. The questionnaire was to be self-completed, and consisted of eight questions. The questions covered topics such as: necessary support, barriers to participation and average time spent participating in physical activity. The questionnaires were distributed to members of the various support groups either at group meetings or by post. Individuals completed the questionnaire by themselves or with the help of a carer.

Results – focus groups

The three themes that emerged from the focus group results were: (1) perception of the barriers to and enjoyment of physical activity; (2) disease specific consideration; and (3) confidence in Health Professionals.

1. Perception, barriers and enjoyment of physical activity

Of the 24 individuals that participated, all agreed that physical activity was a positive experience that had the potential to make them “feel better”. The physical activities most frequently identified as being beneficial and enjoyable were swimming, stretching and walking.

The reasons for participating in physical activity were varied, but in all four focus groups it was mentioned that day-to-day physical functioning deteriorated as the level of physical activity reduced. Individuals felt that exercise was an effective way of preventing physical deterioration. For example, an individual with MS stated: "*exercise helps us to focus on the positive aspects of our mobility*". This opinion was reiterated in all the focus groups and appeared to be an important incentive to participation.

The facilities and environment were consistently identified as a barrier to physical activity. Individuals within all four groups expressed the view that the natural environment is inherently inaccessible. This included; access routes, doorways being too narrow for wheelchairs to pass through, and a lack of lifts. Individuals highlighted several safety issues such as wet floors in changing rooms, poorly maintained equipment and unsuitable hoists in pool areas. Costs that arose due to membership and travel were discussed. This appeared to be a universal barrier to exercise throughout all condition groups. Having to attend a new scheme or environment caused worries, and individuals recognised the limited intervention duration available through primary health care services and the NHS.

All individuals agreed that the social aspect of exercise was important and that attending exercise sessions with others enhanced the feeling of "normality". The idea of a group for people in similar situations was generally perceived as positive.

Individuals were able to recall bad experiences associated with fitness centres in the past. These memories acted to prevent their attendance, as an individual with MD stated:

> "*I would have fear of doing something if I had not done it for a while…as I would not be sure if [I] would judge it right…like*

when I went swimming...I was so self conscious in the changing room and this was scary and really affected my confidence."

Fear and worry was associated with adapting to the new environment. The unknown location and surroundings, the new equipment and different people contributed to this. Individuals needed reassurance that their needs would be met and that staff would be sensitive to and knowledgeable about their condition. This need was highlighted especially in those users who had a bad experience previously. An individual with Parkinson's disease recalled a specific incident: "*I really enjoyed the treadmill, but when I fell over on it, there was no one there to help me*". There was also fear of not performing the exercise 'correctly' and that this would be embarrassing for them. The memory of falls and confidence in their ability also was mentioned as a worry. Individuals requested a supported environment that could aid these aspects.

2. Disease specific considerations

The disease progression and hope in exercise and recovery was important and influenced a participant's motivation and feeling towards physical activity. Participants identified a specific need to consider two aspects associated with their disease. First, the physical problems associated with each disease and second, the nature of the disease and its responsiveness to change. Disease considerations influenced some participants' faith in exercise. Table 1.0 identifies the disease specific barriers mentioned for all the conditions identified.

Table 1. Disease specific considerations for Motor Neurone Disease, Multiple Sclerosis, Parkinson's Disease and Muscular Dystrophy.

Disease	Barrier
MND	Walking is hard, legs need to be conditioned Fatigue Incontinence Fear of falling Progression of disease exercise becomes less safe Can easily overdo it resulting in aches, physical and mental fatigue. Cramps occur regardless of activity levels. Unpredictable nature of the disease.
MS	Warmer environments cause overheating Overstretching Easy access to the toilet
PD	Difficulty moving about in public spaces e.g. swimming pool Medication effects timing and coordination and consideration is needed as to when it is taken Swimming pools temperature is too cold and individuals can't move fast enough to get warm Losing balance
MD	Fatigue or 'overdoing' an activity Fear of adverse event in a new environment

3. Confidence in Health and Fitness Professionals

All of the focus group participants agreed that staff in fitness facilities would benefit from some training to help them understand the specific neurological

conditions and which exercises would benefit them. Informational support was essential and the instructor needed to be aware of exactly what can be obtained. Many individuals felt that they had a lack of confidence in the fitness staff with regards to their condition and what exercises were appropriate for them. An individual with MND identified that the rarity of the disease meant that people, including GPs, did not always understand. An individual with MD stated: "*I want a trainer to be familiar with [my] condition and confident to deal with me. [I'm] fed up with constantly having to explain everything.*"

Individuals with MS suggested that support from a specialist neuro-physiotherapist would help the exercise sessions and make them feel more confident. Eighteen participants stated that they would only feel comfortable with some form of physiotherapist support. Additionally, it was indicated that support from professionals such as physiotherapists and occupational therapists to assist with the transition from rehabilitation settings such as hospitals to community settings such as leisure centres would help and would reduce the reluctance to participate.

The participants wanted the choice of activities that they enjoy, which sometimes included other activities like ballroom dancing. The gym instructor also needed to know other aspects regarding the conditions e.g. lifting and handling issues for MD. The knowledge of each participant to manage their own condition was evident and there was a need for fitness professionals to take it in and remember it when dealing with a specific client, although instructors did learn with time and appeared more proficient and confident with the different conditions as time passed. An individual with MD stated that having to ask for help was horrible:

> "*At first I had no confidence in the new machines; I want the instructor to be familiar with the condition and confident to deal*

with me". Ideally participants often requested having someone there they already knew. An individual with MD stated "*I like to have a point of contact, [I] feel safer if I know someone there and I would be scared to turn up cold*".

Results Questionnaire

A total of 115 questionnaires were distributed and 80 (70%) were completed. Age of responders in years ranged from 42 to 68, mean (SD) 55 (13), 48 (60%) were women, 27 (33.75%) people had the diagnosis of multiple sclerosis, 30 (37.5%) muscular dystrophy, 13 (16.25%) Parkinson's disease, 10 (12.5%) 'other' (stroke or motor neurone disease).

All responders provided estimates of the time spent exercising during a typical week, ranging from 32 to 140 minutes a week. Sixteen (20%) individuals reported not participating in any physical activity at all, and those that did report exercising did so for a mean (SD) 108 (76) minutes a week,

When asked to rank their favourite exercise activities, most people prioritised walking and swimming, then stretching and exercise classes. Responders were happy to access these activities in the usual way, at gyms, leisure or community centres, or to practice at home. Half the responders reported the main barriers were; staff lack of knowledge of neurological disability, staff lack of knowledge of suitable exercises for their condition and feelings of embarrassment at not being able to perform the exercises and navigate a facility. One third of responders cited concerns over cost, suitability of the environment, time constraints and lack of personal care support. Half the responders wanted to exercise with people either with their condition or another disability. Only six people wanted to exercise exclusively with non-disabled individuals. The final question asked

who the individual would like to support them while they were exercising; 43 of the 80 individuals reporting that this would be a physiotherapist and 25 reporting that they would like a specially trained fitness professional who had support from a physiotherapist, nine a fitness professional and eight a trained carer.

Conclusions Aim 1

Individuals with progressive neurological conditions indicated they enjoyed participating in a range of activities from walking, swimming to group exercises and that they would like to access these activities in a number of different community settings. It was notable when considering the delivery of exercise that the majority of individuals indicated that they would prefer to exercise in a group of people with the same or other disabilities, with relatively few indicating they would like to exercise alone. The majority of individuals indicated they would prefer to exercise with the support of health and fitness professionals with expertise relevant to their condition.

