

# RI LTNC Newsletter

## Edition 3: Autumn 2008

### New research will strengthen evidence base

#### Editor's foreword

by **Maggie Winchcombe, Adviser, LTNC RI**  
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At this half-way point in the Long Term Neurological Conditions Research Initiative (LTNC RI) we are pleased to tell you that an additional four studies will soon be underway to add to our knowledge about the experiences that people with long term neurological conditions (LTNC) have of health and social care services.

Currently seven projects are in progress. The new research will investigate influential aspects of rarer neurological conditions; what is required for people with neurological conditions to feel included in service development and delivery; different ways that care-givers can sustain their roles, and finally, developments in vocational rehabilitation services.

You will find more details about them on page 2.

The initiative started in 2006 and aimed to build the evidence base to support services in meeting the quality requirements of the National Service Framework. It will finish at the end of 2010, by which time all the research teams will have published their findings and an over-arching report will analyse and evaluate the initiative and make recommendations for the future.

The LTNC RI newsletter complements our dedicated web-site, [www.ltnc.org.uk](http://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 <http://www.ltnc.org.uk/>, 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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# New LTNC research: 2008-2010

The following studies are due to start this autumn

## A review and study of the epidemiology and natural history of progressive neurological disease, based on what people themselves think is important and what they want from services.

This will be led by Professor Cath Sackley at the University of Birmingham and will report in September 2010. The team will analyse the relevant published literature and synthesise existing databases to provide economic models that reflect the progression of LTNCs at different stages.



Cath (pictured left) explains: "People with rarer progressive neurological conditions have complex needs requiring specialist expertise and resources, yet little is known about the incidence, prevalence and course

of disease, and their effects on individuals, their families, or how services support them. Our findings will provide information to assist service planning and inform the implementation and audit of the NSF LTNC."

## How do carers of people with long-term neurological conditions experience the provision of replacement (or respite) care?

Dr Diana Jackson from Kings College London will lead this study. It will produce information to underpin guidelines on developing flexible services to meet carers' needs. It will examine the concepts of 'carer', 'replacement care' and 'respite care' and have a particular focus on carers from ethnic minorities. An economic analysis will show the likely cost of providing different models of care.



Diana (pictured left) says: "We'll conduct a survey to determine the availability, suitability and flexibility of the different models of replacement (or respite) care that carers of people with LTNCs require to give them

more choice over how they spend their time. Currently, we do not know which model of care would best suit the personal circumstances of those who need it, nor the relative costs and benefits of providing it."

## **A case study on the impact of inclusive practice in Neuro-Rehabilitation / Neuro-Psychiatry services**

This study will be facilitated by Dr Tina Cook at Northumbria University, but takes the innovative approach of being led by people who use, as well as those who work in, the services. It aims to look at how different people understand the terms 'integrated service' and 'inclusive ways of working'.



Tina (pictured left) tells us: "It is important that the awareness, contribution and effects of being included are researched. We will use 'facilitated action research' to work with people who use services, to find out

more about them in order to improve practice. The study will lead to information about how services could be more inclusive and will help to raise awareness about how segregation and exclusion affects people's ability to reach their potential."

## **Vocational rehabilitation services: establishing a base-line to measure progress**

The final details of this study were not available at the time of writing. They will be published in the next newsletter.

For more details go to : [www.ltnc.org.uk/news](http://www.ltnc.org.uk/news)

# LTNC focus

## The Quality Neurology project (2007-2009)

**Quality Neurology is a pilot audit project for the NSF for Long Term Neurological Conditions which brings together the MS Society, Parkinson's Disease Society, Motor Neurone Disease Association & Ataxia UK, in collaboration with the 'Integrated Services' research team at York University (see page 5).**

Alun Davies of the MS Society reports on progress: "Good work is being done on meeting the NSF quality requirements (QRs) by Primary Care Trusts (PCTs) but there are no standardised ways of comparing the results and little independent service-user involvement in developing them. Eight PCT pilot sites, out of a possible ten, have been recruited to evaluate their progress against the QRs, by using an audit tool that we have developed. The aim of the audit tool is to create a standardised interpretation with a focus on what the QRs mean to service-users.

The tool, in the form of an interactive Excel spreadsheet, includes questions from a service-user perspective and is cross-referenced against national policy requirements; World Class Commissioning, Better Metrics, 7 Key Challenges for Health and the National Minimum Standards for Care Homes for Adults. A focus group methodology has been developed to test the audit findings against service-user experience and a peer-review system is being developed.

Using independently-run focus groups allows service users to talk openly and confidentially. The peer-review process will validate the action plans that will be the outcome of the whole process.

There have been some minor technical problems with the audit tool – and some minor issues around interpretation in using the tool, which we will continue to address as we update and refine it. Of the sites that have started completing the tool, all are using different methods. We will continue to monitor how it is implemented and maintain development of the focus group methodology and pre-pilot test as appropriate."

