



A Longitudinal, Multi-Centre, Cohort Study of Community Rehabilitation Service Delivery in Long-Term Neurological Conditions

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8 **A Longitudinal, Multi-Centre, Cohort Study of Community Rehabilitation Service Delivery in**
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10 **Long-Term Neurological Conditions**

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ABSTRACT

Objectives: Part A. To pilot the use of a register to identify and monitor patients with complex needs arising from long-term neurological conditions (LTNC). **Part B.** To determine the extent to which patients' needs for health and social services are met following discharge to the community after in-patient rehabilitation; to identify which factors predict unmet needs and to explore the relationship between service provision and outcomes at 12 months.

Design: A multi-centre, prospective, cohort study surveying participants at 1, 6 and 12 months using postal/online questionnaires and telephone interview.

Setting: Consecutive discharges to the community from all nine tertiary, specialist, inpatient neuro-rehabilitation services in London over 18 months in 2010-2011.

Participants: Out of 576 admissions 428 patients were recruited at discharge: 256 responded at 4 weeks, 212 at 6 months and 190 at 12 months.

Measures: Neurological Impairment Scale, The Needs and Provision Complexity Scale, The Northwick Park Dependency Scale, Community Integration Questionnaire, Zarit Burden Inventory.

Results: n=322(75%) expressed willingness to be registered, but in practice less than half responded to questionnaires at 6 and 12 months (49 and 44% respectively), despite extensive efforts to contact them, with no significant differences between responders and non-responders. Significant unmet needs were identified within the first year following discharge, particularly in rehabilitation, social work support and provision of specialist equipment. Dependency for basic care and motor and cognitive impairment predicted services received, together accounting for 40% of the variance. Contra to expectation, patients whose rehabilitation needs were met were more dependent and less well integrated at 12 months post discharge than those with unmet needs.

Conclusions: Registration is acceptable to most patients, but questionnaires/telephone interviews may not be the most efficient way to reach them. When community resources are limited service provision tends to be focused on the most dependent patients.

ARTICLE SUMMARY**Article focus**

- Is a register of people with long-term neurological conditions feasible to monitor needs, service provision and outcomes?
- To what extent are patients' needs met after discharge and what are the major gaps in service provision?
- Is there a relationship between 'metness of need' in the six months following discharge to the community and outcomes?

Key Messages

- The majority of patients are agreeable to being registered but attrition is high. A workable register would need to be based around regular, face-to-face, integrated care planning meetings. The Needs and Provision Complexity Scale offers a practical framework for identifying unmet need in such meetings.
- Unmet needs were most evident for rehabilitation, social work support and provision of specialist equipment.
- Patients who were more dependent were still less well integrated into the community at 12 months despite being more likely to have had their needs met,

Strengths and limitations of this study

- This study provides the first detailed longitudinal examination of services provided in the community in relation to needs at discharge for a large cohort of patients discharged from specialist neurorehabilitation services in the UK.
- The study had a high attrition rate and participants were only recruited from London hospitals.

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INTRODUCTION

There is increasing recognition internationally of the importance of post-acute rehabilitation services, based in the community, for long-term neurological conditions (LTNCs) and the need to demonstrate their cost-effectiveness.(1-5). There has also been increased recognition of the needs and burden experienced by the families and carers of people with LTNCs.(6, 7) While some progress has been made in demonstrating the value of community programmes for specific conditions such as traumatic brain injury and stroke, comparatively little is known about the organisation, delivery and effectiveness of generic rehabilitation services in the community, in spite of the fact that they constitute the majority of rehabilitation services (8-11).

Long-term neurological conditions (LTNC) affect not only the individuals concerned but also their family and carers. In the UK, a series of National Service Frameworks (NSF) have laid down standards for service provision across a wide range of conditions.(12) Published in 2005 with a 10-year implementation plan, the primary focus of the UK National Service Framework (NSF) for Long Term Conditions was on neurological conditions.(13)

This NSF sets out 11 standards or 'Quality Requirements' for rehabilitation and social support for patients living with neurological disability.(13) It emphasises a biopsychosocial approach, addressing all stages in the 'care pathway' from diagnosis to death (see Figure 1a), and highlights in particular the need for life-long access to services in the community.(14) Quality Requirement 1 (the 'backbone' standard of the NSF for LTNC) recommends that patients with complex needs should have integrated care planning with regular reviews and a single point of contact to coordinate inter-agency input.

LTNC represent a diverse group of conditions, encompassing people with widely different needs for services, against which the adequacy of service provision must be judged. Unfortunately, these needs are largely unreported through current information systems, so the epidemiology of 'need' for healthcare and social support is not fully understood.(15) Previous reports have highlighted a paucity of knowledge about how rehabilitation and support services are delivered in the community, compared to hospital-based services (16) – and also that community-based care is often fragmented.(17) Particular concerns were raised about lack of support for patients with complex needs arising from 'hidden disabilities' due to cognitive/behavioural problems and their families.(17)

To support implementation of the NSF for LTNC, the UK Department of Health commissioned the NHS Information Centre to develop a LTNC dataset for monitoring implementation and for benchmarking performance against the NSF quality requirements. As part of that development, the Dataset Development

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3 Group recommended the establishment of an LTNC register to identify those patients with complex needs
4 arising from LTNC and to support integrated care planning and long-term follow-up, in order to monitor
5 their changing needs over time and the services that are provided to support them. The group also
6 recommended a shortlist of tools to measure long term outcomes from rehabilitation support services,
7 including measures of dependency on others for care, community integration and carer burden.
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12 In 2008, the UK National Institute for Health Research (NIHR) funded a project to develop and pilot an LTNC
13 Register, and to use this to follow longitudinally a cohort of patients with complex needs arising from LTNC.
14 The purpose of the study was to examine the extent to which their current needs for health and social
15 services support were met by existing services, to identify any gaps in service provision, and to examine the
16 extent to which meeting their needs might lead to improved outcomes.
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22 This article reports the key findings of that study:
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- 24 • In Part A, we describe the development and piloting of an LTNC register and a feasible dataset that
25 could be used in the course of routine practice to monitor needs, inputs and outcomes for people
26 with LTNC in the community.
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- 28 • In Part B, we describe how the dataset was used to follow a cohort of patients with complex
29 neurological disability over a one year period after discharge from tertiary in-patient specialist
30 rehabilitation services, to address the following research questions:
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 - 32 ○ Do patients want to be entered on an LTNC register?
 - 33 ○ What proportion of patients would use such a register, and are there any characteristics
34 that identify those patients most likely to do so?
 - 35 ○ To what extent are their needs met and what are the main gaps in service provision?
 - 36 ○ What predicts the extent to which needs are met?
 - 37 ○ Is there a relationship between 'metness of need' in the critical first 6 months following
38 discharge to the community, and 'outcomes' in terms of carer burden and community
39 integration at 1 year?
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METHODS

Part A - Development of the LTNC register

Published in 2009 the LTNC database brought together a series of discrete datasets to capture episodes of health and social care as the patient moved through the care pathway from diagnosis to end-of-life care. The overall scheme of the LTNC dataset is summarised in Figure 1b. However, before data could be collected in routine clinical practice, the data collection tools had to be made fit for purpose. We therefore refined the database to include a manageable set of tools to identify patient needs, service inputs and patient outcomes for community-based rehabilitation and support services which could be used to inform integrated care planning, both at an individual and a population level.

A disease or case-register is a database that attempts 'to identify all cases of a disease or condition in an identified denominator population'.⁽¹⁸⁾ This definition distinguishes a register from a clinical database, which lacks a defined denominator population and does not attempt to identify all the cases in a specified population. The target population for the LTNC register is the subgroup of patients with complex needs who require integrated service provision from a range of health and social care agencies. Existing coding systems in the UK are primarily based on diagnosis (eg ICD-10 codes in secondary care and Read codes in primary care), which is generally a poor indicator of needs for services. The LTNC register therefore includes a brief dataset for prospective data collection to confirm that the registered patient has:

- a) a neurological condition that is likely to have an enduring effect
- b) complex needs for care/support, that are likely to require integrated care planning, either now or in the relatively near future.

Table 1 sets out the core information elements of the LTNC register as defined by the Dataset Development Group. This core set includes:

- The Neurological Impairment Scale as a measure of overall severity of the presenting condition⁽¹⁹⁾,
- The Needs and Provision Complexity Scale as a measure of needs for health and social care services and the extent to which these needs are met.⁽²⁰⁾

The group also highlighted the need for other measures to support the evaluation of outcome. Based on evidence from previous research incorporating the opinions and experience of both service users and professionals the following tools were selected on the basis that (a) they are psychometrically robust and applicable in LTNC, (b) they are freely available and not restricted by license and (c) are easily understood and timely to apply.⁽²¹⁻²³⁾ All the tools are suitable for completion either by self-report questionnaire or administered at interview by professionals.

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Table 1: LTNC Register Core Dataset*

Domain	Data fields	Value list / Data description
1. LTNC	Do they have an LTNC?	Yes/ no/ not sure
<i>If yes:</i> 1a. Record Neurological condition	Diagnosis or nature of condition	ICD-10 and /or Read codes Free text to describe neurological condition if no code exists
1b. Long term	Is the condition likely to have an enduring effect ?	Yes / No / Not sure
2. Needs for care/support	Do they have complex needs arising from the LTNC?	Yes / No / Not sure
<i>If yes:</i>		
2a. Record Impairment severity	Neurological Impairment Scale	17 item scores
2b. Record needs for health and social care	The Needs & Provision Complexity Scale (NPCS-Needs)	15 item scores
3. Need for integrated care planning (ICP)	Do they require integrated care planning	Yes / No / Not sure
4. Person responsible for registration	Name of registering clinician	Name and Signature
5. If yes to 1, 2, and 3		
5a: Are they having integrated care planning?	When was last ICP review?	Date
5b: Is there a single point of contact?	Named person or post	Name Job title/ contact details

* LTNC= Long term neurological condition; ICP=Integrated care planning

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Measurement tools included in the dataset

Neurological Impairment Scale (NIS): The NIS comprises a brief 17-item checklist of the major neurological impairments (motor/sensory loss, cognitive, communication, emotional, behaviour) that make up a complex presentation in people with LTNCs (19). Item severity scores range from 0-3 to assess the impact of these impairments at a functional level, giving a total score range 0-50. Originally developed as part of the core minimum dataset alongside the UK Functional Assessment Measure (24), the NIS is shown to be a valid and reliable measure of neurological impairment suitable for use across a wide range of neurological conditions.

The Needs and Provision Complexity Scale (NPCS): The NPCS is a 15-item measure with six subscales (total score range 0-50) in two principal domains ('Health' and 'Social care'). It is designed to be used as a simple tool to evaluate needs for health and social care and to identify gaps in service provision, both at the level of the individual and across populations.(20) It has two parts:

- '*NPCS-Needs*' is completed by the treating clinician(s) to evaluate each patient's needs for health and social care in any given period.
- '*NPCS-Gets*' is a mirror-image of the same tool, completed at the end of that period to evaluate the levels of service that have been provided in relation to those needs.

Subtracting NPCS-Needs scores from NPCS-Gets scores provides a measure of 'metness of needs' and a simple costing algorithm provides a generic estimate of the likely cost implications of addressing the unmet needs.

The Northwick Park Dependency Scale (NPDS): The NPDS is a measure of dependency of the individual on help from others in two main parts:(25)

- The 'Basic Care Needs' (BCN) section (score range 0-65) comprises 12 items covering the daily activities needed for everyday functioning. These include the capacity for both physical performance (NPDS-PD) (e.g. washing, dressing, toileting, eating and drinking etc.) and appropriate cognitive behaviour (NPDS-CB) (e.g. communication, safety awareness etc.).
- The 'Special Nursing Needs' (SNN) section (score range 0-35) includes seven items indicating the need for nursing care, such as a wound requiring dressings.

The NPDS is now widely used in the UK and has been translated into several languages. It is shown to be psychometrically robust.(26)

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3 *Community Integration Questionnaire (CIQ)*: The CIQ is a measure of community integration after traumatic
4 brain injury that is suitable for self-completion by the patient or a carer by proxy(26). It consists of 15 items
5 with a total score range from 0-29 comprising three subscales: (i) Home integration (range 0-10) (ii) Social
6 integration (range 0-12) and (iii) Productivity (0-7). Although not yet formally tested in a wider population
7 of patients with LTNC, the psychometric properties of the CIQ have been well established in the context of
8 brain injury. (27, 28)
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15 *Zarit Burden Inventory (ZBI)*: The ZBI is designed to capture the impact of a caring role on the carer's
16 personal and social well-being (29). It consists of 22 items (total score 0-88). For each item the carer rates
17 how often they are affected by the negative aspects of their caring situation on a scale ranging from 0
18 (never) to 4 (nearly always). Originally developed in the context of dementia, the ZBI has been used in LTNC
19 and other advanced conditions and is shown to be valid for assessing carer burden in these conditions.(30,
20 31)
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25 *Questionnaire administration*

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28 As many of the participants had complex disabilities with cognitive/ communication difficulties, three types
29 of media were used to gather data in order to maximise response rate and ensure accessibility.

30 Respondents could choose from the following options:

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33 a) paper-based postal-questionnaire
34
35 b) web-based survey tool, using Survey Methods software (Survey Methods Inc.
36 www.surveymethods.com)
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38 c) questionnaire administered by a researcher at telephone interview.
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40 All questionnaires were piloted prior to use. Wherever possible, follow-up telephone interviews were used
41 to complete missing information from questionnaires, and this provided further feedback to refine the
42 data-gathering tools. The changes related to presentation (plain language, font size etc) and did not affect
43 the structure or content of the measurement instruments.
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47 **PART B – Longitudinal Cohort Study**

48 In Part B, the LTNC dataset was used to monitor a cohort of patients over a 1 year period following
49 discharge from all tertiary specialised in-patient rehabilitation services across the London region.
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53 **Participating centres**

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55 Nine 'Level1' services provide a comprehensive network of tertiary specialist in-patient neurological
56 rehabilitation across the London Region of the UK. They provide specialised rehabilitation for the
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3 population of patients with complex needs that are beyond the scope of their local (Level 2 and 3)
4 rehabilitation services (<http://www.bsrm.co.uk/index.htm>).⁽³²⁾ Patients discharged from these units are
5 therefore likely to have complex needs for ongoing rehabilitation and support services in the community.
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7 All nine services participated in recruitment in our study.
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Participants

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12 Recruitment occurred over an 18-month period in 2010 – 2011. Consecutive in-patients across the nine
13 services with a LTNC at the point of discharge were considered eligible to participate, and were approached
14 for consent, which was taken in writing by the discharging clinician after a suitable period for reflection.
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16 Where cognitive or communication problems prevented their direct participation a family member or carer
17 was identified to assist (or respond on behalf of) the patient.
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Data Collection Procedure

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24 For all consenting patients, their discharge team completed a recruitment form that included:

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26 a) Severity of impairment (NIS)
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28 b) Needs for ongoing services (NPCS-Needs)
29
30 c) Whether the patient was willing to be included in the pilot LTNC Register
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32 d) Details of any community rehabilitation support services to which patients had been referred
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34 e) Contact details for a named individual to approach for follow-up questionnaires (usually either the
35 patient or a family carer).
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38 This information was then sent to the research team who contacted the named individual to answer
39 questions / address any concerns and to establish their preferred medium for response (ie postal
40 questionnaire, web-based survey or telephone interview). Tools included in the questionnaire were self-
41 report versions of:
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- 44 a) Dependency (NPDS): including basic care needs (NPDS-BCN) and special nursing needs (NPDS-SNN)
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46 b) Community integration (CIQ)
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48 c) Carer Burden (ZBI) – if the individual had a family (or other informal) carer
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50 d) Services received (NPCS-Gets) in the last 6-month period – recorded at 6 and 12 months
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53 Participants were contacted at one, six and 12 months after discharge and asked to complete a
54 questionnaire/interview. A second follow-up call was made if a response had not been received within a
55 fortnight. Up to five attempts were made to reach respondents by telephone before desisting.
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Efforts to maximize response rates

Across the three response phases, paper questionnaires were consistently the most commonly used method (approximately 80 to 84% of respondents); 10 to 13% responded online and 3 to 5% were administered at telephone interview. Over the course of the study, a total of 1211 questionnaires were sent and 225 re-sent; 1607 phone calls were made to achieve the 658 questionnaires received.

Data management and analysis

Data were entered into a spreadsheet (Microsoft Excel) and after cleaning and validation, were extracted to SPSS (IBM Statistics) version 19 for statistical analysis. Despite the ordinal nature of the data, in view of the large sample size and the fact that linear regression modelling used in the latter part of the analysis relies on parametric assumptions, parametric techniques were used throughout with descriptive statistics reported in the form of percentages or means, standard deviations and range. Non-parametric analyses are available on request from the author but did not yield different results. In view of the multiple tests, the threshold for significance was set at $p < 0.01$.

Our part 1 analyses included a descriptive analysis of all available respondents at each time point. To determine whether patients would want to use an LTNC register, we examined the proportions who agreed to be included and those who actually responded to our requests for follow-up information on each occasion, as an indication of those most likely to use the register.

We examined the characteristics of patients who responded at each time point in terms of demographics, severity of impairment and needs for services. We looked in particular for any statistical differences between the "best responder" group (those who responded at all three time points) and the 'non-responders' (who did not respond on any occasion). To identify predictors of the extent of rehabilitation received (NPCS-Gets) at six months post-discharge we began with a series of univariate regression analyses including all those who responded at 6 months ($n=212$). Specifically we examined which of the following variables (recorded at baseline) predicted the overall level of rehabilitation services received:

- a) demographics
- b) level of impairment both physical (NIS-Physical), and cognitive (NIS cognitive)
- c) level of dependency - physical (NPDS-PD) and cognitive (NPDS-CB) and total basic care needs (total NPDS-BCN) were entered as separate variables
- d) special nursing needs (NPDS-SNN)
- e) social integration in the community (CIQ).

The best individual predictors were then included in a single stepwise multiple regression analysis.

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5 The second part of our analysis explored the relationship between outcomes and the extent to which an
6 individual's needs for services were met. Here the longitudinal trends for change over successive time
7 periods were the specific focus of interest, so only the 'best responders' (for whom data were available at
8 all three time points) were included.
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- 13 • Differences between NPCS 'Needs' and 'Gets', and between NPCS-Gets during the first and second
14 6 month period were tested by paired t tests.
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- 17 • Discrepancy scores between the needs identified by the treating clinicians at discharge (NPCS-
18 Needs) and services received during the first six month period (NPCS-Gets) were calculated on a
19 case-by-case basis as a measure of the extent to which individual needs were met (i.e. 'Metness of
20 need' = 'NPCS-Gets' minus 'NPCS needs')
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29 To examine the relationship between outcome (in terms of community integration and carer burden) at 12
30 months and the extent to which individual needs for rehabilitation were met during the critical first 6
31 months, discrepancy scores for the NPCS Rehabilitation subscale were entered as predictor values in a
32 longitudinal linear regression analysis. We examined outcomes, (CIQ and ZBI) in comparison with 'metness
33 of need' in the Rehabilitation subscale of the NPCS. We also dichotomized patients into those whose
34 rehabilitation needs were met or exceeded in the first six months (Gets minus Needs ≥ 0) and those who
35 had unmet needs (Gets minus Needs < 0). Although we expected the level of community integration to be
36 affected by physical and cognitive dependency, we hypothesized that patients whose needs for rehabilitation
37 and support were met would achieve better integration than those with unmet needs.
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50 RESULTS

51 Recruitment and response rates

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54 Out of a total of 576 admissions, 499 patients were assessed as eligible for inclusion in an LTNC register and
55 approached by the clinical teams for permission to include them in the study, of which 428 (92%) were
56 recruited. Across the nine units just 7% of those approached declined to participate in the study. The
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participation and attrition rates throughout the study are displayed in Figure 2. The characteristics of the 428 patients recruited, are shown in Table 2 .

Table 2: Characteristics of the 428 Patients recruited, the ‘best responder’ (n=134) and the non-responder (n=123) group.

