

# RI LTNC Newsletter

## Edition 6: Autumn 2010

### A bumper edition!

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This is our penultimate newsletter for the research initiative so we have made it a bumper edition! As well as our regular updates you will find a feature on our two baseline studies and an article on the 'Fitness Enablement' study to whet your appetite for the final reports available from our website. We also give you details of other reports and developments.

There are still six studies to report, so look out for our final edition early next year. A report summarising all the findings from the research, and making recommendations for the future, will be published in 2011.

The LTNC newsletter complements our dedicated website, 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 website, and other accessible formats can be produced on request. I hope you find it interesting. Please let us know what you think!

If you don't already receive email alerts from us, but would like to, please contact [sophie@ltnc.org.uk](mailto:sophie@ltnc.org.uk) to be added to our mailing list.



### STOP PRESS

Latest Final Reports now available at [www.ltnc.org.uk](http://www.ltnc.org.uk)

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

"Integrated services for people with long-term neurological conditions: an evaluation of the National Service Framework"

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

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# LTNC Focus

The National Service Framework (NSF) for LTNCs was launched in 2005 and aimed to 'bring with long-term neurological conditions'. So, 5 years on, what does the research tell us about

As two important baseline studies reach completion Michele Peters, a member of the Oxford University research team (User and Carer Survey), and Dr. Sylvia Bernard, a member of the York University team (Integrated Services Study), talk to Dr. Alice Maynard<sup>1</sup>, an equality consultant, about their findings.

**Alice Maynard:** What are the main 'headlines' from your research?

**Michele Peters:** Overall we have found that there has been progress towards achieving the goals of the NSF, but it is patchy. People with LTNCs have diverse needs and make use of a very broad range of health and social services, so it's not a question of an easy 'quick fix'. We need to build on the progress that has been made and keep the momentum going towards integrated services that provide appropriate, effective, accessible and timely care.

**Sylvia Bernard:** Our findings also indicate that progress towards implementing the quality requirements of the NSF is mixed and there still is a need to keep focussed on developing effective services for people with LTNCs. The review showed there is little published evidence about the cost-effectiveness of integrated services for people with LTNCs, or what works well from the point of view of people using services. However, there were some clear messages from the people we interviewed that having a single specialist professional or team of professionals co-ordinating care was vital to continuity of care. The importance of ongoing support was stressed by many respondents in our study.

**Alice:** Is there evidence of a trend towards improved integration or co-ordinated services?

**Michele:** Just over a third (36%) of our sample felt that there was a single health or social care professional who co-ordinated their care, but only 24% felt that health and social services worked well together in planning services. As this was a one-off survey, we cannot know whether this constitutes an improvement or not, but indications are that more can be done to provide individuals with integrated services.

**Sylvia:** The theme of integration ran throughout the NSF for LTNCs. Our study shows that its implementation has been hindered by competing policy, organisational and financial priorities. Nearly half-way through the ten-year implementation period only half of Primary Care Trusts (PCTs) had a written action plan for implementation and very few had carried out their plans. The models we identified as important to integrating services were found across PCT areas, but there were noteworthy gaps.

<sup>1</sup> For further information about Dr Alice Maynard go to; <http://www.futureinclusion.com/principal/>

### about a structured and systematic approach to delivering treatment and care for people progress towards meeting this aim?

**Alice:** What aspects did you investigate to see whether the NSF has led to the required improvements?

**Sylvia:** Given the long-term and fluctuating nature of neurological conditions we anticipated that the main outcome required from a well-integrated service is the experience of continuity of care. We undertook in-depth case studies in six service systems across England, with varying levels of social and health care integration, using the continuity of care concept as a framework for our approach. Our interviews with people with LTNCs identified a number of factors that could promote continuity of care, including:

- Having a single person or team co-ordinating care across professional boundaries and providing advocacy where necessary
- This person or team having specialist knowledge of LTNCs and available systems of support
- Flexibility in how, when and where services and support are delivered
- Long-term involvement
- Proactive monitoring and/or follow-up

From this we found 3 different models that promoted continuity of care for people with LTNCs. These were the ready availability of:

- Community inter-disciplinary neuro-rehabilitation teams (CIRNs)
- Nurse specialists
- Pro-active, holistic day opportunities that offer peer support, social and leisure pursuits and access to meaningful, creative, learning and/or employment opportunities in the community.

We also conducted a benchmarking survey of English PCTs that showed there is considerable variation in the availability of services to promote continuity of care for people with LTNCs.

