

RI LTNC Newsletter

Edition 5: Winter 2009

First wave of final reports

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In this edition I am pleased to tell you about progress with the first set of results from the research initiative. One study has now been completed and published, several are in the process of being finalised and three more studies are due for completion early in 2010. In our last newsletter we featured an interview with a researcher involved in the study entitled "*Transition to adulthood: the experiences and needs of young men with Duchenne Muscular Dystrophy (DMD), and their families*". It can now be downloaded from www.ltnc.org.uk in full or as a summary.

Two studies are also in the process of completing the reporting stage prior to publication. The first is "*The needs for, and experiences of, services, by individuals with progressive neurological conditions and their carers: a benchmarking study*" and the second is "*Long-term involvement in fitness enablement (LIFE) study*".

We expect to publish these on our web-site in the New Year. They will be closely followed by reports on the "*Quality Neurology Project*" and the "*Integrated services for people with long-*

term neurological conditions: an evaluation of the National Service Framework".

If you do not already receive an email alert from us, but would like to, please write to sophie@ltnc.org.uk so that you're added to our mailing list.

The initiative is due to finish in 2011, when a report summarising all the findings from the research and making recommendations for the future, will be published.

The LTNC newsletter complements our dedicated website, www.ltnc.org.uk, with the aim of spreading the word as widely as possible about this initiative from the Department of Health's Policy Research Programme. An 'easy-read' version of this newsletter can be downloaded from the site, and other accessible formats can be produced on request. I hope you find it interesting. Please let us know what you think!

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LTNC Focus

A preview of the next two studies to finish

The needs for, and experiences of, services, by individuals with progressive neurological conditions and their carers: a benchmarking study

Researcher: Professor Ray Fitzpatrick, email: raymond.fitzpatrick@nuffield.ox.ac.uk

The main aim for this research was to provide a clear evidence base of people's experiences of services in order to be able to start measuring the impact of the NSF on the quality of service provision.

A large-scale survey of people with 3 different neurological conditions (and their carers) was undertaken after extensive preparatory work. This included literature reviews, qualitative interviews to inform the design of the survey and piloting it with people affected by one of the conditions. People with LTNCs were recruited to the survey through membership of the 3 main

support organisations and they, in turn, recruited carers.

This resulted in 2,563 individuals and 1,910 carers returning questionnaires. Early indications are that the study has generated a wealth of new information about people's experiences and perceptions of services, including how well they currently meet the NSF's Quality Requirements.

The full report will be made available on the website in early 2010 as soon as the final stage of the reporting process has been completed.

Long-term involvement in fitness enablement (LIFE) study.

Researcher: Dr Helen Dawes, email: hdawes@brookes.ac.uk

This innovative research study aimed to establish how people with LTNCs would like to be supported to do exercises; to provide information on what community facilities people with LTNCs can use easily, and to determine whether exercise delivered in a leisure centre, combined with a "Physical Activity Support System" (PASS), is effective.

The work started from the premise that regular exercise provides health and social benefits for all, but that people with LTNCs are not very likely to do it. Although they may get some support to take exercise via the NHS, it is usually time-limited and intermittent. Many people with LTNCs could use their local leisure centres, which would be a relatively low-cost option, but not many of them do. So what would make the difference so that more people use them?

The study also aimed to provide evidence for a larger trial which would test how effective and cost-effective supported exercise for people with

LTNCs is. It involved the use of sophisticated technology to measure and monitor the mobility of people with different neurological conditions – by using gait parameters. It also led to the development of the PASS, a handbook and the involvement of fitness trainers and physiotherapists.

Preliminary findings indicate that participants adhered well to the programme, but that individuals did not necessarily increase their overall activity levels, suggesting that they might have adapted their weekly routines by reducing activities in other ways. However, although there was no significant change in outcomes, there appear to be signs that health and well-being were moderately affected and this is an aspect that needs further exploration.

The full report will be made available on the website in early 2010 as soon as the final stage of the reporting process has been completed.

LTNC Studies

Information & updates

For more details about each project, and to access the latest research reports, follow the project link shown, or go direct to the LTNC website - www.ltnc.org.uk.