As expected, our study highlighted previously described barriers to exercise such as high costs, poor access, inappropriate facilities and equipment. However within focus groups emotional issues such as embarrassment were raised and in support of this observation, the most common barrier to participation in questionnaire responses was that of embarrassment. This finding has not been reported in other conditions and may link with the strongly reported desire to exercise amongst individuals with disabilities. Other issues highlighted in this group compared with other conditions by were the concerns of individuals of a perceived lack of knowledge of their condition and of suitable safe exercises prescribed by fitness professionals. Most people indicated that they would prefer to exercise with physiotherapy

support and then by the less costly option of a fitness professional supported by a physiotherapist.

Findings: AIM 2

To determine community mobility in individuals with a range of neurological conditions

Introduction

Mobility is one of the key physical dimensions of life that contributes to the quality of life. A decrease in mobility can result in a vicious downward cycle of reducing body function and activity [1]. There is limited evidence, but people with neurological conditions appear to be less mobile. Mobility can be measured in a number of ways. In this study we have utilized activity questionnaires in line with actual measures of home activity and examined these in relation to detailed measures of walking endurance, speed, balance, style, symmetry and effort, measured in the clinic. The initial phase of this study involved the development of the clinical gait analysis tool GAIT. The tool was developed to enable detailed gait analysis to be performed in a simple quick manner in the clinic. The outputs (papers, patents and conference presentations are presented in relation to this development in the Appendix). The GAIT provides detailed spatiotemporal measures from which walking speed, balance, style, symmetry and effort can be obtained.

Methods

Participants with LTNC were recruited. This study was approved by the Oxfordshire and Birmingham Ethics Committees trial registration with UKCRN (4121) and EudraCT (2007-004454-85).

Baseline body function, activity and impairment measures were taken. Furthermore the Physical Activity Scale for the Elderly[33] (PASE) was administered. The questionnaire measures physical activity levels with scores ranging from 0 to 400, with a higher score indicating more physical activity. The scale determines activity levels in three different domains; social, home and work. Participants then walked in a corridor free of obstacles at their self selected walking speed (SSWS) over a distance of 10 metres and then for 2 minutes. Participants aimed to walk at least twice over the 10 metre distance while an Inertial Measurement Unit (IMU) was placed with adhesive tape over the projected centre of mass which is located over the 4th lumbar vertebra[26 34]. Raw data from the IMU, which is a small matchbox sized device, including signals from three accelerometers, magnetometers and three gyroscopes is taken and processed by a method published by Esser et al[35] to transpose the acceleration vectors from the object to the global frame. Gait measures of walking endurance, speed, balance, style, symmetry and effort can then be obtained.

After the assessment the participants were given a Step Activity Monitor (SAM) which is an advanced pedometer that can count the amount of steps per minute. Participants were instructed to wear the SAM for eight days, 24 hours a day. SAM cadences (∂_s) (steps/min) were compared with IMU output ∂_x and time and duration spent walking above self selected walking speed (SSWS) during recorded SAM data was calculated.

Statistics

IMU and SAM analysis was done in a custom build program in LabVIEW 8.5. Statistics were performed in SPSS 17 for Windows.

Results

Participants' physical activity levels and descriptive data are displayed in Table 1

Table 1 Aim II Physical Activity Characteristics

	N	Total (N=99) Mean (SD)
Gender (male)	99	51 (52%)
Age (Years) *range*	99	56 (12.88)
Barthel Index	99	18.57 (1.96)
Weight (kg)	97	79.6 (14.90)
Height (m)	99	1.7 (0.09)
BMI (kg/m^2)	97	27.0 (4.37)
Distance walked in 2 mins (m)	93	102.0 (47.73)
Time taken to walk 10m (s)	80	11.3 (7.56)
PASE	98	92.3 (66.02)
PASE social	9	21.50

	8	(23.48)
PASE home	9 8	64.32 (44.13)
PASE work	9 8	92.32 (66.02)
Falls (yes): median (range)	2 9	1 (1 – 9)
SAM	9 0	2936 (2229)

SAM: Step activity monitor (step count)
PASE: Physical activity scale for the elderly; Ranges from (low score = less activity) 0 – 400+ (high score = high activity)

Further analysis of eight day 24 hour step activity monitors in relation to gait factors is currently in process. Papers describing the validation for the measures are attached in the Appendix. Papers describing community mobility over one week and gait factors relating to mobility are in preparation.

Discussion

Our findings confirm lower physical activity levels measured by the PASE in home, social and work domains in people with LTNC compared with healthy older adults; aged 50-64 154.3(80.4) (males) females 137.9 (76.7) (females). We found when considering individuals who were ambulatory that their daily step counts were less than half of those previously reported in healthy adults.

Future analysis will be performed to explore whether individuals are active for periods of more than 10 minutes at their normal walking pace in order to attain health benefits and achieve government physical activity guidelines. The relationship of home walking activity will be related to clinical gait measures.

Findings: AIM 3

To determine whether physical activity delivered with a physical activity support system (PASS) is feasible and able to change individual physiological and psycho/social variables?

The PASS was developed from theoretical frameworks and focus group findings (AIM 1) and piloted. We piloted single case trials with people with a range of neurological conditions in different fitness centres in Oxford. We observed that the delivery of exercise for people with neurological conditions in community facilities was feasible and enjoyable for the clients. We selected participants with a range of cognitive, physical and behavioral impairments and found certain factors were important for successful exercise prescription in the community. The importance of explaining and adapting programmes to allow for an individual's body function (behavioural, cognitive and physical) was clearly evident. The factors highlighted confirmed the focus group work described in AIM 1. We also found variability in facilities and the attitudes of staff across community fitness centres in Oxfordshire. In exploratory pilot work we explored with clients fitness centres that were both IFI marked and those that were not. We found that due to the stringent requirements for facilities (such as having a shared changing room suitable for people with a disability, or the equipment being purchased prior to IFI systems were established) that

many older buildings were unable to meet all IFI standards. However some of these facilities had excellent staff and fitness trainers who were qualified and able to support people with LTNC. Whereas occasionally IFI approved centres were not necessarily in general any more accessible for people in wheelchairs and did not always have the most experienced staff. In this study we chose to utilize IFI centres, but other centres which meet DDA requirements and are staffed by trained exercise professionals to Register of Exercise Professionals (REPS) level 3 or above and preferably level 4

From this piloting a physical activity support system (PASS) was defined. Roles and responsibilities for participants, fitness and health professionals for the Phase II trial were subsequently created.

Developed Physical activity provision support system (PASS) for people with LTNC

The support system was developed from the Phase I research and includes: practical information for the client, health professional support and fitness instructor exercise prescription. The components of the support are described below.

1. Client information: On entry to the scheme the client is given a physical activity support scheme (PASS) booklet containing information of how to go about initiating exercise in community facilities [www.brookes.ac.uk/lifesci/lifepass]. The information booklet covers practical issues such as, how to park if required, how to find and get to the fitness room, where the toilets and changing areas are, and how to meet the fitness professional. More general information is provided of what to

expect when they attend, their role in exercise planning, what to wear, how often to exercise and general advice and tips on what to expect when exercising, what to expect from the fitness trainer, and when and how to seek support.

Specific local information can be given regarding local centres, the contact details of the lead fitness professional at that centre and how to travel to and attend sessions. Information can be slotted onto the back page by the supporting health professional so that it can be used in different centres and regions. The importance of including advice and support about reaching the centre was highlighted during pilot trials where individuals often failed to initiate exercise.

