NIHR Service Delivery and Organisation programme

NHS
National Institute for Health Research

**HS&DR Protocol - project ref**: [08/1809/235]
**Version**: **#0001833**
**Date**: 01/05/2008

# The Evaluation of Community Rehabilitation Services in Long-Term Neurological Conditions

| | |
|---|---|
| **Chief investigators:** | **Dr Richard Siegert/<br>Prof Lynne Turner-Stokes** |
| **Sponsor:** | **Kings College London** |
| **Funder:** | **SDO Programme** |
| **NIHR Portfolio number:** | **UK CRN 7503** |
| **ISRCTN registration (if applicable):** | |

KING'S College LONDON
University of London

The North West London Hospitals NHS
NHS Trust

Northwick Park Hospital
Watford Road
Harrow
Middlesex
HA1 3UJ

# Evaluation of Community Rehabilitation Service Delivery in Long-Term Neurological Conditions

## Aims/Objectives:

This study builds on our existing body of research within the NIHR programme by addressing the delivery of specialist neuro-rehabilitation services in the community for people with long term neurological conditions (LTNCs). The objectives are to set up and pilot a register that will identify people with LTNCs who have complex needs, examine the provision of community-based specialist neuro-rehabilitation and support for this group, and evaluate the reliability, validity and applicability of a new tool for assessing service provision in relation to need.

### Aims are to:

- Determine whether the LTNC register provides a practical tool to identify and monitor people with complex needs who are discharged from specialised in-patient rehabilitation services.
- Evaluate whether the Northwick Park Complexity Scale (NPCS) provides a reliable and valid assessment of service provision in relation to need for on-going community-based rehabilitation and support in this group.
- Examine referral patterns for further community rehabilitation, along with the inputs prescribed and received at six months post-discharge.
- Identify the variables that influence the quantity and quality of rehabilitation received post-discharge and its outcomes with respect to disability and community integration.
- Determine the differential costs and cost-outcomes of different models of community neuro-rehabilitation.

## Background:

The National Service Framework (NSF) for LTNCs promotes joined-up services to provide holistic, person-centred care (Department of Health, 2005). Key Quality Requirements (QRs) include ‘Early Specialist rehabilitation' (QR4), ongoing rehabilitation and support in the community (QR5), vocational rehabilitation (QR6) and support for families and carers (QR10). Critically, integrated care planning (QR1) provides the backbone to the NSF recommendations. Community rehabilitation teams are uniquely placed to support integrated care planning, but are short on the ground. It is vital therefore to be able to evaluate service provision in relation to need, both at an individual and a population level, in order to focus future service development efficiently.

The London Specialised Neuro-rehabilitation Consortium (LSNRC) provides a model for coordinated network-based commissioning and provision of specialised in-patient neuro-rehabilitation services across the London region (31 PCTs). The network includes nine units with an annual throughput of approximately 500 cases. It works with a range of community rehabilitation services and presents a unique opportunity to track the movement of patients between the various services in the pathway, and to compare outcomes and longer term benefits (including health economic evaluation) from the different service models.

A range of sudden onset and progressive LTNCs, including acquired brain injury (any cause), spinal cord injury, peripheral neuro-myopathies (including Guillain Barre) and progressive conditions (e.g. MS are catered for, with a focus on adults of working age with ‘complex rehabilitation needs that are beyond the scope of district and local services'. A high proportion of people discharged from these services are expected to need integrated care planning, on-going community rehabilitation and vocational support. However, whilst some receive excellent support from specialist coordinated community teams, others receive either nothing, or short-term input from intermediate care teams which tend to favour the needs of older adults (Rusconi and Turner-Stokes, 2003).

All units in the consortium contribute to a common database providing systematic data on demographics, complexity of rehabilitation needs, levels of disability, discharge destination etc. A preliminary mapping exercise of existing services for on-going community rehabilitation and support within the London region revealed a variety of different service models. We have chosen to follow a cohort of patients joining this community rehabilitation pathway because it is likely to yield a high proportion of people with complex needs, representing a broad range of LTNCs, including both physical disabilities and challenging cognitive/behavioural impairments.