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# LTNC Focus

## Establishing the Baseline

**Michele:** Our starting point was the NSF Quality Requirements (QRs) and the survey questions related to aspects of the QRs that could be usefully examined by asking individuals with LTNCs. For instance, one specific 'evidence-based marker of good practice for QR1' (i.e. 'person-centred care') was 'having a named point of contact'. We found that 53% of respondents had an assigned professional that they felt that they could contact. By framing our questions accordingly, we could assess how many individuals reported which aspects of the NSF were currently implemented. There was a variation across the different QRs in terms of achieving the standards set by the NSF. The divided pattern of views is consistent with findings from the York study that considers progress towards integration 'patchy and slow'.

**Alice:** Are there any pointers to indicate why some areas are markedly better than others?

**Sylvia:** The NSF came with no targets and no new funding at a time when many NHS organisations were experiencing severe financial deficits. The overwhelming view from the staff we interviewed was that the NSF for LTNCs could not compete with more highly performance managed work streams and those that came with new money or financial incentives. Where progress had been made, this was often driven by front line staff or voluntary sector organisations, rather than strategic level integrated service planning.

**Alice:** Were there any indications that NSF QRs for carers are being met?

**Michele:** It is a goal of the NSF that carers should be able to choose how much caring they do rather than being constrained, or obliged to fulfil caring tasks. However fewer than half the sample of carers had ever had a discussion about the amount of caring they undertook. Having been given a brief explanation of a carer assessment, only 21% of respondents reported having received one. However 44% felt they did not need one. 23% had not received an assessment and would have liked one, a similar proportion to the number who had received an assessment. Some caution is required; for example, 12% were unsure whether they had had a carer assessment. Nevertheless it would appear that assessments are still unevenly made available to carers.

**Final reports for the two studies are available from [www.ltnc.org.uk](http://www.ltnc.org.uk), or by clicking below:**

["The needs for, and experiences of, services, by individuals with progressive neurological conditions and their carers: a benchmarking study"](#)

["Integrated services for people with long-term neurological conditions: an evaluation of the National Service Framework"](#)

These reports were funded by the NIHR Service Delivery and Organisation (SDO) programme, based at the National Institute for Health Research Evaluations, Trials and Studies Coordinating Centre (NETSCC), at the University of Southampton and are also available from their website [www.sdo.nihr.ac.uk/](http://www.sdo.nihr.ac.uk/). Project references; [Parker SDO ref 08/1610/124 and Fitzpatrick SDO ref 0-8/1610/123](#)

# Exercise and keeping fit

when you have a neurological condition

This innovative phased study looked at how people with LTNCs would like to be supported to take exercise. It used a methodology developed by the MRC to work with service users, and tested a physical activity support system (PASS) that would enable them to use community leisure centres.

## Professor Helen Dawes, principal researcher, reports:

“From our Phase I pilot work we developed a method for supporting people with LTNCs to exercise in community fitness centres. Using a methodology developed by the Medical Research Council (MRC) to work with service users, we set out to enable people with LTNCs to develop and control their own tailor-made exercise programme with the support of an information booklet, a qualified fitness trainer and a health professional (physiotherapist). The initial appointment at the centre was arranged by the physiotherapist who then introduced the participant to the fitness trainer.

The exercise prescription provided by the fitness trainer was directed by the participant, with the health professional providing support.



We then tried the scheme out in Phase II and found that it enabled people with LTNCs to use fitness centres safely and effectively. The 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 exercise on body function, health and wellbeing measures, supporting the implementation of a Phase III trial.”



The final report for this study can be downloaded from [www.ltnc.org.uk](http://www.ltnc.org.uk).

# Updates from research teams

For more details of each project and the latest research reports please click on the links within the text

## 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](mailto:diana.m.jackson@kcl.ac.uk)

Project link - [www.ltnc.org.uk/research\\_files/Support\\_for\\_carers.html](http://www.ltnc.org.uk/research_files/Support_for_carers.html)

The final report for this study is being prepared and will be available to download shortly.

## 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](mailto:Tariq.Saleem@kcl.ac.uk)

Project link - [www.ltnc.org.uk/research\\_files/Defining\\_palliative\\_care\\_needs.html](http://www.ltnc.org.uk/research_files/Defining_palliative_care_needs.html)

Tariq tells us: "We are working hard towards completion of our report. We were pleased that 2 abstracts were accepted for presentation in June 2010 at the 6th Research Congress of the European Association for Palliative Care." The final report will be available to download by the end of the year.