Individuals are encouraged to exercise in a centre that can support people with disability. This research utilised six Inclusive Fitness Initiative (IFI) fitness centres across Oxfordshire and Birmingham which have an established level of facility, equipment, staff training and marketing for supporting for the needs of disabled and non-disabled people that aims to raise physical activity participation levels (http://www.inclusivefitness.org/index.php). However there are currently only approximately 200 such centres across the UK. If there is no local IFI centre, the English Federation of Disability Sport (EFDS) and NHS Choices (www.nhs.uk/choices) may suggest an appropriate place in a locality. Our experience suggests that a successful venue will provide appropriate facilities with good physical access to the gym and fitness area and with changing rooms and toilet facilities for everyone, including a changing room where carers of either gender can help. The venue should be able to provide appropriate fitness equipment suitable for people with a range of disabilities and staff who are appropriately trained to support exercise

referrals. The venue should follow good practice with monitoring by the fitness professional of the participant's engagement and progress with their programme and give feedback to clients and referring clinicians.

2. Health Professional (physiotherapist) support: Clients often have uncertainties about exercise and our pilot work suggested that some form of health professional support / encouragement was vital for people to initiate using community facilities. We utilised a physiotherapist in this role, as people with different long-term neurological conditions had specifically endorsed physiotherapists as their preferred professional for exercise support. The physiotherapist contacted participants by phone and guided them through the PASS information booklet. The therapist then arranged a shared appointment with the client and local fitness professional at their chosen exercise centre so that the therapist could support both the client and the fitness instructor in enabling safe exercise. In summary, the therapist provided: knowledge and experience of common and less well known neurological conditions, advice on how to modify programmes to accommodate for changing/deteriorating conditions, knowledge of impairments specifically associated with neurological conditions and an understanding of medications related to these conditions. Practical advice was also provided on: how to enable clients with altered muscle tone or altered flexibility to most effectively use equipment, on timing of medication in relation to exercise and how to accommodate condition specific problems. Following the first session further support could be provided. The level of support would vary according to the patient's requirements and the level of expertise of the fitness professional.

3. The Fitness professional and exercise prescription: UK exercise referral schemes recommend that instructors should be qualified in the discipline(s) they instruct and that they should be registered with

the Register of Exercise Professionals (REPs) to the appropriate level. Most centres will have a REPs level 3 or above instructor running the ERS and prescribing the exercise, but level 2 instructors may support clients when they are performing the exercise programme. Fitness instructors will be qualified in a range of awards but the 'Supervising Exercise with Disabled People' or 'Exercise Programming with Disabled People' both provide instructors with knowledge for safe exercise prescription and supervision of clients with a range of impairments. The fitness professional works with each client to 'tailor' the exercise programme to each client's hopes, health and fitness needs and to promote independent use of the centre as far as possible. At the initial assessment safety screening is completed by the fitness professional often using a standardised pre activity readiness questionnaire or PAR-Q. Exercise sessions are supported by fitness professional and reflect individual requirements but normally last thirty minutes to one hour. The exercise content is set from the initial profile of the client's fitness, their goals and the neurological condition. Appropriate equipment is used with exercise performed at the required intensity, duration, frequency and progressed according to exercise prescription principals in order to achieve the desired outcome. Monitoring of clients and feedback to referring health professionals is standard practice in exercise referral schemes

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Findings: AIM 4

To determine the need for a trial to determine whether a physical activity provision support system is effective and cost-effective in improving activity levels for neurological patients compared with waiting list control patients and to inform the design of such a trial

Background

We have developed a physical activity support system (PASS) to support community based exercise in people with long term neurological conditions (LTNC) (described above) designed to alleviate many of the concerns that people with neurological conditions have. This phase of the research examined the feasibility and effect of supported community exercises supported by PASS for people with LTNC.

Methods

People with neurological conditions including multiple sclerosis, Parkinson's disease, motor neurone disease, a range of neuromuscular conditions, traumatic brain injury and cerebral palsy from Oxford and Birmingham were recruited through local neurological services and DENDRON to the Long Term Individual Fitness Enablement (LIFE) study. The study was approved by Oxfordshire and Birmingham Ethics Committees, and registered with UKCRN (4121) and EudraCT (2007-004454-85). As this was an exploratory trial, no formal power calculation was performed: however, we estimated that a total sample size of 100 should allow the detection, with 90% power, of a moderate to large treatment effect of 2/3 of a standard deviation.

Design

A Phase II randomised controlled trial with blinded assessor

Protocol

Participants were randomly allocated to an immediate community exercise group or a control group who were offered a later entry into the programme. Randomisation was achieved by computer generated random block sizes of 2 and 4 by Birmingham Primary Care Clinical Trials and Research Unit and

stratified by Barthel Index and condition. Allocation and block size was concealed from the assessor and study coordinator. Study physiotherapists were informed of allocation by the trials unit statistician via email following baseline assessments, and revealed group allocation to the participants. Participants and the study physiotherapists were not blinded to group allocation. Participants were asked to refrain from tobacco, food, drink and exercise or physical activities for at least 2 hours before attending assessment sessions. A researcher masked to allocation assessed participants (assessors reporting being aware of group allocation in ~15% of cases). Participants were informed and reminded through the trial that the assessor was blinded to treatment assignment for the duration of the study. Only the study statisticians and the data monitoring committee saw unblinded data, but none had contact with study participants.

Patients with a reliable and confirmed diagnosis of a long-term neurological condition determined by local neurologists were invited to take part in the study Patients were eligible for inclusion in the study if they were aged 18 years or over, able to engage with training in an exercise facility or gym, able to walk 10 metres using an aid or assistance, and able to participate for the complete duration of the study. Patients were excluded if they were unable to meet the study criteria, had any contraindications to exercise [20,21] or were unwilling to participate in the programme. All patients who gave informed consent were studied at baseline and followed up at 3 months on a range of measures. These assessments were carried out at the Oxford Centre for Enablement at the Nuffield Orthopaedic Centre, and at the University of Birmingham.

Baseline demographic information recorded included diagnosis, age, gender, height, time since disease onset, independence in activities of daily living (ADL) using the Barthel ADL Index[22] [0 to 20, with higher scores

indicating higher levels of independence] and cognitive function using the short orientation memory concentration test[23][0 to 28, with higher scores indicating higher cognitive function].

The primary measures were activity levels as recorded by gym attendance and overall activity measured by the Physical Activity Scale for the Elderly (PASE) [24] a self-report questionnaire of activities undertaken in home, work and social domains over the previous seven days, classified according to the number of days and hours for a range of activities such as walking, exercise, and household activities [scored 0-400 where a higher score indicates a greater level of physical activity] [24].

Secondary measures included: individual daily step counts measured for eight consecutive days following the assessment using an accelerometer, the Step Activity Monitor (SAM TM OrthoCare Innovations, Cyma Corporation)[28, 29]; falls occurence[25]; the two minute walk distance using a sixteen metre indoor walkway; the time to walk 10 metre [best of three] [22];, maximal isometric muscle strength and power using a 'leg power meter' (Medical Laboratory Workshops, Nottingham) [26] and isometric muscle strength from legs (hip flexor/extensor, knee flexor/extensor and ankle flexor/extensor); grip strength measured using a hand grip myometer Lafayette, US)[27]; and weight (Tanita Scales, UK, kg) . Health status was measured using the health status measure (General Health Status questionnaire SF-36)[28], and fatigue was measured using the Fatigue Severity Scale[29] (Krupp et al. 1989) with a mean score of 4 or more defined as an individual having significant fatigue[30].