## Need:

The NSF for LTNCs implementation plan stresses the need for service networks, whereby specialist services support local teams to provide care in the community for people with complex needs. However, successful management of these services requires sophisticated organisation across a number of health, social care and other service boundaries, and involvement of people with LTNCs and their families. The development of coordinated systems for prospective data collection in the course of routine practice therefore plays an important role in the assimilation of ‘practice-based evidence’ (Horn and Gassaway, 2007) to define both the need for services and its outcomes.

The SDO report on Specialist Rehabilitation for Neurological Conditions (Gladman et al., 2007) found that apart from stroke, specialist neurological rehabilitation services for people with LTNCs were disjointed or absent in the community. Moreover, the evidence for their effectiveness had not been evaluated. Support for people with ‘hidden disabilities' (e.g. cognitive and communication difficulties) and vocational rehabilitation services were identified as major service gaps. There are also particular challenges in providing services for certain groups of people such as individuals with brain injuries and challenging behaviours combined with pre-morbid alcohol and drug problems, or those who lack insight into their needs for rehabilitation.

The study will provide information relevant to SDO priorities by delivering a comprehensive account of the quantity and nature of rehabilitation received by people with a broad range of neurological conditions. In piloting the LTNC register and datasets, we will address how continuity is maintained within rehabilitation services. We will also examine any gaps between the level of services needed and those provided and address the health economic costs of filling those gaps.

## Methods:

### (a) Setting

The setting covers the interface between nine specialised in-patient neuro-rehabilitation services across the London region and the community rehabilitation services that provide on-going support to discharged patients.

### (b) Design

A longitudinal questionnaire-based cohort study assessing patients discharged from specialised in-patient neuro-rehabilitation services across the London region at four weeks, six and twelve months post-discharge. Details of community services accessed by this group will also be collected.

### (c) Data collection

#### Phase 1: Pilot study and repeatability testing (Month 1-6)

We will pilot the LTNC register and test the repeatability of the self-report *Needs & Provision*

*Complexity Scale* (NPCS). Fifty consenting patients will be purposively selected to represent a range of conditions and service needs. They will be entered onto the prototype register to test the paperwork and database, and asked to complete the NPCS on two occasions one week apart, to test agreement between the two ratings. Reasons for declining to be registered will be noted.

**Phase 2: Longitudinal cohort study (Months 7-30)**
We will attempt to recruit a consecutive cohort of patients (approximately n=500) discharged from each of the nine rehabilitation services within the London Neuro-rehabilitation Consortium (LSNRC) over a-12 month period. They will be adults predominantly of working age representing a range of neurological conditions (‘sudden-onset' and ‘progressive') and disabilities (physical, communicative, cognitive/behavioural). The majority are expected to have complex needs requiring integrated care-planning and on-going community rehabilitation/support.

Building on previous experience and user feedback from our other studies, we will develop and refine a schedule of questionnaires that can be completed in both paper format and on-line. Consenting participants will complete these at three time points: 3-4 weeks, six months and one year post discharge, to determine their met and unmet needs for community rehabilitation services.

We will examine:

- The types of impairment and disability ( physical, cognitive etc) in the study population
- Levels of functional dependency and carer burden
- Community integration
- Services received and their associated costs and the overall degree of satisfaction among service users with respect to the extent of service provided.
- The estimated cost of addressing any identified gaps in services

We will also attempt to map the geographical distribution of existing community rehabilitation/support and describe the types of service available.

**Phase 3: Write-up and dissemination (Months 31-36)** :
(i) Write up and dissemination of findings (ii) development of good practice guidelines.

**Plan of Investigation:**
On discharge from the specialist neuro-rehabilitation unit the clinical team will:

- Consider whether the individual meets the LTNC register criteria, and seek their permission to include them on the prototype register, which will be managed by the research team.
- Inform patients and their carers about the cohort study, provide them with an information sheet about it written in plain English, answer questions and invite them to participate.

