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Service Delivery and Organisation Programme

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

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Glossary of terms/abbreviations

BCN – Basic Care Needs

BI – Barthel Index

CIQ – Community Integration Questionnaire

CRT – Community Rehabilitation Team

CSRI – Client Service Receipt Inventory

ERG – External reference group

HRG – Healthcare Resource Group

ICD-10 – International Classification of Disease Version 10

ICP – Integrated Care Planning

LSNRC – London Specialised Neuro-Rehabilitation Consortium

LTNC – Long-Term Neurological Condition

NIHR – National Institute for Health Research

NHS – National Health Service

NIS – Neurological Impairment Scale

NPCNA – Northwick Park Care Needs Assessment

NPCS – Needs and Provision Complexity Scale

NPDS – Northwick Park Dependency Scale

NPDS-P – NPDS Physical subscale

NPDS-CB – NPDS Cognitive/Behavioural subscale

NSF – National Service Framework

PbR – Payment by Results

PCT – Primary Care Trust

QIPP - Quality, Innovation, Productivity and Prevention

QR – Quality Requirement

R&D – Research and Development

SDO – Service Delivery & Organisation

SNN – Special Nursing Needs

UKROC – United Kingdom Rehabilitation Outcome Collaboration

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The Principal Investigators within each centre were:

Northwick Park:	Dr Andrew Thu (Consultant)
Maudsley:	Dr Simon Fleminger (Consultant)
Edgware:	Ana Bajo (Psychologist)
Blackheath:	Tanya Hodnett (Manager)
Homerton:	Dr Clarence Liu (Consultant)
Queens Square:	Dr Diane Playford (Consultant)
Putney:	Dr Sophie Duport (Research Manager)
King's:	Dr Julian Harriss (Consultant)
Wolfson:	Dr Pradeep Deshpande (Consultant)

Co-Applicants

The following co-applicants helped to develop the study proposal

Barbara Howe – Commissioning lead for specialist neurological services at the time of the application

Daniel Sims – Finance officer, King's College London

Irene Higginson – Head of Department of Palliative Care, Policy and Rehabilitation, King's College London

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Contributions of authors

Richard J. Siegert (Professor of Psychology and Rehabilitation) analysed recruitment data, the longitudinal cohort study data, evaluated the psychometric properties of the Needs and Provision Complexity Scale, and contributed towards writing the report.

Lynne Turner-Stokes (Professor of Rehabilitation) analysed the level and type of services patients received in the community, the extent to which needs were met and contributed towards writing the report.

Paul McCrone (Professor of Health Economics) analysed the differential costs and costs outcomes of models of community neuro-rehabilitation and contributed towards writing the report.

Diana Jackson (Senior Research Fellow, Health Services Research) analysed referral patterns for community rehabilitation services, findings from the survey of community rehabilitation teams and contributed towards writing the report.

Paul Bassett (Medical Statistician) carried out statistical analyses of service data.

Diane Playford (Senior Lecturer and Honorary Consultant Neurologist) was an active member of the LTNC study steering group providing oversight throughout.

Simon Fleminger (Consultant Neuropsychiatrist) was an active member of the LTNC study steering group providing oversight throughout.

Project Steering Group

The project steering group consisted of the applicants, members of the research team and principal investigators for each site. The group met on average quarterly and were key in guiding progress.

Public and Patient Involvement

The impetus for this study came from users themselves in the preparation of the NSF for Long Term Conditions, when they highlighted the gap between hospital care and rehabilitation and care in the community - and called for research in this area. User and carer involvement was integral to the planning and execution of the programme through our established patient and carer groups, and national voluntary organisations.

The external reference panel for the LTNC dataset included both individual users/carers and representatives of user organisations led by Nicola Russell of the MS Trust. We continued to liaise with those groups throughout the planning and development stages of this programme. Patient involvement was harnessed in terms of the research process, and particularly in the drafting and layout of questionnaires, and of the on-line survey, to make these as applicable and user-friendly as possible.

Our questionnaires evolved from those developed in the course of our earlier research into experiences of carers of people with LTNCs in the community. Members of our established Project Advisory Panel for that research comprised six carers and four representatives of voluntary organisations for people with LTNCs (Headway, Encephalitis Society, MS Society, Motor Neurone Disease Association), who were instrumental in influencing the design and content of the original questionnaire study at three-monthly meetings.

During the pilot phase of this study we took extensive feedback from participants regarding the nature and content of the questionnaires, which influenced their further development.

Community rehabilitation services

We are most grateful to those community services that completed the questionnaires describing their services.

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Ethics

Approval for the study was granted by Bromley Research Ethics Committee (Ref no: 09/H0805/25) and subsequently 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.

CLRN Registration

The study was registered with the Comprehensive Local Research Network ID number 7503

Project Funding

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Executive Summary

Background

The National Service Framework (NSF) for Long-Term Neurological Conditions (LTNCs) emphasises the need to place patients and families at the centre of service provision, and promotes integrated community-based services focussed on a person-centred model of service delivery.

A previous report funded by the NIHR SDO programme (Gladman 2007) demonstrated that community services for LTNCs were fragmented or missing. Particular gaps were highlighted in services for people with cognitive deficits and/or challenging behaviours.

Given the life-long nature of LTNC, it is critical to be able to identify and track patients via longitudinal data collection. The NSF for LTNC Expert Reference Panel therefore recommended the development of: (a) a LTNC register to identify patients with complex needs and (b) a dataset to support long-term follow-up by monitoring their changing needs over time and the support services they receive.

The register and dataset have the potential to provide benchmarking of service provision and 'practice-based evidence' for the effectiveness of interventions on a national scale. But before data can be collected in routine clinical practice, the data collection tools must be made fit for purpose. Further, to gather prospective information on service costs and cost benefits, we need simple and practical tools to collate these data.

Aims

1. To pilot the use of an LTNC register and its associated tools as a means to identify and monitor patients with LTNC who have unmet needs.
2. To describe the needs of this group for on-going community based rehabilitation and support.
3. To identify any unmet needs and determine which variables predict the level of rehabilitation services received.
4. To examine the relationship between provision of rehabilitation and outcomes with respect to disability and community integration.
5. To examine the health economic aspects of met and unmet health and social care needs.
6. To identify the differential cost and cost-outcomes of different models of community neurorehabilitation/support services.

Methods

The research had five components:

1. A rapid literature review of evidence on best models of integrated service provision for LTNCs in the community.
2. Piloting and feasibility testing of the LTNC register, including:
3. Development and testing of a manageable set of tools/questionnaires to support data collection for the register, both by clinicians and patients and/or their proxies.
4. Evaluation of a new tool - the Needs and Provision Complexity Scale (NPCS) - as a simple practical instrument for evaluating met and unmet needs.
5. A longitudinal cohort study using postal survey questionnaires to follow up consecutive patients discharged over a 12-month period from the nine specialised (Level 1) rehabilitation units within the London region.

The following were measured:

- neurological impairments
- physical, cognitive and behavioural disability
- needs for and provision of health and social services (including community rehabilitation)
- community integration and participation
- perceived carer burden
- client satisfaction

The extent to which needs for health and social care were met was compared with outcome.

Health economic modelling:

Information on health and social care services used in the past six months, and care hours from family carers, allowed costs of current care to be estimated by combining the service use information with appropriate unit cost data.

Cost estimates of providing unmet community rehabilitation needs were made using the same unit cost data. Multivariate regression analyses were conducted to identify predictors of (a) current costs (b) potential costs if services were provided to meet needs.

To assess the development of integrated services locally during implementation of the NSF, we mapped community rehabilitation and support services that patients were referred to, and surveyed services offered by clinical teams and perceived barriers to services and service utilisation.

Results

An appropriate set of tools was developed for inclusion in the LTNC register. Of those asked, 96% of patients were willing to be registered, but only about one-third responded consistently to questionnaires.

The data provided support for the utility of the Needs and Provision Complexity Scale (NPCS) as a brief and practical tool for assessing complex needs among a group with significant physical and cognitive impairments. Two-thirds of the group required medical support and assistance with personal care; over 90% required on-going community rehabilitation.

The NPCS also provides a simple, reliable and scale-able tool for measuring met and unmet needs for health and social care. At six months post discharge, it demonstrated significant gaps between needs and service provision, especially regarding on-going community rehabilitation, equipment and social support. By contrast, needs for medical and nursing care were relatively well met. Provision of support for personal care above the level of predicted need suggested a deterioration of independence for some patients after discharge from in-patient rehabilitation, possibly due to the failure to meet their needs for rehabilitation and social support.

We found no evidence that demographic variables (age, gender, marital status, education, diagnosis) predicted how much rehabilitation/support people received after discharge from hospital. The best single predictor was dependency for basic care needs which accounted for 33% of variance in total NPCS score. Motor and cognitive impairment improved the predictive ability of the model to 40%. Similarly, we found no evidence that people with cognitive behavioural problems were likely to receive less rehabilitation - cognitive behavioural needs predicting 22% of the NPCS score. Whether disability is physical or cognitive, more disabled patients receive greater levels of health and social services. Clinical teams, however, reported insufficient staff and resources to support patients with complex needs – especially in vocational rehabilitation.

The relationship between levels of rehabilitation received after discharge and outcomes (dependency, community integration and perceived carer burden) was explored. We hypothesised that outcomes would be better when needs for rehabilitation and support were well-met. In fact we demonstrated the opposite relationship. The overall level of health and social services received was a strong negative predictor of community integration at six months and a positive predictor of dependency and perceived carer burden. At first sight it seems surprising that having one’s needs for healthcare and rehabilitation met is associated with poorer outcomes. However, at a practical level this is logical. Rehabilitation is a goal-oriented process, and therapy interventions will normally be withdrawn once goals have been met. Given the scarcity of community rehabilitation services it makes clinical sense for therapy teams to focus their efforts on patients with the greatest needs for support.

The average cost of formal care across the sample was £10,486 in the first six months. When informal care costs were included, the mean cost rose to £28,352. In-patient care accounted for 46% of total costs. Over half of the patients received care from family/friends, which accounted for 62% of total costs. During the second six-month period, use of many health and social care services reduced. Total formal care costs fell to an average of £6,824, but reliance on informal care increased – so that by 12-months it accounted for 75% of total costs. Total mean costs had reduced slightly to £25,803.

Over the whole 12-month follow-up period, significant predictors of total cost were cognitive and motor problems, and being in the physical, hidden or mixed dependency groups compared to being independent. This model could explain 35% of variation.

Costs-analysis of met and unmet needs demonstrated a relative under spend on rehabilitation, social care and equipment at 6 months, compared with predicted needs, and an overspend on personal care and accommodation. Applying the costing algorithm within the NPCS suggests that appropriate investment in rehabilitation and support services could potentially save on average over £10,000 per person per year of over expenditure on personal care and accommodation – although admittedly families and informal carers currently bear the brunt of the extra costs.

Conclusions

Our findings suggest that a register in the form tested here would be used and appreciated by at least a third of patients. However, postal/telephone follow-up is labour intensive, and may not capture some of the most vulnerable patients. Integrated care planning reviews should normally involve face-to-face meetings with patients and/or carers and this may offer an appropriate route to data collection for the register.

While community-based services provided specialist multi-disciplinary care, some were under-staffed, and others felt under pressure to increase throughput of patients at the expense of providing high quality holistic services in the longer term, especially for patients with complex needs.

The NPCS forms a simple practical tool to capture met and unmet needs and so assist clinical teams to identify and address any gaps in service provision at either an individual or population level.

Failure to meet needs for rehabilitation, social support and equipment provision in this sample was demonstrably associated with increased requirements for personal care. The burden of caring for people with LTNCs fell largely on their families and this burden increased over time

This study was confined to the London region for pragmatic reasons. Further work is now required to match provision to need in other parts of the country and to provide more detailed analysis of the costs and cost-benefits of meeting unmet needs, so to determine future priorities for investment in service development.

The Report

1 Introduction

1.1 Background to the present research

An estimated 350,000 people across the UK need help with daily living activities because of a neurological condition, and some 850,000 people care for someone with a neurological condition.[1] A long-term disabling condition affects not only the individual concerned but also their family and carers. Moreover, the demand for specialist rehabilitation services is expected to increase substantially due to an aging population and improved survival rates for conditions such as stroke and traumatic brain injury.

However, the evidence for the effectiveness of rehabilitation remains limited and most research to date has focused on in-patient services. There is little sound research on what happens to people after their discharge into the community or how effective such services are at reducing disability and maximising participation in the community. Indeed a previous report for the Service Delivery and Organisation (SDO) "Specialist Rehabilitation for Neurological Conditions" (Gladman, 2007)[2] noted that the only robust evidence was for specialist stroke units and that *"..the evidence base to guide commissioners in the provision of services is inadequate. Only stroke services have a robust body of evidence to support them. For most other neurological conditions, the evidence base is absent (rather than negative)"* (p.4).

This and other reports have highlighted the difficulty for commissioners purchasing community rehabilitation services in the absence of any strong evidence for or against any specific models of service delivery. Major service gaps exist, particularly for: (i) People with 'hidden disabilities' (i.e. cognitive or communication difficulties), (ii) Vocational rehabilitation and (iii) Individuals with brain injuries and challenging behaviours/pre-morbid alcohol/drug problems.

Standards for rehabilitation services for people with long-term neurological conditions[1] in the United Kingdom are enshrined in the National Service Framework (NSF) for Long Term Conditions (LTNCs) published in May 2005. This NSF was released in March 2005 following the advice of the appointed

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[1] The NSF defines a long-term neurological condition as one that results from disease of, injury or damage to the body's nervous system (the brain, spinal cord and/or their peripheral nerves), which will affect the individual and their family in one way or another for the rest of their lives.

External Reference Group (ERG). The NSF for LTNCs represented a new style of NSF, with less emphasis on national targets, standards and milestones and greater emphasis on outcomes, and increasing emphasis on a more holistic approach addressing all stages in the 'care pathway'.

In contrast to its predecessors, the implementation costs of this particular NSF were to be met from increased funding allocations in general health and social services, competing with other priorities. In place of standards, mandatory targets and milestones, this new-style NSF had 'Quality Requirements' to be implemented locally over a period of 10 years. Local bodies could set their own pace of change within this period, according to local priorities, allowing a more holistic approach to service planning and evaluation throughout the care pathway.

Such longer-term interventions, however, are poorly recorded and largely unreported through current information systems, so the epidemiology of 'need', as opposed to 'disease', is not fully understood. This has tended to leave commissioners confused about where to prioritise investment - and even after investment, how to tell when the standards have been met.

The NSF for LTNCs promotes joined-up services to provide holistic, person-centred care.[1] Key Quality Requirements (QRs), which are set out in Appendix 1, include 'Early Specialist rehabilitation' (QR4), on-going rehabilitation and support in the community (QR5), vocational rehabilitation (QR6) and support for families and carers (QR10). Critically, integrated care planning (QR1) provides the backbone to the NSF recommendations.

However, the resources necessary to support integrated care planning are limited, and this presents a major threat to implementation of the NSF. Figure 1 (the Fish Diagram) below summaries the NSF quality requirements along the care pathway from diagnosis to death, and also the requirement for service integration in the 'body of the fish' that represents long-term community-based living.[3]

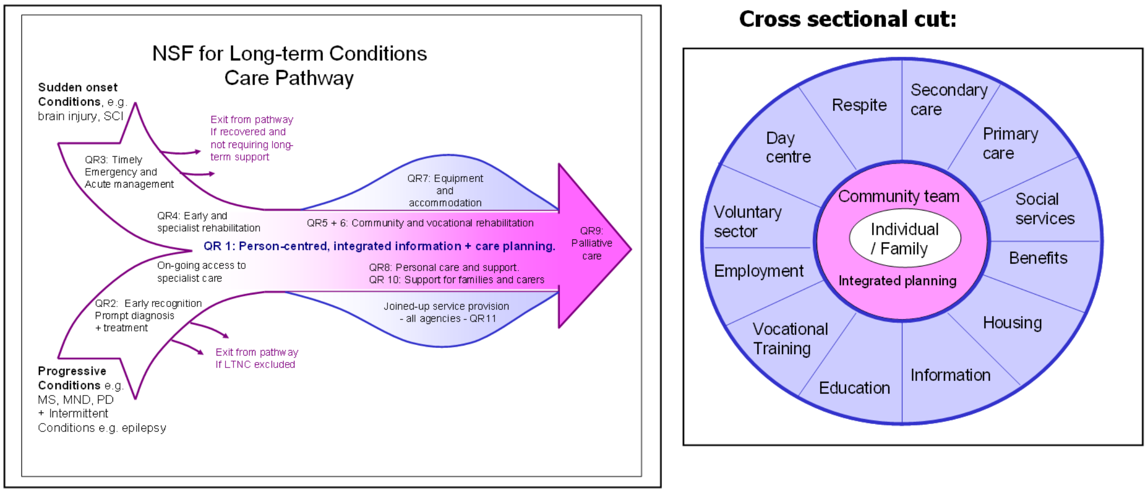


Figure 1. The fish diagram (Turner-Stokes and Whitworth, 2005)

There are a number of challenges to implementation of this framework:

1. Service integration is needed at a number of levels: vertical integration is required between primary, secondary and tertiary health care; and horizontal integration is required between:
    - health and social services and other services
    - statutory and non-statutory sectors
    - specialist and non-specialist care
    - different levels of professionals and care workers

and indeed between the person with a LTNC (and their family or friends) and any element of the service system.

2. 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.
3. Patients with LTNCs cannot be identified through any existing data within the datasets that flow centrally to the Department of Health. Tracking and tracing this largely unidentifiable group through so many different types of service is complex.

However, if it were possible to a) identify those patients with LTNCs who have complex needs requiring integrated care planning, b) determine how well their needs are met and c) whether or not they have an integrated care plan, this in itself provides the best chance of ensuring that they can access the other services and support. The main *outcome* we might expect from service integration is continuity of care and this concept formed the basis for this study.