Exercise Intervention

Participants allocated to the exercise programme undertook a community gym-based exercise intervention immediately following randomisation. The intervention, comprising of gym induction and exercise sessions, took place at Inclusive Fitness Initiative (IFI) gyms and IFI pending centres in Birmingham and Oxford. IFI gyms offer an inclusive exercise environment, a physically accessible fitness facility, equipment designed, tested and used by people with disabilities, and fitness staff with expertise in exercise prescription. To support the intervention, the Physical Activity Support System (PASS) detailed previously was utilised. This included the provision of information on participating in exercise for participants (based on the expert patient model), information on exercise for neurological conditions for the fitness trainers, and practical advice and support for both patients and fitness trainers from a physiotherapist who was present at the initial exercise induction and gave further support as needed. The exercise intervention, delivered by the fitness professionals, was self-directed by patients to meet their own fitness goals but included endurance, muscle strength, flexibility and cardiovascular fitness components at a therapeutic level. Following induction, participants attended the gym for a 3 month period. Participants were informed of the current government guidance for exercise (five aerobic sessions and two strength sessions a week)[31] and encouraged to attend regularly. The number and length of sessions was then determined by each individual. Travel and gym costs were met by the study.

Participants allocated to the control group continued with their standard care for the 3-month period between their first and second assessment. Following the second assessment, control participants were offered the 3-month exercise intervention; they knew that this would occur.

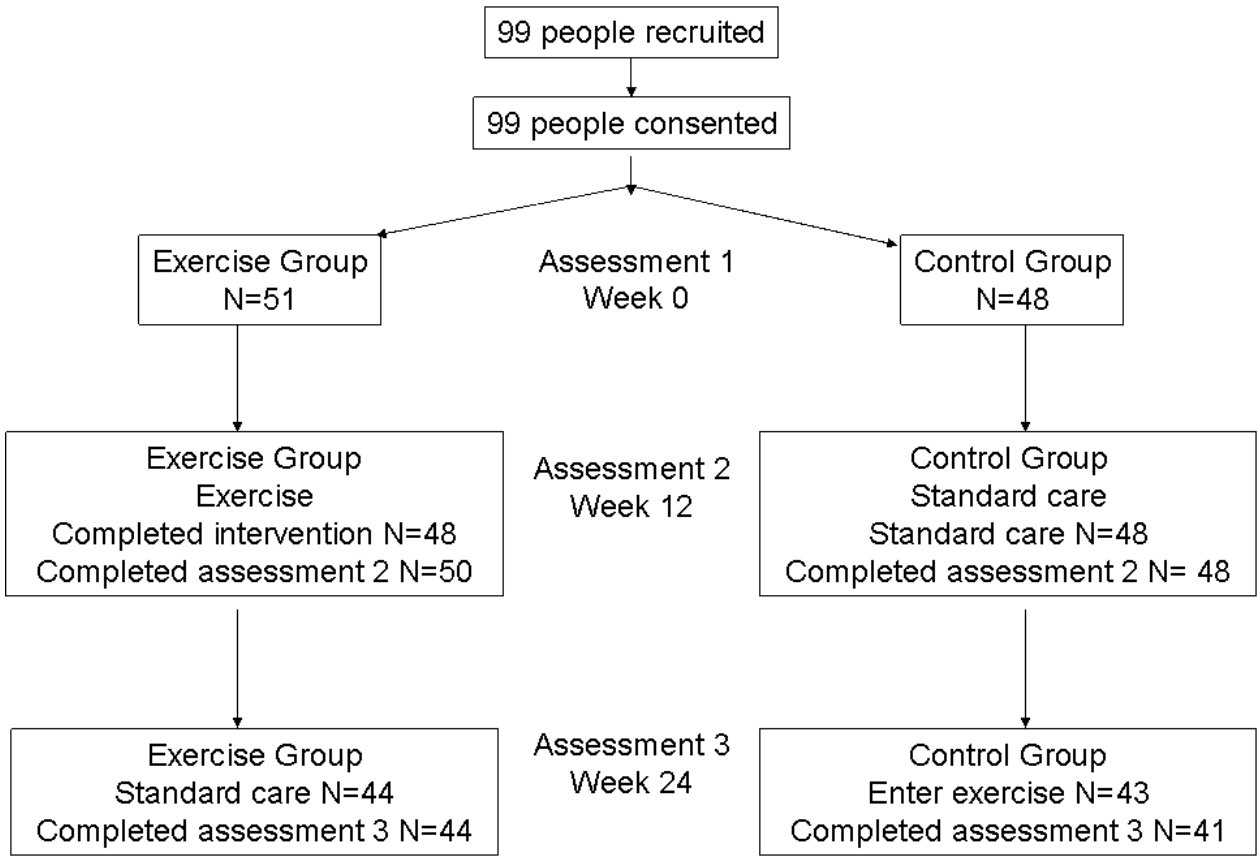
Data analysis and statistics

Data analysis was carried out according to a pre-established analysis plan. Descriptive statistics were calculated for demographic characteristics, attendance at centres, components of the PASE, 10 metre walk (seconds), two-minute walk distance (metres), Step Activity Monitors (steps taken), health (SF12) and fatigue (FSS). Independent t tests were carried out on the scores of the control and exercise group on all measures at baseline. To estimate effect sizes, intention-to-treat analysis was used. Missing data points were less than 5% on main measures and therefore data imputation was not performed. On observation of the high level of variability in baseline measures, and investigate change in primary and secondary measures, an independent t test equal variance was employed on the change scores. Further effect size analysis was then performed on the change scores. All the above analyses were performed with the SPSS version 17.0 (SPSS Chicago, Illinois, USA). Intention to treat analysis (all individuals entering the study were reassessed whether they adhered to the intervention or not) was performed so as to give a true picture of the effect of the intervention and avoid a bias of excluding from the analysis individuals who dropped out of the intervention.'

Results

There were no protocol deviations. Ninety-nine patients with LTNC consented to participate in the study. Baseline characteristics for participants are given in table 1.

Figure 1 Consort flow diagram of people through the exercise intervention


99 people recruited
99 people consented
Exercise Group
N=51
Assessment 1
Week 0
Control Group
N=48
Exercise Group
Exercise
Completed intervention N=48
Completed assessment 2 N=50
Assessment 2
Week 12
Control Group
Standard care
Standard care N=48
Completed assessment 2 N= 48
Exercise Group
Standard care N=44
Completed assessment 3 N=44
Assessment 3
Week 24
Control Group
Enter exercise N=43
Completed assessment 3 N=41

As shown by Figure 1 only one patient in the exercise group was lost to follow-up. Within the exercise group two patients were considered intervention protocol violators. The proportion of patients experiencing any adverse event was similar between the exercise and control groups: two (3.9 %) of exercise and three (6.25%) of control, respectively, the proportion of patients experiencing a severe expected related adverse event (both cardiac related), as judged by the investigators, was: one (1.9 %) of exercise versus one (2.1 %) of control of the 99 patients, respectively.. Figure 1 shows the flow of participants through the study. Only the intention to treat analysis is reported. The incidence of falls in the control group remained similar across assessment one and two with mean 11 (range:1-5) to 12 (1-6) falls. In the exercise group there was a trend of reduced number of falls from 18 (1-9) to 15 (1-6) (p=).

People in the intervention group (Data available n= 48) attended an average of 14 (SD 9, range 0-39) total exercise sessions with attendance being higher in the first six weeks: n= 43 attended a mean of eight sessions (SD 5, range 1-19) in the first six weeks and six (SD 5, range 0-20) in the last six weeks. Nineteen (44%) of participants completed one or more, four (8%) two or more and one, 2 % three or more sessions a week over the 12 weeks.