For each patient the clinical team will complete a brief summary report including:

- Contact details for the individual (or a carer who will respond on their behalf if they are unable to complete the survey themselves).
- A brief neurological impairment set and evaluation of their needs for on-going care and support and anticipated service provision, using the NPCS (both parts).
- Plans for follow-up detailing referral to community rehabilitation teams and contact details.
- Any cultural or language needs, or other challenges to follow-up (eg lack of a permanent residence, asylum-seeking) that the researchers will need to allow for.
- Consenting patients will be given Survey pack 1 to take home. For those who decline, basic demographic data (age, sex, diagnosis) will be collected by clinicians and stored anonymously to allow later statistical comparison between participants and non-participants on core variables.

*Time 1: 3-4 weeks post-discharge*

A researcher will phone consenting participants to confirm willingness to participate, answer any questions/concerns and ask them to complete and return Survey Pack 1 (re-sending the pack, if necessary). A web-based version will be made available for those preferring to complete on-line.

***Survey Pack Time 1 includes:***

- General demographic questions
- Measures of physical disability/functioning: The Barthel Index (Collin et al., 1988), The Northwick Park Dependency Scale (Turner-Stokes et al., 1998)
- A measure of cognitive and behavioural impairments: The Memory and Behaviour Problem Checklist (Zarit and Zarit, 1990a)
- A measure of perceived carer burden: The Zarit Burden Interview (Zarit and Zarit, 1990b)
- Measures of participation: The Community Integration Questionnaire (Willer et al., 1994), BICRO-39 scales (Powell et al., 1998)
- Two parts of the Needs & Provision Complexity Scale (NPCS)

*Time 2: Six months post-discharge*

The researcher will re-contact each participant to ask them to complete a second questionnaire either by postal questionnaire or on-line. A follow-up call will take place if the response has not been received within a fortnight.

***Survey Pack Time 2 includes:***

- Repeat survey pack 1 questionnaires (including NPCS (both parts) and a re-evaluation of status on the LTNC pilot register) plus:
- Measures of service utilisation and barriers to care - Client Service Receipt Inventory (Beecham and Knapp, 2001)
- Services Obstacles Scale (Marwitz and Kreutzer, 1996)
- A brief questionnaire to evaluate participants' satisfaction with the services provided; their perception of any shortfalls in service provision; and contact details for any community rehabilitation services used.
- Participants will be asked for feedback on the survey and to rate the questionnaires regarding ease of use and relevance

*Time 3: One year post-discharge*

A repeat set of questionnaires will be sent out. Status on the LTNC pilot register will be determined and participants will be asked if they have had an integrated care plan review in the past year.

**Questionnaire to community services:**

Community rehabilitation services accessed by participants will be contacted for information on their model of service delivery to include (a) service specification and mode of operation, (b) staffing levels, team structure, representation of the different disciplines, (c) contracted costs and charges, (d) perceived strengths/weaknesses of the service, including shortfalls in service provision, (e) use of key rehabilitation concepts such as inter-professional teamwork, goal-setting, ICF, person-centeredness and (f) user involvement in service evaluation and planning.

We anticipate some differences in perception between professionals and respondents regarding the need for further rehabilitation. For a sub-group of individuals reporting dissatisfaction with their rehabilitation provision we will, with their permission, contact the service to obtain the provider's view of the reported shortfall and the reasons for it.

### (d) Data analysis

Data will be transferred to SPSS version 19 for analysis.

Descriptive statistics will be used to describe:

- Uptake among participants for the LTNC register and rates of successful follow-up.
- Demographic and other details of the cohort (age, sex, diagnosis, impairments, levels of physical and cognitive disability, care needs, social integration).
- The type and level of community services patients were referred to on discharge as compared to those they received.
- The retrospective division at six months of patients into groups needing ‘high level' intervention (from specialist community neuro-rehabilitation teams), ‘medium level' (from generalist or intermediate care teams) and ‘low level' intervention (receiving little or none).