Variables		Recruited sample N=428		Best responders N=134		Non-responders N=123		Chi-squared *
		N	%	N	%	N	%	P value
Gender	Male	270	(63.1)	86	(64.2)	80	(65.0)	0.90
	Female	158	(36.9)	48	(35.8)	43	(35.0)	
Diagnosis	Brain injury	315	(73.6)	97	(72.8)	85	(69.1)	0.35
	- Stroke/SAH*	212	(49.5)	70	(52.2)	57	(46.3)	
	- TBI*	63	(14.7)	16	(11.9)	18	(14.6)	
	- Other ABI*	40	(9.3)	11	(8.2)	10	(8.1)	
	Spinal Cord Injury	38	(8.9)	8	(6.0)	11	(8.9)	
	Peripheral Neuropathy	26	(6.1)	8	(6.0)	9	(7.3)	
	Progressive LTNC	21	(4.9)	5	(3.7)	10	(8.1)	
	Other	27	(6.3)	16	(11.9)	7	(5.7)	
	Missing	1	(0.2)	0	(0)	1	(0.8)	
Discharge destination	Home	333	(77.8)	115	(85.8)	89	(72.4)	0.009
	Nursing Home	51	(11.9)	9	(6.7)	19	(15.4)	0.03
	On-going Rehab	18	(4.2)	6	(4.5)	5	(4.1)	1.0
	Hospital	4	(1.0)	2	(1.5)	1	(0.8)	1.0
	Other	19	(4.4)	2	(1.5)	9	(7.3)	0.03
Referred to ongoing rehabilitation	Yes	378	(88.3)	124	(92.5)	110	(89.4)	0.33
	No	41	(9.6)	7	(5.2)	11	(8.9)	
	Not answered	9	(2.1)	3	(2.2)	2	(1.6)	
Permission to include on the Register	Yes	322	(75.2)	108	(80.6)	90	(73.2)	0.23
	No	13	(3.0)	3	(2.2)	7	(5.7)	
	Not answered	93	(21.7)	23	(17.2)	26	(21.1)	
At recruitment		Mean	SD	Mean	SD	Mean	SD	T-test* P value
Age	Years	49.1	(15.2)	50.2	(14.0)	47.8	(15.9)	0.19
Neurological Impairment	NIS-Motor	8.1	(5.1)	8.3	(5.0)	8.9	(5.4)	0.36
	NIS-Cognitive	4.4	(3.1)	4.4	(3.2)	4.8	(3.0)	0.34
	Total	12.8	(6.4)	13.1	(6.4)	13.9	(6.7)	0.37
Needs for health and social care	NPCS Health	11.5	(4.3)	11.4	(4.2)	11.9	(4.5)	0.31
	NPCS-Social support	6.2	(4.3)	5.6	(4.0)	6.7	(4.8)	0.04
	NPCS-Total	17.7	(7.8)	17.0	(7.6)	18.7	(8.4)	0.09

*Difference between best responders and non-responders.

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Do patients want to be entered on an LTNC register, and which patients might be most likely to use it?

Consent to participate in the study questionnaires did not necessarily mean that individuals would be willing to have their details included in a register. Three-quarters of the recruited group (n=322 (75%)) indicated, at discharge from hospital, that they were willing to be included in a pilot LTNC register. On the other hand only 13 (3%) declined. The remaining 93 (22%) did not answer the question. However, only a proportion of these actually responded to questionnaires when subsequently approached in the community. At one month post discharge, 59% responded; at 6 months 49%; and at 12 months just 44%. The response across the three time periods was not consistent: 123 (29%) did not respond to a questionnaire in any of the phases; 20 - 21% responded to one or two phases and just 134 (31%) responded to all three phases. This latter group of 'best responders' was considered to be the group of patients most likely to engage in follow-up using an LTNC register. Interestingly there was no significant difference between the 'best responders' and the 'non-responders' in terms of their expressed willingness to be included in the register.

Characteristics of the responding patients across the three phases

Respondents were similar at each phase in terms of gender ratio, age, marital status and educational level. The only significant trend over time was a greater attrition for non-white British subjects, reflected in the loss of 39% of Black and 49% Asian/other participants as compared with only 18% attrition for white participants. (Full details are given in the main study report (33). The 'best responders' were more likely to have been discharged home than the non-responders, a greater proportion of whom were in nursing home or other residential care. Otherwise there were no significant differences in demographics between these two groups, and they had similar levels of impairment and needs for services at recruitment (see Table 2).

The extent to which needs were and were not met

Table 3 shows descriptive statistics for measures of impairment, needs, inputs and outcome across the three follow-up phases. Again there was no difference between the groups responding at each time period with respect to their severity of impairment (total NIS score) or need for services (NPCS-Needs), nor with respect to their outcomes in terms of dependency (NPDS) integration (CIQ) or carer burden (ZBI).

The level of services received during the first 6 months was significantly lower than the needs identified at discharge for both health care (Mean difference 1.8 (95% CI 1.1, 2.4) $t = 5.1$, $p < 0.001$) and social care (Mean difference 1.7 (95% CI 1.1, 2.2) $t = 5.9$, $p < 0.001$). There was a modest overall decline in the levels of

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both health and social support services during the second six months, even though the levels of dependency, community integration and carer burden remained similar. However, this could simply have

Table 3: Descriptive statistics for measures of severity, needs inputs and outcome across the three Phases after Discharge.

Time	Phase 1 1 month N=256	Phase 2 6 months N= 212	Phase 3 12 months N=190	'Best responders' at recruitment and phase 3. N=134
Measure (Scoring range)	Mean (SD) Range (Min-Max)	Mean (SD) Range (Min-Max)	Mean (SD) Range (Min-Max)	Mean (SD) Range (Min-Max)
At recruitment				
Impairment				
NIS-Motor	7.8 (4.9) 0-25	7.9 (5.1) 0-25	8.1 (5.0) 0-25	8.3 (5.0) 0-25
NIS cognitive	4.3 (3.1) 0-14	4.5 (3.2) 0-13	4.2 (3.0) 0-13	4.4 (3.2) 0-13
NIS Total (0-50)	12.4 (6.4) 1-31	12.7 (6.5) 1-31	12.7 (6.2) 1-31	13.1 (6.4) 1-31
Level of services required (NPCS-Needs)				
Health and care	11.3 (4.1) 0-21	11.4 (4.2) 0-20	11.2 (4.2) 0-21	11.4 (4.2) 0-20
Social support	5.7 (4.0) 0-19	6.1 (4.2) 0-19	5.8 (4.0) 0-19	5.6 (4.0) 0-19
Total (0-50)	17.0 (7.5) 0-36	17.5 (7.7) 1-36	17.0 (7.6) 0-36	17.0 (7.6) 0-36
At follow-up period				
NPCS-Health Gets (0-25)	Not applicable	9.4 (4.7) 0-20	8.5 (4.8) 0-21	8.4 (4.9) 0-21
NPCS-Social Gets (0-25)	Not applicable	4.6 (3.5) 0-15	3.8 (3.1) 0-15	3.8 (3.2) 0-15
NPCS-total Gets (0-50)	Not applicable	14.0 (7.1) 0-29	12.5 (7.1) 0-34	12.4(7.2) 0-34
NPDS (0-100)	12.7 (13.9) 0-66	12.2 (13.8) 0-61	11.2 (13.5) 0-60	11.4 (13.5) 0-60
CIQ (0-29)	12.1 (4.9) 0-26	11.0 (5.7) 0-27	12.3 (5.7) 0-27	12.3 (5.8) 0-27
ZBI (0-88)	24.4 (16.7) 0-82	24.4 (17.5) 0-82	25.5 (18.9) 0-88	26.9 (18.6) 0-84

NPCS = Needs and Provision Complexity Scale; NIS=Neurological Impairment Scale,
CIQ= Community Integration Questionnaire; ZBI = Zarit Care Burden Interview

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3 been due to differences in the responder populations at 6 and 12 months. Therefore, a paired analysis was
4 conducted for just the best responder group, who responded on all three occasions. Although these best
5 responders (n=134) formed less than one third of the total population, there was no evidence that they
6 differed in any significant respect from the recruited population (see Tables 2 and 3).
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11 Table 4 shows a more detailed evaluation of the met and unmet needs across the time frame of the study
12 for this 'best responder group. It also records the change in outcomes. As recorded elsewhere for the full
13 cohort(20, 33), this subgroup analysis confirms significant levels of unmet needs with respect to
14 rehabilitation, social support and equipment provision during the first critical 6 months following
15 discharge(20, 33). It also records a significant decline in service provision between months 6 and 12,
16 despite their continuing levels of dependency and carer burden. The level of community integration
17 appears to increase briefly at 6 months and then subside to baseline levels at 12 months.
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24 However, within the study sample there is clearly significant variation, both with respect to the level of
25 services provided and outcome. It is therefore pertinent to examine what predicts the levels of service
26 provision, especially during the first critical 6 months after discharge to the community, and whether there
27 is a relationship between 'metness of needs' and outcome.
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Table 4: Best-responder population (n=134): Descriptive statistics and significant differences in needs, inputs and outcomes at baseline, 6 and 12 months

	Missing	Baseline	6 months	Difference tested by paired T Tests				Missing	12 months	Mean difference	95% CI	P value	Effect size*
		Mean (SD)	Mean (SD)	Mean difference	95% CI	P value	Effect size*		Mean (SD)				
NPCS		Needs	Gets at 6 months	Difference in needs and levels of service received during the first 6 months					Gets at 12 months	Difference in level of services received during the 1st and 2nd 6-month periods			
Health and Personal care domain													
Health	2	2.3 (1.5)	2.4 (1.7)	0.04	-0.3, 0.4	0.81	0.03	2	2.2 (1.6)	-0.1	-0.4, 0.1	0.25	0.06
Personal care	7	3.7 (2.7)	3.6 (2.6)	0.02	-0.4, 0.5	0.92	0.01	8	3.3 (2.6)	-0.4	-0.7, 0.1	0.02	0.15
Rehabilitation	5	5.3 (1.9)	3.6 (2.0)	-1.7	-2.1, -1.3	<0.001	0.89	8	2.9 (2.2)	-0.8	-1.2, -0.5	<0.001	0.40
Total	13	11.4(4.2)	9.5 (4.7)	-1.6	-2.5, -0.8	<0.001	0.38	16	8.4 (4.9)	-1.4	-2.0, -0.8	<0.001	0.30
Social care and support domain													
Social support	12	2.8 (2.6)	1.6 (2.0)	-1.2	-1.7, -0.7	<0.001	0.46	15	1.2 (1.7)	-0.4	-0.7, -0.1	0.005	0.20
Equipment	4	1.2 (0.9)	0.8 (0.8)	-0.4	-0.6, -0.2	<0.001	0.44	6	0.6 (0.8)	-0.2	-0.4, -0.1	0.004	0.25
Accommodation	2	1.6 (1.9)	1.8 (2.0)	0.2	-0.1, 0.5	0.16	0.11	2	1.9 (1.9)	0.1	-0.1, 0.4	0.23	0.05
Total	14	5.6 (4.0)	4.1 (3.2)	-1.5	-2.2, -0.9	0.07	0.37	18	3.8 (3.2)	-0.4	-0.8, 0.0	0.06	0.13
Total Needs and Provision													
TOTAL	22	16.8 (7.6)	13.7 (6.9)	-3.1	-4.3, -1.8	<0.001	0.41	29	12.1 (7.1)	-1.9	-2.7, -1.1	<0.001	0.27
Outcome measures (total scores)													
Dependency (NPDS)	0	12.8 (13.3)	12.4 (14.4)	-0.4	-1.6, 0.8	0.51	0.03	0	11.4 (13.5)	-1.0	-1.9, 0.0	0.05	0.07
Integration (CIQ)	24	12.3 (4.9)	11.4 (5.6)	-1.0	-1.7, 0.2	0.01	0.22	21	12.4 (5.7)	0.9	-0.4, 1.5	0.002	0.16
Carer burden (ZBI)	53**	23.7 (17.1)	24.1 (17.2)	0.4	-2.1, 2.9	0.75	0.06	55**	25.3 (18.1)	1.5	-0.5, 3.5	0.15	0.09

NPCS = Needs and Provision Complexity Scale; SD= standard deviation; 95%CI = 95% Confidence Interval

*Effect sizes for the first 6 months were calculated as mean difference / SD baseline and for the second 6 months: mean difference / SD at 6 months

** Carer burden scores were only recorded where a family carer was involved.

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What predicts the level of services received?

The univariate regression analyses showed that none of the demographic variables (Age, Gender, Ethnicity, Marital Status, Education, Diagnosis) predicted a significant proportion of the variance in total NPCS-Gets at six months (n=212). Results of a stepwise regression analysis that included the best predictors from univariate analyses are presented in Table 5. In both the univariate analyses and in the stepwise model dependency (NPDS-BCN) was the best single predictor accounting for 33% of the model variance. The addition of Motor and Cognitive Impairment (as measured by the NIS subscales at recruitment) improved the predictive ability of the stepwise model by small but significant increments to a total R² of 40 percent.

Table 5: Stepwise regression analyses of best individual predictor variables of services received (NPCS gets) during the first 6 months after discharge

Stepwise Models	β	CI (95%)	p	R ²	ΔR^2
NPDS -BCN	0.34	0.26 – 0.43	.001	0.33	-----
NPDS-BCN	0.23	0.12 – 0.34	.001	0.38	0.05
NIS-Motor	0.37	0.13 – 0.60	.001		
NPDS-BCN	0.18	.06 – 0.30	.001	0.40	0.02
NIS-Motor	0.40	0.17 – 0.63	.001		
NIS-Cognitive	0.34	0.02 – 0.67	.001		

Variables not included in the stepwise were CIQ and SNN

Is there a relationship between ‘metness of need’ in the first critical 6 months and outcome in terms of community integration and carer burden?

Taking community integration scores (CIQ) at 12 months as the dependent variable, a stepwise regression was carried out using physical dependency (NPDS-PD) and cognitive dependency (NPDS-CB) at baseline, and ‘metness’ of rehabilitation needs at six months as independent variables. This revealed that 31% of the variance in community integration could be explained by physical and cognitive dependency; the more dependent patients being less well integrated at 12 months. The extent to which their rehabilitation needs had been met was positively correlated with dependency at baseline (rho 0.20, p=0.03), and added only 2% to the predictor model, so that together they explained 33% of the variance. However, the relationship was not in the expected direction. Patients (n=31) who received rehabilitation services that met or exceeded the levels of need predicted at discharge showed significantly lower gains in CIQ than those in who provision did not meet their predicted need (n=71): Mean difference 2.6 (95% CI 0.9, 4.3, p=0.003).

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3 A similar stepwise regression was performed for carer burden (ZBI) at 12 months. Here only cognitive
4 dependency was entered into the model, predicting 12% of the variance and metness of rehabilitation
5 needs was excluded as a predictor variable. There was no significant difference in carer burden between
6 patients with 'met' and 'unmet' needs for rehabilitation.
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DISCUSSION

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12 This paper describes further development of the LTNC dataset to identify a manageable set of tools suitable
13 for use in routine practice to measure needs, inputs and outcomes from community-based rehabilitation
14 and support services. In a cohort of nearly 500 patients with complex needs arising from a LTNC, the large
15 majority were willing in principle to be registered and have their data included in the dataset. However, in
16 practice, only a minority (less than one third) responded regularly when asked to provide information
17 about their ongoing needs and the level of services received. Although these 'best responders' included a
18 higher proportion of non-white british patients, they were not otherwise distinguishable from the non-
19 responder group, in terms of severity of impairment, disability or needs for services.
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27 However the high attrition rate among those participants who agreed to participate suggests that a register
28 based on postal/telephone follow-up will be labour intensive and might fail to engage a significant
29 proportion of the most vulnerable patients. Consequently integrated care planning reviews should normally
30 involve face-to-face meetings with the patient and carer. This is likely to offer the most effective route for
31 data collection for the register. In this context the NPCS provides a simple and practical tool to capture met
32 and unmet needs and so assist clinical teams to identify and address any gaps in service provision at either
33 an individual or an organisational level.
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40 Longitudinal study of this best responder group revealed that they changed little in terms of dependency
41 or community integration during the year following discharge from in-patient specialist rehabilitation, and
42 the burden on their carers also remained stable. In common with the larger cohort, they had significant
43 unmet needs for health and social care services – particularly with respect to rehabilitation, social worker
44 support and provision of specialist equipment.(20) Physical disability was the best single predictor of
45 services received, followed by cognitive/behavioural disability. In contrast to some other studies there was
46 no strong evidence that those with hidden disabilities were less able to access services than those with
47 physical disability.(17) However, this may be due to the targeted efforts of the in-patient teams to set up
48 services for them following discharge to the community.
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We had expected to demonstrate that patients whose needs for community-based rehabilitation were met had better outcomes in terms of community integration, and reduced burden on carers. In fact, if anything we showed the opposite. Over and above the relationship with physical and cognitive dependency, patients whose rehabilitation needs were met or exceeded had made less gains in integration at twelve months post discharge than those with unmet needs. Whilst counter-intuitive, on a clinical level this paradoxical finding is hardly surprising. In a health culture where resources are limited, services will be focussed on those who have the greatest need. Professionals are likely to withdraw sooner from those patients who improve over time, and to target their resources on those who continue to require their help.

A weakness of this study was that needs were not reassessed at each time point. so we cannot determine whether under provision of services with respect to predicted needs reflected unmet or changing levels of need. This argues for the importance of continued review in future studies, measuring both needs and inputs to capture change over time. The NPCS provides a simple practical means to do this.

Other weaknesses are as follows:

- While the cohort was large it only included patients from tertiary rehabilitation services in the greater London metropolitan area and experiences might be different in other parts of the UK particularly rural regions.
- There was a high attrition rate at each phase of the longitudinal study. Although there were no differences between responders and non-responders on any demographic variables except for ethnicity, we cannot discount the possibility of response bias.

Despite these recognised limitations, the study provides useful insights into the potential value of an LTNC register and its associated tools as a means to monitor needs, inputs and outcomes for patients with LTNC.

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Competing interests:

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3 There are no significant competing interests. All authors have completed the BMJ Declaration of Competing
4 Interests form available on request from the corresponding author.
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8 Outcome measurement is a specific research interest of our centre. LTS was the lead developer of the
9 NPDS, NIS and NPC, but neither she nor her employing institution has any financial interest in the tools
10 which are disseminated free of charge. None of the authors has any personal financial interests in the work
11 undertaken or the findings reported. All authors are employed by universities/hospitals which may cite this
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15 influenced the submitted work.
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21
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26 in this article represent the first publication of emerging findings from the larger study, for which the final
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29 Foundation.
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39 **Copies of the NIS, NPDS and NPC** are available free of charge from our website

40 (www.csi.kcl.ac.uk/tools.html) and copies of the full questionnaire and other tools used in this study are
41 available from the corresponding author.
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46 **Ethics approval:** Approval for the study was granted by Bromley Research Ethics Committee (Ref no:
47 09/H0805/25) and subsequently the R&D centres of the seven participating NHS trusts. The remaining two
48 recruiting centres were in the independent sector - approval for recruitment was obtained through their
49 internal clinical and research governance processes.
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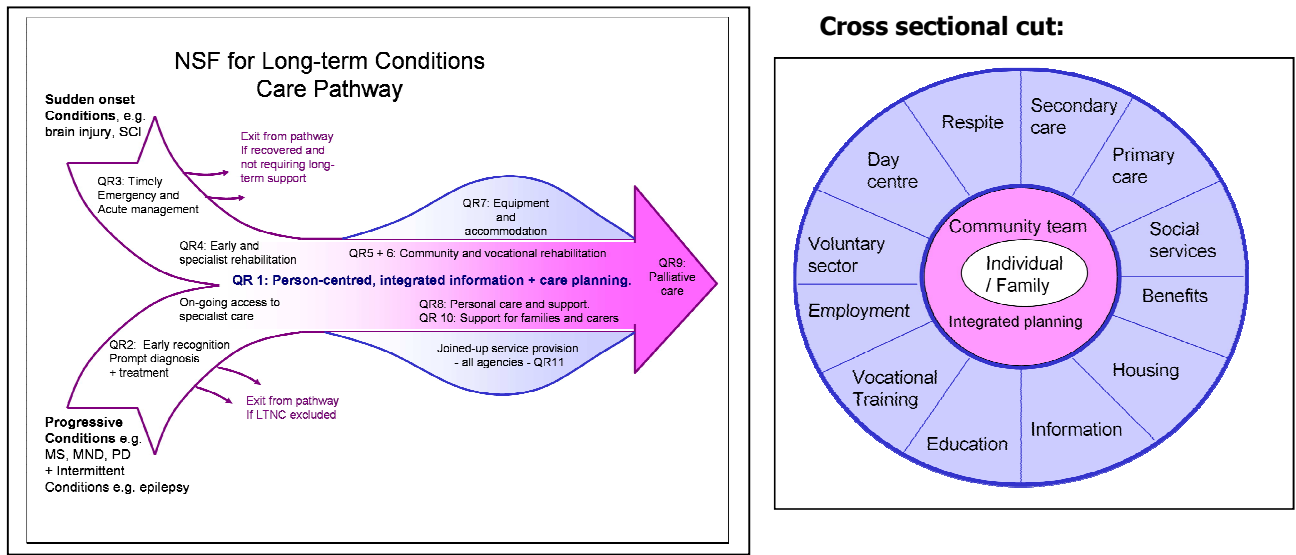
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54 **Registration:** The study was registered with the NIHR Comprehensive Local Research Network: ID number
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3 **Author contributions:** RJS was the principal investigator for the larger study of which this formed a part. He
4 took the lead role in execution and governance of the study and had overall responsibility for study
5 reporting. LTS was the lead clinician, led the design of the study, and the development of the LTNC register
6 and dataset. LTS and RJS wrote the first draft of the article together. DMJ was responsible for data-checking
7 and quality and also contributed to writing the article. EDP and SF were co-applicants on the study and
8 members of the project steering group, contributing to direction and decision-making as the study
9 progressed. All co-authors reviewed and commented on the manuscript.
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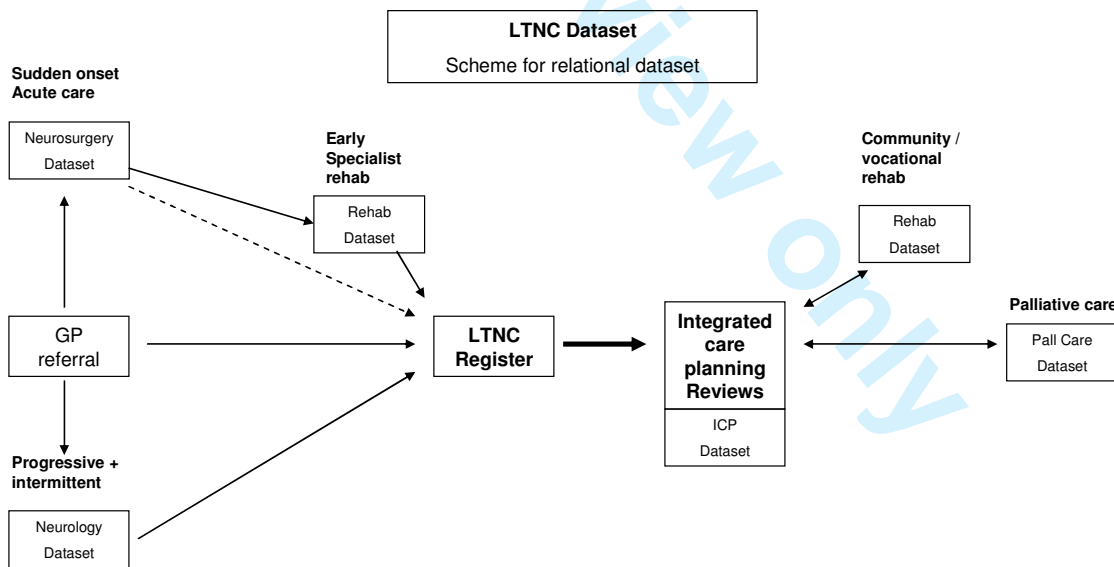
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16 **Data sharing:** Not available at the current time as further articles are currently in development. Data
17 sharing may be available in the future – please contact the corresponding author.
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Figure 1a: A schematic diagram of The NSF for LTNC care pathway and quality requirements