Table 1 Baseline Characteristics of Participants

	Delayed Exercise (N=48)		Immediate Exercise (N=51)		p-value	Total (N=99)	
	N	**Mean (SD)**	**N**	**Mean (SD)**		**N**	**Mean (SD)**
Gender (male)	48	28 (58%)	51	23 (45%)	0.2	99	51 (52%)
Age (Years)	48	57 (12.31)	51	55 (13.43)	0.4	99	56 (12.88)
range		*26-82*		*23-75*			23-82
Barthel Index	48	19 (2.17)	51	19 (1.76)	0.8	99	18.57 (1.96)
range		11-20		16-20			13-20
Weight (kg)	47	80.9 (13.43)	50	78.4 (16.20)	0.4	97	79.6 (14.90)
Height (m)	48	1.7 (0.09)	51	1.7 (0.10)	0.4	99	1.7 (0.09)
BMI (kg/m^2)	47	27.3 (4.14)	50	26.7 (4.60)	0.5	97	27.0 (4.37)
range		20-40.6					18.2-40.7
Distance walked in 2 mins (m)	44	105.9 (46.87)	49	98.6 (48.71)	0.5	93	102.0 (47.73)
range		19.8-188		10-192			10-192
Time taken to walk 10m (s)	36	10.0 (4.92)	44	12.3 (9.10)	0.2	80	11.3 (7.56)
range		3.59-23.1		4.16-44.47			3.59-44.47
Left Hand Grip (kg)	36	29.7 (10.92)	45	25.0 (11.23)	0.06	81	27.1 (11.27)
range		6-49		4.5-50.5			4.5-50.5
Right Hand Grip (kg)	36	29.4 (12.08)	45	26.7 (12.51)	0.3	81	27.9 (12.32)
range		2-51		6.5-57			2-57
Power - left (N)	40	82.1 (69.3)	39	81.4 (57.22)	0.9	79	81.8 (63.22)
range		0-306.2		0-270.2			0-306.2

Power - right (N)	33	80.7 (80.2)	35	84.15(66.23)	0.9	68	82.5 (72.84)
range		0-363.3		0-306			0-363.2
Leg strength megascore	47	0.05 (0.63)	51	-0.02 (0.69)	0.6	98	0.01 (0.66)
PASE	48	88.2 (57.31)	50	96.3 (73.78)	0.5	98	92.3 (66.02)
range		5-253.8		0-311.22			0-311
FSS	46	4.4 (1.33)	51	4.4 (1.55)	0.9	97	4.5 (1.44)
range		1.33-6.67		1-7			1-7
SOMC	37	25.8 (3.39)	44	26.3 (2.56)	0.4	81	26.1 (2.97)
range		16-28		19-28			16-28
SF-36: Mental Component *range*	35	50.5 (12.67) 24.76-66.43	43	51.4 (12.43) 29.9-72.79	0.8	78	50.9 (12.46) 24.76-72.79
SF-36: Physical Component *range*	35	28.6 (11.13) 7.34-53.46	43	28.9 (11.56) 7.67-52.73	0.9	78	28.8 (11.30) 7.34-53.46
Falls (yes): median (range)	11	1 (1 – 5)	18	2 (1 – 9)	0.1	29	1 (1 – 9)
SAM	44	3051 (2347)	46	2827 (2129)	0.6	90	2936 (2229)
range		30-9455		16-8300			16-9455

SAM: Step activity monitor (step count)

SF36: General Health Status questionnaire; Ranges from 0 – 100 (high score = good)

SOMC: short orientation memory concentration examination; Ranges from 0 – 28 (high score = good)

FSS: Fatigue severity scale; 4+ = fatigue (high score = bad)

PASE: Physical activity scale for the elderly; Ranges from 0 – 400+ (high

score = good)

Power leg extension press

Leg strength megascore : [Z scores were calculated for each leg muscle and then a megascore for all muscles was calculated by averaging the Z-transformed items for all leg muscles]

Table 2 Change scores (Assessment 2-1) for the exercise and control group with between group independent T test = variance, one tailed and effect size data

Change scores Ass2- Ass1	**Delayed Exercise (N=48)**			**Immediate Exercise (N=50)**			**P value**	**Effect size**
	N	**Mean**	**(SD)**	**N**	**Mean**	**(SD)**		
Weight (kg)	41	-0.37	2.72	45	-0.44	2.66	0.46	-0.02
BMI (kg/m2)	41	-0.13	0.95	45	-0.15	0.95	0.45	-0.03
2 mins (m) distance	**43**	**0.82**	**21.58**	**45**	**7.13**	**20.23**	**0.08**	**0.30**
10m walk time (s)	36	0.04	3.29	41	-0.20	5.35	0.41	-0.06
Left Hand Grip (kg)	**36**	**0.18**	**5.07**	**42**	**1.75**	**4.34**	**0.07**	**0.33**
Right Hand Grip (kg)	36	0.90	5.39	42	1.35	4.35	0.69	0.09
Power - left (N)	**25**	**10.23**	**47.53**	**29**	**27.38**	**47.20**	**0.10**	**0.36**

Power - right (N)	18	12.64	39.35	25	14.43	40.14	0.44	0.05
Leg strength megascore	35	0.09	0.71	44	0.14	0.62	0.38	0.07
PASE social	35	15.08	32.57	44	11.61	29.16	0.31	-0.11
PASE home	**35**	**9.34**	**42.26**	**43**	**-1.37**	**28.85**	**0.10**	**-0.30**
PASE work	35	9.17	27.34	44	1.30	34.46	0.37	-0.25
PASE	46	25.43	62.23	49	11.12	48.11	0.11	-0.26
FSS	45	-0.15	0.91	50	-0.30	1.64	0.38	-0.12
SOMC	37	0.49	3.48	42	-0.30	1.64	0.08	-0.31
SF-36: P component	33	0.66	8.79	42	4.12	9.31	0.05	0.38
SF-36: M component	33	1.10	11.95	42	0.86	12.10	0.47	-0.02
SAM	39	-377.87	1055.48	38	-218.63	1567.94	0.30	0.12

SAM: Step activity monitor (step count)

SF36: General Health Status questionnaire; Ranges from 0 – 100 (high score = good)

SF-36 P component: physical

SF-36 M component: mental

SOMC: short orientation memory concentration examination; Ranges from 0

– 28 (high score = good)
FSS: Fatigue severity scale; 4+ = fatigue (high score = bad)
PASE: Physical activity scale for the elderly; Ranges from 0 – 400+ (high score = good)
Power leg extension press
Leg strength megascore : [Z scores were calculated for each leg muscle and then a megascore for all muscles was calculated by averaging the Z-transformed items for all leg muscles]
Mixed model ANOVA between groups analysis $p \leq 0.05$ = *
Effect size: calculated from change scores (μ1 – μ2/s) Cohen's criteria (Cohen: 0.1 - 0.3 = small effect, **0.3 - 0.5 = moderate effect, > 0.5 = large effect**)

Table 2 shows change data for the intervention period and effect size and level of significance. Effect size analysis on the change data for the control and exercise group revealed moderate or above effect sizes in two minute distance, left hand grip, left leg power and in the SF36 RP, SF, CH and physical component scores. Moderate effect sizes are highlighted in bold. Interestingly activity levels as measured by the PASE reduced during the intervention in the exercise group.

Discussion

When considering the feasibility of the developed physical activity system for supporting community exercise in LTNCs, participants adhered to the community exercise programme well, generally achieving 14 attendances over the 12 weeks and attendance of more than once a week in 44% of participants. This level of adherence compares favorably to primary care exercise referral schemes running in a subset of the exercise centres (42%

completion of weekly twelve week scheme) [27] and ties in with evidence from exercise referral schemes where 66% of people nominate once a week as their preferred exercise frequency [32]. We found that community exercise supported in this way was well tolerated with only three dropouts during the exercise intervention.

We found no significant changes in our outcome measures. This was expected considering the small sample size, range of neurological conditions, heterogenous level of mobility and disability in the study, and complexity of delivering the intervention to the range of individuals. However when analysing the change data we observed moderate effect sizes in some markers of mobility and wellbeing, which is a positive finding that supports the need for a fully powered follow on Phase III trial. The ability of this scheme to support activity in the longer term and associated health and wellbeing benefits and cost/benefit analysis now needs to be explored.