The psychometric properties and utility of the NPCS will be determined by analysing:

- Agreement between the two ratings using Cohen's kappa tests to evaluate repeatability.
- Validity will be examined through correlation with physical and cognitive disability, service provision and satisfaction.
- Comparison of NPCS ‘before and after’ scores, supplemented by item-by-item analysis, will identify levels of service provision in relation to individual needs, highlight principal gaps in service provision and quantify under or over-provision of rehabilitation.

Qualitative analysis of feedback from centres and participants will be used to establish:

- Ease of register completion
- Levels of satisfaction with services and their provision over time
- Face validity and utility of the NPCS

Variables influencing the level of rehabilitation services received will be determined by:

- Comparing the dichotomised demographic and other characteristics of patients at Time 1 that predict (a) the three types of service (b) duration of services offered.
- Testing the hypothesis that those living alone, or with no permanent residence and/or asylum seeking status; and also those with cognitive/behavioural problems and/or alcohol/drug abuse are likely to receive lower levels of rehabilitation.
- Testing the hypothesis that higher levels of service are associated with improved outcome, controlling for confounding factors, such as baseline levels of disability.

Reduction in care needs and improvements in independence, community integration and carer burden over time will be described and compared both within and between groups at six and twelve months through:

- Longitudinal data analysis of repeated measures using mixed effects modelling (Brown and Prescott, 2006) to account for confounding by intra-subject correlations (Diggle et al., 1994).
- We will test the hypothesis that, after controlling for baseline disability, individuals receiving higher levels of rehabilitation input achieve better outcomes in terms of improved community integration and reduction of care burden, than those receiving little or no rehabilitation.

Health economic analysis will be carried out by:

- Collating information on health and social care service use (including community rehabilitation, and informal care from family members) over the preceding six months at times 2 and 3.
- Costs of current care will be estimated by combining the service use information with

appropriate unit cost data (Curtis, 2007). Estimates of the costs of providing unmet community rehabilitation needs will be made using the same unit cost data.

- Multivariate analyses will be conducted to identify predictors of (i) current costs and (ii) potential costs if services were provided to meet needs. The models will need to take account of likely skewed cost data and will use generalised linear models and bootstrapping (McCrone et al., 2001; McCrone et al., 2004).
- Cost-outcomes will be explored by comparing service costs with score changes on the clinical measures. Cost-outcome ratios (cost divided by the change score) will indicate the cost that would be incurred to achieve a unit-improvement in each outcome measure.
- Regression models will be used to determine the impact that the cost of individual services have on outcomes.

## Project Management:

### CORE MANAGEMENT TEAM

**Dr Richard Siegert**, Department of Palliative Care, Policy & Rehabilitation, King's College London.

**Professor Lynne-Turner Stokes**, Director, Regional Rehabilitation Unit, Northwick Park Hospital, Harrow, Middlesex.

**Dr Bernadette Khoshaba**, Research Associate, Department of Palliative Care, Policy & Rehabilitation, King's College London.

**Christine O'Connell**, Research Assistant, Department of Palliative Care, Policy & Rehabilitation, King's College London.

### STEERING ADVISORY GROUP

**Dr Diana Jackson**, Department of Palliative Care, Policy & Rehabilitation, King's College London.

**Professor Paul McCrone**, Institute of Psychiatry, Kings College London.

**Mr Paul Bassett**, Private Consultant.

**Dr Simon Fleminger**, South London and Maudsley NHS Foundation Trust, London.

**Dr Diane Playford,** Institute of Neurology, University College, London.

### CO-APPLICANTS

**Mrs Barbara Howe**, London Specialised Commissioning Group, NHS London

**Professor Irene Higginson**, Head of Department of Palliative Care, Policy & Rehabilitation, King's College London.

## Service users/public involvement:

The external reference panel for the LTNC dataset includes both individual users/carers and representatives of user organisations led by Nicola Russell of the MS Trust. We will continue to liaise closely with both these groups throughout this programme. Patient involvement will be harnessed both in terms of the research process and discussion of the findings and future directions. We have a letter from Heiko Kausch confirming the group's involvement and this was provided with our earlier letter of 14.08.08 responding to the Commissioning Group's queries.