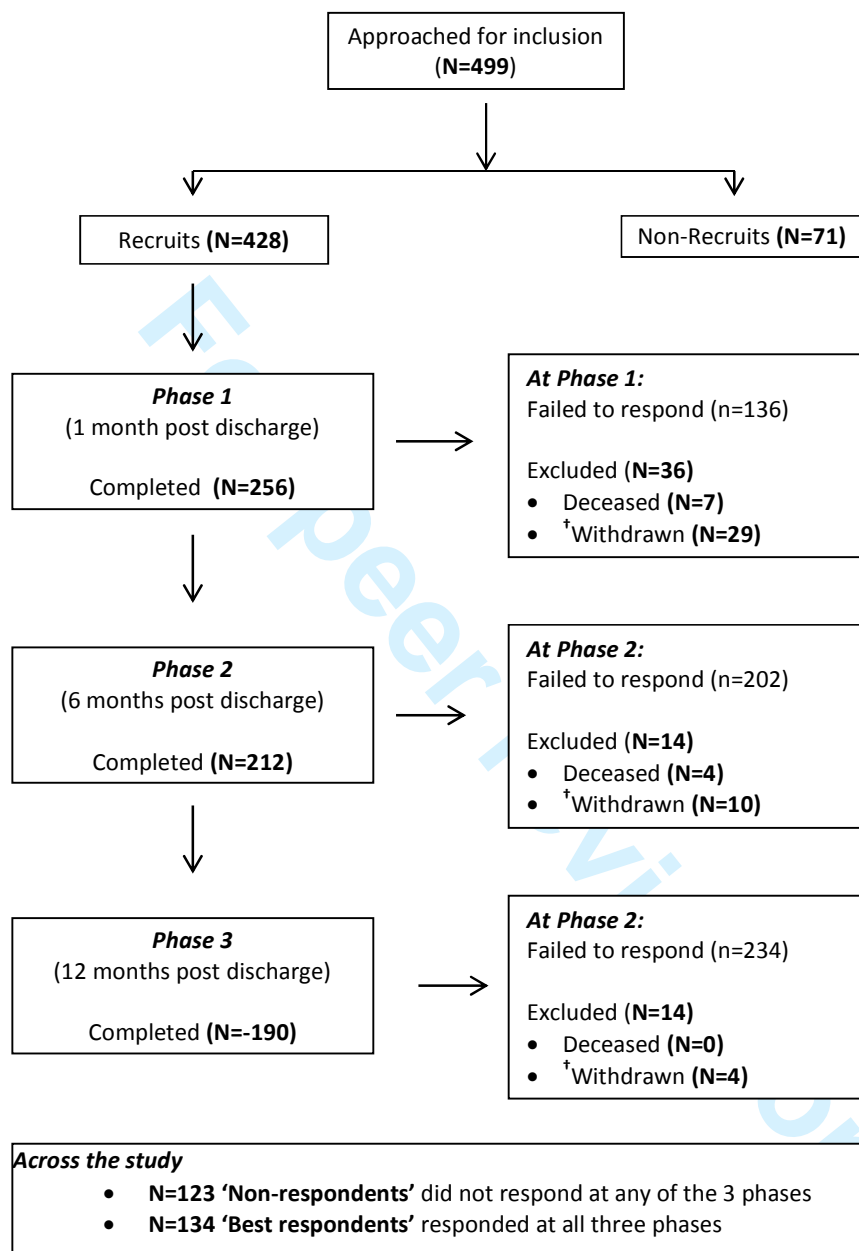
Legend to Figure 1a: The 'fish diagram' illustrates how the different Quality Requirements (QRs) of the NSF fit along the care pathway. The cross sectional diagram illustrates the range of services that may be needed by a patient with complex needs(14) (Reproduced with permission from Prof Lynne Turner-Stokes).

Figure 1b: The overall scheme of the LTNC dataset



Legend to Figure 1: The LTNC dataset is made up of a relational database with seven datasets linked via the patient's identifier (NHS number) following the overall schema of the LTNC pathway. The LTNC register identifies those patients with complex needs who form the denominator for datasets in the later stages of the pathway (Reproduced with permission from Prof Lynne Turner-Stokes).

Figure 2: Recruitment and participation pathway



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STROBE Statement—checklist of items that should be included in reports of observational studies

	Item No	Recommendation
Title and abstract □	1	(a) Indicate the study's design with a commonly used term in the title or the abstract (b) Provide in the abstract an informative and balanced summary of what was done and what was found
Introduction □		
Background/rationale□	2	Explain the scientific background and rationale for the investigation being reported
Objectives□	3	State specific objectives, including any prespecified hypotheses
Methods □		
Study design□	4	Present key elements of study design early in the paper
Setting□	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection
Participants□	6	(a) <i>Cohort study</i> —Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up <i>Case-control study</i> —Give the eligibility criteria, and the sources and methods of case ascertainment and control selection. Give the rationale for the choice of cases and controls <i>Cross-sectional study</i> —Give the eligibility criteria, and the sources and methods of selection of participants (b) <i>Cohort study</i> —For matched studies, give matching criteria and number of exposed and unexposed <i>Case-control study</i> —For matched studies, give matching criteria and the number of controls per case
Variables□	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable
Data sources/ measurement□	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group
Bias□	9	Describe any efforts to address potential sources of bias
Study size□	10	Explain how the study size was arrived at
Quantitative variables□	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why
Statistical methods□	12	(a) Describe all statistical methods, including those used to control for confounding (b) Describe any methods used to examine subgroups and interactions (c) Explain how missing data were addressed (d) <i>Cohort study</i> —If applicable, explain how loss to follow-up was addressed <i>Case-control study</i> —If applicable, explain how matching of cases and controls was addressed <i>Cross-sectional study</i> —If applicable, describe analytical methods taking account of sampling strategy (e) Describe any sensitivity analyses

Continued on next page

Results

Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed (b) Give reasons for non-participation at each stage (c) Consider use of a flow diagram
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders (b) Indicate number of participants with missing data for each variable of interest (c) <i>Cohort study</i> —Summarise follow-up time (eg, average and total amount)
Outcome data	15*	<i>Cohort study</i> —Report numbers of outcome events or summary measures over time <i>Case-control study</i> —Report numbers in each exposure category, or summary measures of exposure <i>Cross-sectional study</i> —Report numbers of outcome events or summary measures
Main results	16	(a) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included (b) Report category boundaries when continuous variables were categorized (c) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses

Discussion

Key results	18	Summarise key results with reference to study objectives
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence
Generalisability	21	Discuss the generalisability (external validity) of the study results

Other information

Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based
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*Give information separately for cases and controls in case-control studies and, if applicable, for exposed and unexposed groups in cohort and cross-sectional studies.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at <http://www.plosmedicine.org/>, Annals of Internal Medicine at <http://www.annals.org/>, and Epidemiology at <http://www.epidem.com/>). Information on the STROBE Initiative is available at www.strobe-statement.org.



A Longitudinal, Multi-Centre, Cohort Study of Community Rehabilitation Service Delivery in Long-Term Neurological Conditions

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8 **A Longitudinal, Multi-Centre, Cohort Study of Community Rehabilitation Service Delivery in**
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10 **Long-Term Neurological Conditions**
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13 Richard J Siegert^{1*}, Diana M Jackson², E Diane Playford³, Simon Fleminger⁴ & Lynne Turner-Stokes^{2,5}
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34 Keywords: Rehabilitation; neurological disorders; health services needs; delivery of health care,
35 integrated, Needs and Provision Complexity Scale
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58 **WORD COUNT = 7,174 (excluding Title page, tables, figures and references)**
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Running Head: Long-Term Neurological Conditions

ABSTRACT

Objectives: Part A. To pilot the use of a register to identify and monitor patients with complex needs arising from long-term neurological conditions (LTNC). **Part B.** To determine the extent to which patients' needs for health and social services are met following discharge to the community after in-patient rehabilitation; to identify which factors predict unmet needs and to explore the relationship between service provision and outcomes at 12 months.

Design: A multi-centre, prospective, cohort study surveying participants at 1, 6 and 12 months using postal/online questionnaires and telephone interview.

Setting: Consecutive discharges to the community from all nine tertiary, specialist, inpatient neuro-rehabilitation services in London over 18 months in 2010-2011.

Participants: Out of 576 admissions 428 patients were recruited at discharge: 256 responded at 4 weeks, 212 at 6 months and 190 at 12 months.

Measures: Neurological Impairment Scale, The Needs and Provision Complexity Scale, The Northwick Park Dependency Scale, Community Integration Questionnaire, Zarit Burden Inventory.

Results: n=322(75%) expressed willingness to be registered, but in practice less than half responded to questionnaires at 6 and 12 months (49 and 44% respectively), despite extensive efforts to contact them, with no significant differences between responders and non-responders. Significant unmet needs were identified within the first year following discharge, particularly in rehabilitation, social work support and provision of specialist equipment. Dependency for basic care and motor and cognitive impairment predicted services received, together accounting for 40% of the variance. Contra to expectation, patients whose rehabilitation needs were met were more dependent and less well integrated at 12 months post discharge than those with unmet needs.

Conclusions: Registration is acceptable to most patients, but questionnaires/telephone interviews may not be the most efficient way to reach them. When community resources are limited service provision tends to be focused on the most dependent patients.

ARTICLE SUMMARY**Article focus**

- Is a register of people with long-term neurological conditions feasible to monitor needs, service provision and outcomes?
- To what extent are patients' needs met after discharge and what are the major gaps in service provision?
- Is there a relationship between 'metness of need' in the six months following discharge to the community and outcomes?

Key Messages

- The majority of patients are agreeable to being registered but attrition is high. A workable register would need to be based around regular, face-to-face, integrated care planning meetings. The Needs and Provision Complexity Scale offers a practical framework for identifying unmet need in such meetings.
- Unmet needs were most evident for rehabilitation, social work support and provision of specialist equipment.
- Patients who were more dependent were still less well integrated into the community at 12 months despite being more likely to have had their needs met,

Strengths and limitations of this study

- This study provides the first detailed longitudinal examination of services provided in the community in relation to needs at discharge for a large cohort of patients discharged from specialist neurorehabilitation services in the UK.
- The study had a high attrition rate and participants were only recruited from London hospitals.

INTRODUCTION

There is increasing recognition internationally of the importance of post-acute community rehabilitation services for long-term neurological conditions (LTNCs), and also the need to demonstrate their cost-effectiveness.(1-5) There has also been increased recognition of the needs and burden experienced by the families and carers of people with LTNCs.(6, 7) While some progress has been made in demonstrating the value of community programmes for specific conditions such as traumatic brain injury and stroke, comparatively little is known about the organisation, delivery and effectiveness of generic rehabilitation services in the community, in spite of the fact that they constitute the majority of rehabilitation services. (8-11)

LTNCs affect not only the individuals concerned but also their family and carers. In the UK, a series of National Service Frameworks (NSF) have laid down standards for service provision across a wide range of conditions.(12) Published in 2005 with a 10-year implementation plan, the primary focus of the UK National Service Framework (NSF) for Long Term Conditions was on neurological conditions.(13)

This NSF sets out 11 standards or 'Quality Requirements' for rehabilitation and social support for patients living with neurological disability.(13) It emphasises a bio-psychosocial approach, addressing all stages in the 'care pathway' from diagnosis to death (see Figure 1a), and highlights in particular the need for life-long access to services in the community.(14) Quality Requirement 1 (the 'backbone' standard of the NSF for LTNC) recommends that patients with complex needs should have integrated care planning with regular reviews and a single point of contact to coordinate inter-agency input (<http://www.ltn.org.uk/index.html>; accessed 09.01.14).

LTNCs represent a diverse group of conditions, encompassing people with widely different needs for services, against which the adequacy of service provision must be judged. Unfortunately, these needs are largely unreported through current information systems, so the epidemiology of 'need' for healthcare and social support is not fully understood.(15) Previous reports have highlighted a paucity of knowledge about how rehabilitation and support services are delivered in the community, compared to hospital-based services (16) – and also that community-based care is often fragmented.(17) Particular concerns were raised about lack of support for patients with complex needs arising from 'hidden disabilities' due to cognitive/behavioural problems, and the impact of these problems on their families.(17)

To support implementation of the NSF for LTNC, in 2006 the UK Department of Health commissioned the NHS Information Centre to develop a LTNC dataset for monitoring implementation and for benchmarking

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3 performance against the NSF quality requirements. An LTNC Dataset Development Group consisting of
4 clinicians, data analysts, Information technologists and patient/carer representatives was convened with
5 the brief to develop an LTNC dataset that met the standards for approval by the UK Information Standards
6 Board. Published in 2009 the LTNC database brought together a series of discrete datasets to capture
7 episodes of health and social care as the patient moved through the care pathway from diagnosis to end-
8 of-life care. As part of that development, the Dataset Development Group recommended the
9 establishment of a LTNC register to identify those patients with complex needs arising from LTNC and to
10 support integrated care planning and long-term follow-up, in order to monitor their changing needs over
11 time and the services provided to support them (http://www.csi.kcl.ac.uk/community_rehabilitation.html;
12 accessed 09.01.14). A register was considered the only reliable way to identify those individuals who need
13 (and want) on-going integrated care planning against which the successful of implementation of the
14 backbone NSF standard could be judged on a longitudinal basis.
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24 A disease or case-register is a database that attempts 'to identify all cases of a disease or condition in an
25 identified denominator population'.⁽¹⁸⁾ This definition distinguishes a register from a clinical database,
26 which lacks a defined denominator population and does not attempt to identify all the cases in a specified
27 population. The target population for the LTNC register is the subgroup of patients with complex needs
28 who require integrated service provision from a range of health and social care agencies. Existing coding
29 systems in the UK are primarily based on diagnosis (eg ICD-10 codes in secondary care and Read codes in
30 primary care), which is generally a poor indicator of needs for services. The LTNC register therefore includes
31 a brief dataset for prospective data collection to confirm that the registered patient has:
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- 37 a) a neurological condition that is likely to have an enduring effect
- 38 b) complex needs for care/support, that are likely to require integrated care planning, either now or
39 in the relatively near future.
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43 In 2009, the UK National Institute for Health Research (NIHR) funded a project to develop and pilot the
44 LTNC Register, and to use this to follow longitudinally a cohort of patients with complex needs arising from
45 LTNCs. The purpose of the study was to refine the LTNC register and its associated dataset, and then to use
46 this to examine the extent to which patients' current needs for health and social services were met, to
47 identify any gaps in service provision, and to examine the extent to which meeting their needs might lead
48 to improved outcomes.
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54 This article is divided into two parts:
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- In Part A, we describe the further development and piloting of the proposed LTNC register and a feasible dataset that could be used in the course of routine practice to monitor needs, inputs and outcomes for people with LTNCs in the community.
- In Part B, we used the dataset to follow a cohort of patients with complex neurological disability for a one year period after discharge from tertiary in-patient specialist rehabilitation services, to address the following research questions:
 - Do patients want to be entered on an LTNC register?
 - What proportion of patients would use such a register, and are there any characteristics that identify those patients most likely to do so?
 - To what extent are their needs met and what are the main gaps in service provision?
 - What predicts the extent of health and social care services received?
 - Is there a relationship between ‘metness of need’ in the critical first 6 months following discharge to the community, and ‘outcomes’ in terms of carer burden and community integration at 1 year?

METHODS

Part A - Development of the LTNC register

The overall scheme of the LTNC dataset is summarised in Figure 1b. However, before data could be collected in routine clinical practice, the data collection tools had to be made fit for purpose. We therefore refined the database to include a manageable set of tools to identify patient needs, service inputs and patient outcomes for community-based rehabilitation and support services which could be used to inform integrated care planning, both at an individual and a population level.

Table 1 sets out the core information elements of the LTNC register as defined by the original Dataset Development Group. This core set includes:

- The Neurological Impairment Scale as a measure of overall severity of the presenting condition. (19)
- The Needs and Provision Complexity Scale as a measure of needs for health and social care services and the extent to which these needs are met. (20)
- The Northwick Park Dependency Scale (21)

The LTNC Dataset Development Group also highlighted the need for other measures to support the evaluation of long term outcomes at the level of societal participation, including measures of community re-integration and carer burden, although specific tools were not stipulated.

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3 Based on evidence from previous research incorporating the opinions and experience of both service users
4 and professionals, we selected the Community Integration Questionnaire and the Zarit Carer Burden
5 Interview on the basis that (a) they are widely used, psychometrically robust and applicable in LTNC, (b)
6 they are freely available and not restricted by license and (c) they are easily understood and timely to
7 apply.(22-25) Importantly, all of these are suitable for completion either by self-report questionnaire or
8 administered at interview by professionals.
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Table 1: LTNC Register Core Dataset*

Domain	Data fields	Value list / Data description
1. LTNC	Do they have an LTNC?	Yes/ no/ not sure
<i>If yes:</i> 1a. Record Neurological condition	Diagnosis or nature of condition	ICD-10 and /or Read codes Free text to describe neurological condition if no code exists
1b. Long term	Is the condition likely to have an enduring effect ?	Yes / No / Not sure
2. Needs for care/support	Do they have complex needs arising from the LTNC?	Yes / No / Not sure
<i>If yes:</i>		
2a. Record Impairment severity	Neurological Impairment Scale	17 item scores
2b. Record needs for health and social care	The Needs & Provision Complexity Scale (NPCS-Needs)	15 item scores
3. Need for integrated care planning (ICP)	Do they require (and want) integrated care planning	Yes / No / Not sure
4. Person responsible for registration	Name of registering clinician	Name and Signature
5. If yes to 1, 2, and 3		
5a: Are they having integrated care planning?	When was last ICP review?	Date
5b: Is there a single point of contact?	Named person or post	Name Job title/ contact details

* LTNC= Long term neurological condition; ICP=Integrated care planning

Measurement tools included in the dataset

Neurological Impairment Scale (NIS): The NIS comprises a brief 17-item checklist of the major neurological impairments (motor/sensory loss, cognitive, communication, emotional, behaviour) that make up a complex presentation in people with LTNCs.(19) Item severity scores range from 0-3 to assess the impact of these impairments at a functional level, giving a total score range 0-50. Originally developed as part of the core minimum dataset alongside the UK Functional Assessment Measure,(26) the NIS is shown to be a valid and reliable measure of neurological impairment suitable for use across a wide range of neurological conditions.(19) It forms a part of the UK Rehabilitation Outcomes Collaborative (UKROC) national clinical dataset for specialist rehabilitation services (for further information see www.csi.kcl.ac.uk/ukroc.html; accessed 09.01.14)

The Needs and Provision Complexity Scale (NPCS): The NPCS is a 15-item measure with six subscales (total score range 0-50) in two principal domains ('Health' and 'Social care'). It is shown to be valid and reliable (27). It is designed to be used as a simple tool to evaluate needs for health and social care and to identify gaps in service provision, both at the level of the individual and across populations.(20) It has two parts:

- 'NPCS-Needs' is completed by the treating clinician(s) to evaluate each patient's needs for health and social care in any given period.
- 'NPCS-Gets' is a mirror-image of the same tool, completed at the end of that period to evaluate the levels of service that have been provided in relation to those needs.