Central to the implementation of the NSF is the need for an efficient and effective database that can:

- define the need for services
- demonstrate provision against those needs and
- support evaluation of the outcomes of interventions at a person-centred level.

Given the life-long nature of LTNCs, it is critical to be able to identify and track patients over time with longitudinal data collection. The NSF for LTNCs Expert Reference Panel therefore recommended the development of a LTNC register to identify patients with complex needs arising from a LTNC and to support long-term follow-up, in order to monitor their changing need over time and the services that are provided to support them.

A disease or case-register is a database that attempts 'to identify all cases of a disease or condition in an identified denominator population'.[4] 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.

Registers of specific diseases, conditions or procedures have flourished in the UK since their wider use was advocated in the 1999 White Paper entitled *Saving Lives: Our Healthier Nation*[5] to improve the knowledge base regarding:

- incidence and prevalence
- aetiology
- evaluating and improving service delivery
- longitudinal aspects of conditions

Registers have many potential uses including directing patient care, informing population-based decisions regarding service planning and development, and for outcomes and health economic research. Newton and Garner[4] specified the requirements for a successful register as follows:

- an appropriate multi-disciplinary team
- stable funding
- focused aims
- a data collection system/design that relates well to the register’s function
- good leadership

1.2 The LTNC Register and dataset

As part of the implementation plans for the NSF for LTNCs, the Department of Health commissioned the NHS Information Centre to develop a LTNC dataset for monitoring implementation and benchmarking performance against the NSF standards. The dataset incorporates the data requirements for a LTNC register.

Published in 2009, this dataset has the potential to provide this ‘practice-based evidence' on a national scale, but before data can be collected in routine clinical practice, the data collection tools must first be made fit for purpose. That is, we require a manageable set of tools that are:

1. Accessible by patients and their carers to report their needs and experience of services.
2. Timely for clinicians to apply in the course of routine clinical practice.
3. Known to provide valid and reliable information.

Further, if we wish to gather prospective information on service costs and cost benefits, we need simple and practical tools with which to collate these data.

Details of the LTNC register and dataset and the rationale for development may be found on the NHS Information Centre website[6] but are summarised briefly below.

The aim of the dataset is to support the tracking of patients through the various services to evaluate access and response times.

The overall scheme of the dataset is summarised in Figure 2. It is made up of a relational database with seven datasets linked via the patient's identifier (NHS number). The LTNC register and ICP reviews provide the main backbone linking the various other episodes together.

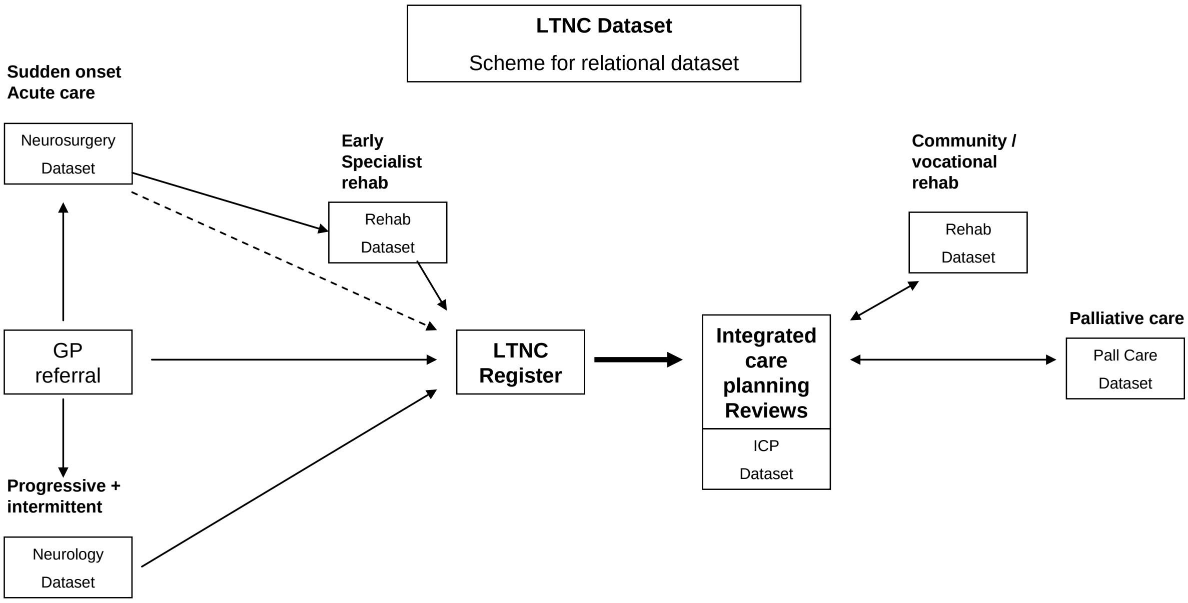


Figure 2. The overall scheme of the LTNC dataset

The datasets include standard information regarding referral, admission and discharge data, alongside performance indicators (response times, length of stay) and outcomes. Much of this is standard data currently collected in one form or another. The dataset provides a common framework for such data collection, adapted to suit the nature of the services at different stages along the pathway.

With the exception of QRs 2 and 3, the recommendations of the NSF are primarily focused towards individuals who have complex needs arising from a LTNC. Many patients presenting with neurological symptoms or injury who receive investigation (QR2) or acute management (QR3±4) will fortunately turn out not to have an LTNC, or will make a good recovery, so that they do not require the on-going support and services described by the later QRs and can exit safely from the pathway. Others will have continuing needs, and some of those will have very complex needs requiring integrated service provision from a range of health and social care agencies, as shown in the cross sectional cut in Figure 1.

The key is therefore to be able to identify those patients who have significant or complex on-going needs arising from their LTNC, and who require the implementation of QR 1 and the other NSF recommendations.

Diagnostic codes (ICD-10 in secondary care and Read codes in primary care) will not identify all these individuals because:

- Some patients will not yet have a formal diagnosis.
- Some have a condition for which there is no code.
- The diagnosis itself does not signify the severity or impact of the condition in terms of disability, needs for care or restriction of participation.[7] Some diagnoses will have been missed e.g. brain injury may be overlooked due to the severity of other injuries when a person is admitted following major trauma.

The identification of people to whom the NSF recommendations apply requires prospective data collection, which confirms that they have:

- A LTNC – i.e. a neurological condition that is likely to have an enduring effect.
- The LTNC gives rise to a level of impairment and/or disability that results in significant or complex needs for care/support, that are likely to require integrated care planning, either now or in the relatively near future.

In order to support the fullest possible capture of patients eligible for registration, the LTNC Development Group recommended two levels of data capture.[6]

1. The simplest level of data for identification of someone with a LTNC who may require integrated care planning in order to support a low threshold for inclusion.

The simple level data (see Table 1) would allow an individual to be registered by a named clinician who takes clinical responsibility for their designation as someone with an LTNC. However, at this level, the data do not provide any evidence of the basis on which the registration was made.

Table 1. Simplest level registration data

Domain	Data fields	Existing source
Demographics	GP/NHS records	Name DOB Address, post code Gender
Practice details	GP/NHS records	GP identifier PCT
1. LTNC	*Do they have an LTNC?*	☐ Yes ☐ No ☐ Not sure
2. Needs for care/support	*Do they have complex needs arising from the LTNC?*	☐ Yes ☐ No ☐ Not sure
3. Need for integrated care planning (ICP)	*Do they require integrated care planning*	☐ Yes ☐ No ☐ Not sure ☐ Declined
4. Person responsible for registration	*Name of registering clinician*	Name Signature
If yes to 1, 2, and 3		
5. Single point of contact	*Is there a named person or post acting as single point of contact?*	☐ Yes ☐ No ☐ Not sure ☐ Declined

2. More detailed information captured at formal assessment to confirm their individual requirements – whether they do need and want integrated care planning, and if so to monitor whether this is actually taking place (see Table 2)

Table 2 shows the more detailed level of information against which clearer criteria for registration could be established in future - either locally or nationally. This more detailed data would not necessarily be recorded at registration, but would be part of the assessment at integrated care planning, and would be reviewed at each annual ICP meeting, along with other detailed assessment of needs.

Table 2. More detailed level data collection recorded at clinical review

Domain	**Data fields**	**Response**
1. Confirmation of LTNC		
a. Neurological condition	*Diagnosis* *or nature of condition*	ICD-10 and /or Read codes *Option of free text to describe neurological condition if no code exists)*
b. Long term	*Is the condition likely to have an enduring effect?*	☐ *Yes* ☐ *No* ☐ *Not sure*
2. Severity		
a. Severity of impairment	*Neurological Impairment Scale (NIS)*	Record NIS
b. Level of needs for health and social care	*The Needs & Provision Complexity Scale (NPCS) – Part A: 'Needs'*	*Record NPCS-Needs*
b. Met and unmet needs	*The Needs & Provision Complexity Scale (NPCS) – Part B: 'Gets'*	*Record NPCS-Gets*
3. Integrated care planning		
	Date of last ICP review:	Date
4. Single point of contact - details	*Named person or post:*	Name Job title/ contact details

1.3 Data collection tools within the dataset

The dataset incorporates a number of data collection tools, which have been specifically designed for use with LTNCs in general and are not condition-specific.

The measurement of impairment and its associated functional impact provides a better indication of the severity of the condition itself, than a diagnostic code.

The Neurological Impairment Scale (NIS) for LTNCs provides a brief evaluation of the major neurological impairments (motor/sensory loss, cognitive, communication, emotional, behaviour) that make up a complex presentation in people with LTNC, as well as their functional impact.[8] As well as being included in the LTNC register data subset, the NIS is included in the data subset for early specialist in-patient rehabilitation, which is now gathered on a national level by the UK Rehabilitation Outcome Collaborative (UKROC database).[9]

Whether or not the individual requires care and support, however, depends on many other factors including personal, environmental and other contextual issues. Hence it is appropriate to use a more direct evaluation of needs, as well as the level of provision offered to meet them.

The Needs and Provision Complexity Scale (NPCS) is a simple pragmatic tool to evaluate the complexity of needs for care and support in two principal domains (Healthcare and Social services/support).

Although the NPCS was conceptualised and developed by the LTNC dataset development group,[6] it had not previously been validated. Therefore a first formal psychometric evaluation of the tool is performed as part of this project.

1.4 How will the register and integrated care planning be commissioned?

In the longer term, registration and integrated care planning for people with LTNCs will need to be built into the commissioning framework for long term care in the community. Work under the Department of Health's Long term Conditions QIPP programme is currently underway to address these longer term aspects of care, and to develop 'year of care' tariffs for reimbursement of service provision in this context.[10]

The LTNC Development group proposed that taking on the role of the 'single point of contact' for a given patient with a LTNC should be identified within the Healthcare Resource Group (HRG) structure to attract a year of care payment and banded according to complexity (as measured by the NPCS) or the intensity of intervention required. By identifying the healthcare costs associated with different levels of complexity, the developments described in this project therefore have potential to inform tariff development under the Payment by Results (PbR) programme.

1.5 R&D context to this study

This project builds on previous and current research by the applicants, funded through the NIHR. Our work on the needs of carers of people with LTNCs (R&D projects 053/0007, and 053/0012) has led to the development of a set of validated postal/web-based questionnaires. These allow people with LTNCs and/or their carers to report their experiences of health and social care in the community, including the receipt and costs of services, so that health economic evaluation is built into the work.[11]

As a result, members of our team have made a significant contribution to the Long-Term Neurological Conditions Research Initiative (LTNC-RI), which aimed to update and extend available evidence on the nature, quality and outcomes of care for people with Long-Term Neurological Conditions (LTNCs) in England.[12]

The main implications for practice and policy arising from this body of work centred on the importance of continuity in terms of team working, management and information. The establishment and development of Community Inter-disciplinary Neuro-Rehabilitation Teams was singled out as one of the core health-care components that ensures continuity. Thus our on-going research into the delivery of effective community rehabilitation in the form of the study reported here is timely.

In addition, co-applicant LTS [13] holds an NIHR programme grant (RP-PG-0407-10185), now in its fourth year, for the development of casemix classification in rehabilitation, and a national dataset for collating case episode data (including complexity and costing information) from specialist in-patient neurorehabilitation services across the UK. However, longitudinal follow-up to record community rehabilitation interventions and to evaluate the long-term benefits of support and rehabilitation fell outside the scope of that development. This project developed and piloted the methodology to support such evaluation in a pan-London cohort. Running the two projects in parallel allowed this longitudinal evaluation to be developed as an integral part of the data collection, so that the methodology can subsequently be rolled out at a national level.

1.6 The present study

1.6.1 Overall aims

The overall aim of the present study was to develop and test the efficacy of both the LTNC tools and register as a means to follow a cohort of patients with complex needs.

- In the first stage we examined the feasibility and utility of a register, and also evaluated the reliability, validity and utility of the Needs and Provision Complexity Scale (NPCS) for assessing the provision of community rehabilitation and support in relation to need.
- Using this and a selection of other tools, we then followed a longitudinal cohort of patients with complex needs following discharge from specialist in-patient rehabilitation to describe:
    - The extent to which their rehabilitation needs were met and any specific areas of shortfall.
    - Longer term outcomes in relation to services provided.
    - Different models of rehabilitation compared in terms of outcomes/cost-outcomes.

1.6.2 Setting

In order to identify patients likely to have complex needs arising from LTNCs, we used the patient group served by the London Specialised Neuro-Rehabilitation Consortium (LSNRC).

The LSNRC provides a model for coordinated network-based commissioning and provision of specialised in-patient neuro-rehabilitation services across the London region (31 Primary Care Trusts (PCTs) covering a population base in excess of seven million).

- Nine in-patient rehabilitation services fulfil the requirements for a Level One Specialised Rehabilitation service, according to the Department of Health's National Definition Set for Specialised Services.[14]
- They represent a range of service models - five of them catering for people with predominantly physical disabilities, and the remaining four for people who are physically more able but require cognitive/behavioural rehabilitation. Their combined capacity is approximately 200 beds, with an annual throughput of over 500 cases.
- While the services are primarily focused on adults of working age, older people are usually accepted on the basis of a single incident injury in a previously fit individual. Services cover a range of neurological conditions including acquired brain injury, spinal cord injury, peripheral neuro-myopathies (including Guillain-Barré) and progressive conditions (e.g. Multiple Sclerosis).
- Admission criteria include 'complex rehabilitation needs that are beyond the scope of district and local services'. A high proportion of individuals discharged from these services are likely to have complex needs requiring integrated care planning and on-going needs for rehabilitation in the community, including the need for vocational support.[15]
- On-going needs for rehabilitation at discharge are well-described in discharge summaries and range from interventions focussed on higher level function and participation issues (e.g. vocational rehabilitation), to interventions focussed on lower levels of functional ability, such as optimising care and symptom management - either at home or in residential settings.

Experience to date suggests that community rehabilitation is patchy, some patients receiving excellent support from specialist coordinated community teams, and others receiving either nothing, or short-term generalist input from intermediate care teams focussed predominantly on the needs of older adults.[16] Recognising the need for coordination of in-patient and community rehabilitation services, the consortium has undertaken a preliminary mapping exercise of the existing services for on-going community rehabilitation and support for people with LTNC within the various sectors of the London region.[17] This has demonstrated a wide variety of different service models.

In the present research we have chosen to follow this particular group of patients joining the community rehabilitation pathway through the London-wide network of specialised rehabilitation services, because:

- It was anticipated that this cohort would yield a high proportion of people with complex needs, representing a broad range of neurological conditions, including both physical disabilities and challenging cognitive/behavioural impairments.
- The consortium works with a well-described collection of community rehabilitation services in a range of different models.

This combination presented a unique opportunity to track the movement of patients between the various different services in the pathway and to compare outcomes (including health economic evaluation) from the different service models. Whilst this study is focussed upon the large cohort of patients within the London region, we plan to extend this research nationally through future funded proposals.

1.6.3 Specific Research Questions

We recruited a cohort of consecutive patients discharged over 12 months from the nine rehabilitation units within the London Specialised Neurorehabilitation Consortium (LSNRC) and followed this sample using the NPCS alongside a set of postal/web-based questionnaires, supplemented by telephone enquiry over a period up to one year.