The project is due to finish in September 2009.

For further information Alun can be contacted on: [adavies@mssociety.org.uk](mailto:adavies@mssociety.org.uk)

# Research updates

## **The needs of individuals with progressive neurological conditions and their carers and their experiences of services: a benchmarking study (2006- 2009)**

**Summary by Professor Ray Fitzpatrick**  
email: [raymond.fitzpatrick@nuffield.ox.ac.uk](mailto:raymond.fitzpatrick@nuffield.ox.ac.uk)

This research aims to provide a clear quantitative and qualitative evidence base for three progressive neurological conditions: Parkinson's Disease (PD), Multiple Sclerosis (MS) and Motor Neurone Disease (MND). It will give us a picture of current patterns of health, quality of life, access and experience of services, for individuals and their carers, so that progress can be measured.

Ray tells us that the qualitative interviews are all now finished. They have involved 271 individuals (116 people with MND, 67 with MS and 88 with PD), as well as 211 carers (104 cared for someone with MND, 38 for someone with MS and 69 for someone with PD). Their responses are now being analysed and an interim report is being prepared to go back to the branches of voluntary organisations that have assisted the team. It will also be disseminated through the departmental website (<http://www.publichealth.ox.ac.uk/units/hsru/PROGRESSIVE%20NEUROLOGICAL%20CONDITIONS/Intro>) and discussed with the Research Advisory Group of people with LTNCs and carers to inform subsequent work.

The next stage is to conduct the survey that will build the quantitative evidence and this is due to start in October. The research team has been in discussion with users, particularly via the MND Association, to assess how communication difficulties might affect people's participation. The main issue being considered is whether email is more user-friendly than postal contact for some respondents.

## **Integrated services for people with long-term neurological conditions: an evaluation of the National Service Framework. (2006-2009)**

**Summary by Dr Sylvia Bernard**  
email: [smb509@york.ac.uk](mailto:smb509@york.ac.uk)

This project aims to identify what factors help or hinder the development of integrated services for people with LTNCs. Then, a benchmarking system will be designed, based on these factors, which will be used to assess whether the NSF for LTNCs has influenced the way services have been integrated.

Sylvia reports that they have now undertaken their literature searches. The final number of papers from which data were extracted for the review is 46 evaluations and 88 descriptions. Analysis of this material is currently underway. In addition, the case study fieldwork is progressing, with 139 staff interviews and 59 service-user interviews, across six sites, having been completed at the time of writing. There is ongoing collaboration with the Quality Neurology project team (see page 4).

The team fed back the initial findings to their Project Advisory Group this summer for discussion and advice on proceeding with the next stage of work. A report on the initial findings is planned for autumn 2008. Analysis of the case study fieldwork will identify benchmarks of good practice for continuity of care, which will inform the design of the questionnaire for the national survey.

# Research updates

## Support for carers, particularly those with multiple caring roles: an investigation of support needs and the cost of provision (2006-2009)

Summary by Dr Diana Jackson  
email: [diana.m.jackson@kcl.ac.uk](mailto:diana.m.jackson@kcl.ac.uk)

This study aims to increase our understanding of the problems faced by people who care for someone with a LTNC, in order to learn from their experiences what has helped, or would have helped.

Diana says that their data collection is continuing. However, early findings from telephone interviews with a diverse range of carers confirm a need for clearly set out pathways to guide them through the process of accessing personalised support from statutory and voluntary organisations.

The vital importance of taking account of the cared-for person and their difficulties, as well as carers' multiple responsibilities and their desire to participate in activities of their choosing outside the home, is becoming much clearer. Carers' ideas for improvements in services are being collated and will contribute to good practice guidelines to inform future service development.

Research into 'respite' or 'replacement' care, reported on page 2, will extend and complement the findings from this work.

## Long-term Involvement in Fitness Enablement (LIFE) study (2006- 2009)

Summary by Dr Helen Dawes  
email: [hdawes@brookes.ac.uk](mailto:hdawes@brookes.ac.uk)

This research aims to establish how people would like to be supported to do exercises; to provide information on what community facilities currently exist that people with LTNCs can use, and to determine whether exercise delivered in a leisure centre, combined with a physical activity support system (PASS), is effective.

The second phase of the study is now underway and interim findings from the pilot work are being analysed. Focus groups have involved people with Muscular Dystrophy, Parkinson's Disease, Motor Neurone Disease and Multiple Sclerosis. Some participants are living in residential care homes. It is proving difficult to recruit people with Cerebral Palsy, although various routes are still being tried until recruitment closes in October 2008. It is also becoming apparent from individuals' feedback that transport difficulties are a major barrier to participation in the project. The shortage of Inclusive Fitness Initiative (IFI) Centres in Oxford and Birmingham is also a factor. The IFI is a programme that supports the fitness industry to become more inclusive, catering for the needs of disabled and non-disabled people. For more information go to: <http://www.inclusivefitness.org/gettingpeopleactive/>.