Subtracting NPCS-Needs scores from NPCS-Gets scores provides a measure of 'metness of needs' and a simple costing algorithm provides a generic estimate of the likely cost implications of addressing the unmet needs. (20) The algorithm can be downloaded from www.csi.kcl.ac.uk/npcs.html; accessed 09.01.14).

The Northwick Park Dependency Scale (NPDS): The NPDS is a measure of dependency of the individual on help from others in two main parts:(21)

- The 'Basic Care Needs' (BCN) section (score range 0-65) comprises 12 items covering the daily activities needed for everyday functioning. These include the capacity for both physical performance (NPDS-PD) (e.g. washing, dressing, toileting, eating and drinking etc.) and appropriate cognitive behaviour (NPDS-CB) (e.g. communication, safety awareness etc.).
- The 'Special Nursing Needs' (SNN) section (score range 0-35) includes seven items indicating the need for nursing care, such as a wound requiring dressings.

The NPDS is now widely used in the UK and has been translated into several languages. It is shown to be psychometrically robust.(28) It, too, forms a part of the UKROC dataset, where algorithms within the

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UKROC software translate it into the Barthel Index (ref) and also into the Northwick Park Care Needs assessment - a directly costable measure of care needs in the community (29, 30).

Community Integration Questionnaire (CIQ): The CIQ is a measure of community integration after traumatic brain injury that is suitable for self-completion by the patient or a carer by proxy. It consists of 15 items with a total score range from 0-29 comprising three subscales: (i) Home integration (range 0-10) (ii) Social integration (range 0-12) and (iii) Productivity (0-7). It was originally designed for including in the US TBI Model Systems dataset. Although not yet formally tested in a wider population of patients with LTNC, the psychometric properties of the CIQ have been well established in the context of brain injury. (31, 32)

Zarit Burden Interview (ZBI): The ZBI is designed to capture the impact of a caring role on the carer's personal and social well-being (33). It consists of 22 items (total score 0-88). For each item the carer rates how often they are affected by the negative aspects of their caring situation on a scale ranging from 0 (never) to 4 (nearly always). Originally developed in the context of dementia, the ZBI has been used in LTNC and other advanced conditions and is shown to be valid for assessing carer burden in these conditions.(34, 35)

Questionnaire administration

As many of the participants had complex disabilities with cognitive/ communication difficulties, three types of media were used to gather data in order to maximise response rate and ensure accessibility.

Respondents could choose from the following options:

- a) paper-based postal-questionnaire
- b) web-based survey tool, using Survey Methods software (Survey Methods Inc. www.surveymethods.com)
- c) questionnaire administered by a researcher at telephone interview.

All questionnaires were piloted prior to use. Wherever possible, follow-up telephone interviews were used to complete missing information from questionnaires, and this provided further feedback to refine the data-gathering tools. The changes related to presentation (plain language, font size etc) and did not affect the structure or content of the measurement instruments.

PART B – Longitudinal Cohort Study

In Part B, the LTNC dataset was used to monitor a cohort of patients over a 1 year period following discharge from all tertiary specialised in-patient rehabilitation services across the London region.

Participating centres

Nine 'Level1' services provide a comprehensive network of tertiary specialist in-patient neurological rehabilitation across the London Region of the UK. They provide specialised rehabilitation for the population of patients with complex needs that are beyond the scope of their local (Level 2 and 3) rehabilitation services (<http://www.bsrm.co.uk/index.htm>; accessed 09.01.14).(36) Patients discharged from these units are therefore likely to have complex needs for ongoing rehabilitation and support services in the community. All nine services participated in recruitment in our study.

Participants

Recruitment occurred over an 18-month period in 2010 – 2011. Consecutive in-patients across the nine services, were eligible to participate if they had a LTNC at discharge (ie a neurological condition that was considered likely by the treating team to have an enduring effect). They were approached for consent by a member of the treating team. This was taken in writing on a standard consent form at least 24 hours after provision of an information sheet, a verbal explanation of the study and the opportunity to ask questions. Where cognitive or communication problems prevented their direct participation a family member or carer was identified to assist (or respond on behalf of) the patient and as the primary point of contact for further questionnaires.

Data Collection Procedure

For all consenting patients, their discharge team completed a recruitment form that included:

- a) Severity of impairment (NIS)
- b) Needs for ongoing services (NPCS-Needs) as rated by their multidisciplinary (MD) team
- c) Whether the patient would be willing to be included in a LTNC Register
- d) Details of any community rehabilitation support services to which patients had been referred
- e) Contact details for a named individual to approach for follow-up questionnaires (usually either the patient or a family carer).

Baseline data were recorded by the treating MD team as part of their discharge planning. This approach to shared decision-making in the assessment of needs reduced the potential for clinician bias across different disciplines, as the representation of disciplines within the teams was broadly similar across the nine specialist rehabilitation units. Teams were asked to record the NPCS-Needs in relation to services that they reasonably expected the patient to receive, based on the referrals they were making for ongoing support and rehabilitation after discharge, rather than those they might wish for 'in an ideal world'.

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This recruitment information was then sent to the research team who contacted the named individual to answer questions / address any concerns and to establish their preferred medium for response (ie postal questionnaire, web-based survey or telephone interview).

Tools included in the questionnaire were self-report versions of:

- a) Dependency (NPDS): including basic care needs (NPDS-BCN) and special nursing needs (NPDS-SNN)
- b) Community integration (CIQ)
- c) Carer Burden (ZBI) – if the individual had a family (or other informal) carer
- d) Services received (NPCS-Gets) in the last 6-month period – recorded at 6 and 12 months

Participants were contacted at one, six and 12 months after discharge and asked to complete a questionnaire/interview (the Month 1 responses acting as baseline for these self-report measures). A second follow-up call was made if a response had not been received within a fortnight. Up to five attempts were made to reach respondents by telephone before desisting.

Efforts to maximize response rates

Across the three response phases, paper questionnaires were consistently the most commonly used method (approximately 80 to 84% of respondents); 10 to 13% responded online and 3 to 5% were administered at telephone interview. Postal and online questionnaires were followed up by telephone wherever possible to fill in any missing information. Over the course of the study, a total of 1211 questionnaires were sent and 225 re-sent; 1607 phone calls were made to achieve the 658 questionnaires received.

Data management and analysis

Data were entered into a spreadsheet (Microsoft Excel) and after cleaning and validation, were extracted to SPSS (IBM Statistics) version 19 for statistical analysis. Despite the ordinal nature of the data, in view of the large sample size and the fact that linear regression modelling used in the latter part of the analysis relies on parametric assumptions, parametric techniques were used throughout with descriptive statistics reported in the form of percentages or means, standard deviations and range. Non-parametric analyses are available on request from the author but did not yield different results. In view of the multiple tests, the threshold for significance was set at $p < 0.01$.

The first stage of our analyses included a descriptive analysis of all available respondents at each time point. To determine whether patients would want to use an LTNC register, we examined the proportions who agreed to be included and those who actually responded to our requests for follow-up information on each occasion, as an indication of those most likely to use the register.

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5 We examined the characteristics of patients who responded at each time point in terms of demographics,
6 severity of impairment and needs for services. We looked in particular for any statistical differences
7 between the “best responder” group (those who responded at all three time points) and the ‘non-
8 responders’ (who did not respond on any occasion). To identify predictors of the extent of rehabilitation
9 received (NPCS-Gets) at six months post-discharge we began with a series of univariate regression analyses
10 including all those who responded at 6 months (n=212). Specifically we examined which of the following
11 variables (recorded at baseline) individually predicted the overall level of rehabilitation services received
12 within the first 6 months:
13

- 14 a) demographics (i.e. age, gender, marital status, education, ethnicity, diagnosis)
- 15 b) level of impairment both physical (NIS-Physical), and cognitive (NIS Cognitive)
- 16 c) level of dependency - physical (NPDS-PD) and cognitive (NPDS-CB) and total basic care needs
17 (NPDS-BCN) were entered as separate variables
- 18 d) special nursing needs (NPDS-SNN)
- 19 e) social integration in the community (CIQ).

20
21 For the demographic variables, age was treated as continuous and the remaining five were all coded as
22 ‘dummy’ or categorical variables. Physical and cognitive impairment were treated as separate variables in
23 light of previous studies suggesting that people with ‘hidden disabilities’ received fewer services. The best
24 individual predictors (i.e. only those variables that predicted a statistically significant proportion of variance
25 in univariate regression analyses) were all included in a single stepwise multiple regression analysis to
26 identify the best model.
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29 The second stage of our analysis explored the relationship between patient-reported outcomes and the
30 extent to which an individual’s needs for services were met. Here the longitudinal trends for change over
31 successive time periods were the specific focus of interest, so only the ‘best responders’ (for whom data
32 were available at all three time points) were included.
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- 34 • Differences between NPCS ‘Needs’ and ‘Gets’, and between NPCS-Gets during the first and second
35 6 month period were tested by paired t tests.
- 36 • Discrepancy scores between the needs identified by the treating clinicians at discharge (NPCS-
37 Needs) and services received during the first six month period (NPCS-Gets) were calculated on a
38 case-by-case basis as a measure of the extent to which individual needs were met (i.e. ‘Metness of
39 need’ = ‘NPCS-Gets’ minus ‘NPCS needs’)
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Services provided in the first 6-month period after discharge from in-patient rehabilitation were considered to be particularly critical to support adjustment and (where possible) re-ablement following newly-acquired disability. To examine the relationship between outcome (in terms of community integration and carer burden) at 12 months and the extent to which individual needs for rehabilitation were met during the first 6 months, discrepancy scores for the NPCRS Rehabilitation subscale were entered as predictor values in a longitudinal linear regression analysis. We examined outcomes, (CIQ and ZBI) in comparison with 'metness of need' in the Rehabilitation subscale of the NPCRS. We also dichotomized patients into those whose rehabilitation needs were met or exceeded in the first six months (Gets minus Needs ≥ 0) and those who had unmet needs (Gets minus Needs < 0). For this analysis the variables entered into the model were selected on a priori theoretical grounds. Although we expected the level of community integration to be negatively affected by physical and cognitive dependency, we hypothesized that patients whose needs for rehabilitation and support were met would achieve better integration than those with unmet needs.

RESULTS

Recruitment and response rates

Out of a total of 576 admissions, 499 patients were assessed as eligible for inclusion in the study, because they had a LTNC that was likely to have an enduring effect. They were approached by the clinical teams for permission to include them in the study, of which 428 (92%) were recruited. Across the nine units just 8% of those approached declined to participate in the study. Some centres were notably more successful at recruiting than others. Highest recruitment rates ($>93\%$ of admissions) were seen where a single individual (eg a consultant or a dedicated recruitment officer) took responsibility for recruiting all participants within that unit. Lower rates (approximately 2/3 of admissions overall) were achieved where recruitment was left to one of several members of the team (eg a keyworker or one of the junior medical staff), who were less familiar with the study.

The participation and attrition rates throughout the study are displayed in Figure 2. The characteristics of the 428 patients recruited, are shown in Table 2 .

Table 2: Characteristics of the 428 Patients recruited, the 'best responder' (n=134) and the non-responder (n=123) group.

Variables		Recruited sample N=428		Best responders N=134		Non-responders N=123		Chi-squared *
		N	%	N	%	N	%	P value
Gender	Male	270	(63.1)	86	(64.2)	80	(65.0)	0.90
	Female	158	(36.9)	48	(35.8)	43	(35.0)	
Diagnosis	Brain injury	315	(73.6)	97	(72.8)	85	(69.1)	0.35
	- Stroke/SAH*	212	(49.5)	70	(52.2)	57	(46.3)	
	- TBI*	63	(14.7)	16	(11.9)	18	(14.6)	
	- Other ABI*	40	(9.3)	11	(8.2)	10	(8.1)	
	Spinal Cord Injury	38	(8.9)	8	(6.0)	11	(8.9)	
	Peripheral Neuropathy	26	(6.1)	8	(6.0)	9	(7.3)	
	Progressive LTNC	21	(4.9)	5	(3.7)	10	(8.1)	
	Other	27	(6.3)	16	(11.9)	7	(5.7)	
Missing	1	(0.2)	0	(0)	1	(0.8)		
Discharge destination	Home	333	(77.8)	115	(85.8)	89	(72.4)	0.009
	Nursing Home	51	(11.9)	9	(6.7)	19	(15.4)	0.03
	On-going Rehab	18	(4.2)	6	(4.5)	5	(4.1)	1.0
	Hospital	4	(1.0)	2	(1.5)	1	(0.8)	1.0
	Other	19	(4.4)	2	(1.5)	9	(7.3)	0.03
Referred to ongoing rehabilitation	Yes	378	(88.3)	124	(92.5)	110	(89.4)	0.33
	No	41	(9.6)	7	(5.2)	11	(8.9)	
	Not answered	9	(2.1)	3	(2.2)	2	(1.6)	
Permission to include on the Register	Yes	322	(75.2)	108	(80.6)	90	(73.2)	0.23
	No	13	(3.0)	3	(2.2)	7	(5.7)	
	Not answered	93	(21.7)	23	(17.2)	26	(21.1)	
At recruitment		Mean	SD	Mean	SD	Mean	SD	T-test* P value
Age	Years	49.1	(15.2)	50.2	(14.0)	47.8	(15.9)	0.19
Neurological Impairment	NIS-Motor	8.1	(5.1)	8.3	(5.0)	8.9	(5.4)	0.36
	NIS-Cognitive	4.4	(3.1)	4.4	(3.2)	4.8	(3.0)	0.34
	Total	12.8	(6.4)	13.1	(6.4)	13.9	(6.7)	0.37
Needs for health and social care	NPCS Health	11.5	(4.3)	11.4	(4.2)	11.9	(4.5)	0.31
	NPCS-Social support	6.2	(4.3)	5.6	(4.0)	6.7	(4.8)	0.04
	NPCS-Total	17.7	(7.8)	17.0	(7.6)	18.7	(8.4)	0.09

*Difference between best responders and non-responders.

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Do patients want to be entered on an LTNC register, and which patients might be most likely to participate?

Consent to participate in the study questionnaires did not necessarily mean that individuals would be willing to have their details included in a register. Three-quarters of the recruited group (n=322 (75%)) indicated, at discharge from hospital, that they were willing to be included in a pilot LTNC register. On the other hand only 13 (3%) declined. The remaining 93 (22%) did not answer the question mostly due to a failure on the part of the clinician to ask. However, only a proportion of these actually responded to questionnaires when subsequently approached in the community. At one month post discharge, 59% responded; at 6 months 49%; and at 12 months just 44%. The response across the three time periods was not consistent: 123 (29%) did not respond to a questionnaire in any of the phases; 20 - 21% responded to one or two phases and just 134 (31%) responded to all three phases. This latter group of 'best responders' was considered to be the group of patients most likely to engage in follow-up using an LTNC register, but interestingly there was no significant difference between the 'best responders' and the 'non-responders' in terms of their expressed willingness to be included in the register.

Characteristics of the responding patients across the three phases

Respondents were similar at each phase in terms of gender ratio, age, marital status and educational level. The only significant trend over time was a greater attrition for non-white British subjects, reflected in the loss of 39% of Black and 49% Asian/other participants as compared with only 18% attrition for white participants. The 'best responders' were more likely to have been discharged home than the non-responders, a greater proportion of whom were in nursing home or other residential care. Otherwise there were no significant differences in demographics between these two groups, and they had similar levels of impairment and needs for services at recruitment (see Table 2).

The extent to which needs were and were not met

Table 3 shows descriptive statistics for measures of impairment, needs, inputs and outcome across the three follow-up phases. Again there was no difference between the groups responding at each time period with respect to their severity of impairment (total NIS score) or need for services (NPCS-Needs), nor with respect to their outcomes in terms of dependency (NPDS) integration (CIQ) or carer burden (ZBI).

Table 3: Descriptive statistics for measures of impairment severity (NIS, motor, cognitive), service needs (NPCS-Needs), service inputs (NPCS-Gets) and patient reported outcome (CIQ, ZBI) across the three Phases after Discharge and for the group that responded at all three phases.

Time	Phase 1 1 month post discharge N=256	Phase 2 6 months post discharge N= 212	Phase 3 12 months post discharge N=190	'Best responders' at recruitment and phase 3 N=134
Measure (Scoring range)	Mean (SD) Range (Min-Max)	Mean (SD) Range (Min-Max)	Mean (SD) Range (Min-Max)	Mean (SD) Range (Min-Max)
At recruitment				
Impairment				
Physical NIS-Motor (range 0-26)	7.8 (4.9) 0-25	7.9 (5.1) 0-25	8.1 (5.0) 0-25	8.3 (5.0) 0-25
Cognitive NIS Cognitive (range 0-21)	4.3 (3.1) 0-14	4.5 (3.2) 0-13	4.2 (3.0) 0-13	4.4 (3.2) 0-13
NIS Total (0-50)	12.4 (6.4) 1-31	12.7 (6.5) 1-31	12.7 (6.2) 1-31	13.1 (6.4) 1-31
Level of services required (NPCS-Needs)				
Health and care NPCS-Health Needs (range 0-25)	11.3 (4.1) 0-21	11.4 (4.2) 0-20	11.2 (4.2) 0-21	11.4 (4.2) 0-20
Social support NPCS-Social Needs (range 0-25)	5.7 (4.0) 0-19	6.1 (4.2) 0-19	5.8 (4.0) 0-19	5.6 (4.0) 0-19
Total NPCS Needs (0-50)	17.0 (7.5) 0-36	17.5 (7.7) 1-36	17.0 (7.6) 0-36	17.0 (7.6) 0-36
At follow-up period				
Service provision				
Health and care NPCS-Health Gets (0-25)	Not applicable	9.4 (4.7) 0-20	8.5 (4.8) 0-21	8.4 (4.9) 0-21
Social support NPCS-Social Gets (0-25)	Not applicable	4.6 (3.5) 0-15	3.8 (3.1) 0-15	3.8 (3.2) 0-15
Total NPCS-Gets (0-50)	Not applicable	14.0 (7.1) 0-29	12.5 (7.1) 0-34	12.4(7.2) 0-34
Outcome measures				
Dependency NPDS (0-100)	12.7 (13.9) 0-66	12.2 (13.8) 0-61	11.2 (13.5) 0-60	11.4 (13.5) 0-60
Integration CIQ (0-29)	12.1 (4.9) 0-26	11.0 (5.7) 0-27	12.3 (5.7) 0-27	12.3 (5.8) 0-27
Carer burden ZBI (0-88)	24.4 (16.7) 0-82	24.4 (17.5) 0-82	25.5 (18.9) 0-88	26.9 (18.6) 0-84

NPCS = Needs and Provision Complexity Scale; NIS=Neurological Impairment Scale,
CIQ= Community Integration Questionnaire; ZBI = Zarit Care Burden Interview