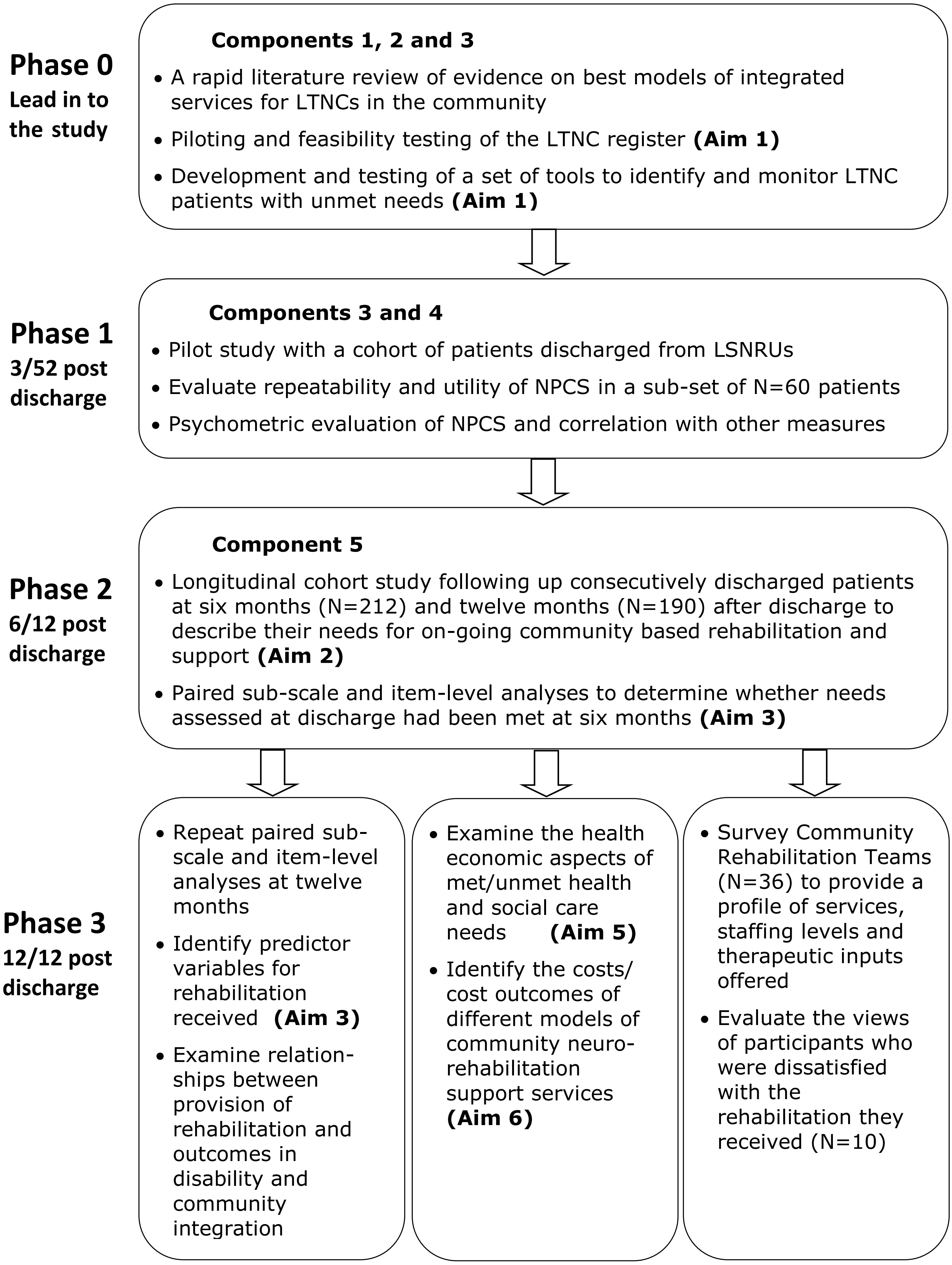
The specific research questions that we aimed to address were as follows:

1. Does the LTNC register provide a practical tool to identify and monitor people with complex needs?
2. Does the NPCS provide a reliable, valid assessment of service provision in relation to need?
3. What are the needs of this group for on-going community-based rehabilitation and support?
4. Where are they referred to for further rehabilitation and what kind of rehabilitation is prescribed?
5. What type and amount of rehabilitation (if any) have they received at six months post-discharge?
6. Which variables influence the quantity and quality of rehabilitation that different patients get?
7. Is there a relationship between the quality and quantity of rehabilitation after discharge and outcomes with respect to disability and community integration?
8. What are the differential costs and cost-outcomes of different models of community neuro-rehabilitation?

1.7 Structure of the report

The structure of this report reflects how our overall aim and key objectives are broken down into the specific research questions specified above.

Figure 3 provides an overview of the constituent work streams that were carried out in relation to the aims and research questions. These questions are then answered under individual chapters.



Phase 0
Lead in to the study

Components 1, 2 and 3

- A rapid literature review of evidence on best models of integrated services for LTNCs in the community
- Piloting and feasibility testing of the LTNC register **(Aim 1)**
- Development and testing of a set of tools to identify and monitor LTNC patients with unmet needs **(Aim 1)**

Phase 1
3/52 post discharge

Components 3 and 4

- Pilot study with a cohort of patients discharged from LSNRUs
- Evaluate repeatability and utility of NPCS in a sub-set of N=60 patients
- Psychometric evaluation of NPCS and correlation with other measures

Phase 2
6/12 post discharge

Component 5

- Longitudinal cohort study following up consecutively discharged patients at six months (N=212) and twelve months (N=190) after discharge to describe their needs for on-going community based rehabilitation and support **(Aim 2)**
- Paired sub-scale and item-level analyses to determine whether needs assessed at discharge had been met at six months **(Aim 3)**

Phase 3
12/12 post discharge

- Repeat paired sub-scale and item-level analyses at twelve months
- Identify predictor variables for rehabilitation received **(Aim 3)**
- Examine relationships between provision of rehabilitation and outcomes in disability and community integration

- Examine the health economic aspects of met/unmet health and social care needs **(Aim 5)**
- Identify the costs/ cost outcomes of different models of community neuro-rehabilitation support services **(Aim 6)**

- Survey Community Rehabilitation Teams (N=36) to provide a profile of services, staffing levels and therapeutic inputs offered
- Evaluate the views of participants who were dissatisfied with the rehabilitation they received (N=10)

Figure 3. Overview of the work streams carried out

The remaining chapters in this report are organised as follows:

Chapter 2 Provides a brief, update and narrative review of literature on community rehabilitation for LTNCs published since the Gladman report[2].

Chapter 3 Describes the study setting, methods and procedures.

It details:

- Stage 1 development work for testing the feasibility of a LTNC register including psychometric evaluation of the Needs and Provision Complexity Scale (NPCS).
- Stage 2 longitudinal cohort study including psychometric properties of all the questionnaires used at four weeks, six months and 12 months post-discharge.

Chapter 4 Reports findings relevant to the question of whether or not a register of people with LTNCs is feasible.

Chapter 5 Reports the psychometric analyses that address the question as to whether the NPCS is a good measure of service provision in relation to need.

Chapter 6 Provides a detailed descriptive account of the needs for healthcare, rehabilitation and social support, as rated by their clinical team, of all participants recruited at discharge from nine specialist tertiary rehabilitation services.

Chapter 7 Provides a detailed descriptive account of the types of services the patients were referred to upon discharge and the geographic distribution of these services.

Chapter 8 Provides a detailed account of the actual level of services that patients report having received after six months in the community and identifies areas of met and unmet needs.

Chapter 9 Reports the findings of regression analyses that attempt to identify which variables are the best predictors of the level of rehabilitation people receive after discharge into the community.

Chapter 10 Reports the findings of regression analyses that consider whether the levels of rehabilitation services received can predict two subsequent outcomes - community integration and carer burden.

Chapter 11 Reports the findings of regression analyses to determine whether levels of met need/unmet need predict community integration and carer burden.

Chapter 12 Provides a detailed description of the costs of services used after discharge and examines demographic and clinical factors associated with service costs. This chapter also examines the cost of services necessary to meet unmet need.

Chapter 13 Reports the results of a survey of community services that patients were referred to and the characteristics of these services.

Chapter 14 Summarises the findings regarding participants' overall satisfaction with rehabilitation and their perceptions of barriers to service delivery at six months post-discharge. In addition, it looks at the perceived rehabilitation needs of a sub-group of 10 participants who considered their services to be inadequate, and compares these with the views of professionals who were responsible for their care.

Chapter 15 Provides an overall summary and discussion of the main findings, relates these findings to existing research, considers the limitations of the present study, and suggests recommendations for future research.

2 Update of community rehabilitation for long term neurological conditions literature

2.1 Objectives

The Gladman (2007) report[2] included a systematic review of the literature on community rehabilitation for long term conditions and that review comprised part of the research and policy background to the present project. Hence while the current research project did not entail a systematic review it was nonetheless considered important to complete a limited update of the relevant literature, given that the review by Gladman and colleagues only covered articles published before January 2007. Consequently we repeated the search strategy used in the Gladman report for the intervening time period.

2.2 Literature search strategy

The following databases were searched for the period January 2006 – July 2011:

The full search criteria are listed in Appendix 2. Note that variations of these search terms were used according to specific database requirements). The search was undertaken and performed by one researcher (BK). The same researcher (BK), along with the assistance of the Principal Investigator (RS), undertook the selection process. All titles and abstracts (where available) were read by both reviewers to check for their potential relevance.

References were excluded if they:

- Did not concern one of the specified neurological conditions
- Were not about community rehabilitation
- Did not refer to a specialist rehabilitation service
- Were not published in English.

All other articles were included.

2.3 Included studies

When all searches were completed, grouped and compared, after removing duplicates, the number of returned references totalled 237. These references were subsequently screened for relevance. Where this was not immediately obvious from the title the abstracts were sought and also screened for relevance. Of the 237 initial references 69 met the inclusion criteria and the complete article was acquired for each of these. Based upon reading the full article, 23 papers were retained for inclusion in our review. These 23 articles were grouped into: Systematic reviews/meta-analyses, empirical studies, government reports, expert opinion using high level guidance reports, and qualitative/mixed method approaches. These studies have been briefly summarised below and are tabulated in Appendix 3.

2.3.1 Recent reviews and Meta-Analyses

Bernard et al. 2007 from the Social Policy Research Unit of the University of York[18] examined the impact of the NSF for people with LTNCs using a tripartite research methodology. This included: (i) a rapid systematic review, (ii) in-depth case studies of six neurology 'service systems' and (iii) a national survey of staff and service users regarding benchmarks established in the earlier two phases of this study.

- The literature review concluded that the evidence base about a) the impact and costs of integrated models of care for people with LTNCs; and b) the service delivery and organisation elements that need to be in place to make these models operate well, was weak.
- Bringing together the views and experiences of staff and people with LTNCs in the case study sites, they identified three models of 'best practice' for integrated service delivery, each of which contributed to the experience of continuity of care;
    - Nurse specialists;
    - Community interdisciplinary neurological rehabilitation teams (CINRTs) and
    - Day centre care ('milieu-based care') offering peer support, social and leisure opportunities, as well as access to meaningful activity and/or learning and employment opportunities.
- They observed that 'nearly half-way through the ten-year implementation period of the NSF for LTNCs, only half of Primary Care Trusts (PCTs) had a written action plan for implementation and very few had carried out their plans' (p.16), noting that the good intentions of the NSF had been undermined by competing clinical, organisational, financial and political priorities.

However Bernard and colleagues acknowledge that their conclusions are tempered by the paucity of high quality RCTs found in their literature review, representativeness of persons interviewed for their case studies and the complexities inherent in benchmarking different models of care in the community.

Ellis et al.[19] completed a Cochrane review using individual patient data of the empirical evidence for the efficacy of stroke liaison workers for increasing participation and improving well-being for patients and carers, as measured by improving social activities, participation and mental health. Of the 16 studies involving 4,759 participants, there did not appear to be any significant benefits for patients in terms of their perceived health, mood, activities or participation. However, patients appeared to be more satisfied that someone had really listened to them, and carers appeared to be more satisfied with aspects of the care provided. In addition patients with mild to moderate disability benefited from a reduction in disability and death. The authors discuss these findings in relation to the methodological problems entailed in evaluating complex or broad-spectrum psychosocial interventions in the absence of any sound theoretical understanding of the mechanism by which they are believed to act, and the absence of a single, widely accepted outcome measure.

In a systematic review and meta-analysis Ferrarello et al.[20] evaluated the efficacy of motor rehabilitation and physiotherapy interventions conducted late after stroke. This study included 15 RCTs involving 700 participants and studies were evaluated by quality. They concluded that the application of such interventions late after stroke improves motor and functional outcomes compared with no treatment or a placebo and reported an effect size of 0.29 (95% CI 0.14 – 0.45).

Kim et al.[21] systematically reviewed evidence for post-traumatic brain injury (TBI) rehabilitation interventions used to enhance community integration relevant to occupational therapy. They concluded the evidence was very promising for multidisciplinary rehabilitation in improving community integration after TBI. However their review was based on 10 studies and only one of these studies was rated 'excellent' in methodological quality. Moreover the diversity of designs and measures employed precluded any quantitative analysis.

Gary et al.[22] reported a 'comprehensive review' of literature on racial and ethnic differences in outcomes after TBI in the US. They concluded that African Americans and Hispanics had worse functional outcomes, lower community integration, higher carer burden and were less likely to receive treatment and be in employment than Whites. While not a systematic review their article reviewed 39 peer-reviewed journal articles on the topic.

In a Cochrane review of the effectiveness of multi-disciplinary (MD) rehabilitation for patients with Multiple Sclerosis (MS), Khan et al.[23] found 'strong evidence' that in-patient MD and/or out-patient rehabilitation can produce short term and long term gains for up to 12 months at the levels of activity and participation for patients with MS. For lower intensity programmes conducted over a longer period in the community there was strong evidence for modest longer term gains in quality of life; and limited evidence for benefits to carers in terms of general health and engagement in social activities. Although some studies reported potential for cost-savings, at the current time there is no convincing evidence regarding the long-term cost effectiveness of these programmes.

A Cochrane review of multi-disciplinary rehabilitation for patients with Motor Neurone Disease[24] found no Randomised Control Trials (RCTs), but a small number of cohort studies providing lower level evidence that low intensity community-based programmes improved survival, reduced hospitalisation and led to improvement in some mental health domains of quality of life, at no increased cost.

McCabe et al.[25] systematically reviewed literature from 1985 – 2005 on the effect of rehabilitation interventions (of any kind) on subsequent community integration. Their search strategy identified 38 relevant articles for inclusion but only a single RCT. They concluded that there was 'limited' evidence for a range of interventions on five separate aspects of community integration. However, the strength of this evidence was severely limited by the lack of RCTs.

2.3.2 Randomised Controlled Trials (RCTs)

Harrington et al.[26] reported a single-blind, parallel group RCT (N=243) that evaluated a community based exercise and education scheme in the South-West of England, developed to improve integration and well-being for stroke survivors and their families. This low-cost (£99 per patient) community intervention was more successful than standard care in improving physical integration at one year. Significant differences on primary outcome measures of mobility, activity and participation were observed at both nine weeks and 12 months post-stroke.

Bjorkdahl et al.[27] in Sweden reported an RCT that examined whether three weeks rehabilitation in the home for younger patients with stroke would improve activity (measured by the Assessment of Motor and Process Skills, AMPS) compared to standard out-patient rehabilitation. This RCT did not show significant differences in improvement in activity between the two groups, although there were indications of early improvement in the home group and associated lower costs. The authors note that this RCT involved a relatively small sample with a heterogeneous range of stroke pathologies which might limit its generalisability.

Trexler et al.[28] reported a small prospective RCT of 22 people with Acquired Brain Injury (ABI) receiving either resource facilitation (i.e. assigned a resource facilitator to help them return to work) or standard follow-up at baseline and six months. Participation increased in both groups but the percentage of the RF group employed at follow-up was greater than in the control group (64% as compared with 36%), although no significant differences were found on a measure of depression. However a major limitation of this study, apart from its small sample, was that all the participation data was collected and provided by the resource facilitators themselves.

2.3.3 Longitudinal Cohort Studies

Winstanley et al.[29] used path analysis to develop a multivariate model of relative distress and family functioning after TBI using data from 134 consecutive referrals to 11 units providing brain injury rehabilitation in New South Wales in Australia. They concluded that the distress levels of carers were not a direct function of the impairment exhibited by the person with the TBI - but rather that the impairment level was mediated by the degree of community participation achieved by the person with a TBI. The authors argued from their findings for increased provision of respite care and case management services to assist carers and promote their well-being.

However all 134 TBI cases were 'very severe' and caution is needed before extrapolating these findings to people with mild or moderate TBI. Moreover the sample size of 134 is arguably marginal for structural equation modelling including 10 variables as was the case here.

An uncontrolled pre-test post-test evaluation design was adopted and implemented by Egan et al.[30] to describe the effects of a community Stroke Navigation program. Using standardised measures and a mixed methods approach, the results in the sample of 35 stroke survivors and 26 carers who received navigation services demonstrated a small improvement in community reintegration among the stroke survivors, but not a significant change amongst the caregivers. Nor did it alter physical and emotional health amongst the survivors of stroke or carers. However, the lack of a control group or any long term follow-up were major limitations in this study, as was the fact that all 'stroke navigation services' were delivered by a single occupational therapist.

2.3.4 Cross-sectional surveys

A number of North American studies have used cross-sectional surveys to explore ethnic, gender and socioeconomic differences in outcome after stroke or TBI (Roth et al., Sandera et al., Colantonio et al., Mascialino et al.). The methods and quality of these studies is varied as are the findings with the only consistent finding being typically poorer outcomes on a range of indices, including community integration, for African Americans after a brain injury.

Kim and Moon[31] used a postal survey to assess the needs of 123 family members caring for stroke survivors in South Korea. They found that caregiver needs differed across treatment settings and phases and caregivers in out-patient clinic services showed the lowest satisfaction of their needs in acquiring health information and support.

Mosconi et al.[32] surveyed 234 families of people in Italy recovering from a severe brain injury to determine their needs and burdens and also surveyed 57 volunteer organisations. Over half of the sample of families (54 percent) felt they had not been involved, or indeed informed in the hospital discharge process. Few families reported receiving adequate help from community social services. Of the 234 families, two-thirds experienced financial difficulties and their social relationships, travelling hobbies and spare time were significantly reduced. It is important to note however that both the Korean and Italian surveys had response rates around 50 percent and it is conceivable that families that are happy with services are less inclined to participate.

2.3.5 Case Control Studies

Smith et al.[33] compared the efficacy, for 17 carers of a person with a TBI, of a community rehabilitation service with 24 carers who received a more traditional out-patient service. They concluded that carers who received a community based intervention showed better outcomes in terms of met family need, family functioning and carer acceptance, although not in terms of carer psychopathology. However this ‘quasi-experimental non-equivalent groups post test only design’ was severely limited by the lack of any baseline measures.

2.3.6 Qualitative Studies

Reed et al.[34] used a phenomenological approach (semi-structured, in-depth interviews) to explore the needs of 12 stroke survivors and their perceptions of the extent to which a community rehabilitation programme met these needs. They concluded that stroke survivors required a range of both internal and external resources to rehabilitate themselves and participate in the community, and a community stroke programme goes some way towards providing the necessary resources.