Our study does have significant limitations. This is a small phase II RCT scale study of 99 patients, and any future study will need to be powered for associations and statistical models. Our group was generally high functioning which may be a bias when attempting to recruit to exercise studies[28]. Finally the optimal dose and content of exercise interventions for people with LTNC has not been established and we may have given too much or too little. To evaluate optimal exercise dose was outside the remit of this study but in our provisional analysis we found no relationship between the number of sessions attended and any of the body function, activity or participation outcome measures, which suggests that the optimal dose question is multifactoral in the range of neurological conditions studied. Future studies are needed to explore the optimal content of an exercise programme in relation to optimal mobility, health and wellbeing benefits across a range of

people.

The observation of reduced physical activity levels in response to the exercise intervention needs further exploration. This finding may be due to a lack of sensitivity of the PASE questionnaire to changes in physical activity occurring in the social exercise domain from the intervention or due to a reduction in physical activity levels in other domains i.e. at home or other social physical activities as a coping response to the targeted exercise intervention. Certainly reduced physical activity in other domains has been observed in other groups participating in exercise. However we did observe moderate effect sizes in outome measures including the primary outcome measure, which would suggest that the targeted exercise intervention (exercise: physical activity that is planned and structured and targets one or more aspects of fitness) is beneficial compared to everyday physical activity (physical activity: encompasses anything that involves movement, from participating in sport, to washing up) .

Low levels of physical activity and exercise in people with LTNCs who were expressing a desire to be more active initiated this programme of research. We set out to develop a physical activity support system for people with LTNC to exercise in the community alongside other exercise referral schemes and investigate its implementation. Our findings so far are positive and suggest similar participation can be achieved as in standard exercise referral schemes despite the complexity of the physical and/or cognitive impairments in this group of individuals. Considering the increasing burden of LTNCs in the UK aging population, our findings support the funding of a Phase III trial.

Suggested summary guidelines for creating or managing an 'exercise' facility for supporting people with LTNCs

The following barriers and facilitators should be addressed.

Barriers:

- Practical and organisational factors - a lack of suitable local gyms that can be accessed easily and safely
- Equipment – a lack of equipment suitable for and usable by disabled people.
- Transport - often unavailable, inappropriate and costly
- Negative personal experiences and attitudes - fear and embarrassment of exercising (especially in the presence of obviously fit and healthy people?)
- Perceptions that fitness instructors will lack knowledge about their condition and how to help them participate in exercise safely and effectively

Facilitators:

- Individually tailored gym programmes
- An exercise place that actively supports people with similar conditions and disabilities
- An exercise programme that considers individual motivators for exercise, including factors such as weight control or body shape

Suggested system

The support system has five key components

- Access and transport advice

- The Fitness Instructor
- The Gym
- Health professional support (physiotherapist)
- How to exercise safely handbook (www.brookes.ac.uk/lifesci/lifepass).

1. Access and Transport Advice

Advice should include: practical issues including where to find the gym, how to use local voluntary car services, taxis, or public transport, and where to park. Community or hospital therapists or health workers may help individuals decide the best route to their local gym by providing advice and transport options. Transport that is sustainable (i.e. practical and affordable after completion of the project) should be encouraged

In our pilot study where this support was not provided; patients often failed to initiate or delayed starting exercise programmes because of concerns that included: how to get the gym, find their way around the building, and/or access changing rooms and toilets (37).

2. The Fitness Instructor

The handbook details what to expect at their first appointment. Information is provided of how an exercise programme will be supported, and to encourage participants to express their hopes, health and fitness needs to the fitness instructor who will work with them to design their individual programme.

The Register of Exercise Professionals level 3 or above (REPs) fitness

trainer should always available at the first session. Ideally this person will be REPs level 4 qaulified with skills in neurological populations or long-term conditions. At the first meeting the fitness instructor was introduced to participants by a physiotherapist. Having completed a safety screening assessment using a standardized pre activity readiness questionnaire or PAR-Q (38) the fitness instructors profiled participants and instructed the individual how to perform each exercise and use the equipment safely. During the first visit the participant, fitness instructor and physiotherapist established whether the equipment was accessible, usable or, how to adapt equipment for the individual. Individuals were profiled and exercise programmes developed that met individuals needs and desires but that contained cardiovascular, flexibility, muscle endurance and strengthening exercises programmed at an appropriate intensity, duration, frequency and progression according to exercise prescription principals (American College of Sports Medicine 1995) [13, 33]. Individuals need to be carefully monitored to take into account variability in a participant's condition on a day to day basis.

3. The Gym/fitness centre

Inclusive Fitness Initiative (IFI) gyms can be used to deliver the intervention (http://www.inclusivefitness.org/). The IFI is a charitable project that focuses on creating a structure to support both disabled and non-disabled people to exercise. Accreditation for the IFI programme requires the gym to fulfill certain criteria, including building access, equipment and staff training. However, Inclusive Fitness Initiative Gyms are not available in all settings in the UK. Other facilities can be appropriate as long as they meet access, equipment and staff attitude

parameters set out by the Disability Discrimination Act (2005).

In general the following requirements were found to be important:

5. Access – there should always be good physical access to the gym and fitness area with changing rooms and toilet facilities for everyone.
6. Fitness equipment – There should be fitness equipment suitable for people with a range of disabilities. Fitness equipment should include adaptable or removable seats for people in wheelchairs with room to manoeuver around equipment.
7. Communication – Exercise facilities ideally should include induction loops for the hearing impaired and appropriate signage for visually impaired and email, internet or phone systems to enable easy booking of exercise sessions. Staff at the exercise facility should have been provided with disability awareness training to ensure they are able to communicate with disabled people and listen to their needs.
8. Monitoring – Fitness instructors should be appropriately qualified (REPS level 3 or above) to prescribe, monitor and adapt exercising programmes.

4. Health professional/worker

In order to address the concerns of people with LTNC regarding individuals supporting exercise having appropriate knowledge of their condition a health worker was found to play an essential role in linking health to fitness services. A physiotherapist is well qualified to provide the role of support into community exercise facilities and physiotherapists were specifically highlighted by people with LTNCs as their preferred

professional in this role. Elsewhere it may be appropriate for this to be different and depend on local service structures. The physiotherapist was the primary contact for the participant and fitness instructor for support and information on safe appropriate exercise considering their condition. From Phase I work the importance of supporting the initial visit by arranging and attending the first appointment has been stressed. For every participant, typically three physiotherapy supports were given (face to face or telephone) over the twelve-week period. Many preferred on-going support using phone and text communication especially as they were able to text comments to the physiotherapist at their convenience. Exercise groups for participants or buddying systems may help attendance and adherence.

The physiotherapist should have a range of specialist skills in the assessment and treatment of long term conditions and experienced in exercise delivery. They should have specialist knowledge and expertise in evaluating a range of impairments associated with long term conditions that might directly affect exercise such as problems with tone, muscle power, sensation and range of movement and understand the medication interactions related to these impairments or associated impairments. The overall aim was for the physiotherapist to ensure the exercises of the participant's choice could be safely and effectively undertaken as independently as possible without the need for one to one support. When the fitness trainer was inexperienced in exercise prescription in a particular condition, typically rarer LTNC, the physiotherapist provided appropriate information and support.

5. The handbook

Considering the evidence for supported evidence a handbook can be

given out to all patients which containspractical advice on how to safely exercise and gain maximum benefit.