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3 The level of services received during the first 6 months was significantly lower than the needs identified at
4 discharge for both health care (Mean difference 1.8 (95% CI 1.1, 2.4) $t = 5.1$, $p < 0.001$) and social care
5 (Mean difference 1.7 (95% CI 1.1, 2.2) $t = 5.9$, $p < 0.001$). There was a modest overall decline in the levels of
6 both health and social support services during the second six months, even though the levels of
7 dependency, community integration and carer burden remained similar. However, this could simply have
8 been due to differences in the best responder group at 6 and 12 months. Therefore, a paired analysis was
9 conducted for just the best responder group, who responded on all three occasions. Although these best
10 responders ($n=134$) formed less than one third of the total population, there was no evidence that they
11 differed in any significant respect from the recruited population (see Tables 2 and 3).
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19 Table 4 shows a more detailed evaluation of the met and unmet needs (as measured by the NPCCS) for this
20 'best responder group during the first 6 months. It also shows the change in levels of service provided
21 during the second 6 month period, and the change in outcomes across the three time points of the study.
22 As recorded elsewhere for the full cohort(20, 37), this subgroup analysis confirms significant levels of
23 unmet needs with respect to rehabilitation, social support and equipment provision during the first critical
24 6 months following discharge(20, 37). It also records a significant decline in service provision between
25 months 6 and 12, despite continuing high and unchanging levels of dependency and carer burden. On the
26 other hand, needs for medical and nursing inputs, personal care and accommodation were well met. The
27 level of community integration appears to increase briefly at 6 months and then subside to baseline levels
28 at 12 months.
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37 However, within the study sample there is clearly significant variation, both with respect to the level of
38 services provided and outcome. It is therefore pertinent to examine what predicts the levels of service
39 provision, especially during the first critical 6 months after discharge to the community, and whether there
40 is a relationship between 'metness of needs' and outcome.
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Table 4: Best-responder population (n=134): Descriptive statistics and significant differences in needs, inputs and outcomes at baseline, 6 and 12 months

	Missing	Baseline	6 months	Difference tested by paired T Tests				Missing	12 months	Mean difference	95% CI	P value	Effect size*
		Mean (SD)	Mean (SD)	Mean difference	95% CI	P value	Effect size*		Mean (SD)				
NPCS		Needs	Gets at 6 months	Difference between needs identified at discharge and levels of service received during the first 6 months					Gets at 12 months	Difference in level of services received during the 1st and 2nd 6-month periods			
Health and Personal care domain													
Health	2	2.3 (1.5)	2.4 (1.7)	0.04	-0.3, 0.4	0.81	0.03	2	2.2 (1.6)	-0.1	-0.4, 0.1	0.25	0.06
Personal care	7	3.7 (2.7)	3.6 (2.6)	0.02	-0.4, 0.5	0.92	0.01	8	3.3 (2.6)	-0.4	-0.7, 0.1	0.02	0.15
Rehabilitation	5	5.3 (1.9)	3.6 (2.0)	-1.7	-2.1, -1.3	<0.001	0.89	8	2.9 (2.2)	-0.8	-1.2, -0.5	<0.001	0.40
Total	13	11.4(4.2)	9.5 (4.7)	-1.6	-2.5, -0.8	<0.001	0.38	16	8.4 (4.9)	-1.4	-2.0, -0.8	<0.001	0.30
Social care and support domain													
Social support	12	2.8 (2.6)	1.6 (2.0)	-1.2	-1.7, -0.7	<0.001	0.46	15	1.2 (1.7)	-0.4	-0.7, -0.1	0.005	0.20
Equipment	4	1.2 (0.9)	0.8 (0.8)	-0.4	-0.6, -0.2	<0.001	0.44	6	0.6 (0.8)	-0.2	-0.4, -0.1	0.004	0.25
Accommodation	2	1.6 (1.9)	1.8 (2.0)	0.2	-0.1, 0.5	0.16	0.11	2	1.9 (1.9)	0.1	-0.1, 0.4	0.23	0.05
Total	14	5.6 (4.0)	4.1 (3.2)	-1.5	-2.2, -0.9	0.07	0.37	18	3.8 (3.2)	-0.4	-0.8, 0.0	0.06	0.13
Total Needs and Provision													
TOTAL	22	16.8 (7.6)	13.7 (6.9)	-3.1	-4.3, -1.8	<0.001	0.41	29	12.1 (7.1)	-1.9	-2.7, -1.1	<0.001	0.27
Outcome measures (total scores)													
Dependency (NPDS)	0	12.8 (13.3)	12.4 (14.4)	-0.4	-1.6, 0.8	0.51	0.03	0	11.4 (13.5)	-1.0	-1.9, 0.0	0.05	0.07
Integration (CIQ)	24	12.3 (4.9)	11.4 (5.6)	-1.0	-1.7, 0.2	0.01	0.22	21	12.4 (5.7)	0.9	-0.4, 1.5	0.002	0.16
Carer burden (ZBI)	53**	23.7 (17.1)	24.1 (17.2)	0.4	-2.1, 2.9	0.75	0.06	55**	25.3 (18.1)	1.5	-0.5, 3.5	0.15	0.09

NPCS = Needs and Provision Complexity Scale; SD= standard deviation; 95%CI = 95% Confidence Interval

*Effect sizes for the first 6 months were calculated as mean difference / SD baseline and for the second 6 months: mean difference / SD at 6 months

** Carer burden scores were only recorded where a family carer was involved.

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What predicts the level of services received in the first six months after discharge?

The univariate regression analyses showed that none of the demographic variables (Age, Gender, Ethnicity, Marital Status, Education, Diagnosis) nor carer burden (ZBI) recorded at baseline were significantly related to the levels of service received (total NPCS-Gets) at six months. The baseline measures of impairment (NIS), dependency (NPDS), nursing needs (NPDS-SNN) and community integration (CIQ), however, all predicted a significant proportion of the variance, as well as demonstrating significant inter-relationships as shown in Table 5

Table 5: Correlation matrix of predictor variables of services received (NPCS gets) at 6 month (n=212)

Variable	NPCS –Gets 6 Months	NIS- Motor	NIS- Cognitive	NPDS- Physical	NPDS- Cog/Behav	SNN
NIS-Motor	0.44**					
NIS-Cognitive	0.38**	0.15*				
NPDS-Physical	0.58**	0.67**	0.36**			
NPDS-Cog/Behav	0.45**	0.20**	0.62**			
NPDS-BCN	0.62**	0.62**	0.45**	0.98**		
NPDS-SNN	0.45**	0.23**	0.11	0.35**	0.22**	
CIQ	-0.45**	-0.48**	-0.40	-0.57**	-0.46**	-0.15
ZBI	0.30**	0.08	0.34**	0.20*	0.36**	-0.00

* $p < 0.05$; ** $p < 0.01$; N ranges from 149-206 due to missing data. For the ZBI correlations N ranges from 115-119 reflecting the subset of participants with a carer.

Results of a stepwise regression analysis that included the significant predictors from univariate regression analyses are presented in Table 6. In both the univariate analyses and in the stepwise model dependency (NPDS-BCN) was the best single predictor accounting for 33% of the model variance. The addition of Motor and Cognitive Impairment (as measured by the NIS subscales at recruitment) improved the predictive ability of the stepwise model by small but significant increments to a total R^2 of 40 percent. Community integration and special nursing needs did not add significantly to the prediction of variance and so were excluded by the stepwise regression.

Table 6: Stepwise regression analyses of best individual predictor variables of services received (NPCS gets) during the first 6 months after discharge

Stepwise Models	β	CI (95%)	P	R ²	ΔR^2
NPDS -BCN	0.34	0.26 – 0.43	.001	0.33	-----
NPDS-BCN	0.23	0.12 – 0.34	.001	0.38	0.05
NIS-Motor	0.37	0.13 – 0.60	.001		
NPDS-BCN	0.18	.06 – 0.30	.001	0.40	0.02
NIS-Motor	0.40	0.17 – 0.63	.001		
NIS-Cognitive	0.34	0.02 – 0.67	.001		

Is there a relationship between ‘metness of need’ in the first critical 6 months and outcome in terms of community integration and carer burden at twelve months?

We wished to determine whether the extent to which rehabilitation needs were met impacted on community integration and carer burden at 12 months, over and above any relationship between these outcomes and dependency. Taking community integration scores (CIQ) at 12 months as the dependent variable, a stepwise regression was carried out using physical dependency (NPDS-PD) and cognitive dependency (NPDS-CB) at baseline, and ‘metness’ of rehabilitation needs at six months as independent variables. This revealed that 31% of the variance in community integration could be explained by physical and cognitive dependency; the more dependent patients being less well integrated at 12 months. The extent to which their rehabilitation needs had been met was positively correlated with dependency at baseline (ρ 0.20, $p=0.03$), and added only 2% to the predictor model, so that together they explained 33% of the variance. However, the relationship was not in the expected direction. Patients ($n=31$) who received rehabilitation services that met or exceeded the levels of need predicted at discharge showed significantly lower gains in CIQ than those for whom provision did not meet their predicted need ($n=71$): Mean difference 2.6 (95% CI 0.9, 4.3, $p=0.003$).

A similar stepwise regression was performed for the dependent variable carer burden (ZBI) at 12 months, entering physical dependency (NPDS-PD) and cognitive dependency (NPDS-CB) at baseline, and ‘metness’ of rehabilitation needs at six months as independent variables. Here only cognitive dependency remained in the final model, predicting 12% of the variance in carer burden, with the other two variables not

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3 improving the model significantly. There was no significant difference observed in carer burden scores
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5 between patients with 'met' and 'unmet' needs for rehabilitation.
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DISCUSSION

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9 This paper describes further development of the LTNC dataset to identify a manageable set of tools suitable
10 for use in routine practice to measure needs, inputs and outcomes from community-based rehabilitation
11 and support services. In a cohort of nearly 500 patients with complex needs arising from a LTNC, the large
12 majority were willing in principle to be registered and have their data included in the dataset. However, in
13 practice, only a minority (less than one third) responded regularly when asked to provide information
14 about their ongoing needs and the level of services received. Reasons for attrition were mostly unknown
15 since, for ethical reasons, all participants had the right to withdraw at any stage without any explanation.
16 The 'best responders' included a higher proportion of white British patients, and were more likely to be at
17 home, but were not otherwise distinguishable from the non-responder group, in terms of severity of
18 impairment, disability or needs for services.
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27 The level of attrition observed here was not dissimilar from other series. A similar loss to follow-up of
28 registered brain injured patients has been noted in a number of other studies. Corrigan et al. analysed
29 three USA datasets covering several thousand adults with traumatic brain injury, of whom only 58% could
30 be followed-up 1-year post injury(38). In the UK, Wade and colleagues reported a similar rate of attrition
31 (59% at 6 months) and highlighted the difficulties of follow-up in brain-injured patients, which include
32 itinerancy, and lack of motivation or ability to respond (39). The higher proportion of non-respondents in
33 nursing homes or other in-patient settings observed in our study is likely to reflect a) the fact that many
34 were unable to respond for themselves and b) the difficulty of identifying someone willing and able to
35 respond on their behalf in these settings. Culturally-related psychosocial factors, such as cultural mistrust
36 and perceptions of exploitation in medical research by minority groups, are known to affect research
37 participation and may be associated with attrition from registers more generally by people from black and
38 ethnic minority groups when compared with other populations (38, 40, 41).
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48 Whatever the reasons for it, the high attrition rate among those participants who agreed to participate
49 suggests that a register based on postal/telephone follow-up will be labour intensive and might fail to
50 engage a significant proportion of the most vulnerable patients. In clinical practice, integrated care
51 planning reviews most commonly involve face-to-face meetings with the patient and carer. In the authors'
52 view, this is likely to offer a more effective route for data collection for the register. The NPCP provides a
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3 simple and practical tool to capture met and unmet needs in this context, and so may assist clinical teams
4 to identify and address any gaps in service provision at either an individual or an organisational level.
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8 Longitudinal study of the best responder group revealed that they changed little in terms of dependency or
9 community integration during the year following discharge from in-patient specialist rehabilitation, and the
10 burden on their carers also remained stable. In common with the larger cohort, they had significant unmet
11 needs for health and social care services – particularly with respect to rehabilitation, social worker support
12 and provision of specialist equipment.(20) Physical disability was the best single predictor of services
13 received, followed by cognitive/behavioural disability. In contrast to some other studies there was no
14 strong evidence that those with hidden disabilities were less able to access services than those with
15 physical disability.(17) However, this may be due to the targeted efforts of the in-patient teams to set up
16 services for them following discharge to the community.
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24 We had expected to demonstrate that patients whose needs for community-based rehabilitation were met
25 had better outcomes in terms of functional independence and community integration, with reduced
26 burden on carers. In fact, if anything we showed that their outcomes were worse. Over and above the
27 relationship with physical and cognitive dependency, patients whose rehabilitation needs were met or
28 exceeded during the initial 6 months had made fewer gains in integration at twelve months post discharge
29 than those with unmet needs. Whilst counter-intuitive, on a clinical level this paradoxical finding is not
30 entirely surprising. The most likely explanation reflects the 'inverse therapy rule', which is simply that in a
31 health culture where resources are limited, services will be focussed on those patients with the severest
32 problems who have the greatest need.(42) Professionals are likely to withdraw sooner from those patients
33 who improve quickly over time and meet their goals early on in the programme, and to target their
34 resources on those who continue to require their help.
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44 A weakness of this study was that needs were not re-assessed at each time point, so we cannot determine
45 whether under provision of services with respect to predicted needs reflected unmet or changing levels of
46 need. This argues for the importance of continued review in future studies, measuring both needs and
47 inputs to capture change over time. The NPCS provides a simple practical means to do this.
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52 Other weaknesses are as follows:

- 53 • While the cohort was large it only included patients from tertiary rehabilitation services in the
54 greater London metropolitan area and experiences might be different in other parts of the UK
55 particularly rural regions.
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- The high attrition rates in the longitudinal study are discussed above. While there were no discernable differences between responders and non-responders on any demographic variables, except for ethnicity and discharge destination, non-response bias is likely to be present. Consequently it is uncertain how well the findings of this study might apply to the broader population of people with LTNCs.
- We carried out more than 30 statistical tests, which carries the risk of type I error rate inflation, and we dealt with this by setting the P-value for significance at 0.01. We could have set a more stringent P-value at 0.001 for an overall alpha level of 0.05 – the Bonferroni method. However, this can increase the likelihood of type II errors, so that truly important differences are deemed non-significant, and create more problems than it solves.⁽⁴³⁾ The Bonferroni method is concerned with the general null hypothesis – that all null hypotheses are true simultaneously – which is rarely of interest or use to researchers. Moreover, we are confident that the adjusted level does not alter the principal conclusions of the study.

Despite these recognised limitations, the study provides useful insights into the potential value of an LTNC register and its associated tools as a means to monitor needs, inputs and outcomes for patients with LTNC. It identifies significant gaps in service provision of both health and social services support in comparison with individual needs.

The study demonstrates that a registry would be feasible and acceptable to most patients. We suggest that face-to-face interviews conducted as a part of integrated care planning are likely to offer a better opportunity for both information gathering and reassessment of needs against which the adequacy of services delivered may be evaluated. The inverse therapy effect is an important but little recognised phenomenon, reflecting the fact that those patients who remain dependent continue to require and consume the bulk of available resources. This is always likely to be a confounder to be taken account of in longitudinal observational studies that seek to establish a relationship between more intensive rehabilitation and better outcomes.

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Competing interests:

There are no significant competing interests. All authors have completed the BMJ Declaration of Competing Interests form available on request from the corresponding author.

Outcome measurement is a specific research interest of our centre. LTS was the lead developer of the NPDS, NIS and NPCCS, but neither she nor her employing institution has any financial interest in the tools which are disseminated free of charge. None of the authors has any personal financial interests in the work undertaken or the findings reported. All authors are employed by universities/hospitals which may cite this article as part of their research evaluation processes, including the UK Research Excellence Framework 2013. LTS, DMJ and RJS have received financial support from the NIHR to attend conferences to disseminate the submitted work. We do not consider that any of these relationships or activities have influenced the submitted work.

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Copies of the NIS, NPDS and NPCCS are available free of charge from our website (www.csi.kcl.ac.uk/tools.html) and copies of the full questionnaire and other tools used in this study are available from the corresponding author.

Ethics approval: Approval for the study was granted by Bromley Research Ethics Committee (Ref no: 09/H0805/25) and subsequently the R&D centres of the seven participating NHS trusts. The remaining two recruiting centres were in the independent sector - approval for recruitment was obtained through their internal clinical and research governance processes.

Running Head: Long-Term Neurological Conditions

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3 **Registration:** The study was registered with the NIHR Comprehensive Local Research Network: ID number
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7 **Author contributions:** RJS was the principal investigator for the larger study of which this formed a part. He
8 took the lead role in execution and governance of the study and had overall responsibility for study
9 reporting. LTS was the lead clinician, led the design of the study, and the development of the LTNC register
10 and dataset. LTS and RJS wrote the first draft of the article together. DMJ was responsible for data-checking
11 and quality and also contributed to writing the article. EDP and SF were co-applicants on the study and
12 members of the project steering group, contributing to direction and decision-making as the study
13 progressed. All co-authors reviewed and commented on the manuscript.
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20 **Data sharing:** Not available at the current time as further articles are currently in development. Data
21 sharing may be available in the future – please contact the corresponding author.
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Figure legends**Figure 1a: A schematic diagram of The NSF for LTNC care pathway and quality requirements**

Legend to Figure 1a: The 'fish diagram' illustrates how the different Quality Requirements (QRs) of the NSF fit along the care pathway. The cross sectional diagram illustrates the range of services that may be needed by a patient with complex needs(14) (Reproduced with permission from Prof Lynne Turner-Stokes).

Figure 1b: The overall scheme of the LTNC dataset

Legend to Figure 1: The LTNC dataset is made up of a relational database with seven datasets linked via the patient's identifier (NHS number) following the overall schema of the LTNC pathway. The LTNC register identifies those patients with complex needs who form the denominator for datasets in the later stages of the pathway (Reproduced with permission from Prof Lynne Turner-Stokes).

Figure 2: Recruitment and participation pathway

For peer review only

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8 **A Longitudinal, Multi-Centre, Cohort Study of Community Rehabilitation Service Delivery in**
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10 **Long-Term Neurological Conditions**
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34 Keywords: Rehabilitation; neurological disorders; health services needs; delivery of health care,
35 integrated, Needs and Provision Complexity Scale
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Running Head: Long-Term Neurological Conditions

ABSTRACT

Objectives: Part A. To pilot the use of a register to identify and monitor patients with complex needs arising from long-term neurological conditions (LTNC). **Part B.** To determine the extent to which patients' needs for health and social services are met following discharge to the community after in-patient rehabilitation; to identify which factors predict unmet needs and to explore the relationship between service provision and outcomes at 12 months.

Design: A multi-centre, prospective, cohort study surveying participants at 1, 6 and 12 months using postal/online questionnaires and telephone interview.

Setting: Consecutive discharges to the community from all nine tertiary, specialist, inpatient neuro-rehabilitation services in London over 18 months in 2010-2011.

Participants: Out of 576 admissions 428 patients were recruited at discharge: 256 responded at 4 weeks, 212 at 6 months and 190 at 12 months.

Measures: Neurological Impairment Scale, The Needs and Provision Complexity Scale, The Northwick Park Dependency Scale, Community Integration Questionnaire, Zarit Burden Inventory.

Results: n=322(75%) expressed willingness to be registered, but in practice less than half responded to questionnaires at 6 and 12 months (49 and 44% respectively), despite extensive efforts to contact them, with no significant differences between responders and non-responders. Significant unmet needs were identified within the first year following discharge, particularly in rehabilitation, social work support and provision of specialist equipment. Dependency for basic care and motor and cognitive impairment predicted services received, together accounting for 40% of the variance. Contra to expectation, patients whose rehabilitation needs were met were more dependent and less well integrated at 12 months post discharge than those with unmet needs.

Conclusions: Registration is acceptable to most patients, but questionnaires/telephone interviews may not be the most efficient way to reach them. When community resources are limited service provision tends to be focused on the most dependent patients.

ARTICLE SUMMARY**Article focus**

- Is a register of people with long-term neurological conditions feasible to monitor needs, service provision and outcomes?
- To what extent are patients' needs met after discharge and what are the major gaps in service provision?
- Is there a relationship between 'metness of need' in the six months following discharge to the community and outcomes?

Key Messages

- The majority of patients are agreeable to being registered but attrition is high. A workable register would need to be based around regular, face-to-face, integrated care planning meetings. The Needs and Provision Complexity Scale offers a practical framework for identifying unmet need in such meetings.
- Unmet needs were most evident for rehabilitation, social work support and provision of specialist equipment.
- Patients who were more dependent were still less well integrated into the community at 12 months despite being more likely to have had their needs met,

Strengths and limitations of this study

- This study provides the first detailed longitudinal examination of services provided in the community in relation to needs at discharge for a large cohort of patients discharged from specialist neurorehabilitation services in the UK.
- The study had a high attrition rate and participants were only recruited from London hospitals.