White et al.[35] used a modified grounded theory approach to interview 12 stroke survivors in Australian and identified major issues around knowledge and education concerning stroke, communication with health professionals and discharge to the community. This study also identified a need for on-going health professional education to enhance stroke delivery services.

Rotondi et al.[36] looked at the needs of persons with traumatic brain injury and their primary family caregivers. They found that respondents described their needs according to ‘phases of transition’ - i.e. acute care, in-patient rehabilitation, return home and living in the community. The major themes in both *return home* and *living in the community* included guidance, life planning, community integration and behavioural and emotional issues. They reported insufficient education and preparation for the future, suggesting that divisions of needs do occur over the course of treatment and rehabilitation, which indicates that services must be responsive to patients’ changes in needs over time.

2.4 Summary and Conclusions

Since the Gladman report[2] in 2007, there has been a modest improvement in the evidence for community rehabilitation services for LTNCs with increased evidence emerging for longer physiotherapy after stroke, community rehabilitation for MS and community exercise programmes for stroke survivors. There is also evidence, mostly from the US, of ethnic disparities in the provision of rehabilitation services.

Perhaps most germane to the present study, is the conclusion from a recent SDO report[18], that five years after national implementation of the NSF for LTNCs, only half the PCTs surveyed had begun to implement the framework.

The present study extends the work of both the Gladman report and Bernard et al. and is the very first study that attempts to capture a detailed evaluation of service provision in relation to individual needs for health or social services, or to examine on an individual level basis the effect of 'met' and 'unmet' needs on outcomes such as disability, community integration and carer burden.

3 Methods

3.1 Overview

This chapter describes the study setting and the methods and procedures used at discharge and each of the three subsequent phases of this research.

The study was conducted in two main stages:

- Stage 1 consisted of a study to determine the feasibility of an LTNC register, including developing and refining the measures, evaluating the NPCS and developing the questionnaires and database to gather the information.
- Stage 2 was a longitudinal study to follow a group of LTNC patients with complex needs over the course of 12 months following discharge from acute in-patient rehabilitation, to examine their needs for rehabilitation/support and the extent to which these were met, together with the outcomes in terms of both effectiveness and cost-benefits.

We also surveyed a sample of community rehabilitation services to describe the distribution and types of community services available, exploring their geographic location in relation to patient discharge destinations, and the perspective of service providers on any gaps in service provision. This survey of services was intended to provide additional information regarding the extent and reasons for unmet needs and the availability of local services, rather than relying solely on the perspective of the service users.

3.2 Study setting

The setting for this research covered the interface between the nine in-patient units that form the London Specialised Neuro-rehabilitation Consortium (LSNRC) and the community rehabilitation services providing on-going support to patients discharged from these units.[15]

As noted in Chapter one, this setting was chosen because:

- A high proportion of people discharged from these services are expected to need integrated care planning, on-going community rehabilitation and vocational support.
- The patient group represents a wide range of LTNCs.
- The network of in-patient and community-based rehabilitation services across London offers a variety of different service models with the potential to address the on-going rehabilitation needs of patients with complex needs.

3.3 Stage 1 pilot and development study

3.3.1 Aims and objectives

The primary aims were:

1. To examine the feasibility of setting up a register of LSNRC patients at the point of their discharge back into the community.
2. To determine the psychometric properties, including the utility, of the self-report Needs and Provision Complexity Scale (NPCS).
3. To develop the toolset and database to gather the information.

Specific objectives were:

- To invite a consecutive cohort of patients discharged from LSNRC units over a 12-month period to be included on the register in order to determine the uptake of registration.
- To identify those patients willing also to participate in the Stage 2 longitudinal cohort study.
- To undertake an evaluation of the repeatability, validity and utility of the NPCS.
- To develop and test the associated paperwork - including the questionnaires and core dataset to be recorded.

3.3.2 Procedure for assessment of uptake of registration:

All patients due to be discharged from the nine specialised in-patient rehabilitation centres were assessed by their clinical team (see 3.3.4 for details of the standardised assessment tools used at all nine centres). Those patients in need of on-going rehabilitation and/or their carers were asked if they would agree to be included on the prototype register. If they declined, reasons for this were to be noted where possible.

For all patients who were included on the register (irrespective of whether they went on to participate in the cohort study), a core set of demographic and clinical data were collected by the discharge team and stored anonymously to allow statistical comparison between those who did and did not subsequently participate in the cohort study. These data (set out in Table 3) comprised patients' date of birth, gender, diagnosis, date of discharge, discharge destination, contact details and confirmation of their inclusion on the LTNC register.

3.3.3 Procedure for identifying those willing to be included in the cohort study:

Registered patients were assessed against the criteria for participating in the cohort study:

- **Inclusion criteria**: All persons with a LTNC at the point of discharge from one of the nine specialised units participating in the study were considered eligible to participate. Where cognitive / communication problems prevented the person participating directly, it was anticipated that a family member or carer would be identified to assist them.
- **Exclusion criteria**: All patients who met the inclusion criteria were included unless they (or their carer/proxy) declined to participate.

All patients meeting the eligibility criteria were given a verbal explanation about the study, provided with an information sheet and given the opportunity to ask any questions. If the patient, or their carer by proxy, agreed to take part, consent was taken by the discharge clinician.

3.3.4 Information collected at Recruitment (Phase 0)

The Protocols for recruitment and follow-up are set out respectively in Appendices 4 and 5. For all consenting patients, the clinical team completed a summary report at Phase 0 - the time of discharge from in-patient rehabilitation.

Two key measures were collected at recruitment (see sections 1.3 and 3.4 for details and justification of these tools). These were:

- The Neurological Impairment Scale - an estimation of severity of impairment.
- The Needs and Provision Complexity Scale (NPCS) – an evaluation of the individual’s need for on-going service provision/care and support.

Also documented were:

- Follow-up plans detailing referral to community rehabilitation teams and contact details.
- Any cultural/language needs or other challenges to follow-up, such as lack of a permanent residence or asylum-seeking status.
- The name and contact details for the person who agreed to be contacted and respond to questionnaires as part of the longitudinal data collection in phases 1, 2 and 3. This could be either the patient him/herself or a nominated respondent appointed on their behalf.

This information, along with signed consent forms, was sent by registered post or faxed to the research team at the project co-ordinating centre. The team subsequently assumed responsibility for the procedures entailed in the psychometric evaluation of the NPCS and the longitudinal cohort study.

3.3.5 Evaluation of the Needs and Provision Complexity Scale

Repeatability and utility of the self-report NPCS

The NPCS is divided into two parts;

- Part A describes the level of a patient's need for health and social care.
- Part B describes the level of provision against those needs.

It was originally designed to be administered by clinicians (as administered for Part A at phase 0). In this study, however, we introduced a self-complete version of the NPCS Part B to be completed by the patient or their carer in order to reflect person-centred experiences.

As this was the first application of a self-completed version, we conducted a repeatability study to evaluate intra-rater agreement between two administrations of the tool with respect to services provided during the same reference period.

When patients were first contacted in the community to confirm their involvement and organise posting of the first set of patient-completed questionnaires at phase 1, they were asked if they would mind repeating one of the questionnaires a second time. Participants who agreed were sent out a second copy of the NPCS and asked to complete this seven days after completing and posting the first. Based on the number needed to test agreement using Cohen's Kappa statistics, our target for recruitment for this evaluation was 50 patients.

Patients were also asked to provide feedback about the tool. In particular, those participants who returned questionnaires with missing data were telephoned to complete the missing items and also asked if there were any aspects of the NPCS they found difficult or unclear. This information was used in an iterative manner to improve the clarity and presentation over successive versions of the questionnaire in the early stages of development.

Validity

NPCS validity was examined through correlation with other relevant measures collected as part of the subsequent cohort study. These included a measure of disability and dependency (Northwick Park Dependency Scale), a measure of perceived barriers to rehabilitation services (Services Obstacles Scale) and a measure of community integration and participation (Community Integration Questionnaire). Details of each of these measures and their key references are provided in section 3.4 below.

3.3.6 Development and testing of the questionnaires and database

The questionnaires included the demographic items and measurement tools described in section 3.4.

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

- a paper-based postal-questionnaire
- a web-based survey tool, using Survey Methods software (Survey Methods Inc. www.surveymethods.com)
- telephone administration.

Experience from previous work by our group[11] had shown that while many of the general population prefer the internet, not everyone has access to it and some (particularly those with visual or reading difficulties) prefer pencil-and-paper questionnaires.

Wherever possible, follow-up telephone interviews were used to complete missing information from postal or web-based questionnaire and this had the added benefit of helping to maintain a good relationship with participants.

Some people with more severe cognitive or communicative difficulties required the full questionnaire to be administered over the telephone. Some simply preferred this means as they valued the opportunity for discussion with the researcher about the challenges they were facing back in the community.

Participants were asked informally how user-friendly they found the questionnaires and the researcher/caller used this as an opportunity to provide any extra help needed to complete and return the measures. For example, a small number of participants found it less taxing to complete the questionnaires via telephone interview.

A prototype version of the questionnaire pack was initially developed by the research team and modified after feedback from five service users prior to the start of the study. In particular the number of questionnaires was reduced to minimise burden on participants. For example we had planned to include a rather lengthy questionnaire that asks about memory and behavioural problems but this was abandoned. The other changes all involved simplifying the language, using larger and clearer fonts, and making the instructions clearer.

The first wave of participants who returned the NPCS with missing data were contacted by telephone to fill in the gaps and were also asked about their experience in completing the questionnaires. From the feedback received, it was apparent that the early version of the patient-completed version of the NPCS was too complicated for a significant number of participants and several iterations were then trialled until telephone feedback was consistently positive and missing data minimised. As a result, the presentation format of the NPCS was different for the first 47 participants who returned Phase 1 questionnaires. At that point a briefer and more user-friendly version was introduced and used for the remaining participants in Phase 1 and all participants in Phases 2 and 3.

The changes only related to the presentation of questions and did not affect the overall structure of the questionnaires. Therefore these first 47 respondents were not excluded from the analysis of NPCS data. However, as they could have affected the repeatability of NPCS scores in the first ten or so subjects who contributed to that part of the study in Phase 1, an additional sample of ten NPCS scores repeated at after seven days was collected during Phase 3.

3.4 Measurement tools

Although details of the measurement tools are given in the Questionnaire booklet (Appendix 6), they are also briefly described below, along with a summary of evidence of their reliability. Building on our previous extensive research into the needs of carers in the context of LTNCs (R&D project 053/0007, and NIHR 053/0012), tool selection was based in part on the basis of instruments that are known to work and be accessible for self-report by patients and/or their carers.

3.4.1 The 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. Its associated functional category scores (16 items are scored 0-3 and one item 0-2) provide a simple assessment of the impact of these impairments at a functional level. Total scores can range from 0 to 50.

The NIS was originally developed as a checklist for use as part of the core minimum dataset alongside the UK Functional Assessment Measure.[37] The functional severity scores for each item have been added more recently, but evaluation demonstrates that the tool has good scaling properties as an ordinal measure of impairment severity in two principal domains ('physical' and 'cognitive/behavioural' impairment), with inter- and intra-rater reliability.[8, 38]

3.4.2 The Needs and Provision Complexity Scale (NPCS)

The NPCS is a 15-item measure with six subscales that was developed to evaluate the complexity of needs for heath and social care in six principal domains (Healthcare and nursing, Personal care, Rehabilitation, Social/Family support, Equipment, Accommodation).[39] As noted above, it has two parts (dubbed 'Needs' and 'Gets'). Part A (NPCS-Needs) evaluates each patient's needs for health and social care and Part B (NPCS-Gets) evaluates the level of provision in relation to those needs. Total scores range from 0 to 51 and cover Low to High levels of needs. It is designed to be used as a simple tool to identify gaps in service provision, both at the level of the individual and across populations.

The NPCS had not been previously subjected to formal evaluation, so an evaluation was included as part of this study.

3.4.3 The Northwick Park Dependency Scale (NPDS)

The Northwick Park Dependency Scale (NPDS) and Care Needs Assessment (NPCNA)[40, 41] was used to rate the dependency of the person cared for. This scale is divided into two parts:

The 'Basic Care Needs' section (NPDS-BCN) comprises 12 items covering the daily activities needed for everyday functioning. These include the capacity for both physical performance (e.g. washing, dressing, toileting eating and drinking etc.) and appropriate cognitive behaviour (e.g. communication, safety awareness etc.). Each item requires the carer to choose from four to six ranked options, which reflect the amount of help needed with that activity. The score range is 0 to 65, higher scores indicating a greater level or dependency.

The 'Special Nursing Needs' section (NPDS-SNN) includes seven items indicating the need for nursing care, such as a wound requiring dressings, which are scored 0 if absent and 5 if present, giving a maximum possible score of 35.

NPDS data are entered into specifically designed software, which applies a computerised algorithm to generate the Northwick Park Care Needs Assessment (NPCNA).[41] This provides an estimation of the weekly care hours that the individual would require in the community, the care package that would need to be provided to meet those needs and the weekly average cost of providing this care formally.

The NPDS is now widely used in the UK and has been translated into several languages.[42, 43] It is shown to be psychometrically robust.[44]

3.4.4 Community Integration Questionnaire (CIQ)

The Community Integration Questionnaire (CIQ) was developed to provide a measure of community integration after traumatic brain injury that is suitable for self-completion by the patient or a carer by proxy.[45, 46] It consists of 15 items relevant to: (i) Home integration, (ii) Social integration and (iii) Productive activities. It is scored to provide subtotals for each of these three domains, as well providing a total score as for community integration overall.

The CIQ can be completed by either the person affected by neurological problems or by their proxy. The basis for scoring is primarily the frequency of performing certain activities or roles, with secondary weight given to whether or not activities are done jointly with others, as well as the nature of the relationship with these other persons.

The psychometric properties of the CIQ have been well established, with adequate test-retest reliability, internal consistency,[46] inter-rater reliability[47] and validity[48] reported.

3.4.5 Zarit Burden Interview (ZBI)

This commonly used measure of burden was designed to capture the impact that caring has on carers' personal and social well-being.[49] Using a scale from 0 (never) to 4 (nearly always), carers rate how often they are affected by the negative aspects of their caring situation that are perceived to impact most powerfully on their well-being.

The ZBI was originally developed in the context of dementia, but has also been used in other advanced and long term neurological conditions, including stroke and acquired brain injury. Both the full scale and its short forms have been shown to be valid for assessing carer burden in these conditions.[50-52]

3.4.6 Services Obstacle Scale (SOS)

This scale was developed to evaluate individuals' and caregivers' perceptions of brain injury services in the community with regard to quality and accessibility.[53] It is made up of six items that ask people about the barriers or obstacles to rehabilitation services that they perceive in their community. The SOS has three main components: (1) satisfaction with treatment resources; (2) finances as an obstacle to receiving services; and (3) transportation as an obstacle to receiving services. The items are all rated on a Likert scale from *strongly disagree* (1) to *strongly agree* (7).

The SOS was originally developed and validated for use with TBI[54] but its wording was modified slightly in the present study to make it applicable to a broader range of conditions.

3.4.7 Client Service Receipt Inventory (CSRI)

The Client Service Receipt Inventory (CSRI)[55] was developed to collect retrospective data on service use by individuals over a defined period. All services used can be individually costed and this information collated to provide overall costs for full care packages. The CSRI can be administered by interview or postal questionnaire.

Adaptability is a hallmark of the instrument, in that services are selected for their relevance to the cohort being examined. In the longitudinal cohort study, information about the health and social services received was collected at Phases two and three for the previous six months.

Table 3 sets out the variables and measures used in data collection at each phase of the study.

Table 3. Summary of data collected across all phases of the research

	Timing of data collection			
	Phase 0	**Phase 1**	**Phase 2**	**Phase 3**
Variables and measures included	**At the time of discharge**	**3-4 wks Survey pack 1**	**6 months Survey pack 2**	**12 months Survey pack 3**
Registration data:				
Date of Birth	✓			
Gender	✓			
Diagnosis	✓			
Date of discharge	✓			
Discharge destination	✓			
Contact details*	✓			
LTNC register inclusion	✓			
Cohort study demographics:				
Gender	✓	✓	✓	✓
Date of Birth	✓	✓	✓	✓
Marital status	✓	✓	✓	✓
Ethnicity	✓	✓	✓	✓
Education	✓	✓	✓	✓
Work status	✓	✓	✓	✓
Measures:				
Neurological Impairment Scale **(NIS)**	✓			
Needs and Provision Complexity scale **(NPCS)**	✓	✓	✓	✓
Northwick Park Dependency Scale **(NPDS)**		✓	✓	✓
Community Involvement Questionnaire **(CIQ)**		✓	✓	✓
Zarit Burden Interview **(ZBI)**		✓	✓	✓
Services Obstacles Scale **(SOS)**			✓	✓
Client Service Receipt Inventory **(CSRI)**			✓	✓
Additional data:				
Telephone interviews with dissatisfied participants			✓	✓
Brief survey of community rehabilitation teams			✓	✓

*In cases where patients were unable to respond for themselves, contact details of their main carer were collected.

3.5 Stage 2 Longitudinal cohort study

3.5.1 Phase 1 data: Three-four weeks post-discharge

Upon receiving their recruitment data all participants were contacted by telephone within a week of discharge. The researcher would

- establish contact with the patient or carer who was primarily responsible for completing the survey,
- confirm that they were still prepared to participate,
- answer any questions and address any concerns raised, and
- confirm their address and post out the survey pack to be completed within three to four weeks of their discharge date.

At phase 1, the NPCS was included in the questionnaires and used for piloting and repeatability testing as described above. This also served to familiarise patients with the questionnaire. It was not necessarily expected that all community services would have ‘kicked in’ this soon after discharge as some community teams have waiting lists, so the first use of the NPCS for the formal evaluation of service provision was at phase 2 (six months post discharge).