A panel of five service-users is supporting and advising on the current project. They include:

*Ann*, mother of a young woman with acquired brain injury, *Norman*, father of young man with traumatic brain injury, *Charles* who has MS, *Dave* who survived a stroke in 1998 and spent 12 months in hospital and nursing homes, *Frank* who survived a stroke three years ago. We are continuing to actively recruit additional service-users and fully expect to have a panel of at least 8 service-users in place before this proposed project commences. As it develops, this group will provide input in respect of rehabilitation services/ service models.

## References:

Beecham J, Knapp M. 2001. Costing psychiatric interventions. In Thornicroft G (ed) Measuring mental health needs. London, Gaskell.

Brown H, Prescott R. 2006. Applied mixed models in medicine. Chichester: John Wiley & Sons.

Collin C, Wade DT, Davis S, Horne V. 1988. The Barthel ADL Index: a reliability study. International Disability Studies 10: 61-63.

Curtis L. 2007. Unit costs of health and social care. Canterbury, Personal Social Services Research Unit.

Department of Health. 2005. National Service Framework for Long-Term Conditions. London.

Diggle PJ, Liang KY, Zeger, SL. 1994. Analysis of longitudinal data. Oxford: Clarendon Press.

Gladman J, Radford K, Edmans J, Sach T et al. 2007. Specialist rehabilitation for neurological conditions: literature review and mapping study.

Horn SD, Gassaway J. Practice-based evidence study design for comparative effectiveness research. Medical Care 2007;45(10 Supl 2):S50-7.

Marwitz, JH, Kreutzer, JS. 1996. The Services Obstacles Scale (SOS). Richmond, VA: Medical College of Virginia, Virginia Commonwealth University.

McCrone P, Johnson S, Thornicroft G. 2001. Predicting the costs of community care for individuals with severe mental illness in South London. Schizophrenia Bulletin 27: 653-660.

McCrone P, Ridsdale L, Darbishire L, Seed P. 2004. Cost-effectiveness of cognitive behavioural therapy, graded exercise and usual care for patients with chronic fatigue in primary care. Psychological Medicine 34:

991-999.

Rusconi S & Turner-Stokes L. 2003. An evaluation of aftercare following discharge from a specialist in-patient rehabilitation service. Disability and Rehabilitation 25: 1281-1288.

Turner-Stokes L, Tonge P, Nyein K, Hunter M, Nielson S, Robinson I. 1998. The Northwick Park Dependency Scale: a measure of nursing dependency in rehabilitation. Clinical Rehabilitation 12: 304-318.

Powell JH, Beckers K, Greenwood RJ. 1998. Measuring progress and outcome in community rehabilitation after brain injury with a new assessment instrument - The Bicro-39 scales. Archives of Physical Medicine and Rehabilitation 10: 1213-1225.

Willer B, Ottenbacher KJ, Greenwood RJ. 1994. The Community Integration Questionnaire: A comparative examination. American Journal of Physical Medicine and Rehabilitation 73: 103-111.

Zarit, S.H., & Zarit, J.M. (1990a). The Memory and Behavior Problems Checklist. Unpublished manuscript, Gerontology Reprints

Zarit, S.H., & Zarit, J.M. (1990b). The Burden Interview. Unpublished manuscript, Gerontology Reprints

***This protocol refers to independent research commissioned by the National Institute for Health Research (NIHR). Any views and opinions expressed therein are those of the authors and do not necessarily reflect those of the NHS, the NIHR,***
***the HS&DR programme or the Department of Health.***