INTRODUCTION

There is increasing recognition internationally of the importance of post-acute community rehabilitation services for long-term neurological conditions (LTNCs), and also the need to demonstrate their cost-effectiveness.(1-5) There has also been increased recognition of the needs and burden experienced by the families and carers of people with LTNCs.(6, 7) While some progress has been made in demonstrating the value of community programmes for specific conditions such as traumatic brain injury and stroke, comparatively little is known about the organisation, delivery and effectiveness of generic rehabilitation services in the community, in spite of the fact that they constitute the majority of rehabilitation services. (8-11)

LTNCs affect not only the individuals concerned but also their family and carers. In the UK, a series of National Service Frameworks (NSF) have laid down standards for service provision across a wide range of conditions.(12) Published in 2005 with a 10-year implementation plan, the primary focus of the UK National Service Framework (NSF) for Long Term Conditions was on neurological conditions.(13)

This NSF sets out 11 standards or 'Quality Requirements' for rehabilitation and social support for patients living with neurological disability.(13) It emphasises a bio-psychosocial approach, addressing all stages in the 'care pathway' from diagnosis to death (see Figure 1a), and highlights in particular the need for life-long access to services in the community.(14) Quality Requirement 1 (the 'backbone' standard of the NSF for LTNC) recommends that patients with complex needs should have integrated care planning with regular reviews and a single point of contact to coordinate inter-agency input (<http://www.ltnc.org.uk/index.html>; accessed 09.01.14).

LTNCs represent a diverse group of conditions, encompassing people with widely different needs for services, against which the adequacy of service provision must be judged. Unfortunately, these needs are largely unreported through current information systems, so the epidemiology of 'need' for healthcare and social support is not fully understood.(15) Previous reports have highlighted a paucity of knowledge about how rehabilitation and support services are delivered in the community, compared to hospital-based services (16) – and also that community-based care is often fragmented.(17) [Particular concerns were raised about lack of support for patients with complex needs arising from 'hidden disabilities' due to cognitive/behavioural problems, and the impact of these problems on their families.](#)(17)

To support implementation of the NSF for LTNC, in 2006 the UK Department of Health commissioned the NHS Information Centre to develop a LTNC dataset for monitoring implementation and for benchmarking

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3 performance against the NSF quality requirements. An LTNC Dataset Development Group consisting of
4 clinicians, data analysts, Information technologists and patient/carer representatives was convened with
5 the brief to develop an LTNC dataset that met the standards for approval by the UK Information Standards
6 Board. Published in 2009 the LTNC database brought together a series of discrete datasets to capture
7 episodes of health and social care as the patient moved through the care pathway from diagnosis to end-
8 of-life care. As part of that development, the Dataset Development Group recommended the
9 establishment of a LTNC register to identify those patients with complex needs arising from LTNC and to
10 support integrated care planning and long-term follow-up, in order to monitor their changing needs over
11 time and the services provided to support them (http://www.csi.kcl.ac.uk/community_rehabilitation.html;
12 accessed 09.01.14). A register was considered the only reliable way to identify those individuals who need
13 (and want) on-going integrated care planning against which the successful of implementation of the
14 backbone NSF standard could be judged on a longitudinal basis.
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24 A disease or case-register is a database that attempts 'to identify all cases of a disease or condition in an
25 identified denominator population'.(18) This definition distinguishes a register from a clinical database,
26 which lacks a defined denominator population and does not attempt to identify all the cases in a specified
27 population. The target population for the LTNC register is the subgroup of patients with complex needs
28 who require integrated service provision from a range of health and social care agencies. Existing coding
29 systems in the UK are primarily based on diagnosis (eg ICD-10 codes in secondary care and Read codes in
30 primary care), which is generally a poor indicator of needs for services. The LTNC register therefore includes
31 a brief dataset for prospective data collection to confirm that the registered patient has:
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- 37 a) a neurological condition that is likely to have an enduring effect
- 38 b) complex needs for care/support, that are likely to require integrated care planning, either now or
39 in the relatively near future.
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43 In 2009, the UK National Institute for Health Research (NIHR) funded a project to develop and pilot the
44 LTNC Register, and to use this to follow longitudinally a cohort of patients with complex needs arising from
45 LTNCs. The purpose of the study was to refine the LTNC register and its associated dataset, and then to use
46 this to examine the extent to which patients' current needs for health and social services were met, to
47 identify any gaps in service provision, and to examine the extent to which meeting their needs might lead
48 to improved outcomes.
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54 This article is divided into two parts:
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Running Head: Long-Term Neurological Conditions

- In Part A, we describe the further development and piloting of the proposed LTNC register and a feasible dataset that could be used in the course of routine practice to monitor needs, inputs and outcomes for people with LTNCs in the community.
- In Part B, we used the dataset to follow a cohort of patients with complex neurological disability for a one year period after discharge from tertiary in-patient specialist rehabilitation services, to address the following research questions:
 - Do patients want to be entered on an LTNC register?
 - What proportion of patients would use such a register, and are there any characteristics that identify those patients most likely to do so?
 - To what extent are their needs met and what are the main gaps in service provision?
 - What predicts the extent of health and social care services received?
 - Is there a relationship between 'metness of need' in the critical first 6 months following discharge to the community, and 'outcomes' in terms of carer burden and community integration at 1 year?

METHODS

Part A - Development of the LTNC register

The overall scheme of the LTNC dataset is summarised in Figure 1b. However, before data could be collected in routine clinical practice, the data collection tools had to be made fit for purpose. We therefore refined the database to include a manageable set of tools to identify patient needs, service inputs and patient outcomes for community-based rehabilitation and support services which could be used to inform integrated care planning, both at an individual and a population level.

Table 1 sets out the core information elements of the LTNC register as defined by the original Dataset Development Group. This core set includes:

- The Neurological Impairment Scale as a measure of overall severity of the presenting condition. (19)
- The Needs and Provision Complexity Scale as a measure of needs for health and social care services and the extent to which these needs are met. (20)
- The Northwick Park Dependency Scale (21)

The LTNC Dataset Development Group also highlighted the need for other measures to support the evaluation of long term outcomes at the level of societal participation, including measures of community re-integration and carer burden, although specific tools were not stipulated.

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3 Based on evidence from previous research incorporating the opinions and experience of both service users
4 and professionals, we selected the Community Integration Questionnaire and the Zarit Carer Burden
5 Interview on the basis that (a) they are widely used, psychometrically robust and applicable in LTNC, (b)
6 they are freely available and not restricted by license and (c) they are easily understood and timely to
7 apply.(22-25) Importantly, all of these are suitable for completion either by self-report questionnaire or
8 administered at interview by professionals.
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Table 1: LTNC Register Core Dataset*

Domain	Data fields	Value list / Data description
1. LTNC	Do they have an LTNC?	Yes/ no/ not sure
<i>If yes:</i> 1a. Record Neurological condition	Diagnosis or nature of condition	ICD-10 and /or Read codes Free text to describe neurological condition if no code exists
1b. Long term	Is the condition likely to have an enduring effect ?	Yes / No / Not sure
2. Needs for care/support	Do they have complex needs arising from the LTNC?	Yes / No / Not sure
<i>If yes:</i>		
2a. Record Impairment severity	Neurological Impairment Scale	17 item scores
2b. Record needs for health and social care	The Needs & Provision Complexity Scale (NPCS-Needs)	15 item scores
3. Need for integrated care planning (ICP)	Do they require (and want) integrated care planning	Yes / No / Not sure
4. Person responsible for registration	Name of registering clinician	Name and Signature
5. If yes to 1, 2, and 3		
5a: Are they having integrated care planning?	When was last ICP review?	Date
5b: Is there a single point of contact?	Named person or post	Name Job title/ contact details

* LTNC= Long term neurological condition; ICP=Integrated care planning

Measurement tools included in the dataset

Neurological Impairment Scale (NIS): The NIS comprises a brief 17-item checklist of the major neurological impairments (motor/sensory loss, cognitive, communication, emotional, behaviour) that make up a complex presentation in people with LTNCs.(19) Item severity scores range from 0-3 to assess the impact of these impairments at a functional level, giving a total score range 0-50. Originally developed as part of the core minimum dataset alongside the UK Functional Assessment Measure,(26) the NIS is shown to be a valid and reliable measure of neurological impairment suitable for use across a wide range of neurological conditions.(19) [It forms a part of the UK Rehabilitation Outcomes Collaborative \(UKROC\) national clinical dataset for specialist rehabilitation services \(for further information see \[www.csi.kcl.ac.uk/ukroc.html\]\(http://www.csi.kcl.ac.uk/ukroc.html\); accessed 09.01.14\)](#)

The Needs and Provision Complexity Scale (NPCS): The NPCS is a 15-item measure with six subscales (total score range 0-50) in two principal domains ('Health' and 'Social care'). [It is shown to be valid and reliable \(27\)](#). It is designed to be used as a simple tool to evaluate needs for health and social care and to identify gaps in service provision, both at the level of the individual and across populations.(20) It has two parts:

- 'NPCS-Needs' is completed by the treating clinician(s) to evaluate each patient's needs for health and social care in any given period.
- 'NPCS-Gets' is a mirror-image of the same tool, completed at the end of that period to evaluate the levels of service that have been provided in relation to those needs.

Subtracting NPCS-Needs scores from NPCS-Gets scores provides a measure of 'metness of needs' and a simple costing algorithm provides a generic estimate of the likely cost implications of addressing the unmet needs. (20) [The algorithm can be downloaded from \[www.csi.kcl.ac.uk/npcs.html\]\(http://www.csi.kcl.ac.uk/npcs.html\); accessed 09.01.14](#).

The Northwick Park Dependency Scale (NPDS): The NPDS is a measure of dependency of the individual on help from others in two main parts:(21)

- The 'Basic Care Needs' (BCN) section (score range 0-65) comprises 12 items covering the daily activities needed for everyday functioning. These include the capacity for both physical performance (NPDS-PD) (e.g. washing, dressing, toileting, eating and drinking etc.) and appropriate cognitive behaviour (NPDS-CB) (e.g. communication, safety awareness etc.).
- The 'Special Nursing Needs' (SNN) section (score range 0-35) includes seven items indicating the need for nursing care, such as a wound requiring dressings.

The NPDS is now widely used in the UK and has been translated into several languages. It is shown to be psychometrically robust.(28) [It, too, forms a part of the UKROC dataset, where algorithms within the](#)

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UKROC software translate it into the Barthel Index (ref) and also into the Northwick Park Care Needs assessment - a directly costable measure of care needs in the community (29, 30).

Community Integration Questionnaire (CIQ): The CIQ is a measure of community integration after traumatic brain injury that is suitable for self-completion by the patient or a carer by proxy. It consists of 15 items with a total score range from 0-29 comprising three subscales: (i) Home integration (range 0-10) (ii) Social integration (range 0-12) and (iii) Productivity (0-7). It was originally designed for including in the US TBI Model Systems dataset. Although not yet formally tested in a wider population of patients with LTNC, the psychometric properties of the CIQ have been well established in the context of brain injury. (31, 32)

Zarit Burden Interview (ZBI): The ZBI is designed to capture the impact of a caring role on the carer's personal and social well-being (33). It consists of 22 items (total score 0-88). For each item the carer rates how often they are affected by the negative aspects of their caring situation on a scale ranging from 0 (never) to 4 (nearly always). Originally developed in the context of dementia, the ZBI has been used in LTNC and other advanced conditions and is shown to be valid for assessing carer burden in these conditions.(34, 35)

Questionnaire administration

As many of the participants had complex disabilities with cognitive/ communication difficulties, three types of media were used to gather data in order to maximise response rate and ensure accessibility.

Respondents could choose from the following options:

- a) paper-based postal-questionnaire
- b) web-based survey tool, using Survey Methods software (Survey Methods Inc. www.surveymethods.com)
- c) questionnaire administered by a researcher at telephone interview.

All questionnaires were piloted prior to use. Wherever possible, follow-up telephone interviews were used to complete missing information from questionnaires, and this provided further feedback to refine the data-gathering tools. The changes related to presentation (plain language, font size etc) and did not affect the structure or content of the measurement instruments.

PART B – Longitudinal Cohort Study

In Part B, the LTNC dataset was used to monitor a cohort of patients over a 1 year period following discharge from all tertiary specialised in-patient rehabilitation services across the London region.

Participating centres

Nine 'Level1' services provide a comprehensive network of tertiary specialist in-patient neurological rehabilitation across the London Region of the UK. They provide specialised rehabilitation for the population of patients with complex needs that are beyond the scope of their local (Level 2 and 3) rehabilitation services (<http://www.bsrm.co.uk/index.htm>; accessed 09.01.14).(36) Patients discharged from these units are therefore likely to have complex needs for ongoing rehabilitation and support services in the community. All nine services participated in recruitment in our study.

Participants

Recruitment occurred over an 18-month period in 2010 – 2011. Consecutive in-patients across the nine services, were eligible to participate if they had a LTNC at discharge (ie a neurological condition that was considered likely by the treating team to have an enduring effect). They were approached for consent by a member of the treating team. This was taken in writing on a standard consent form at least 24 hours after provision of an information sheet, a verbal explanation of the study and the opportunity to ask questions. Where cognitive or communication problems prevented their direct participation a family member or carer was identified to assist (or respond on behalf of) the patient and as the primary point of contact for further questionnaires.

Data Collection Procedure

For all consenting patients, their discharge team completed a recruitment form that included:

- a) Severity of impairment (NIS)
- b) Needs for ongoing services (NPCS-Needs) as rated by their multidisciplinary (MD) team
- c) Whether the patient would be willing to be included in a LTNC Register
- d) Details of any community rehabilitation support services to which patients had been referred
- e) Contact details for a named individual to approach for follow-up questionnaires (usually either the patient or a family carer).

Baseline data were recorded by the treating MD team as part of their discharge planning. This approach to shared decision-making in the assessment of needs reduced the potential for clinician bias across different disciplines, as the representation of disciplines within the teams was broadly similar across the nine specialist rehabilitation units. Teams were asked to record the NPCS-Needs in relation to services that they reasonably expected the patient to receive, based on the referrals they were making for ongoing support and rehabilitation after discharge, rather than those they might wish for 'in an ideal world'.

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This recruitment information was then sent to the research team who contacted the named individual to answer questions / address any concerns and to establish their preferred medium for response (ie postal questionnaire, web-based survey or telephone interview).

Tools included in the questionnaire were self-report versions of:

- a) Dependency (NPDS): including basic care needs (NPDS-BCN) and special nursing needs (NPDS-SNN)
- b) Community integration (CIQ)
- c) Carer Burden (ZBI) – if the individual had a family (or other informal) carer
- d) Services received (NPCS-Gets) in the last 6-month period – recorded at 6 and 12 months

Participants were contacted at one, six and 12 months after discharge and asked to complete a questionnaire/interview (the Month 1 responses acting as baseline for these self-report measures). A second follow-up call was made if a response had not been received within a fortnight. Up to five attempts were made to reach respondents by telephone before desisting.

Efforts to maximize response rates

Across the three response phases, paper questionnaires were consistently the most commonly used method (approximately 80 to 84% of respondents); 10 to 13% responded online and 3 to 5% were administered at telephone interview. [Postal and online questionnaires were followed up by telephone wherever possible to fill in any missing information.](#) Over the course of the study, a total of 1211 questionnaires were sent and 225 re-sent; 1607 phone calls were made to achieve the 658 questionnaires received.

Data management and analysis

Data were entered into a spreadsheet (Microsoft Excel) and after cleaning and validation, were extracted to SPSS (IBM Statistics) version 19 for statistical analysis. Despite the ordinal nature of the data, in view of the large sample size and the fact that linear regression modelling used in the latter part of the analysis relies on parametric assumptions, parametric techniques were used throughout with descriptive statistics reported in the form of percentages or means, standard deviations and range. Non-parametric analyses are available on request from the author but did not yield different results. In view of the multiple tests, the threshold for significance was set at $p < 0.01$.

The first stage of our analyses included a descriptive analysis of all available respondents at each time point. To determine whether patients would want to use an LTNC register, we examined the proportions who agreed to be included and those who actually responded to our requests for follow-up information on each occasion, as an indication of those most likely to use the register.

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5 We examined the characteristics of patients who responded at each time point in terms of demographics,
6 severity of impairment and needs for services. We looked in particular for any statistical differences
7 between the “best responder” group (those who responded at all three time points) and the ‘non-
8 responders’ (who did not respond on any occasion). To identify predictors of the extent of rehabilitation
9 received (NPCS-Gets) at six months post-discharge we began with a series of univariate regression analyses
10 including all those who responded at 6 months (n=212). Specifically we examined which of the following
11 variables (recorded at baseline) **individually** predicted the overall level of rehabilitation services received
12 within the first 6 months:
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- 14 a) demographics (i.e. age, gender, marital status, education, ethnicity, diagnosis)
- 15 b) level of impairment both physical (NIS-Physical), and cognitive (NIS Cognitive)
- 16 c) level of dependency - physical (NPDS-PD) and cognitive (NPDS-CB) and total basic care needs
17 (NPDS-BCN) were entered as separate variables
- 18 d) special nursing needs (NPDS-SNN)
- 19 e) social integration in the community (CIQ).

20
21 For the demographic variables, age was treated as continuous and the remaining five were all coded as
22 ‘dummy’ or categorical variables. Physical and cognitive impairment were treated as separate variables in
23 light of previous studies suggesting that people with ‘hidden disabilities’ received fewer services. The best
24 individual predictors (i.e. only those variables that predicted a statistically significant proportion of variance
25 in univariate regression analyses) were all included in a single stepwise multiple regression analysis to
26 identify the best model.
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29 The second stage of our analysis explored the relationship between **patient-reported** outcomes and the
30 extent to which an individual’s needs for services were met. Here the longitudinal trends for change over
31 successive time periods were the specific focus of interest, so only the ‘best responders’ (for whom data
32 were available at all three time points) were included.
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- 34 • Differences between NPCS ‘Needs’ and ‘Gets’, and between NPCS-Gets during the first and second
35 6 month period were tested by paired t tests.
 - 36 • Discrepancy scores between the needs identified by the treating clinicians at discharge (NPCS-
37 Needs) and services received during the first six month period (NPCS-Gets) were calculated on a
38 case-by-case basis as a measure of the extent to which individual needs were met (i.e. ‘Metness of
39 need’ = ‘NPCS-Gets’ minus ‘NPCS needs’)
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Services provided in the first 6-month period after discharge from in-patient rehabilitation were considered to be particularly critical to support adjustment and (where possible) re-ablement following newly-acquired disability. To examine the relationship between outcome (in terms of community integration and carer burden) at 12 months and the extent to which individual needs for rehabilitation were met during the first 6 months, discrepancy scores for the NPCRS Rehabilitation subscale were entered as predictor values in a longitudinal linear regression analysis. We examined outcomes, (CIQ and ZBI) in comparison with 'metness of need' in the Rehabilitation subscale of the NPCRS. We also dichotomized patients into those whose rehabilitation needs were met or exceeded in the first six months (Gets minus Needs ≥ 0) and those who had unmet needs (Gets minus Needs < 0). For this analysis the variables entered into the model were selected on a priori theoretical grounds. Although we expected the level of community integration to be negatively affected by physical and cognitive dependency, we hypothesized that patients whose needs for rehabilitation and support were met would achieve better integration than those with unmet needs.

RESULTS

Recruitment and response rates

Out of a total of 576 admissions, 499 patients were assessed as eligible for inclusion in the study, because they had a LTNC that was likely to have an enduring effect. They were approached by the clinical teams for permission to include them in the study, of which 428 (92%) were recruited. Across the nine units just 8% of those approached declined to participate in the study. Some centres were notably more successful at recruiting than others. Highest recruitment rates (>93% of admissions) were seen where a single individual (eg a consultant or a dedicated recruitment officer) took responsibility for recruiting all participants within that unit. Lower rates (approximately 2/3 of admissions overall) were achieved where recruitment was left to one of several members of the team (eg a keyworker or one of the junior medical staff), who were less familiar with the study.

The participation and attrition rates throughout the study are displayed in Figure 2. The characteristics of the 428 patients recruited, are shown in Table 2 .

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Table 2: Characteristics of the 428 Patients recruited, the 'best responder' (n=134) and the non-responder (n=123) group.