The phase 1 questionnaire also included baseline evaluation for the two main outcome measures:

- the Northwick Park Dependency Scale as a measure of dependency and care needs on discharge to the community, and
- the Community Integration Questionnaire as a measure of wider social participation.

3.5.2 Phase 2 data: Six months post-discharge

At six months post-discharge, the researcher once again contacted each participant to ask him or her to complete the Phase 2 survey pack (see Appendix 6), either by postal questionnaire or online. This was essentially a repeat of the Phase 1 survey booklet but with one additional questionnaire - The Client Service Receipt Inventory (CSRI). The CSRI was used to collect information on the health and social care services received during the previous six months.

A second follow-up telephone call was made if their completed survey had not been received within a fortnight. Telephone contact was also made to chase up and clarify any missing data. Up to five attempts were made to reach the respondent by telephone as research team resources did not permit more time allocated than this.

3.5.3 Phase 3 data: Twelve months post-discharge

A repeat set of the Phase 2 questionnaires (Survey Pack three) was sent out at 12 months post discharge. Again, patients were asked to report the level of service provision during the preceding 6 months (i.e. between six and 12 months post discharge) using the NPCS-Gets; as well as the NPDS, SOS, CIQ, and CSRI. Their status on the LTNC pilot register was examined and participants were also asked if they had received an integrated care plan review in the past year.

3.5.4 Sub-sample of patients reporting unmet rehabilitation needs

A significant number of patients reported dissatisfaction with the level of rehabilitation services they had received at Phase 3. Possible explanations for a shortfall in services are (a) that more therapy input is required but that local rehabilitation services do not have the resources to provide this or (b) that the patient believes they require further therapy but the professionals consider that they have met their rehabilitation goals and further therapy input would not be effective.

In order to better understand the perceived short-fall in rehabilitation services, and any differences in perception between professionals and respondents regarding their need for further rehabilitation, we undertook a more detailed evaluation for the sub-group of patients reporting dissatisfaction with their level of rehabilitation at Phase 3.

'Dissatisfied participants' were identified from their responses to the three items comprising the *Rehabilitation* domain of the NPCS questionnaire. All those participants who responded that the rehabilitation received was *Not Enough* were contacted directly by phone and invited to take part in a brief phone interview that was structured around the NPCS. Participants were also asked for their permission to contact their Community Rehabilitation Team (CRT) - and if agreeable, the CRT was then contacted by a member of the research team in order to obtain the provider's view of the reported shortfall in service provision and the reasons for it in each case.

3.6 Profile of Community Services

These services were identified by clinicians on discharge of patients for continued rehabilitation and care planning. All community rehabilitation services used by participants were contacted and requested to complete a service profile (see Appendix 9) regarding their model of service delivery including:

- service specification and mode of operation
- staffing levels, team structure, representation of different disciplines
- information about funding streams
- person-centred care
- user-involvement in service evaluation and planning

- perceived strengths/weaknesses of the service including shortfalls in service provision use of key rehabilitation concepts such as inter-professional teamwork, goal-setting, ICF.

Service providers were also asked for their views on any perceived gaps in local service provision

3.7 Data handling and analysis

3.7.1 Procedure for data storage and handling

In order to maintain contact with individual patients we retained identifiable patient data. All data were treated confidentially and data management was conducted in line with the requirements of the Data Protection Act 1998 (UK Government) and Information Commissioner's Office guide to data protection 2010.[56]

On receiving the recruitment paperwork from LSNRC units, the research team entered each participant's data onto a password protected Excel database. All personal information was made anonymous through use of a unique ID number. The hard copies of questionnaires and signed consent forms were filed in a lockable cabinet.

The Excel database played an essential role in maintaining contact with participants and/or their carers as it created a detailed profile of each case and allowed each contact or attempted contact to be logged throughout the study period. This tracking system was used to record:

- the distribution of questionnaires to participants via post or email
- all attempts to contact patients
- follow up telephone calls
- missing data calls
- telephone-administered interviews.

These meticulous records were crucial to document the time and effort involved on the part of the research team to obtain information that was as accurate and complete as possible. Questionnaire data were double-entered by two research assistants and then matched with Excel to ensure accuracy. After cleaning and validation in Microsoft Excel, the data were extracted to SPSS (IBM) v 19 for analysis.

3.7.2 Overview of analysis

Descriptive differences: Descriptive statistics are reported in the form of percentages or summary statistics. Median, inter-quartile range (25th to 75th percentile), minimum and maximum are reported for ordinal data. Means and standard deviations are generally reserved for interval data, except where their use is justified by a large size of normally distributed data.

Missing Data: Completed questionnaire booklets were all checked for missing data on receipt. Participants were then telephoned by the researchers to fill in any missing data over the phone. For each participant with missing data, three telephone calls were attempted before accepting these data as missing. Where data could not be collected, for the purposes of statistical analyses, we used the "Exclude cases pair-wise" option in SPSS wherever possible, to maximise the sample size.

Within and between group comparisons: The majority of tools used in this study generated ordinal level data. Therefore analyses were performed where possible using non-parametric statistics:[57, 58]

- Within group differences were tested by Wilcoxon signed rank tests.
- Between group differences were tested by Mann Whitney tests.
- Correlations were tested by Spearman rank correlation coefficients.

Psychometric analysis was performed for the NPCS:

- To examine the dimensionality or structure we used principal components analysis with Varimax rotation.
- Bartlett's test of sphericity and the Kaiser-Meyer-Olkin (KMO) test were used to ensure the correlation matrix was suitable for factor analysis.
- Cronbach's α was calculated as (i) a measure of internal consistency or reliability for the full scale and (ii) the scale minus each individual item.
- Corrected item-total correlations were also computed.
- Intra-rater agreement of repeated tests was examined using intra-class correlation coefficients for total and subscales, and linear-weighted Cohen's Kappa coefficients for item-by-item analysis.

Regression Analyses of Longitudinal Data: To identify predictors of the level of rehabilitation provided, one-way ANOVA tests were used to test for differences between multiple groups and univariate and stepwise multiple regression analyses were performed to determine how well individual factors at baseline predicted follow-up scores.

It should be noted that attrition was not consistent – that is some patients who did not respond at Phase 1 did respond at phase 2 and so on. To maximise data capture, analyses included all available respondents at each period of analysis wherever possible; i.e. missing data were handled pair-wise, rather than list-wise, unless the longitudinal trends for change over successive time periods were the specific focus of the analysis – in which case we included only the respondents who reported at all three follow-up phases.

Health Economic Analyses: Missing service use items were replaced with mean imputations from other valid cases for each relevant service. Service use patterns and mean costs were compared between the two time periods. Identification of potential cost predictors used univariate and multivariate analyses.

Cost data usually follow a skewed distribution due to a small number of patients having disproportionately high costs. To address this, two forms of model were constructed. First, a linear regression model was used with confidence intervals around coefficients produced using non-parametric bootstrapping. Second, to take account of the actual distribution of the cost data we used a general linear model with a log link and gamma distribution.

4 Does the LTNC register provide a feasible and practical tool to identify and monitor people with complex needs?

4.1 Background and overview

In this section we describe the feasibility of setting up the LTNC register.

Patients with LTNCs present a number of challenges for follow-up:

- Those with acquired brain injury are often an itinerant population pre-morbidly. Not infrequently they are discharged to interim accommodation and are quickly lost to follow-up after leaving in-patient rehabilitation.
- Patients with cognitive problems may be unreliable in keeping appointments.
- Those with communication and reading and/or writing difficulties may have difficulty completing follow-up questionnaires[59] or responding to telephone calls.

By no means all patients with LTNCs want to be on a register. For some the diagnosis of a LTNC may represent a stigma or a barrier to valued activities, such as employment. Others are wary of their personal data being recorded in a central database, even when data are appropriately protected.

Further, the purpose of a registry would not just be for the identification of patients with LTNCs but also for long-term follow-up to determine the extent to which their needs are met in accordance with the NSF quality requirements. Even if patients agree to be entered on the registry, they may lack the ability, motivation, or desire to provide the level of follow-up information required, especially on an on-going basis.

Before setting up an LTNC registry, it is therefore appropriate to determine the level of uptake of such a register by the target population. Also to explore the means by which the registry information will be gathered, and to identify a feasible dataset for keeping the registry updated with the relevant information.

If the registry has applicability for some patients but not others, it is pertinent to understand the characteristics of those patients most likely to respond in order to target the facility appropriately.

4.2 Brief summary of methods

In this study, we approached a consecutive cohort of patients discharged over a 12-month period from the nine specialised rehabilitation units within the London Neurorehabilitation Consortium (LSNRC).

- Those who consented were entered onto a prototype register.

- They were followed over one year using questionnaires to evaluate their needs for health and social care and the services provided to meet those needs.
- We used three types of media (telephone, postal-questionnaire, and internet) to maximize recruitment by ensuring accessibility for this group of patients with complex disability.
- Strenuous efforts were made to make the questionnaires accessible in form and design, and to contact even those patients who are typically hard to reach.

4.2.1 Analysis

In this section we present an analysis of:

- recruitment and attrition rates
- the number of attempts made to contact and follow-up recruits.

We also compare the characteristics of those who consented to registration and continued to respond to questionnaires at months six and 12, compared with those who dropped out.

4.3 Recruitment and reasons for non-recruitment

Out of a total of 576 admissions, 467 patients were approached by the clinical teams for permission to include them in the study, of which 428 (92 percent) were recruited. Across the nine units just 8 percent of those who were recorded as having been approached declined to participate. For ethical reasons it was not possible to ask their reasons for not doing so.

A summary of recruitment by centre is given in Table 4.

Table 4. Total recruitment by Centres

Centre	Total admissions	Total approached	Total recruited	Declined	% Declined	Not approached	% Not approached
Unit 1 (BH)	69	55	**42**	13	24%	14	20%
Unit 2 (BIRU)	33	27	**27**	0	0%	6	18%
Unit 3 (HUH)	79	39	**37**	2	5%	40	51%
Unit 4 (FCRU)	77	58	**58**	0	0%	19	25%
Unit 5 (LU)	20	17	**15**	2	12%	3	15%
Unit 6 (NP)	86	84	**81**	3	4%	2	2%
Unit 7 (RHN)	8	8	**6**	2	25%	**	**
Unit 8 (QS)	99	76	**64**	12	16%	23	23%
Unit 9 (WU)	105	103	**98**	5	5%	2	2%
Total	**576**	**467**	**428**	**39**	**8%**	**109**	**19%**

** Unit 7 stopped recruiting after 3 months for administrative reasons

Inevitably in a busy clinical service, the unit staff will fail to approach some patients. Across the nine units, 19% of patients were not approached, but the proportions ranged from just 2% to over 50%. We therefore obtained permission from the Research Ethics Committee to approach patients directly after discharge to the community to invite them to participate in the study – this led to the inclusion of a further 32 patients, bringing the total sample approached to 499, which is an acceptable 87% of the possible admissions. For 68 (13%) patients, however, it is not known whether they would or would not have opted to participate, had they been approached.

We were interested to understand the reasons why some centres were much more successful in recruiting patients than others. Site visits were conducted at each centre after the end of recruitment to close down the study. These included a debriefing interview to identify any lessons learned from the recruitment process. Recruitment was most successful in those centres where a single named individual took responsibility for consenting patients and ensured that the paperwork was complete (in particular, Unit 6, where the lead consultant took personal responsibility for recruitment; and Unit 9, where a dedicated recruitment officer, funded by NIHR network NHS support funding, took responsibility for recruitment). In centres where this responsibility was delegated to a number of different individuals (e.g. the patient's key-worker or a trainee specialist registrar) there was often some confusion about the purpose of the study, and it was sometimes unclear whether the patient was:

- declining for their details to be included the register
- declining to participate in the follow-up research programme
- both of these.

Ethical permission was granted for recruiting centres to gather and submit summary data only for non-recruits for the purpose of comparison with recruits. Data items included: Age, Gender, Ethnicity, Diagnosis and any reasons for refusing consent (if given). For the services in which this information was available, no significant differences were seen between any of these variables.

Unfortunately, however, the information would have been most valuable in those services with low recruitment rates. As described above, the most common reason for non-recruitment in these centres was local system failure, rather than patient refusal. For the same reason, details of non-recruited patients were hard for the centre to obtain, so any information regarding the non-recruited population within centres is regarded as unreliable.

In total therefore, across the nine London based centres, a total of 499 participants were assessed for eligibility, of whom 428 were recruited into the study at Phase 0 (discharge from in-patient rehabilitation).

4.4 Efforts to maximise questionnaire completion

Questionnaires were completed either in paper form, online or by telephone interview. Table 5 gives a breakdown of each method used for response at each of the three phases.

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 by telephone interview only.

Table 5. Breakdown of questionnaires sent/received by the three methods of response

Phases of recruitment	Method of contact			
	Paper	On-line	Phone interview only	Total
Phase 1: 4 weeks post discharge				
Sent	349 (84%)	55 (13%)	13 (3%)	416
Received	211 (82%)	32 (13%)	13 (5%)	256
Phase 2: 6 months post discharge				
Sent	337 (82%)	49 (12%)	23 (6%)	409
Received	169 (80%)	20 (10%)	23 (11%)	212
Phase 3: 12 months post discharge				
Sent	317 (82%)	50 (13%)	19 (5%)	386
Received	152 (80%)	19 (10%)	19 (10%)	190
Overall project				
Sent	1003 (84%)	153 (13%)	55 (3%)	1211
Received	532 (82%)	71 (13%)	55 (5%)	658

Figure 4 shows the return rates for the recruited project respondents.

It should be noted that attrition was not consistent – that is some patients who did not respond at Phase 1 did respond at phase 2 and so on. This has implications for analysis, as discussed in section 3.7.2.

Of the 428 patients recruited to the study, 123 (29%) did not respond to a questionnaire in any of the phases; 20 to 21% responded to one or two phases and just 134 (31%) responded to all three phases.

This latter group of 'best respondents' was identified as the group most likely to take up registration in the future if a LTNC register were to be provided.

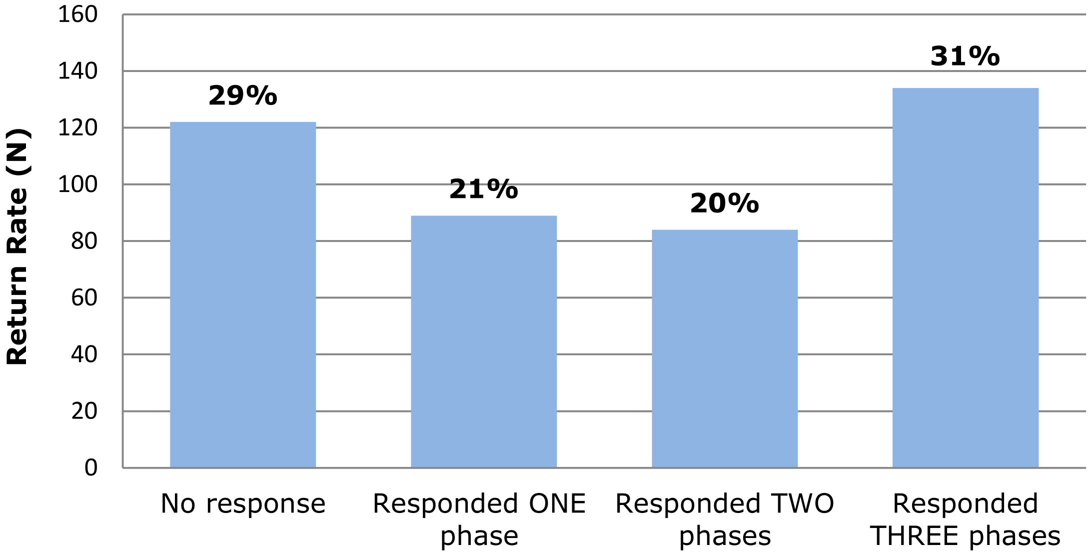


Figure 4. **Return rates for the 428 recruited project respondents**

Table 6 summarises the number of contacts with participants to generate the responses received. A total of 1,211 questionnaires were sent out, with an 18% re-send rate.

More than 1,600 follow-up phone calls were made, to achieve a total of 658 received questionnaires (approximately 50% return). The average time from send out to response was 47 days for Phase 1, reducing to 34 days for Phase 3.

Table 6. Follow-up contact with participants

	Phase 1	Phase 2	Phase 3	Total
Number Of Questionnaires Sent	416	409	386	1211
Number Of Questionnaires Resent	85	87	53	225
Number Of Follow-Up Calls	671	545	391	1607
Number Of Questionnaires Received	256	212	190	658

The reduction in both response times and the number of prompts required over the three phases of follow-up suggests that those still participating at Phase 3 were highly motivated - and possibly also that questionnaire completion got easier over time as respondents became familiar with the questions and knew what to expect.

4.5 Characteristics of the recruited sample

A total of 428 patients (86 percent of the total admitted cohort) consented for recruitment to the study. The demographics of this sample, collected at phase zero on discharge for rehabilitation, are shown in Table 7 below.