Excerpt from Handbook (www.brookes.ac.uk/lifesci/lifepass)

> 'You now need to work out how it will fit in with your daily routine. This will be different for everyone. You may eventually exercise for about twenty to thirty minutes depending on your level of fitness and wellness but initially this may be a lot less, say five minutes, and you will build up gradually……
> It may not be unreasonable to assume going to the gym could take about two hours of your day. If you have a set routine for getting up in the morning or to get to work or start your day then try planning where exercise fits into your daily routine…..
> Make it easy on yourself so that you get the maximum benefit from your gym experience'

The handbook contained information and help on setting realistic exercise related goals such as

> ' you want to strengthen your legs so you can stand for longer, that you enjoy the social side of exercise, or, that you wish to be healthier and lose weight'

The handbook also included advice on some of the more common symptoms someone new to exercise might typically experience and regarding safe effective exercise participation.

Such as:

> Muscle endurance
> If you have muscle weakness then this may lead to muscle fatigue often as a result of lack of endurance or ability to sustain a powerful muscle contraction. Once you start to exercise then it may be that this symptom reduces as the muscle is able to use its energy more efficiently and you become more able to use it.
>
> Flexibility
> Stiffness can occur because you are not moving or not able to move

about easily. Joint stiffness is also a feature of other conditions such as arthritis, wear and tear and age. As long as you do not have pain or swelling with your joint stiffness exercise should have a positive benefit. Joints contain a small amount of fluid that acts as a lubricant, a bit like oil in the car engine, and if the joints are not moving the fluid becomes thicker and stickier which in turn makes the joints feel stiffer ……Some people have spasticity or muscles that work too hard when you aren't even trying to work them. These spastic muscles are often weak and exercising them can help reduce the stiffness in the muscle.

Contractures
Contractures are where the muscles are too tight and prevent a joint moving through normal range. Contractures can happen in any muscle, commonly at the knees and hips in people who do not walk.
Contractures are very difficult to change once established and many people are given stretching exercises to do at home by physiotherapists early on in their care to try to prevent contractures. Only extreme contractures would seriously limit exercise, otherwise it is a matter of adapting the exercise to the range of movement possible.

As a final part to the handbook there was a section on 'frequently asked questions'. Such as 'Will the gym and instructors know about my condition? What should I wear? How often should I exercise? When is the best time to exercise?

Examples of Frequently Asked Questions

How much exercise should I do each week?
The British Heart Foundation recommends five sessions, of thirty minutes per week for adults or two and a half hours per week if you prefer. Many people do not achieve this amount of exercise. However ANY exercise is better than none at all so if you can only manage ten minutes that is still a great start.

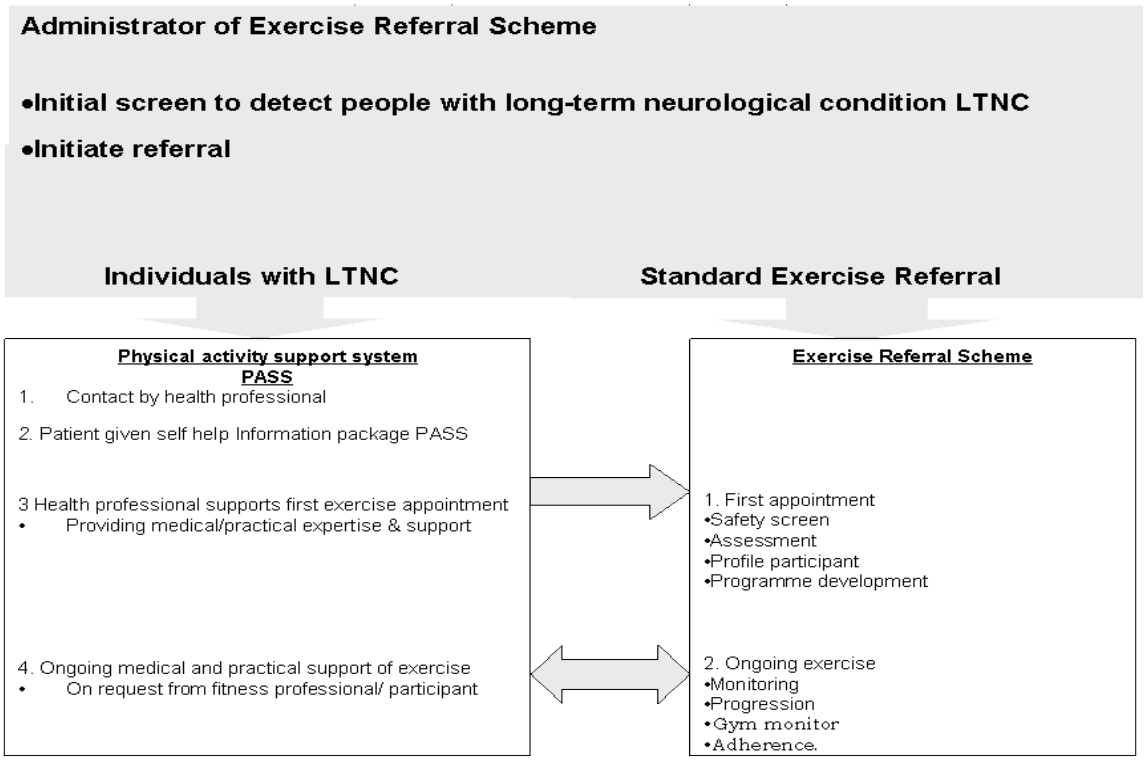
How hard should I work?
This depends on how fit you are. The British Heart Foundation recommends you exercise at a pace to suit your fitness. You should aim for light to moderate intensity to begin with which means that you will feel warmer, possibly be aware that your heart is beating faster but still be able to hold a conversation with someone. Always ask the advice of your fitness instructor as they will be able to help here. The research evidence

to date suggests that mild to moderate exercise intensities are beneficial for people with neurological conditions.

Will the exercise be painful?
The exercise you do at the gym should not be painful. You should not get any pain whilst you are exercising. You may experience some muscle aching or muscle tiredness after exercise particularly if you are not used to exercising. However these feelings should not be long lasting, they should go in two days and in fact as you continue to exercise they should be less and less obvious. is part of finding out what your limit is. If you do overdo it don't panic, ask the advice of the fitness instructor, rest for a couple of days and then return to exercise, but do a bit less than the last time.

Suggested model for implementation alongside current services and cost implications

Figure 1: Possible model for integrating the LTNC PASS alongside standard UK exercise referral



Average gym attendance was one session per week for twelve weeks, with forty four per cent (44 people) attending once per week for the twelve weeks. At the end of the study a third (33) individuals were still exercising. For the duration of the study the physiotherapist gave an average of three one-hour face to face and three 5-20 minute phone calls per patient.

Using recent calculations of Unit costs for Health and Social Care (Curtis 2009 PSSRU) the approximate per patient direct cost for delivering the exercise support system was £180 for the physiotherapist (using the

higher £45/hour figure for 4 hours contact) and £60 for the gym (12 x £5 per gym session). It is estimated if the system was initiated as per UK ERS it may incur a General Practitioner (GP) cost to initiate the referral encountering a further £35 for a GP contact of 12 minutes. In total the PASS delivery would cost an average of £275 per referral for the initial twelve weeks.

The Findings of this study in relation to the National Service Framework for Long Term Neurological Conditions

We conclude this Summary with a digest of the findings in relation to the NSF (see over).

NSF Quality requirement	Evidence from this study	Potential contribution of NSF
• QR1 *A person-centred service* • Coordination of services through the integrated assessment and planning of their health and social care needs, especially at transition to adult services • Requires a care co-ordinator with responsibility for developing a comprehensive care plan • Information needs reviewed regularly	• Individuals reported a desire to participate in community activities and be physically active as statutory services were limited but no obvious coordinated approach between NHS services and community facilities as seen in cardiac rehabilitation services • The Physiotherapist acted to link NHS to community services. This worked well with approximately 1/3 of people achieving ongoing physical activity • Careful assessment and feedback to health professionals/clinics should be encouraged	• Remind commissioners of the importance of linking NHS services to community services • Encourage health and fitness professionals to collaborate to enable this process
• QRs 4,5,6 *rehabilitation, adjustment and social integration* • Enable people with a LTNC to lead a full life in the community	• Barriers for this group appear to be overwhelming for most	• A role for health professionals to actively integrate people into community exercise with fitness professionals.