Variables		Recruited sample N=428		Best responders N=134		Non-responders N=123		Chi-squared *
		N	%	N	%	N	%	P value
Gender	Male	270	(63.1)	86	(64.2)	80	(65.0)	0.90
	Female	158	(36.9)	48	(35.8)	43	(35.0)	
Diagnosis	Brain injury	315	(73.6)	97	(72.8)	85	(69.1)	0.35
	- Stroke/SAH*	212	(49.5)	70	(52.2)	57	(46.3)	
	- TBI*	63	(14.7)	16	(11.9)	18	(14.6)	
	- Other ABI*	40	(9.3)	11	(8.2)	10	(8.1)	
	Spinal Cord Injury	38	(8.9)	8	(6.0)	11	(8.9)	
	Peripheral Neuropathy	26	(6.1)	8	(6.0)	9	(7.3)	
	Progressive LTNC	21	(4.9)	5	(3.7)	10	(8.1)	
	Other	27	(6.3)	16	(11.9)	7	(5.7)	
Missing	1	(0.2)	0	(0)	1	(0.8)		
Discharge destination	Home	333	(77.8)	115	(85.8)	89	(72.4)	0.009
	Nursing Home	51	(11.9)	9	(6.7)	19	(15.4)	0.03
	On-going Rehab	18	(4.2)	6	(4.5)	5	(4.1)	1.0
	Hospital	4	(1.0)	2	(1.5)	1	(0.8)	1.0
	Other	19	(4.4)	2	(1.5)	9	(7.3)	0.03
Referred to ongoing rehabilitation	Yes	378	(88.3)	124	(92.5)	110	(89.4)	0.33
	No	41	(9.6)	7	(5.2)	11	(8.9)	
	Not answered	9	(2.1)	3	(2.2)	2	(1.6)	
Permission to include on the Register	Yes	322	(75.2)	108	(80.6)	90	(73.2)	0.23
	No	13	(3.0)	3	(2.2)	7	(5.7)	
	Not answered	93	(21.7)	23	(17.2)	26	(21.1)	
At recruitment		Mean	SD	Mean	SD	Mean	SD	T-test* P value
Age	Years	49.1	(15.2)	50.2	(14.0)	47.8	(15.9)	0.19
Neurological Impairment	NIS-Motor	8.1	(5.1)	8.3	(5.0)	8.9	(5.4)	0.36
	NIS-Cognitive	4.4	(3.1)	4.4	(3.2)	4.8	(3.0)	0.34
	Total	12.8	(6.4)	13.1	(6.4)	13.9	(6.7)	0.37
Needs for health and social care	NPCS Health	11.5	(4.3)	11.4	(4.2)	11.9	(4.5)	0.31
	NPCS-Social support	6.2	(4.3)	5.6	(4.0)	6.7	(4.8)	0.04
	NPCS-Total	17.7	(7.8)	17.0	(7.6)	18.7	(8.4)	0.09

*Difference between best responders and non-responders.

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Do patients want to be entered on an LTNC register, and which patients might be most likely to participate?

Consent to participate in the study questionnaires did not necessarily mean that individuals would be willing to have their details included in a register. Three-quarters of the recruited group (n=322 (75%)) indicated, at discharge from hospital, that they were willing to be included in a pilot LTNC register. On the other hand only 13 (3%) declined. The remaining 93 (22%) did not answer the question **mostly due to a failure on the part of the clinician to ask**. However, only a proportion of these actually responded to questionnaires when subsequently approached in the community. At one month post discharge, 59% responded; at 6 months 49%; and at 12 months just 44%. The response across the three time periods was not consistent: 123 (29%) did not respond to a questionnaire in any of the phases; 20 - 21% responded to one or two phases and just 134 (31%) responded to all three phases. This latter group of 'best responders' was considered to be the group of patients most likely to engage in follow-up using an LTNC register, but interestingly there was no significant difference between the 'best responders' and the 'non-responders' in terms of their expressed willingness to be included in the register.

Characteristics of the responding patients across the three phases

Respondents were similar at each phase in terms of gender ratio, age, marital status and educational level. The only significant trend over time was a greater attrition for non-white British subjects, reflected in the loss of 39% of Black and 49% Asian/other participants as compared with only 18% attrition for white participants. The 'best responders' were more likely to have been discharged home than the non-responders, a greater proportion of whom were in nursing home or other residential care. Otherwise there were no significant differences in demographics between these two groups, and they had similar levels of impairment and needs for services at recruitment (see Table 2).

The extent to which needs were and were not met

Table 3 shows descriptive statistics for measures of impairment, needs, inputs and outcome across the three follow-up phases. Again there was no difference between the groups responding at each time period with respect to their severity of impairment (total NIS score) or need for services (NPCS-Needs), nor with respect to their outcomes in terms of dependency (NPDS) integration (CIQ) or carer burden (ZBI).

Table 3: Descriptive statistics for measures of impairment severity (NIS, motor, cognitive), service needs (NPCS-Needs), service inputs (NPCS-Gets) and patient reported outcome (CIQ, ZBI) across the three Phases after Discharge and for the group that responded at all three phases.

Time	Phase 1 1 month post discharge N=256	Phase 2 6 months post discharge N= 212	Phase 3 12 months post discharge N=190	'Best responders' at recruitment and phase 3 N=134
Measure (Scoring range)	Mean (SD) Range (Min-Max)	Mean (SD) Range (Min-Max)	Mean (SD) Range (Min-Max)	Mean (SD) Range (Min-Max)
At recruitment				
Impairment				
Physical NIS-Motor (range 0-26)	7.8 (4.9) 0-25	7.9 (5.1) 0-25	8.1 (5.0) 0-25	8.3 (5.0) 0-25
Cognitive NIS Cognitive (range 0-21)	4.3 (3.1) 0-14	4.5 (3.2) 0-13	4.2 (3.0) 0-13	4.4 (3.2) 0-13
NIS Total (0-50)	12.4 (6.4) 1-31	12.7 (6.5) 1-31	12.7 (6.2) 1-31	13.1 (6.4) 1-31
Level of services required (NPCS-Needs)				
Health and care NPCS-Health Needs (range 0-25)	11.3 (4.1) 0-21	11.4 (4.2) 0-20	11.2 (4.2) 0-21	11.4 (4.2) 0-20
Social support NPCS-Social Needs (range 0-25)	5.7 (4.0) 0-19	6.1 (4.2) 0-19	5.8 (4.0) 0-19	5.6 (4.0) 0-19
Total NPCS Needs (0-50)	17.0 (7.5) 0-36	17.5 (7.7) 1-36	17.0 (7.6) 0-36	17.0 (7.6) 0-36
At follow-up period				
Service provision				
Health and care NPCS-Health Gets (0-25)	Not applicable	9.4 (4.7) 0-20	8.5 (4.8) 0-21	8.4 (4.9) 0-21
Social support NPCS-Social Gets (0-25)	Not applicable	4.6 (3.5) 0-15	3.8 (3.1) 0-15	3.8 (3.2) 0-15
Total NPCS-Gets (0-50)	Not applicable	14.0 (7.1) 0-29	12.5 (7.1) 0-34	12.4(7.2) 0-34
Outcome measures				
Dependency NPDS (0-100)	12.7 (13.9) 0-66	12.2 (13.8) 0-61	11.2 (13.5) 0-60	11.4 (13.5) 0-60
Integration CIQ (0-29)	12.1 (4.9) 0-26	11.0 (5.7) 0-27	12.3 (5.7) 0-27	12.3 (5.8) 0-27
Carer burden ZBI (0-88)	24.4 (16.7) 0-82	24.4 (17.5) 0-82	25.5 (18.9) 0-88	26.9 (18.6) 0-84

NPCS = Needs and Provision Complexity Scale; NIS=Neurological Impairment Scale,
CIQ= Community Integration Questionnaire; ZBI = Zarit Care Burden Interview

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3 The level of services received during the first 6 months was significantly lower than the needs identified at
4 discharge for both health care (Mean difference 1.8 (95% CI 1.1, 2.4) $t = 5.1$, $p < 0.001$) and social care
5 (Mean difference 1.7 (95% CI 1.1, 2.2) $t = 5.9$, $p < 0.001$). There was a modest overall decline in the levels of
6 both health and social support services during the second six months, even though the levels of
7 dependency, community integration and carer burden remained similar. However, this could simply have
8 been due to differences in the best responder group at 6 and 12 months. Therefore, a paired analysis was
9 conducted for just the best responder group, who responded on all three occasions. Although these best
10 responders ($n=134$) formed less than one third of the total population, there was no evidence that they
11 differed in any significant respect from the recruited population (see Tables 2 and 3).
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19 Table 4 shows a more detailed evaluation of the met and unmet needs (as measured by the NPCCS) for this
20 'best responder group during the first 6 months. It also shows the change in levels of service provided
21 during the second 6 month period, and the change in outcomes across the three time points of the study.
22 As recorded elsewhere for the full cohort(20, 37), this subgroup analysis confirms significant levels of
23 unmet needs with respect to rehabilitation, social support and equipment provision during the first critical
24 6 months following discharge(20, 37). It also records a significant decline in service provision between
25 months 6 and 12, despite continuing high and unchanging levels of dependency and carer burden. On the
26 other hand, needs for medical and nursing inputs, personal care and accommodation were well met. The
27 level of community integration appears to increase briefly at 6 months and then subside to baseline levels
28 at 12 months.
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37 However, within the study sample there is clearly significant variation, both with respect to the level of
38 services provided and outcome. It is therefore pertinent to examine what predicts the levels of service
39 provision, especially during the first critical 6 months after discharge to the community, and whether there
40 is a relationship between 'metness of needs' and outcome.
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Table 4: Best-responder population (n=134): Descriptive statistics and significant differences in needs, inputs and outcomes at baseline, 6 and 12 months

	Missing	Baseline	6 months	Difference tested by paired T Tests				Missing	12 months	Mean difference	95% CI	P value	Effect size*
		Mean (SD)	Mean (SD)	Mean difference	95% CI	P value	Effect size*		Mean (SD)				
NPCS		Needs	Gets at 6 months	Difference between needs identified at discharge and levels of service received during the first 6 months					Gets at 12 months	Difference in level of services received during the 1st and 2nd 6-month periods			
Health and Personal care domain													
Health	2	2.3 (1.5)	2.4 (1.7)	0.04	-0.3, 0.4	0.81	0.03	2	2.2 (1.6)	-0.1	-0.4, 0.1	0.25	0.06
Personal care	7	3.7 (2.7)	3.6 (2.6)	0.02	-0.4, 0.5	0.92	0.01	8	3.3 (2.6)	-0.4	-0.7, 0.1	0.02	0.15
Rehabilitation	5	5.3 (1.9)	3.6 (2.0)	-1.7	-2.1, -1.3	<0.001	0.89	8	2.9 (2.2)	-0.8	-1.2, -0.5	<0.001	0.40
Total	13	11.4(4.2)	9.5 (4.7)	-1.6	-2.5, -0.8	<0.001	0.38	16	8.4 (4.9)	-1.4	-2.0, -0.8	<0.001	0.30
Social care and support domain													
Social support	12	2.8 (2.6)	1.6 (2.0)	-1.2	-1.7, -0.7	<0.001	0.46	15	1.2 (1.7)	-0.4	-0.7, -0.1	0.005	0.20
Equipment	4	1.2 (0.9)	0.8 (0.8)	-0.4	-0.6, -0.2	<0.001	0.44	6	0.6 (0.8)	-0.2	-0.4, -0.1	0.004	0.25
Accommodation	2	1.6 (1.9)	1.8 (2.0)	0.2	-0.1, 0.5	0.16	0.11	2	1.9 (1.9)	0.1	-0.1, 0.4	0.23	0.05
Total	14	5.6 (4.0)	4.1 (3.2)	-1.5	-2.2, -0.9	0.07	0.37	18	3.8 (3.2)	-0.4	-0.8, 0.0	0.06	0.13
Total Needs and Provision													
TOTAL	22	16.8 (7.6)	13.7 (6.9)	-3.1	-4.3, -1.8	<0.001	0.41	29	12.1 (7.1)	-1.9	-2.7, -1.1	<0.001	0.27
Outcome measures (total scores)													
Dependency (NPDS)	0	12.8 (13.3)	12.4 (14.4)	-0.4	-1.6, 0.8	0.51	0.03	0	11.4 (13.5)	-1.0	-1.9, 0.0	0.05	0.07
Integration (CIQ)	24	12.3 (4.9)	11.4 (5.6)	-1.0	-1.7, 0.2	0.01	0.22	21	12.4 (5.7)	0.9	-0.4, 1.5	0.002	0.16
Carer burden (ZBI)	53**	23.7 (17.1)	24.1 (17.2)	0.4	-2.1, 2.9	0.75	0.06	55**	25.3 (18.1)	1.5	-0.5, 3.5	0.15	0.09

NPCS = Needs and Provision Complexity Scale; SD= standard deviation; 95%CI = 95% Confidence Interval

*Effect sizes for the first 6 months were calculated as mean difference / SD baseline and for the second 6 months: mean difference / SD at 6 months

** Carer burden scores were only recorded where a family carer was involved.

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What predicts the level of services received in the first six months after discharge?

The univariate regression analyses showed that none of the demographic variables (Age, Gender, Ethnicity, Marital Status, Education, Diagnosis) nor carer burden (ZBI) recorded at baseline were significantly related to the levels of service received (total NPCS-Gets) at six months. The baseline measures of impairment (NIS), dependency (NPDS), nursing needs (NPDS-SNN) and community integration (CIQ), however, all predicted a significant proportion of the variance, as well as demonstrating significant inter-relationships as shown in Table 5

Table 5: Correlation matrix of predictor variables of services received (NPCS gets) at 6 month (n=212)

Variable	NPCS –Gets 6 Months	NIS- Motor	NIS- Cognitive	NPDS- Physical	NPDS- Cog/Behav	SNN
NIS-Motor	0.44**					
NIS-Cognitive	0.38**	0.15*				
NPDS-Physical	0.58**	0.67**	0.36**			
NPDS-Cog/Behav	0.45**	0.20**	0.62**			
NPDS-BCN	0.62**	0.62**	0.45**	0.98**		
NPDS-SNN	0.45**	0.23**	0.11	0.35**	0.22**	
CIQ	-0.45**	-0.48**	-0.40	-0.57**	-0.46**	-0.15
ZBI	0.30**	0.08	0.34**	0.20*	0.36**	-0.00

* p< 0.05; ** p<0.01; N ranges from 149-206 due to missing data. For the ZBI correlations N ranges from 115-119 reflecting the subset of participants with a carer.

Results of a stepwise regression analysis that included the significant predictors from univariate regression analyses are presented in Table 6. In both the univariate analyses and in the stepwise model dependency (NPDS-BCN) was the best single predictor accounting for 33% of the model variance. The addition of Motor and Cognitive Impairment (as measured by the NIS subscales at recruitment) improved the predictive ability of the stepwise model by small but significant increments to a total R² of 40 percent. Community integration and special nursing needs did not add significantly to the prediction of variance and so were excluded by the stepwise regression.

Table 6: Stepwise regression analyses of best individual predictor variables of services received (NPCS gets) during the first 6 months after discharge

Stepwise Models	β	CI (95%)	P	R ²	ΔR^2
NPDS -BCN	0.34	0.26 – 0.43	.001	0.33	-----
NPDS-BCN	0.23	0.12 – 0.34	.001	0.38	0.05
NIS-Motor	0.37	0.13 – 0.60	.001		
NPDS-BCN	0.18	.06 – 0.30	.001	0.40	0.02
NIS-Motor	0.40	0.17 – 0.63	.001		
NIS-Cognitive	0.34	0.02 – 0.67	.001		

Is there a relationship between ‘metness of need’ in the first critical 6 months and outcome in terms of community integration and carer burden at twelve months?

We wished to determine whether the extent to which rehabilitation needs were met impacted on community integration and carer burden at 12 months, over and above any relationship between these outcomes and dependency. Taking community integration scores (CIQ) at 12 months as the dependent variable, a stepwise regression was carried out using physical dependency (NPDS-PD) and cognitive dependency (NPDS-CB) at baseline, and ‘metness’ of rehabilitation needs at six months as independent variables. This revealed that 31% of the variance in community integration could be explained by physical and cognitive dependency; the more dependent patients being less well integrated at 12 months. The extent to which their rehabilitation needs had been met was positively correlated with dependency at baseline (ρ 0.20, $p=0.03$), and added only 2% to the predictor model, so that together they explained 33% of the variance. However, the relationship was not in the expected direction. Patients ($n=31$) who received rehabilitation services that met or exceeded the levels of need predicted at discharge showed significantly lower gains in CIQ than those for whom provision did not meet their predicted need ($n=71$): Mean difference 2.6 (95% CI 0.9, 4.3, $p=0.003$).

A similar stepwise regression was performed for the dependent variable carer burden (ZBI) at 12 months, entering physical dependency (NPDS-PD) and cognitive dependency (NPDS-CB) at baseline, and ‘metness’ of rehabilitation needs at six months as independent variables. Here only cognitive dependency remained in the final model, predicting 12% of the variance in carer burden, with the other two variables not

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3 improving the model significantly. There was no significant difference observed in carer burden scores
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5 between patients with 'met' and 'unmet' needs for rehabilitation.
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DISCUSSION

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9 This paper describes further development of the LTNC dataset to identify a manageable set of tools suitable
10 for use in routine practice to measure needs, inputs and outcomes from community-based rehabilitation
11 and support services. In a cohort of nearly 500 patients with complex needs arising from a LTNC, the large
12 majority were willing in principle to be registered and have their data included in the dataset. However, in
13 practice, only a minority (less than one third) responded regularly when asked to provide information
14 about their ongoing needs and the level of services received. Reasons for attrition were mostly unknown
15 since, for ethical reasons, all participants had the right to withdraw at any stage without any explanation.
16 The 'best responders' included a higher proportion of white British patients, and were more likely to be at
17 home, but were not otherwise distinguishable from the non-responder group, in terms of severity of
18 impairment, disability or needs for services.
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27 The level of attrition observed here was not dissimilar from other series. A similar loss to follow-up of
28 registered brain injured patients has been noted in a number of other studies. Corrigan et al. analysed
29 three USA datasets covering several thousand adults with traumatic brain injury, of whom only 58% could
30 be followed-up 1-year post injury(38). In the UK, Wade and colleagues reported a similar rate of attrition
31 (59% at 6 months) and highlighted the difficulties of follow-up in brain-injured patients, which include
32 itinerancy, and lack of motivation or ability to respond (39). The higher proportion of non-respondents in
33 nursing homes or other in-patient settings observed in our study is likely to reflect a) the fact that many
34 were unable to respond for themselves and b) the difficulty of identifying someone willing and able to
35 respond on their behalf in these settings. Culturally-related psychosocial factors, such as cultural mistrust
36 and perceptions of exploitation in medical research by minority groups, are known to affect research
37 participation and may be associated with attrition from registers more generally by people from black and
38 ethnic minority groups when compared with other populations (38, 40, 41).
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48 Whatever the reasons for it, the high attrition rate among those participants who agreed to participate
49 suggests that a register based on postal/telephone follow-up will be labour intensive and might fail to
50 engage a significant proportion of the most vulnerable patients. In clinical practice, integrated care
51 planning reviews most commonly involve face-to-face meetings with the patient and carer. In the authors'
52 view, this is likely to offer a more effective route for data collection for the register. The NPCSS provides a
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Running Head: Long-Term Neurological Conditions

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3 simple and practical tool to capture met and unmet needs in this context, and so may assist clinical teams
4 to identify and address any gaps in service provision at either an individual or an organisational level.
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8 Longitudinal study of the best responder group revealed that they changed little in terms of dependency or
9 community integration during the year following discharge from in-patient specialist rehabilitation, and the
10 burden on their carers also remained stable. In common with the larger cohort, they had significant unmet
11 needs for health and social care services – particularly with respect to rehabilitation, social worker support
12 and provision of specialist equipment.(20) Physical disability was the best single predictor of services
13 received, followed by cognitive/behavioural disability. In contrast to some other studies there was no
14 strong evidence that those with hidden disabilities were less able to access services than those with
15 physical disability.(17) However, this may be due to the targeted efforts of the in-patient teams to set up
16 services for them following discharge to the community.
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24 We had expected to demonstrate that patients whose needs for community-based rehabilitation were met
25 had better outcomes in terms of functional independence and community integration, with reduced
26 burden on carers. In fact, if anything we showed that their outcomes were worse. Over and above the
27 relationship with physical and cognitive dependency, patients whose rehabilitation needs were met or
28 exceeded during the initial 6 months had made fewer gains in integration at twelve months post discharge
29 than those with unmet needs. Whilst counter-intuitive, on a clinical level this paradoxical finding is not
30 entirely surprising. The most likely explanation reflects the 'inverse therapy rule', which is simply that in a
31 health culture where resources are limited, services will be focussed on those patients with the severest
32 problems who have the greatest need.(42) Professionals are likely to withdraw sooner from those patients
33 who improve quickly over time and meet their goals early on in the programme, and to target their
34 resources on those who continue to require their help.
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44 A weakness of this study was that needs were not re-assessed at each time point, so we cannot determine
45 whether under provision of services with respect to predicted needs reflected unmet or changing levels of
46 need. This argues for the importance of continued review in future studies, measuring both needs and
47 inputs to capture change over time. The NPCS provides a simple practical means to do this.
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52 Other weaknesses are as follows:

- 53 • While the cohort was large it only included patients from tertiary rehabilitation services in the
54 greater London metropolitan area and experiences might be different in other parts of the UK
55 particularly rural regions.
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- The high attrition rates in the longitudinal study are discussed above. While there were no discernable differences between responders and non-responders on any demographic variables, except for ethnicity and discharge destination, non-response bias is likely to be present. Consequently it is uncertain how well the findings of this study might apply to the broader population of people with LTNCs.
- We carried out more than 30 statistical tests, which carries the risk of type I error rate inflation, and we dealt with this by setting the P-value for significance at 0.01. We could have set a more stringent P-value at 0.001 for an overall alpha level of 0.05 – the Bonferroni method. However, this can increase the likelihood of type II errors, so that truly important differences are deemed non-significant, and create more problems than it solves.⁽⁴³⁾ The Bonferroni method is concerned with the general null hypothesis – that all null hypotheses are true simultaneously – which is rarely of interest or use to researchers. Moreover, we are confident that the adjusted level does not alter the principal conclusions of the study.