Table 7. Characteristics of recruits at Phase 0 – Discharge (N=428)

Variables		N	%
Gender	Male	270	(63.1)
	Female	158	(36.9)
Age group	16-25	38	(8.9)
	26-35	48	(11.2)
	36-45	79	(18.5)
	46-55	114	(86.6)
	56-65	86	(20.1)
	66-75	49	(11.4)
	76-86	14	(3.3)
Diagnosis	Brain injury	315	(73.6)
	- *Stroke/SAH**	*- 212*	*- (49.5)*
	- *TBI**	*- 63*	*- (14.7)*
	- *Other ABI**	*- 40*	*- (9.3)*
	Spinal Cord Injury	38	(8.9)
	Peripheral Neuropathy	26	(6.1)
	Progressive LTNC	21	(4.9)
	Other	27	(6.3)
	Missing	1	(0.2)
Discharge destination	Home	333	(78)
	Nursing Home	51	(12)
	On-going Rehab	18	(4)
	Hospital	4	(1)
	Other	19	(5)
Permission to include on the Register	Yes	322	(75.2)
	No	13	(3.0)
	Question not answered	93	(23.8)

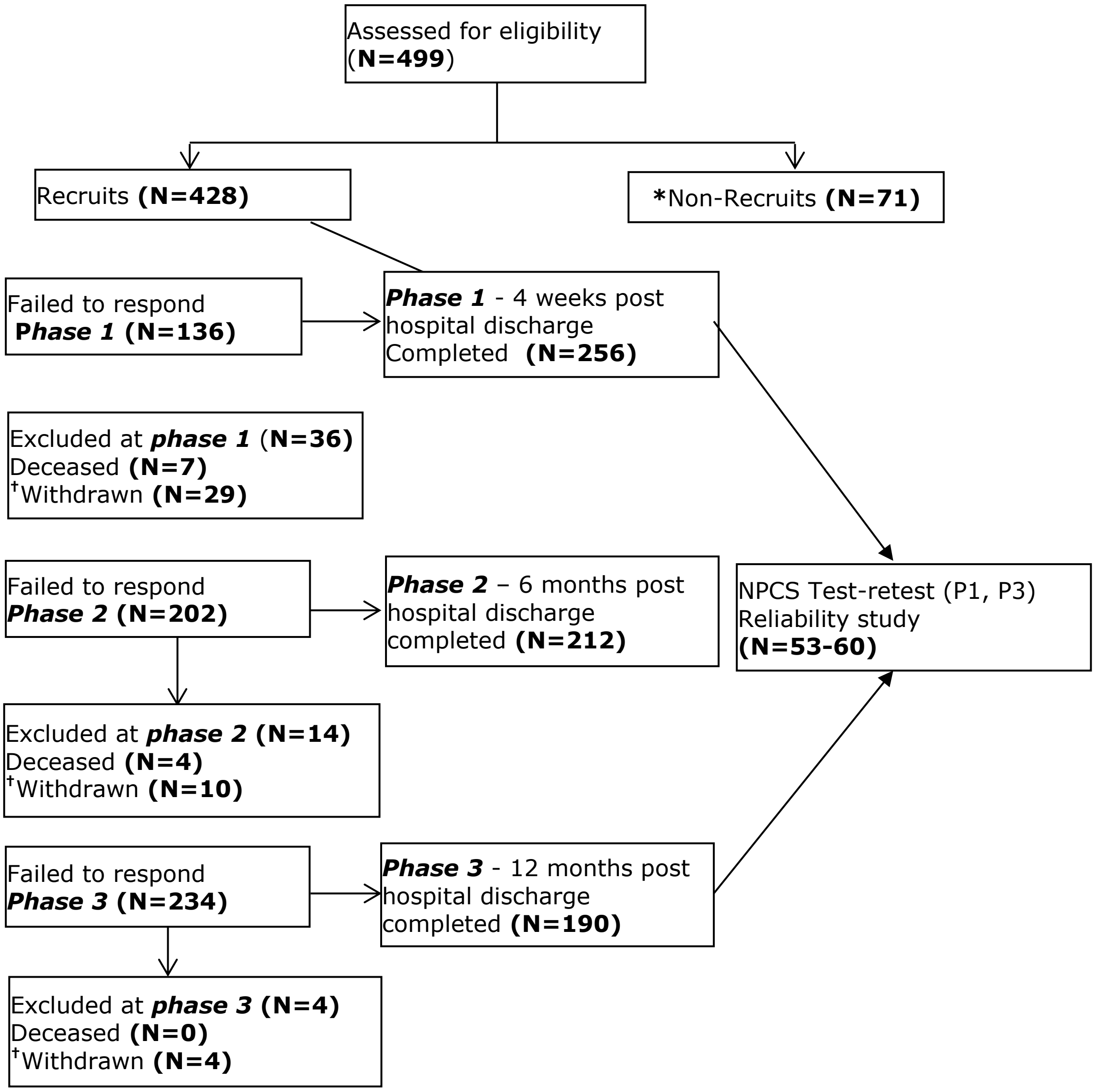
*SAH=Sub-arachnoid haemorrhage; TBI=Traumatic Brain Injury; ABI=Acquired Brain Injury

Three quarters of the recruited population had acquired brain injury (50 percent stroke). As would be expected from this population there were more males than females. The mean age was 49 (SD 15) with a range of 16-86 years, and the majority (78 percent) were discharged home.

Although the recruitment form specifically included the question of whether the patient agreed for their details to be included in the prototype register, this was not complete in 91 out of 428 (21%) of cases, so this information is only known for 335 patients. Of these, 322 (96%) agreed to be included in a register and just 4% declined.

4.6 Attrition after recruitment

The recruitment pathway is depicted in Figure 5. The figure documents the rates of attrition after recruitment and the reasons for attrition are summarised in Table 8 below.



As noted above

- 123 participants did not respond at any of the three phases ('Non-respondents')
- 134 participants responded at all three phases ('Best respondents')

Figure 5. Participation pathway in the LTNC Project

Table 8. Summary of Withdrawn/Deceased

Reason for attrition	Phase 1	Phase 2	Phase 3	Total
Deceased	7	4	0	11
Does not Want To Be Involved Anymore	19	3	2	24
Does not Want To Fill In Another One	2	2	1	5
Unable to Fill Out the questionnaire	1	0	0	1
Hospital In-Patient	2	0	0	2
Un-Contactable (Including Via GP)	5	5	1	11
TOTAL	**36**	**14**	**4**	**54**

4.7 Changes in demographics at successive time points

Table 9 shows the demographics of the sample population at successive time points

The LTNC sample at Phase 1 (3-4 weeks) was:

- Almost two-thirds male, predominantly white and middle-aged.
- The majority of participants are either married/cohabitants (51%) or single (29%).
- About half are registered as long term sick/disabled (51.5%), with another 21% retired and only about 13% are in full or part-time work.

The characteristics of the people lost to the study were compared with the Phase 1 responding sample (i.e. 3-4 weeks post-discharge) to determine whether early attrition was random or not.

The gender ratio of the sample remained approximately stable throughout the study period, as did age, marital status and educational level.

The only significant trend over time was a change in ethnicity, which showed a greater level of attrition for non-white British subjects. This is reflected in the loss at 12 months of approximately 39% of Black and 49% of Asian/Other participants as compared with only 18% attrition for White participants.

Table 9. Demographics at the three phases of the study

		Phase 1 3-4 weeks (N=256) N	 %	Phase 2 6 months (N=212) N	 %	Phase 3 12 months (N=190) N	 %
Gender	Male	166	(64.8)	128	(60.4)	118	(62.1)
	Female	90	(35.2)	84	(39.6)	72	(37.9)
Age	16-25	20	(7.8)	13	(6.1)	15	(7.9)
	26-35	30	(11.7)	24	(11.3)	17	(8.9)
	36-45	48	(18.8)	37	(17.5)	33	(17.4)
	46-55	68	(26.6)	61	(28.8)	54	(28.2)
	56-65	53	(20.7)	46	(21.7)	42	(22.1)
	66-75	30	(11.7)	25	(11.8)	23	(12.1)
	76-86	7	(2.7)	6	(2.8)	6	(3.2)
Ethnicity	White	182	(71.1)	161	(76.0)	149	(78.4)
	Black	36	(14.1)	26	(12.3)	22	(11.6)
	Asian	20	(7.8)	16	(7.5)	13	(6.9)
	Chinese	1	(0.4)	1	(0.5)	1	(0.5)
	Other	15	(5.9)	7	(3.3)	5	(2.6)
	Missing	2	(0.8)	1	(0.5)	0	(0)
Marital status	Married	103	(40.2)	91	(42.9)	80	(42.2)
	Cohabiting	28	(10.9)	22	(10.4)	19	(10.1)
	Separated	13	(5.1)	8	(3.8)	6	(3.2)
	Divorced	19	(7.4)	18	(8.5)	20	(10.6)
	Single	74	(28.9)	57	(26.9)	52	(27.5)
	Civil partnership	1	(0.4)	3	(1.4)	1	(0.4)
	Dissolved civil p-ship	1	(0.4)	0	(0)	1	(0.4)
	Widowed	12	(4.7)	11	(5.2)	6	(3.2)
	Other	5	(2.0)	2	(0.92)	4	(2.0)
	Missing	0	(0)	0	(0)	1	(0.4)
Qualifications	GCSE/O Levels	65	(25.4)	59	(27.8)	48	(25.3)
	A Levels	25	(9.8)	18	(8.5)	16	(8.4)
	Diploma/Professional	60	(23.4)	47	(22.2)	38	(20)
	Bachelor’s degree	29	(11.3)	28	(13.2)	23	(12.1)
	Higher degree	22	(8.6)	17	(8.0)	21	(11.5)
	None	47	(18.4)	43	(20.3)	39	(20.5)
	Missing	8	(3.1)	0	(0)	5	(2.2)
Employment	Full time	27	(10.5)	12	(5.7)	12	(6.3)
	Part time	7	(2.8)	11	(5.2)	10	(5.3)
	Self employed	9	(3.5)	6	(2.8)	5	(2.6)
	Retired	54	(21.1)	47	(22.2)	42	(22.1)
	Unemployed	22	(8.6)	15	(7.1)	13	(6.8)
	Long term sick/disabled	132	(51.5)	117	(55.2)	103	(54.2)
	Student/Training	3	(1.2)	2	(0.9)	2	(1.1)
	Homemaker	2	(0.8)	2	(0.9)	1	(0.5)
	Missing	0	(0)	0	(0)	2	(1.1)

4.8 Impairment

We also wished to establish whether the group who responded to questionnaires was representative of the whole sample in terms of impairment at baseline.

In addition to the demographics at Phase 0, the full Neurological Impairment Scale (NIS) was also completed by the clinical discharge teams for 403/428 (94 percent) of the recruited sample. Figure 6 shows a box plot of the NPCS total scores for those recruits who did (N=256) and did not (N=172) return a questionnaire at Phase 1. There was no difference in the distribution of impairment between the two groups (Mann Whitney -1.49; p=0.14).

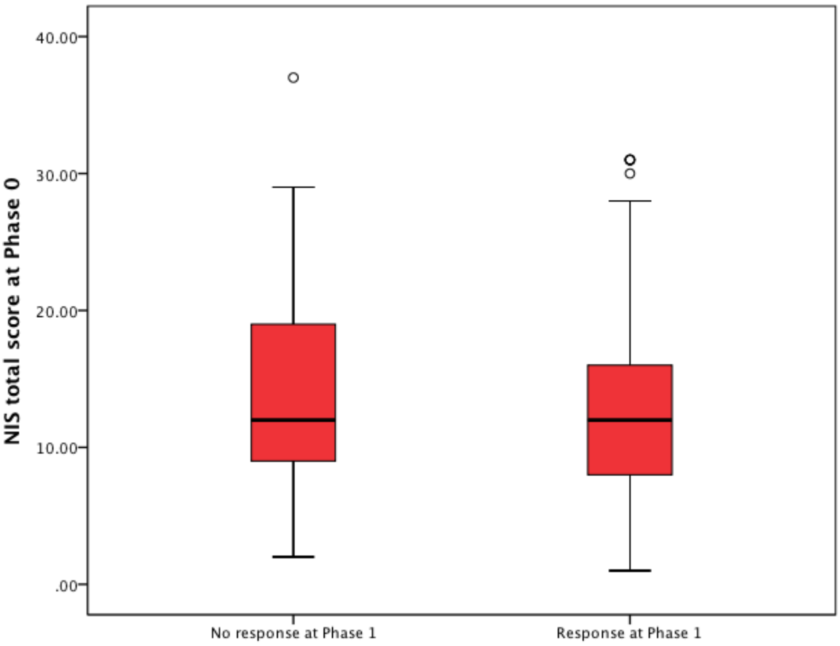


Figure 6. Box plots of the physical and cognitive NIS scores for those who did and did not return a questionnaire at phase 1

It was possible, however, that although the total impairment scale scores were similar, there were more subtle differences - for example in cognitive impairment - which meant that patients with cognitive deficits were more likely to become lost to follow-up. We therefore examined in more detail the motor and cognitive components of the NIS score in ‘non-respondents’ (those patients who never returned a questionnaire after discharge) and ‘best-respondents’ (those who returned a questionnaire at each of the three successive time points).

Table 10 shows the NIS total and subscales for the full recruited sample, the non respondents and the best respondents – also illustrated in Figure 7. There was no statistically significant difference in impairment between the two groups (NIS-Physical Subscale Mann Whitney -0.72 p 0.47; NIS cognitive scale z= -1.30 p=0.19).

Table 10. Neurological Impairment Scale: descriptive statistics for the recruited sample (N=428); non-respondents and best-respondents.

NIS Subscale	Median	IQR	Range
Recruited sample N=428			
Physical (N=413)	8	4-12	0-25
Cognitive / behavioural (N=416)	4	2-6	0-14
Total (N=403)	12	8-17	1-37
Non-respondents (Those not returning sample at any time) (N=123)			
Physical (N=119)	8	5-12	0-25
Cognitive / behavioural (N=118)	4	2-7	0-13
Total (N=113)	12	9-19	2-37
Best-respondents (Those returning at all three time-points) (N=134)			
Physical (N=131)	8	4-12	0-25
Cognitive / behavioural (N=131)	4	2-6	0-13
Total (N=128)	**13**	**9-17**	**1-31**

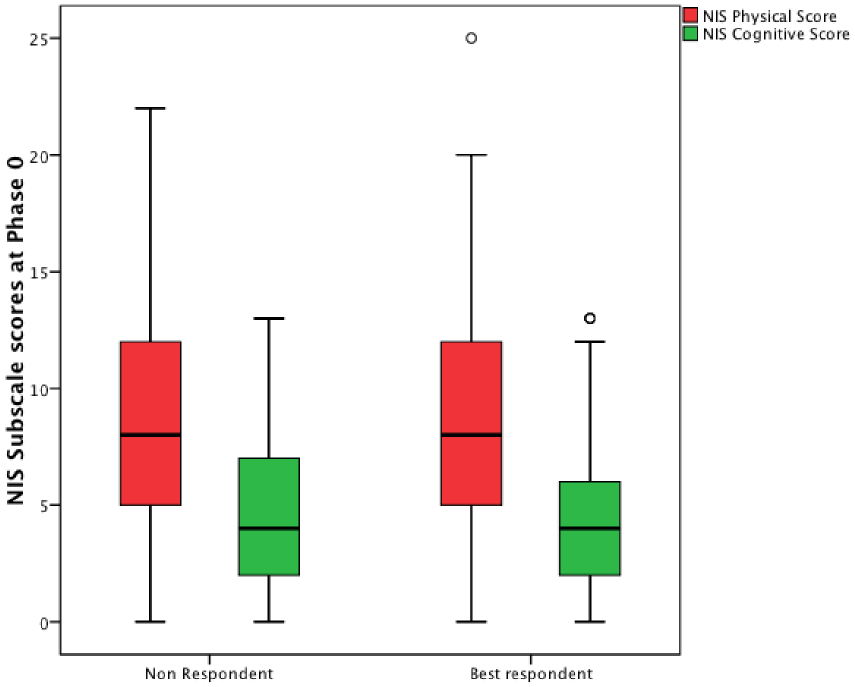


Figure 7. NIS Motor and Cognitive Subscale scores for non-respondents and best respondents.

4.9 Needs for services

Finally, we examined whether the group who responded to questionnaires was representative of the whole sample in terms of their needs for services at baseline. Figure 8 shows box plots of their clinician-rated NPCS-Needs at baseline. There is no difference in the distribution of needs between the two groups - Healthcare Subscale Mann Whitney z=-0.86, p=0.39; social care and support subscale Mann Whitney z=-1.71, p=0.08).

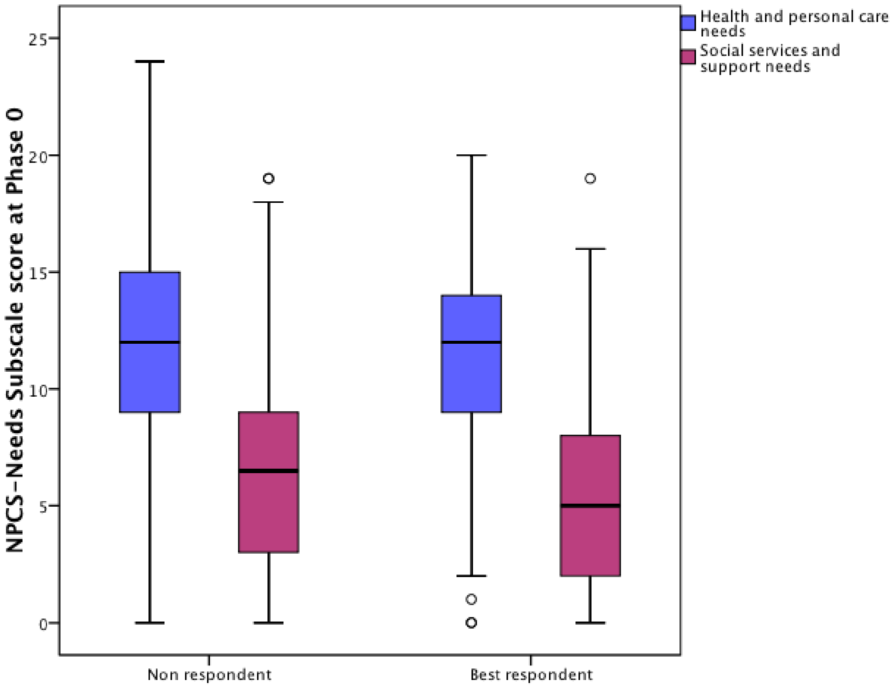


Figure 8. NPCS Needs (Health and Social Services subscale scores) for non-respondents and best respondents.