Evaluation of the NSF for integrated services for people with LTNCs (2006-2009)

Researcher: Dr Sylvia Bernard
email: smb509@york.ac.uk

Project link - www.ltnc.org.uk/research_files/Evaluation_of_NSF.html

Support for carers: an investigation of support needs and the cost of provision (2006-2009)

Researcher: Dr Diana Jackson
email: diana.m.jackson@kcl.ac.uk

Project link - www.ltnc.org.uk/research_files/Support_for_carers.html

Long-term involvement in fitness enablement (LIFE) study (2006-2009)

Researcher: Dr Helen Dawes
email: hdawes@brookes.ac.uk

Project link - www.ltnc.org.uk/research_files/LIFE.html

Defining the palliative care needs of people with late-stage Parkinsons Disease, Multiple System Atrophy and Progressive Supranuclear Palsy

Researcher: Tariq Saleem
email: Tariq.Saleem@kcl.ac.uk

Project link - www.ltnc.org.uk/research_files/Defining_palliative_care_needs.html

Quality Neurology (2007-end of 2009)

Lead Applicant: Alun Davies, MS Society
email: adavies@mssociety.org.uk

Project link - www.ltnc.org.uk/research_files/Quality_Neurology.html

Review of Epidemiology and Service Use in Rare LTNCs (RESULT) study (2009-2010)

Lead Researcher: Prof Cath Sackley
email: c.m.sackley@bham.ac.uk

Project link - www.ltnc.org.uk/research_files/RESULT_study.html

Carers of people with LTNC & respite/ replacement care (2008–2010)

Lead Applicant: Prof. Lynne Turner-Stokes
Researcher: Dr Diana Jackson
email: diana.m.jackson@kcl.ac.uk

Project link - www.ltnc.org.uk/research_files/Carers_of_people_with_LTNC.html

A case study on the impact of inclusive practice in Neuro-Rehabilitation/Neuro-Psychiatry services (2008-2010)

Lead applicant: Dr Tina Cook, Northumbria University
email: tina.cook@northumbria.ac.uk

Project link - www.ltnc.org.uk/research_files/impact_inclusive.html

Mapping Vocational Rehabilitation Services for people with Long Term Neurological Conditions (2009-2010)

Lead Applicants: Prof. Diana Playford and Dr Kate Radford
email: d.playford@ion.ucl.ac.uk

Project link - www.ltnc.org.uk/research_files/mapping_vocational_rehab.html

Research news

New study complements Vocational Rehabilitation Research

The study, called: “An evaluation of Community Rehabilitation Services for people with LTNCs”, is being undertaken by Dr Helena Morris, Research Associate, King’s College. It has been commissioned by the NHS SDO R&D Programme which aims to examine the type and amount of rehabilitation that people with LTNCs receive in the community and their level of satisfaction with these services. It is hoped to identify what influences whether they receive low, medium or high levels of rehabilitation, and what they and their carers think are the major barriers to receiving such services. The study will pilot the use of a LTNC register in the London region, to see if this assists in follow-up, and will also examine the cost-effectiveness of services.

It is planned as a longitudinal cohort study. People will be recruited when they are discharged from each of the nine specialised neuro-rehabilitation units that form part of the London Neuro-rehabilitation Consortium. They will then be assessed through questionnaires at 4 weeks, 6 months and 12 months post-discharge. Researchers will also measure neurological impairments, physical, cognitive and behavioural disability, needs for care and support, community integration and participation, carer ‘burden’, client satisfaction and perceived barriers to services and service utilisation. It is hoped that this will allow them to build up a picture of where the gaps are, and how they can best be overcome.

Glossary of initials

Initial or abbreviation	Explanation
ACPIN	Association of Chartered Physiotherapists in Neurology
ADASS	Association of Directors of Adult Social Services
AT	Assistive Technology (AT, defined as any product or service designed to enable independent living for disabled and older people).
CR	Community Rehabilitation (CR means providing specialist nursing, physiotherapy, occupational therapy, psychological support and other interventions to regain and maintain maximum functional abilities)
DDA	Disability Discrimination Act
FAST	Foundation for Assistive Technology
LTNC	Long Term Neurological Conditions
NIHR	National Institute for Health Research
NRES	National Research Ethics Service
NSF	National Service Framework
PCT	Primary Care Trust
QR	Quality Requirements (set out in the National Service Framework)
RI	Research Initiative
SDO	Service Delivery and Organisation, one of the NIHR funding programmes
VR	Vocational Rehabilitation (VR means providing training and support in developing skills or learning a new trade with the aim of getting a job)