Despite these recognised limitations, the study provides useful insights into the potential value of an LTNC register and its associated tools as a means to monitor needs, inputs and outcomes for patients with LTNC. It identifies significant gaps in service provision of both health and social services support in comparison with individual needs.

The study demonstrates that a registry would be feasible and acceptable to most patients. We suggest that face-to-face interviews conducted as a part of integrated care planning are likely to offer a better opportunity for both information gathering and reassessment of needs against which the adequacy of services delivered may be evaluated. The inverse therapy effect is an important but little recognised phenomenon, reflecting the fact that those patients who remain dependent continue to require and consume the bulk of available resources. This is always likely to be a confounder to be taken account of in longitudinal observational studies that seek to establish a relationship between more intensive rehabilitation and better outcomes.

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Competing interests:

There are no significant competing interests. All authors have completed the BMJ Declaration of Competing Interests form available on request from the corresponding author.

Outcome measurement is a specific research interest of our centre. LTS was the lead developer of the NPDS, NIS and NPCCS, but neither she nor her employing institution has any financial interest in the tools which are disseminated free of charge. None of the authors has any personal financial interests in the work undertaken or the findings reported. All authors are employed by universities/hospitals which may cite this article as part of their research evaluation processes, including the UK Research Excellence Framework 2013. LTS, DMJ and RJS have received financial support from the NIHR to attend conferences to disseminate the submitted work. We do not consider that any of these relationships or activities have influenced the submitted work.

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Copies of the NIS, NPDS and NPCCS are available free of charge from our website (www.csi.kcl.ac.uk/tools.html) and copies of the full questionnaire and other tools used in this study are available from the corresponding author.

Ethics approval: Approval for the study was granted by Bromley Research Ethics Committee (Ref no: 09/H0805/25) and subsequently the R&D centres of the seven participating NHS trusts. The remaining two recruiting centres were in the independent sector - approval for recruitment was obtained through their internal clinical and research governance processes.

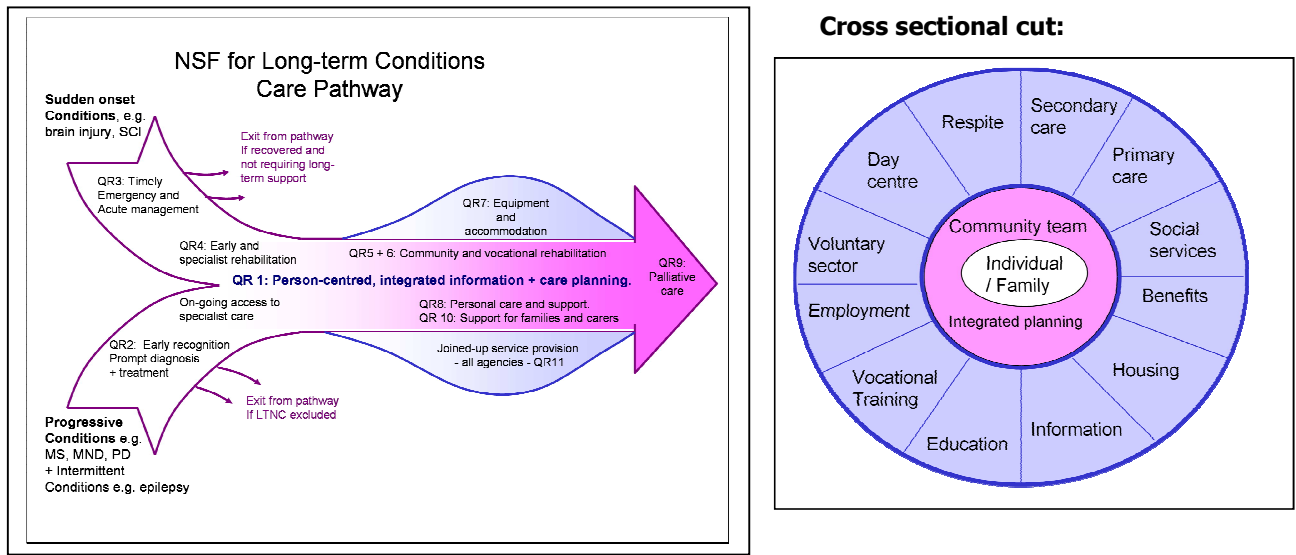
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3 **Registration:** The study was registered with the NIHR Comprehensive Local Research Network: ID number
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8 **Author contributions:** RJS was the principal investigator for the larger study of which this formed a part. He
9 took the lead role in execution and governance of the study and had overall responsibility for study
10 reporting. LTS was the lead clinician, led the design of the study, and the development of the LTNC register
11 and dataset. LTS and RJS wrote the first draft of the article together. DMJ was responsible for data-checking
12 and quality and also contributed to writing the article. EDP and SF were co-applicants on the study and
13 members of the project steering group, contributing to direction and decision-making as the study
14 progressed. All co-authors reviewed and commented on the manuscript.
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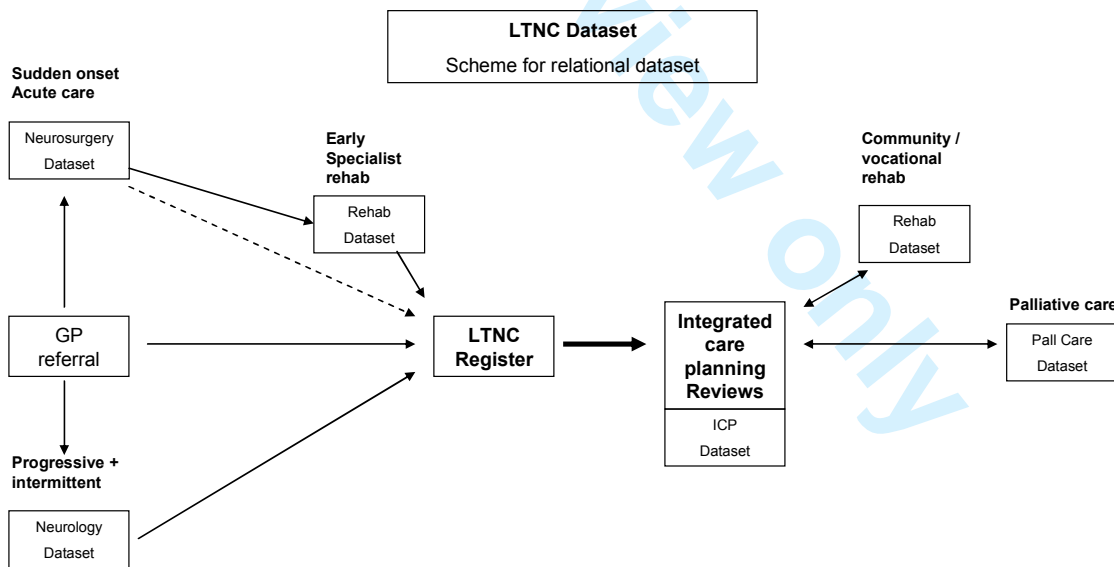
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Figure 1a: A schematic diagram of The NSF for LTNC care pathway and quality requirements



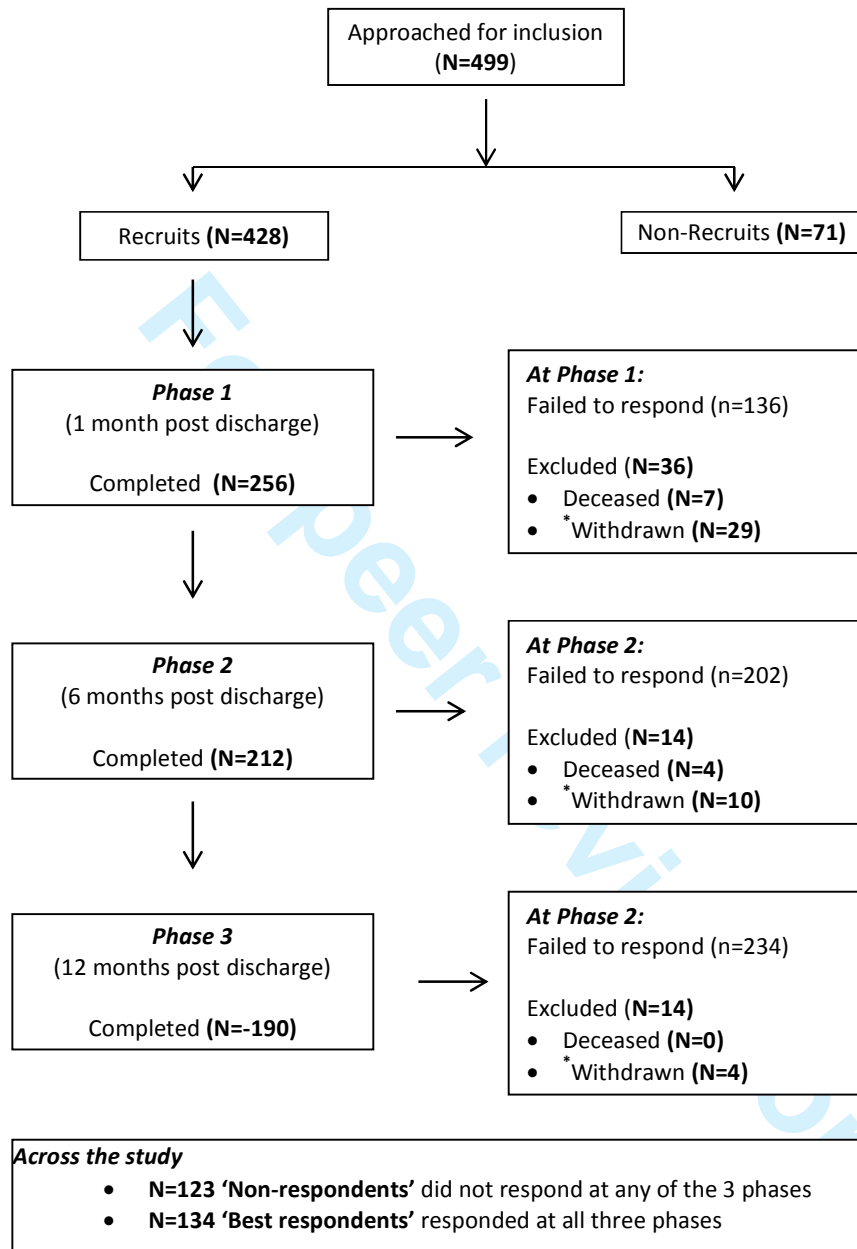
Legend to Figure 1a: The 'fish diagram' illustrates how the different Quality Requirements (QRs) of the NSF fit along the care pathway. The cross sectional diagram illustrates the range of services that may be needed by a patient with complex needs(14) (Reproduced with permission from Prof Lynne Turner-Stokes).

Figure 1b: The overall scheme of the LTNC dataset



Legend to Figure 1: The LTNC dataset is made up of a relational database with seven datasets linked via the patient's identifier (NHS number) following the overall schema of the LTNC pathway. The LTNC register identifies those patients with complex needs who form the denominator for datasets in the later stages of the pathway (Reproduced with permission from Prof Lynne Turner-Stokes).

Figure 2: Recruitment and participation pathway



* Reasons for withdrawal were: Not wanting any further involvement 24/43 (56%), unwilling or unable to fill in questionnaires 6/43 (14%), re-admission to hospital 2/43 (5%) and being uncontactable 11/43 (25%).

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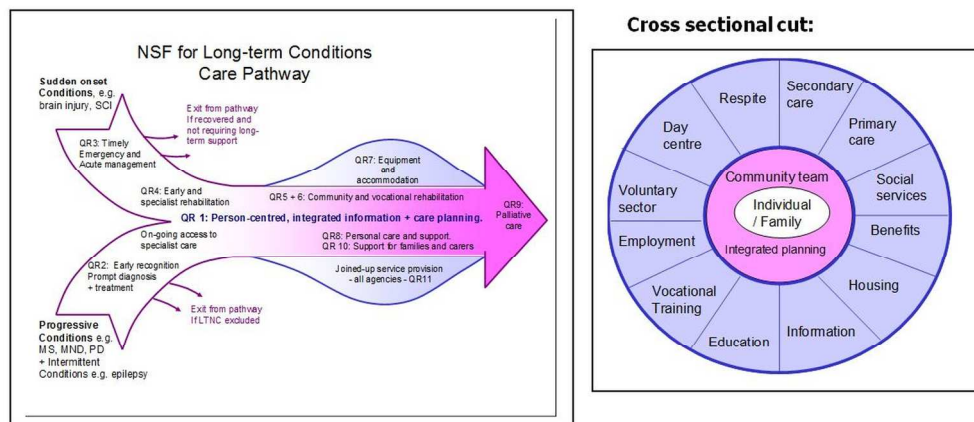
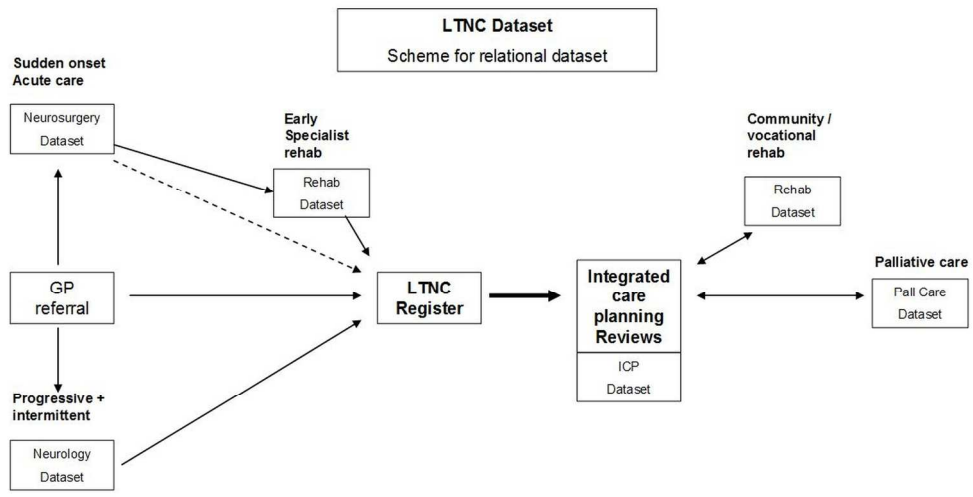


Figure 1a: A schematic diagram of The NSF for LTNC care pathway and quality requirements

Legend to Figure 1a: The 'fish diagram' illustrates how the different Quality Requirements (QRs) of the NSF fit along the care pathway. The cross sectional diagram illustrates the range of services that may be needed by a patient with complex needs(14) (Reproduced with permission from Prof Lynne Turner-Stokes). 206x90mm (300 x 300 DPI)

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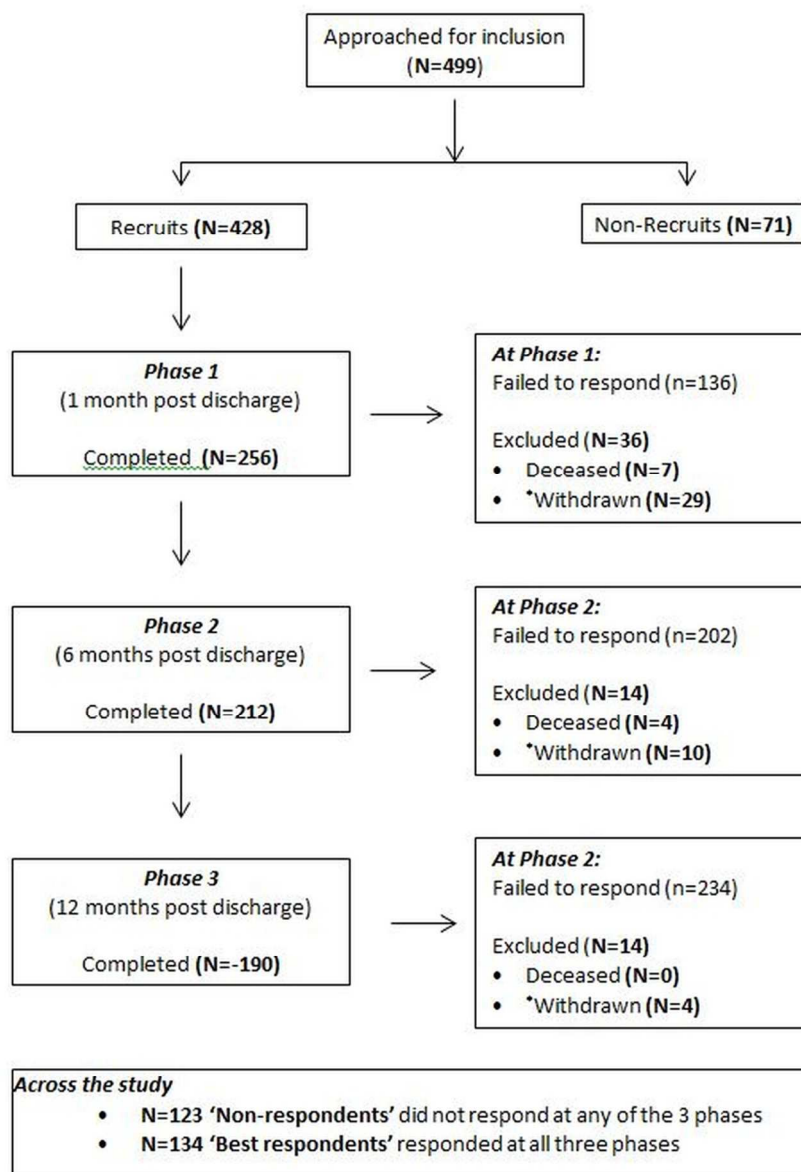


Figure 1b: The overall scheme of the LTNC dataset

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STROBE Statement—checklist of items that should be included in reports of observational studies

	Item No	Recommendation
Title and abstract □	1	(a) Indicate the study's design with a commonly used term in the title or the abstract (b) Provide in the abstract an informative and balanced summary of what was done and what was found
Introduction □		
Background/rationale□	2	Explain the scientific background and rationale for the investigation being reported
Objectives□	3	State specific objectives, including any prespecified hypotheses
Methods □		
Study design□	4	Present key elements of study design early in the paper
Setting□	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection
Participants□	6	(a) <i>Cohort study</i> —Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up <i>Case-control study</i> —Give the eligibility criteria, and the sources and methods of case ascertainment and control selection. Give the rationale for the choice of cases and controls <i>Cross-sectional study</i> —Give the eligibility criteria, and the sources and methods of selection of participants (b) <i>Cohort study</i> —For matched studies, give matching criteria and number of exposed and unexposed <i>Case-control study</i> —For matched studies, give matching criteria and the number of controls per case
Variables□	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable
Data sources/ measurement□	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group
Bias□	9	Describe any efforts to address potential sources of bias
Study size□	10	Explain how the study size was arrived at
Quantitative variables□	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why
Statistical methods□	12	(a) Describe all statistical methods, including those used to control for confounding (b) Describe any methods used to examine subgroups and interactions (c) Explain how missing data were addressed (d) <i>Cohort study</i> —If applicable, explain how loss to follow-up was addressed <i>Case-control study</i> —If applicable, explain how matching of cases and controls was addressed <i>Cross-sectional study</i> —If applicable, describe analytical methods taking account of sampling strategy (e) Describe any sensitivity analyses

Continued on next page

Results

Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed (b) Give reasons for non-participation at each stage (c) Consider use of a flow diagram
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders (b) Indicate number of participants with missing data for each variable of interest (c) <i>Cohort study</i> —Summarise follow-up time (eg, average and total amount)
Outcome data	15*	<i>Cohort study</i> —Report numbers of outcome events or summary measures over time <i>Case-control study</i> —Report numbers in each exposure category, or summary measures of exposure <i>Cross-sectional study</i> —Report numbers of outcome events or summary measures
Main results	16	(a) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included (b) Report category boundaries when continuous variables were categorized (c) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses

Discussion

Key results	18	Summarise key results with reference to study objectives
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence
Generalisability	21	Discuss the generalisability (external validity) of the study results

Other information

Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based
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*Give information separately for cases and controls in case-control studies and, if applicable, for exposed and unexposed groups in cohort and cross-sectional studies.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at <http://www.plosmedicine.org/>, Annals of Internal Medicine at <http://www.annals.org/>, and Epidemiology at <http://www.epidem.com/>). Information on the STROBE Initiative is available at www.strobe-statement.org.