4.10 Limitations

Participant attrition meant that only 212 (50%) participants from the original sample of 426 recruits completed the survey at six months. While we could not discern any broad demographic or diagnostic differences between these two groups, apart from Black British participants having a higher attrition rate, it is possible that some systematic bias was operating here. For example, it might be that people who are really struggling with daily life in the community are less likely to remain in contact with the registry. Alternatively, that those people not receiving the services they expected are more likely to respond.

4.11 Chapter summary

This chapter presents information regarding the feasibility of a LTNC register. Key conclusions are as follows:

- Recruitment rates were higher when a single member of the clinical team took responsibility for consenting patients for inclusion in the register and completing the necessary paperwork.
- Failure to recruit was most often the result of system failure (failure to approach the patient or ask specifically about their wishes regarding registration). Clear data in this respect were missing in 22 percent of the sample.
- However, in those for whom this specific information was obtained, 96 percent wished to be registered and only 4 percent did not.
- Of the three response media available (postal questionnaire, online questionnaire or telephone) the large majority of patients or their proxies (80 to 84%) preferred to use the paper questionnaire booklet.
- However, a very active policy of telephone follow-up was required to prompt completion with over 1,600 telephone calls required to achieve a 50 percent response rate.
- Less than one-third of patients responded to all the questionnaires at all three time-points. However for those who did, the process seemed to become easier with familiarity. Some patients positively valued the telephone contact.
- No clear differences were identified between those who did and did not respond to the questionnaires, except that the non-white British group tended to drop out over time. In particular, there were no differences in motor or cognitive impairment between the two groups.

It is also relevant to note that, in addition to the pragmatic tools used to assess needs provision and outcomes, the questionnaire included much more detailed information about services received collated under the CSRI. These were collected for the purposes of this research to gather health economic information but would not normally form part of LTNC registry tools. It is possible (although unlikely) that the non-respondents were put off by the length of the questionnaire booklet and might have responded to a shorter questionnaire set.

5 Does the NPCS provide a reliable, valid assessment of service provision in relation to need?

5.1 Overview

For people with long-term term/complex conditions the measurement of impairment and the extent of associated functional impact provide a much better indication of the severity of the condition itself than a simple diagnostic code.

To this end, both the Neurological Impairment Scale (NIS) and The Needs and Provision Complexity Scale (NPCS) have been designed specifically for use with LTNCs in general, and are not specific to any one condition. The use of this standard set of tools will provide a common language that will form the basis for future analysis of national trends and allow comparisons across regions, services and conditions.

The NPCS in particular is important, in that it represents the first attempt to develop a measure of both the *need* a person has for rehabilitation - as perceived by their clinical team at discharge, and the degree to which those needs are subsequently *met* – as perceived by the patient.

In the present chapter we report results of the first psychometric evaluation of the NPCS using cross-sectional and longitudinal data from the present study.

We examined the following psychometric characteristics of the NPCS for both the clinician-completed assessments of 'NPCS-Need's and the patient-completed assessment of 'NCPS-Gets'. We expected the performance of these tools to be broadly similar but not identical, as they represent assessment of different 'sides of the same coin'. For both instruments we assessed:

- Internal consistency as measured by Cronbach's α.
- Dimensionality indicated by principal component analysis with Varimax rotation.
- Concurrent validity of the NPCS through correlation with other measures (e.g. physical and cognitive disability, service provision and satisfaction) at six months post-discharge.

In addition as, the self-completed version of the NPCS-Gets was developed for the first time in this project, we also examined the performance of this version for:

- Repeatability (or test-retest reliability)
- Utility as evaluated from user feedback

5.2 Method

5.2.1 Samples in Psychometric analyses

Dimensionality and Internal Consistency

The NPCS-Needs data for all participants, completed by their discharge clinician at Phase 0 (i.e. the time of discharge from in-patient rehabilitation), were used to calculate Cronbach's ɑ and for the principal components analysis. Complete data were available for N=426.

The equivalent analysis was performed for patient-completed NPCS-Gets data on the sample of all the participants who returned the complete NPCS at six months (N=168). *(NB in the section, 'patient-completed NPCS-Gets' refers to self report by either the patient or their proxy).*

To examine the dimensionality or structure of the NPCS completed at discharge by clinicians and at six months by participants, we used principal components analysis with Varimax rotation on both of the two samples. Before attempting this we applied Bartlett's test of sphericity and the Kaiser-Meyer-Olkin (KMO) test to ensure the correlation matrix was suitable for factor analysis. Cronbach's ɑ, a measure of internal consistency or reliability, was calculated for the full NPCS scale and the scale minus each individual item. Corrected item-total correlations were also computed.

Repeatability

To examine test-retest reliability all participants were invited at Phase 1, three to four weeks post-discharge, to complete a second NPCS form a week later. Participants who agreed to participate were mailed the second NPCS as soon as the first completed NPCS had been received. Based on the number needed to calculate kappa coefficients we aimed to recruit at least 50 participants for this evaluation. In the final event N=60 paired responses were received. Despite missing data for some items, the target number was achieved for all but one subscale.

Test-retest reliability or repeatability was assessed by calculating intra-class correlation coefficients (ICCs) and linear weighted kappa coefficients (kw).

Validity

As the NPCS is the first measure of its kind there is no gold standard measure of needs and service provision against which to compare it. However assuming that services provided reflect the level of disability at least to some extent, one would expect some relationship between the NPCS and measures of disability or dependency.

Initial evidence for the concurrent validity of the NPCS was therefore based on Spearman correlations with measures of dependency / social integration at six months after discharge (N=182 to 212). These were:

- The Barthel Index (BI) - independence in activities of daily living.
- The NPDS-Physical subscale (NPDS-P) - i.e. the 13 physical items of the NPDS Basic Care Needs scale summed.
- The NPDS-Cognitive-Behavioural (NPDS-CB) – i.e. the thee NPDS cognitive behavioural items summed.
- The Community Integration Questionnaire (CIQ).
- The Service Obstacles Scale (SOS).

We expected to find a positive relationship between the NPDS-Gets and NPDS-P and NPDS-CB (measures of dependency) and inverse relationships with the Barthel Index and CIQ,(which are measures of independence and social integration. We also expected an inverse relationship with the Service Obstacles Questionnaire.

Utility

As noted in chapter 4, the NPCS was originally developed as a measure for assessment by clinicians. In this study we were particularly keen to record the person-centred experience of service users, and so it was necessary to develop a self-report version of NPCS-Gets, suitable for completion by patients and carers. The questionnaire developed to apply the self-report version was achieved through a process of iterative feedback from participants and adjustment. Although the questionnaire presentation of the tool underwent several iterations during the first 45 to 50 returned in Phase 0, the structure of the tool did not change. By Phase 1, the self-report version had stabilised and no further changes were made thereafter.

5.3 Results

5.3.1 Psychometric Analysis of Clinician-completed NPCS-Needs at Discharge

Bartlett's test of sphericity was significant ($p<0.01$) and the KMO measure of sampling adequacy at 0.92 was well above the minimum value for factor analysis. Two components had eigenvalues greater than 1.0 and the Scree plot also indicated a two factor solution was appropriate. The first two principal components accounted for approximately 66 percent of total variance. There was evidence of a large general factor with all 15 items loading high (i.e. >0.50) on the first un-rotated principal component.

Results of the 2 factor Varimax rotation are presented in Table 11 and show evidence for two distinct factors – one corresponding to the 'Health and personal Care' domain and the other to the 'Social Care and Support' domain. The presence of a substantial general factor is reflected in the fact that it was necessary to conceal loadings < 0.50 to clearly highlight the two distinct rotated factors. Item-total correlations were also consistently high and positive Cronbach's α was also high for the full 15 item scale at 0.94.

Table 11. Results of 2-Factor Varimax rotation with corrected item-total correlations and Cronbach's α for clinician-completed NPCS subscales (N=426)*

Items	Rotated Factors		Corrected Item-total correlation	Cronbach's α If item deleted
	Factor 1	**Factor 2**		
Medical care		0.58	0.69	0.94
Skilled Nursing		**0.74**	**0.70**	**0.94**
No of carers		**0.74**	**0.78**	**0.93**
Care frequency		**0.71**	**0.61**	**0.94**
Personal enabler		**0.67**	**0.75**	**0.94**
No of therapy disciplines		**0.81**	**0.68**	**0.94**
Therapy intensity		**0.73**	**0.59**	**0.94**
Vocational /educational	**0.71**		**0.70**	**0.93**
Social worker /case manager	**0.78**		**0.75**	**0.93**
Family carer support	**0.77**		**0.72**	**0.93**
Residential respite	**0.83**		**0.86**	**0.94**
Daycare	**0.83**		**0.48**	**0.93**
Advocacy support	**0.57**		**0.79**	**0.93**
Equipment	**0.65**	**(0.52)**	**0.80**	**0.93**
Accommodation	**0.53**	**(0.67)**	**0.74**	**0.93**

* Note: All item-factor loadings rounded to 2 decimal places and loadings <0.50 hidden for clarity

5.3.2 Psychometric Analysis of Patient-completed NPCS-Gets at six Months

Bartlett's test of sphericity was significant ($p<0.01$) and the KMO measure of sampling adequacy at 0.70 was above the minimum value for factor analysis. Five components had eigenvalues above 1.0 but this resulted in a fragmented and un-interpretable pattern of factor loadings. Consequently we extracted and rotated two components to permit a comparison with the solution from the clinician-completed NPCS-Needs data.

Thirteen items had loadings above 0.35 on the first un-rotated PC and two items (Vocational Rehabilitation, Residential Respite) had near zero loadings. Table 12 presents the results of the two-factor rotation along with the item-total correlations and corrected coefficient alphas. Inspection of Table 12 reveals good support for a two-factor structure that is quite similar to that observed for the clinician-completed NPCS-Needs. At the same time item-total correlations were generally lower with seven items having a correlation with the total score below 0.30. Cronbach's α was also somewhat lower for the patients although still within the acceptable range at $\alpha=0.75$.

Table 12. Two-factor Varimax rotation and corrected item-total correlations for Patient-completed NPCS-Gets at 6 months* (N=168)

Items	Rotated Factors		Item-Total Correlations	Cronbach's α If item deleted
	Factor 1	Factor 1		
Medical care	.49		.28	.75
Skilled Nursing	.56		.51	.73
No of carers	.73		.63	.73
Care frequency	.76		.62	.70
Personal enabler	.43		.28	.75
No of therapy disciplines	.55		.50	.73
Therapy intensity	.51	-.44	.48	.73
Vocational /educational			-.04	.76
Social worker/case manager			.26	.75
Family carer support		.46	.17	.76
Residential respite		.61	.25	.75
Daycare		.72	.22	.75
Advocacy support		.40	.38	.74
Equipment	.41		.47	.73
Accommodation	.51		.45	.74

*Note: All item-factor loadings rounded to two decimal places and loadings <0.40 removed for clarity.

5.3.3 Repeatability of Patient-completed NPCS-Gets at seven day retest interval

The results of the test-retest or repeatability examination of the NPCS-Gets are presented in Table 13 below and show the ICC and weighted Kappas for the individual NPCS items completed approximately seven days apart. The ICCs range from a minimum of 0.48 (Family carer) to a maximum of 0.93 (Residential respite) and the linear weighted kappas range from) 0.42 to 0.83.

Streiner and Norman note that recommendations on how to interpret Kappa and weighted Kappa vary.[60] However based on their summary table of three different authors, the following guide for interpretation is considered reasonable: 0 to 0.20 poor; 0.21 to 0.40 fair; 0.41 to 0.60 moderate; 0.61 to 0.75 substantial; 0.76 + excellent.

The repeatability of the NPCS at a one-week interval was generally quite good. For example, five of the 15 items showed 'moderate' repeatability and 10 were 'substantial' or 'excellent'. For the six NPCS subscales the ICC values were all in the substantial to excellent range.

Table 13. Test–retest reliability statistics for patient-completed NPCS-Gets items with 7 day retest interval (N= 53–60)

NPCS ITEMS	ICC	Linear Weighted Kappa	Linear Weighted Kappa SE	95% CI +/-	Agreement
Medical (N=59)	.68	.61	.09	.18	64%
Nursing (N=55)	.63	.55	.13	.25	76%
No. of Carers (N=59)	.79	.75	.10	.20	85%
Care Frequency (N=59)	.86	.73	.06	.12	63%
Personal Assistant (N=60)	.49	.47	.10	.20	68%
Therapy Disciplines (N=58)	.58	.52	.09	.18	60%
Therapy Intensity (N=57)	.60	.54	.10	.20	63%
Vocational rehab. (N=59)	.68	.56	.10	.20	92%
Social work/CM (N=60)	.68	.42	.10	.20	72%
Family carer (N=60)	.48	.45	.12	.24	73%
Respite- residential (N=60)	.93	.83	.11	.22	95%
Respite - day care (N=54)	.85	.75	.11	.22	94%
Advocacy (N=53)	.57	.49	.12	.24	77%
Equipment (N=58)	.68	.62	.10	.20	76%
Accommodation (N=57)	.85	.69	.09	.18	76%
HEALTH AND PERSONAL CARE DOMAIN	**ICC**			**95% CI**	
Healthcare (N=50)	.67			.48 - .80	
Personal care (N=53)	.83			.73 - .90	
Rehabilitation (N=50)	.65			.45 - .78	
SOCIAL CARE AND SUPPORT DOMAIN	**ICC**			**95% CI**	
Social/family support (N=47)	.66			.46 - .79	
Equipment (N=53)	.66			.48 - .80	
Accommodation (N=52)	.84			.73 - .90	

5.3.4 NPCS-Gets correlations with other measures of physical and cognitive disability, service provision and satisfaction

Table 14 presents Spearman correlations of the 'Health and personal care' and the 'Social care and support' domains of the NPCS with the Barthel Index, the NPDS-Physical (NPDS-P), the NPDS-Cognitive-Behavioural subscale (NPDS-CB), the services Obstacles Scale (SOS) and the Community Integration Questionnaire (CIQ) at six months after discharge.

Inspection of Table 14 shows both domains have a moderate negative correlation with the Barthel Index and a moderate positive correlation with NPDS-Cognitive-Behavioural Problems. Correlations with the three CIQ subscales tend to be low to moderate and negative.

Table 14. Correlations (Spearman's rho) of NPCS-Gets Domains with measures of dependency and disability at Phase 2 - Six Months after Discharge

Measures of dependency and disability (N=182 to 212)	Health and Personal Care Gets	Social Care and Support Gets
Barthel Index	-0.53*	-0.53*
NPDS –P	0.56*	0.53*
NPDS-CB	0.42*	0.40*
Services Obstacles Scale	0.08	0.14
CIQ – Home Integration	-0.50*	-0.39*
CIQ – Social Integration	-0.21*	-0.31*
CIQ – Productivity	-0.30*	-0.35*

* = p<0.01

As noted above, we did not necessarily expect a close relationship between the disability dependency measures and services provided. However, these correlations show the expected congruent and discriminant relationships and therefore provide some evidence for the concurrent validity of the NPCS.

- The Barthel is primarily an index of physical disability/independence and the higher the score the more independent the person. Hence a moderate negative correlation with the amount of rehabilitation and social support at six months makes perfect sense.
- Similarly a moderate correlation between the two domains and the degree of physical and cognitive dependency reported at six months is expected.
- The negative correlations with the CIQ reflect the fact that the most able and active individuals who are participating more in society – require less rehabilitation and support. This latter finding provides for the discriminant validity of the NPCS domains.
- Interestingly there were no significant correlations with perceived barriers or obstacles to services.

5.4 Limitations

The NPCS Needs data were provided for all patients at the time of discharge by the discharging clinical team. In this situation, there is a range of clinical opinion and by pooling the clinical opinion of the team, rather than relying on a single clinician, we endeavoured to capture the best possible representation of the patient's needs.

However, a different team could have made different recommendations and this should be explored in future work on the NPCS. More importantly, a patient's needs can change over time and assessment of need should have been repeated to be properly compared with gets (as discussed below).

5.5 Chapter summary and discussion

This preliminary psychometric analysis of the NPCS suggests that it is a promising new measure of an individual's requirements for health and social services – and the extent to which those needs are met.

- Factor analysis generally provides support for a scale structure in two main domains ('Health and personal care' and 'social care and support')
- Test-retest repeatability suggests that the self-complete version provides a reliable estimate of services provided

An interesting difference was observed in the factor structure of the NPCS-Needs and NPCS-Gets at 6 months.

- The clinician-completed NPCS-Needs showed high internal consistency, a pronounced general factor and two clear specific factors.
- For the patient-completed NPCS-Gets the internal consistency was lower but in the acceptable range and there was less evidence of a single general factor underpinning the full NPCS. Indeed for the patient version the two un-rotated principal components solution was quite similar to the two factor rotated solution – suggesting two quite independent factors.

These differences need to be interpreted with some caution, as they may in part reflect the smaller numbers in the factor analysis for the NPCS-Gets version. However, they could be interpreted as reflecting that clinicians see both the healthcare and the social support items as a single bundle of the person's needs at discharge, whereas in the community the actual provision of healthcare and social support are quite independent.

This resonates with experience in that community-based health and social services are provided by separate bodies (Primary Care Trusts and Local Authorities respectively), often with little evidence of coordination between them. Therefore, from this preliminary evaluation, it appears that the NPCS may provide quite a good reflection of the reality of service provision as it is currently offered in the community.

6 What are the needs of this group for on-going community-based rehabilitation and support?

6.1 Overview

It is important in planning and commissioning rehabilitation services to be able to evaluate service provision in relation to need, both at an individual and a population level, so as to tailor service delivery most efficiently. The Needs and Provision Complexity Scale was developed to this end as there is no existing tool designed specifically for this purpose. The NPCS measures needs for community care and rehabilitation, assessed by a clinician, and provision against these needs, reported by the service user.