Work is underway towards publishing the results from the initial pilot study, the community mobility data and other selected findings.

## **Transition to adulthood: the experiences and needs of young men with Duchenne Muscular Dystrophy (DMD), and their families (2006-2008)**

**Summary by David Abbott**

**email: [D.Abbott@bristol.ac.uk](mailto:D.Abbott@bristol.ac.uk)**

This study aims to find out about how the experiences of young men living with DMD, and those of their carers, can be improved, particularly during their teenage and early adult years. It is hoped that lessons can be learnt from this research to help other young people living with different LTNCs.

The work is due to finish in December 2008. David reports: "We are still analysing our findings and so can only make some provisional comments at this stage. However, it is apparent that quite a few young men had finished college and were at home not doing very much. Some of them minded about this more than others. Many respondents said they felt bored and sometimes isolated. We did not meet any young men who had finished school or college and found employment – although some had tried. Not everybody was interested in getting a job – some people said it would be difficult because of their health, or because employers would not take them on.

A final report is being prepared once our analysis is complete. We will also write a summary and let all the people who took part in the research know the results. We intend to produce a summary of findings which are most relevant to young people with LTNCs generally."

## **Defining the palliative care needs of people with late stage Parkinson's Disease (PD), Multiple System Atrophy (MSA) and Progressive Supranuclear Palsy (PSP) (2007-2010)**

**Summary by Tariq Saleem**

**email: [Tariq.Saleem@kcl.ac.uk](mailto:Tariq.Saleem@kcl.ac.uk)**

This research sets out to gain better understanding of the experiences and needs of people severely affected by PD, MSA and PSP. This will help to identify the most effective approaches to enhancing quality of life and providing flexible, personalised support from all quarters.

Tariq tells us that recruitment is going well: "We are pleased to have had enthusiastic and committed participation from those experiencing these conditions. Currently 46 people with LTNCs and 33 carers have completed base-line interviews in their homes. Our target is to recruit 60 people by December 2008 and to follow up each participant for at least a year. We have also completed second interviews with 15 patient/carer pairs 4-6 months after we originally saw them, and 10 patient/carer pairs have completed third interviews.

We have now started entering data onto a SPSS\* database. In November we will start conducting preliminary/exploratory analysis for base-line cross-sectional data. This, along with consultation with our patient's advisory group, will inform our interview topic guide for the qualitative part of the study. Follow-up interviews for the quantitative part of the study will continue until January 2010."

\* SPSS is the proprietary name for a data-management programme: Statistical Package for the Social Sciences.

# Publication News

## Report on Assistive Technology Research and Development (2008)

### Foundation for Assistive Technology (FAST)

The 2007-2008 edition of the Annual Parliamentary Report on Assistive Technology Research and Development (available at [http://fast.isledev.co.uk/pagedocuments/File/research/fast\\_reports\\_and\\_papers/Annual\\_Parliamentary\\_Report\\_2007.pdf](http://fast.isledev.co.uk/pagedocuments/File/research/fast_reports_and_papers/Annual_Parliamentary_Report_2007.pdf)) was presented to Parliament in July 2008 and is freely available to download from FAST (<http://fastuk.org/home.php>).

This is the 7th report that FAST has produced for the Department of Health and the information in it is drawn from its national database of assistive technology (AT) research and development. It is designed to reflect the work funded (directly or indirectly) by the UK government, but FAST's database, on their web-site, incorporates work funded from a wider range of sources and offers a comprehensive and up-to-date resource.

## The Experiences and Expectations of Disabled People (2008)

### Bridget Williams, Phil Copestake, John Eversley and Bruce Stafford

Experiences and Expectations of Disabled People, the first comprehensive study of disability issues in six years, looked at key policy areas, including employment, education, transport, health and discrimination, across Great Britain in 2007. The research, which was commissioned by the Office for Disability Issues (ODI), was undertaken by GfK NOP Social Research, Office for Public Management, ppre and the University of Nottingham. It provides a unique snapshot of the lives of nearly 2,000 disabled people. The study was ground-breaking in that it actively involved disabled people throughout the research process. The full report can be downloaded from: <http://www.officefordisability.gov.uk/research/eedp.asp>

## Glossary of initials

<b>AT</b>	Assistive technology (defined as any product or service designed to enable independent living for disabled and older people).
<b>IFI</b>	Inclusive Fitness Initiative (a programme to support fitness centres to be more inclusive of disabled people).
<b>LTNC</b>	Long Term Neurological Conditions
<b>NSF</b>	National Service Framework
<b>PCT</b>	Primary Care Trust
<b>QR</b>	Quality Requirements (set out in the National Service Framework)