The Findings of this study in relation to other policy

The concept of the supported community exercise intervention which encourages self-efficacy and management also fits with the proposals in the recent Green paper ‘Independence, Well-being and Choice. Our vision for the future of social care for adults in England’ [24] by supporting choice.

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- Martin Timms
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Birmingham

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- Ms Nicola Brittle – Primary Care Clinical Sciences
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- Dr Peter Praamstra
- Karen Healy (PD nurse)
- Sarah Coyle (PD nurse)
- Julie Ball (PDS support worker)

- Funding

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Service User Involvement

Service users have been involved in every level of this work, with all work undertaken in full support of the 2004 Department of Health White Paper “Choosing Health” ‘Disabled people themselves, their experiences and preferences should inform policy design and delivery'. This research project was initiated by people with LTNC who on participation in an earlier home exercise programme encouraged the team to evaluate

community exercise outside the home. Service users were central and linked researchers with other current service users to obtain and represent their views on the proposed project and ensure that information from both qualitative and quantitative studies, that is important to users, was considered and fed back into later stages. Sandra Paget was an active member of the steering group and guided the study throughout. Sandra and other users have assisted the team with the dissemination of the research findings to other potential service users and providers. Users were involved following the 'Best practice guidance', (DoH 2006) 'Reward and recognition: Principles and practice of service user payment and reimbursement in health and social care'.

Outputs

Publications

Elsworth, C., Dawes, H., Sackley, C., Soundy, A., Howells, K., Wade, D., Hilton-Jones, D., Freebody, J. and Izadi, H. A study of perceived facilitators to physical activity in neurological conditions. International Journal of Therapy and Rehabilitation 2009, 16, 17-23.

Esser, P., Dawes, H., Collett, J. and Howells, K. 2009. IMU: Inertial Sensing of Vertical CoM Movement. Journal of Biomechanics. 2009 Jul 22;42(10):1578-81. Epub 2009 May 13.

Dawes, H. Editorial , The role of exercise in rehabilitation, Clinical Rehabilitation 2008 Oct-Nov;22(10-11):867-70 Impact factor 1.840

Elsworth, C., Dawes, H., Winward, C., Howells, K., Collett, J., Dennis, A., Sackley, C. and Wade, D. Pedometer step counts in individuals with neurological conditions. Clinical Rehabilitation. 2009 Feb;23(2):171-5. Impact factor 1.840

Conference abstracts followed by presentation:

H Dawes. CE Clarke, P Esser, CE Meek, S Patel, CM Sackley, AA Soundy, C Winwar (on behalf of the LIFE study group) “Long-term Individual Fitness Enablement (LIFE); Parkinson’s disease. An ongoing RCT” Southampton Neurorehabilitation Conference (SOTON) Friday 5th September 2008

Charmaine Meek on behalf of the LIFE study group “Long-term Individual Fitness Enablement (LIFE); Parkinson’s disease. An ongoing RCT” West Midlands ACPIN study day Tuesday 31st March 2009

“Long Term Fitness Enablement (LIFE) for people with long term neurological conditions (LTNC)” [submitted: awaiting decision] South West SAPC (The Society for Academic Primary Care) Regional Meeting Tuesday 23rd and Wednesday 24th March 2010

Esser P, Collett J, Dawes H, Howells K. (2008). Inertial Sensing of Centre of Mass using Quaternions. Journal of Sports Science (abstract) 2008:71 - 72.

Winward, C., Esser, P., Elsworth, C., Dawes, H. and Sackley, C. (2008). Physical activity levels in neurological populations. Journal of Sports Science (abstract) 2008:76.

Dawes, H Longterm individual Fitness Enablement with People with MS Summer 2008. Society for Rehabilitation Research Winter meeting 2008 Clinical Rehabilitation, (clinical Rehabiliation in press).

Elsworth C, Dawes H, Howells KF, Izadi H, Sackley C, Wade D Accuracy of pedometers in individuals with neurological conditions British Association of Sport and Exercise Sciences Annual Conference 2006 (Presentation)

General Dissemination

Oxford Centre for Enablement – outcome measure day 2009-12-04

Clinicians in Birmingham and Oxford trusts
Oxfordshire Community physiotherapists LIFE update 2008
MS, NMD and PD local and national charity meetings 2006 -2009
Oxford Brookes University Bsc Physiotherapy and Sport Science Students 2006-2009
ACPIN Surrey Branch November 2010

Reports

Foundation for Assistive Technology (FAST) The 2008-2009 edition of the Annual Parliamentary Report on Assistive Technology Research and Development July 2009 [report on LIFE study] FAST (http://fastuk.org/home.php).

Invited presentations

UK Physiotherapy Research Society – Exercise in Long-term Neurological Conditions Manchester Summer 2008

Dendron rehabilitation in LTNC Leeds October 2008

Neurorehabilitation within Sensorimotor Networks: Current Concepts and Recent Advances. An interdisciplinary congress. Referents: Heidi Johansen-Berg, Helen Dawes, Peter Grieshofer, Eugen Gallasch. Graz June 2007

Awards

Awarded Groom&Al-Qahtani 2009 prize for Best Oral Presentation. School of Life Sciences, Research Student Symposium, January 2009 P

Esser

Patent

Esser P, Collett J, Dawes H, Howells K. Inertial sensing of centre of mass using quaternions. (2008)

Capacity building

This funding has enabled the development of an ongoing research programme investigating physical activity and exploring its effects in PwLTNCs. The research project built on an emerging programme of research from the Movement Science Group at Oxford Brookes University in PwLTNCs. The group which was started in 2003 has developed into an 18 strong multidisciplinary group. This funding supported the expansion of current capabilities and research skills and enabled the establishment of long lasting working collaborations including those with Birmingham University, the University of Oxford, Local NHS trusts and the fitness industry.

Specifically With regards to capacity building at the University, the PI has been awarded a Professorship. As a result of this study three of the research assistants have been registered for a PhD and one for an Mphil. The Clinical exercise unit has been awarded further funding for equipment for future intervention studies and the group research funding for further trials exploring the utility of the GAIT measure and for safe effective exercise in a range of neurological conditions and in drug using offenders. Certain areas of research capacity such as the measurement of microassays, measurement of mobility, brain and muscle imaging and clinical trials have been subsequently developed both in house and through collaborations.

The research has provided research training at many levels and resulted in the development of a research team with expertise and experience in exploring rehabilitation/exercise interventions. During the course of the study we have involved 5 BSc students working on their final year dissertations. Students have all received GCP training, specific training for the techniques involved in the study and experience of research in PwLTNCs. In collaboration with the Fitness Industry Brookes have developed a distance learning course [currently in the process of achieving register of exercise professionals level 4 status and 20 M level CATS points] for physiotherapists and fitness professionals supporting exercise in people with LTNCs. The first run of the course is due to start in July 2010

Additional Funders

- Thanks to the Parkinson's Disease Society ,the National Institute of Health Research and Birmingham University

Next steps for Research

- Phase III trial evaluating ongoing community exercise physical activity support system for people with LTNC
    - To evaluate change in physical activity, health and wellbeing measures
    - To explore the relationship of exercise uptake to change in health and wellbeing.
    - To explore factors affecting successful implementation of physical activity into everyday lives

    - To explore cost/benefit
- Phase I investigations of safe, optimal exercise dose for people with LTNC

Disclaimer

The views and opinion expressed are those of the author and do not reflect those of the Department of Health.

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