## 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](mailto:c.m.sackley@bham.ac.uk)

Project link - [www.ltnc.org.uk/research\\_files/RESULT\\_study.html](http://www.ltnc.org.uk/research_files/RESULT_study.html)

Cath reports: "We are progressing well with our health economics and cost analysis work and have been engaging with BME community leaders and organisations. We have submitted a paper to the journal Neuroepidemiology and have presented posters at the Society for Academic Primary Care (South West region) (SWASPC) conference. They were entitled 'Using a primary care research database to estimate incidence and prevalence of long-term neurological conditions' and 'The Delphi technique to identify service user priorities in rare neurological conditions'."

## Carers of people with LTNC and respite/replacement care (2008-2010)

Lead Applicant: Prof. Lynne Turner-Stokes

Researcher: Dr David Williams

email: [David.williams@kcl.ac.uk2](mailto:David.williams@kcl.ac.uk2)

Project link - [www.ltnc.org.uk/research\\_files/Carers\\_of\\_people\\_with\\_LTNC.html](http://www.ltnc.org.uk/research_files/Carers_of_people_with_LTNC.html)

David tells us: "We are now undertaking work on how best to define the terms 'carer' and 'respite and replacement care services'. We have liaised with representatives of carer organisations and the Department of Health on this issue. We have also discussed it with our carers' panel and are now planning our survey. By doing this we hope to provide a LTNC perspective on what it means to be a carer and what is required of respite/replacement care services."

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or go to to the LTNC website - [www.ltnc.org.uk](http://www.ltnc.org.uk)

### **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](mailto:tina.cook@northumbria.ac.uk)

Project link - [www.ltnc.org.uk/research\\_files/impact\\_inclusive.html](http://www.ltnc.org.uk/research_files/impact_inclusive.html)

Tina says: "We are in the very early stages of data analysis but, as we are listening to the stories that people are telling us about living with a long term condition, early findings show that people feel included in their treatment and in society when they are generally enabled through equipment, accessible environments and information and also, at a personal level, through their interactions with NHS staff and people in local communities.

One aspect is not sufficient, both together are part of inclusion.

We have had several opportunities to disseminate our work, including an article published in the INVOLVE newsletter".

A copy of the newsletter can be downloaded from the following link:

[http://www.invo.org.uk/pdfs/Newsletter\\_finalwinter10.pdf](http://www.invo.org.uk/pdfs/Newsletter_finalwinter10.pdf)

### **Mapping Vocational Rehabilitation (VR) 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](mailto:d.playford@ion.ucl.ac.uk)

Project link - [www.ltnc.org.uk/research\\_files/mapping\\_vocational\\_rehab.html](http://www.ltnc.org.uk/research_files/mapping_vocational_rehab.html)

Kate reports: "Many medical professionals have advised us that they are not aware of any VR services for people with LTNC in their areas, even if they exist. This confirms the need for this study so that such services can be mapped and a guide published for health care professionals and potential service users to refer to."

# Other news

## Muscular Dystrophy Campaign publishes research report

The research undertaken by David Abbott and Professor John Carpenter at the University of Bristol as part of the RI LTNC has now been published by the Muscular Dystrophy Campaign. To obtain a copy of "Becoming an Adult. Transition for young men with Duchenne Muscular Dystrophy", or to find out more, go to: [www.muscular-dystrophy.org](http://www.muscular-dystrophy.org).

## Quality Neurology

The Quality Neurology project has produced a report about the development of the audit tool. Further development, or adoption, of the tool will continue to be led by Quality Neurology and its partners. More information about the audit tool and its uptake can be found at: [www.csupport.org.uk/care-professionals/toolkit-professionals/used-already-professionals.html](http://www.csupport.org.uk/care-professionals/toolkit-professionals/used-already-professionals.html)

## Publication of the 2010 Report on Research and Developments in Assistive Technology (AT)

The Foundation for Assistive Technology (FAST) is commissioned by the Department of Health to produce an annual report (under Section 22 of the 1970 Chronically Sick and Disabled Persons Act ) which is designed to reflect the work the UK government funds to promote the development of AT. The report will be available to download from FAST's website by the end of the year. For further information go to: <http://fastuk.org/home.php>

## Glossary of initials

Initial or abbreviation	Explanation
AT	Assistive Technology (AT, defined as any product or service designed to enable independent living for disabled and older people).
BME	Black and Minority Ethnic communities
FAST	Foundation for Assistive Technology
MRC	Medical Research Council
LTNC	Long Term Neurological Conditions
NETSCC	National Evaluations, Trials and Studies Co-ordinating Centre
NIHR	National Institute for Health Research
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)