This chapter focuses specifically on the patients' required level and type of services upon discharge from hospital, based upon their discharging clinician's responses to the items of the Needs and Provision Complexity Scale (NPCS). 'Need', as identified by the clinical team, refers to the level and type of services that are necessary for the patient's physical, psychological and social well-being once they have been discharged from hospital and continue their rehabilitation in the community.

This chapter is primarily concerned with answering the following question: 'What are the needs of people with LTNCs for community-based rehabilitation and support after they have been discharged from specialist in-patient rehabilitation?' This question is addressed in the present chapter by a detailed descriptive analysis of the NPCS data provided by members of the clinical team at discharge (i.e. Phase 0).

6.2 Study sample

We analysed the NPCS data for all 428 Phase 0 recruits. See section 4.5 for demographic and diagnostic characteristics of these participants.

6.3 Procedure

The NPCS is an ordinal scale with 15 items, six subscales, two major domains and an overall score that can range from 0-50 (details in Chapter 3.2.2). The summary score sheet also includes a checklist of the specific services required under each heading. Clinicians completed the NPCS for each patient in the week prior to their discharge from the specialist rehabilitation service concerned. Full details of data collection are reported earlier in the Methods chapter.

6.4 Analysis

We calculated frequency statistics for the needs of the 428 recruited patients as estimated by the discharging clinician for the 15 items of the

NPCS. In addition we calculated descriptive statistics of the type of specialty or discipline that was needed by the patient. For example, for the item *Therapy Needs*, we calculated frequencies for both the number of therapy disciplines required and also the actual types of discipline.

6.5 Results

The descriptive analyses for the 15 NPCS items are reported below.

6.5.1 NPCS Item 1: Medical Needs

All patients in the recruitment sample were identified as having on-going needs for medical support. The pie chart in Figure 9 shows that about 40 percent of the sample of 428 only required GP monitoring with 41 percent needing low level specialist and 20 percent active medical specialist monitoring.

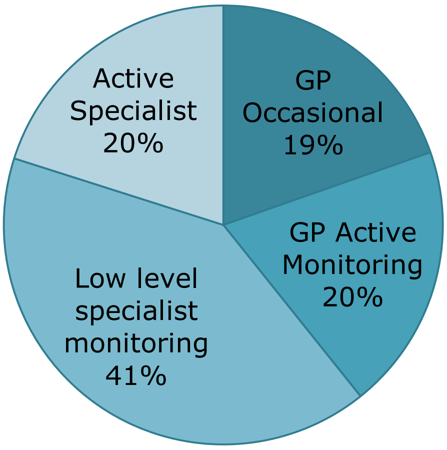


Figure 9. Needs for medical support at recruitment (N=428)

The bar chart below (Figure 10) reports the frequency with which particular medical specialties were needed. Almost a third of patients (32 percent) needed specialist rehabilitation medicine support followed closely by neurologist input (29 percent).

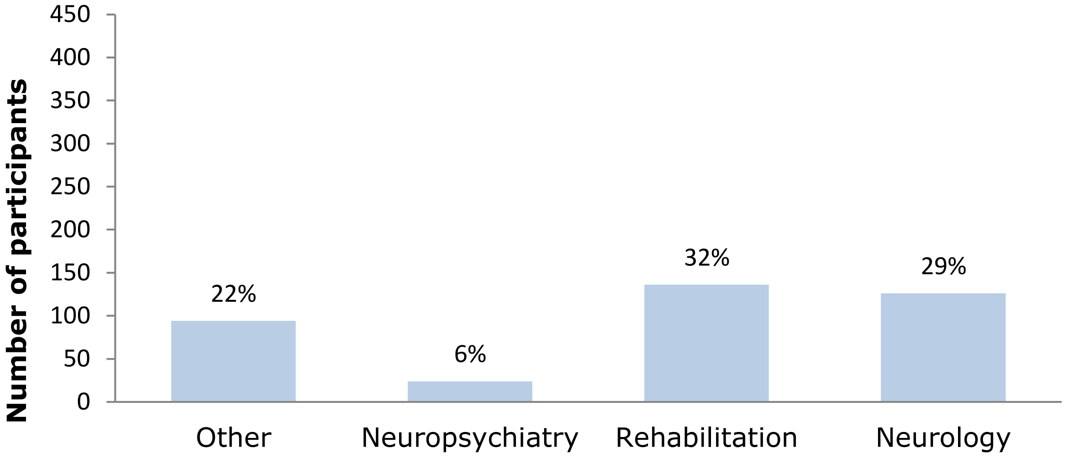


Figure 10. Type of specialist medical care required (N=428)

6.5.2 NPCS Item 2: Nursing Needs

Figure 11 shows that a majority of patients (59 percent) did not require specialist nursing follow-up after discharge, but 40 percent did and nearly a quarter required regular nursing care (weekly or more often). The most frequent type of nursing support required was for a district nurse (17 percent), followed by mental health nursing (12 percent).

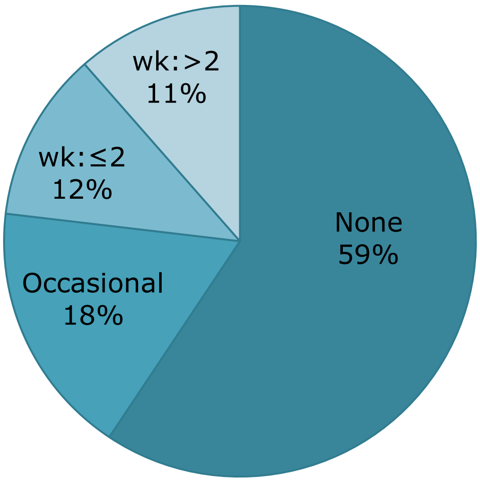


Figure 11. Needs for nursing at recruitment (N=428)

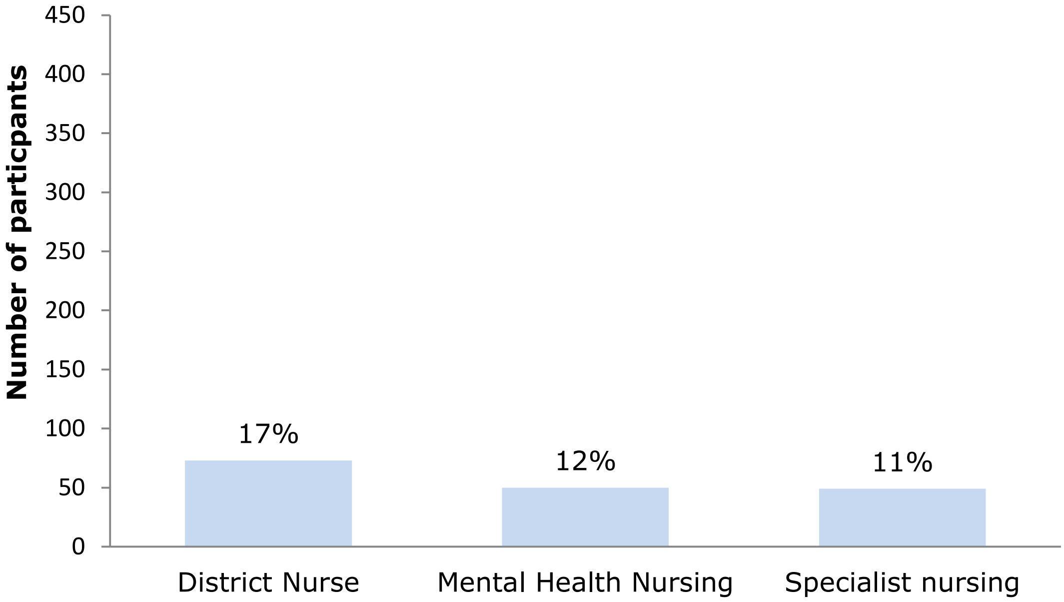


Figure 12. Type of Nursing needs at discharge (N=428)

6.5.3 NPCS Item 3: Number of carers needed

Figure 13 reports the needs of patients for carers at discharge. Only about 37 percent of the total discharge sample did not need any carer support with 51 percent needing one carer and 12 percent needing at least two carers.

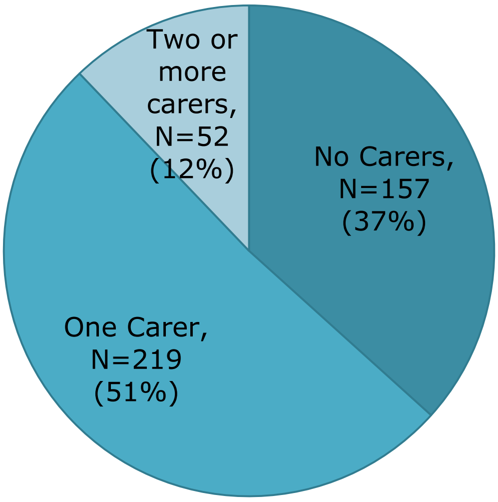


Figure 13. Number of carers needed at discharge (N=428)

6.5.4 NPCS Item 4: Carer frequency needed

Approximately two-thirds of the whole sample needed assistance from a caregiver. For approximately half, this assistance could be provided on the basis of visiting care (in up to 3 visits per day), but 18 percent required more intensive carer support throughout the day. Seven percent required round the clock care. In a third of cases this could be provided by a family member, but otherwise paid carers were required.

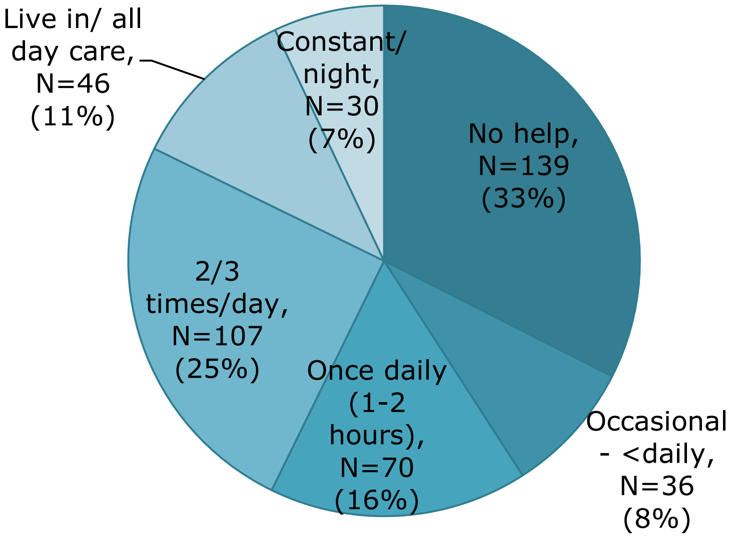


Figure 14. Frequency of carers needed at recruitment (N=428)

Figure 15 shows that over a third of the full sample of 428 participants were expected to receive care from a family member, with almost a quarter expecting to receive paid statutory care. Interestingly 6 percent paid for private care and almost 10 percent obtained care services from 'other' sources.

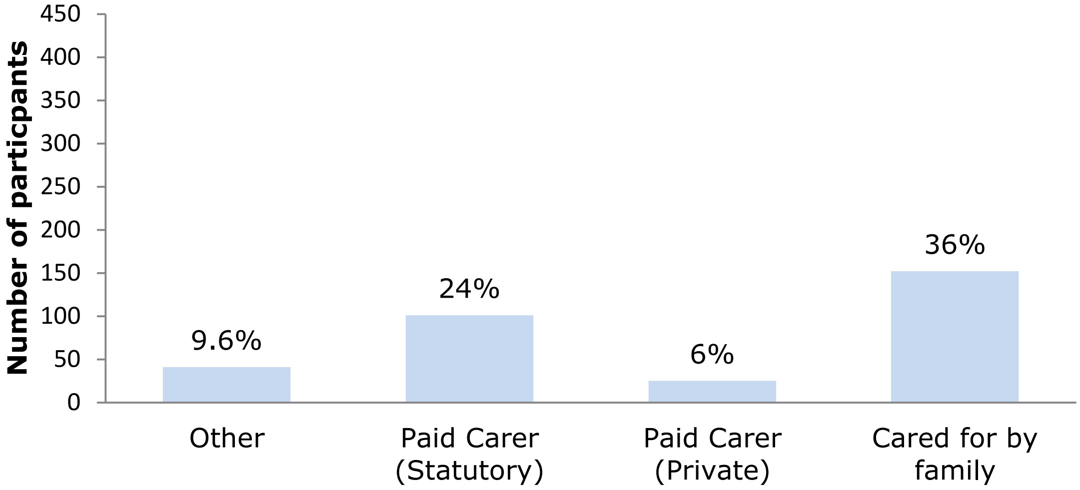


Figure 15. Type of carer required at discharge (N=428)

6.5.5 NPCS Item 5: Personal Enabler Needs

Figure 16 reports the needs of patients for support from a personal enabler to assist the patients with more extended community-based activities.

Again this type of support was required by about two thirds of the sample, and one third required frequent support for personal enablement (more than three times per week).

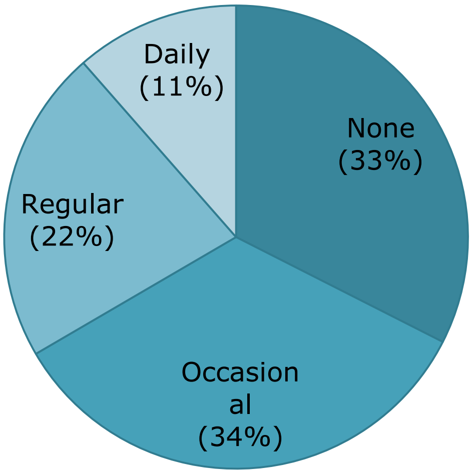


Figure 16. Needs for a personal enabler at discharge (N=428)

6.5.6 NPCS Item 6: Therapy Needs

Figure 17 shows the proportions of patients at discharge requiring different levels of therapeutic input. Around 94% of this sample required on-going therapy, and 85% needed therapy from several disciplines either coordinated or working independently. Occupational therapy (75%) and physiotherapy (72%) were the most frequently needed therapies followed by Speech Language Therapy (40%) and Psychology (38%).

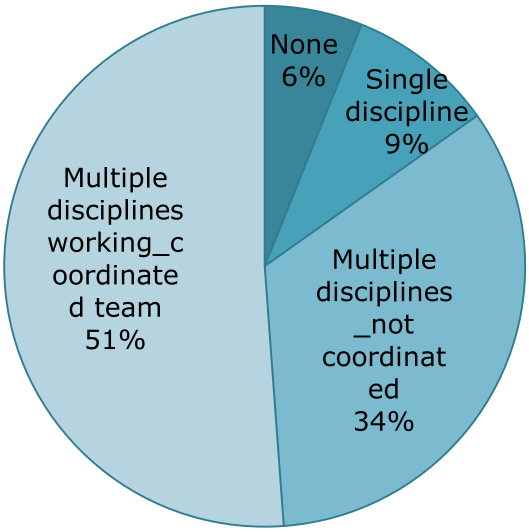


Figure 17. Therapy disciplines needed at discharge (N=428)

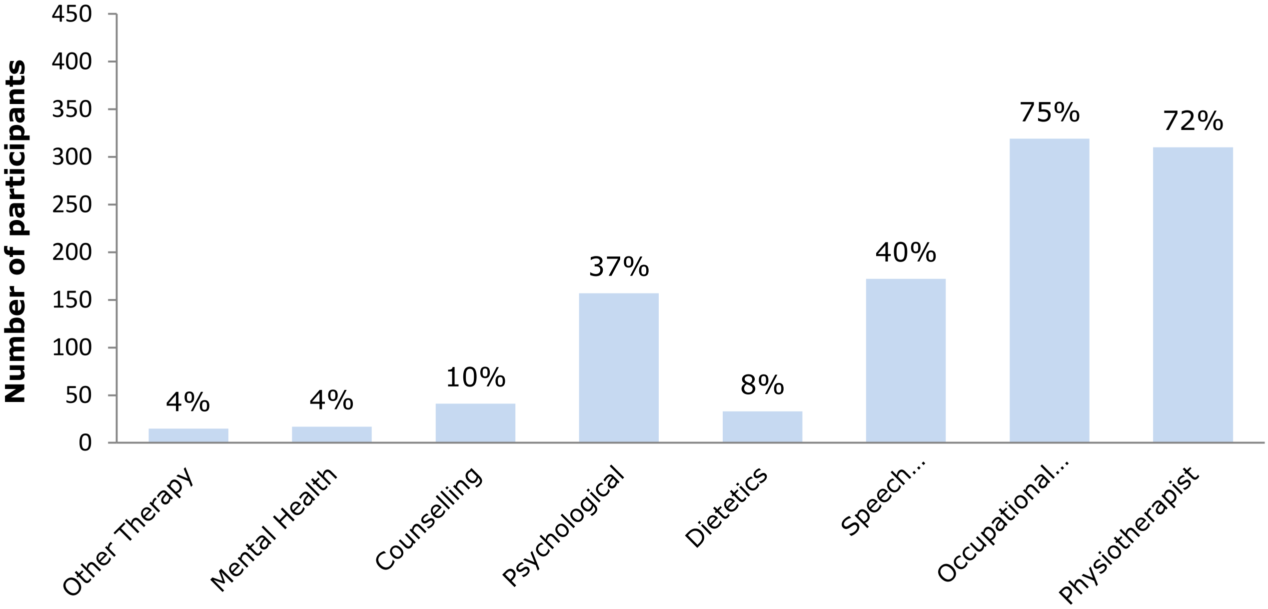


Figure 18. Types of therapy need at discharge (N=428)

6.5.7 NPCS Item 7: Therapy Intensity

Figure 19 reports the results for Therapy Intensity - 83 percent of patients needed regular or frequent on-going therapy.

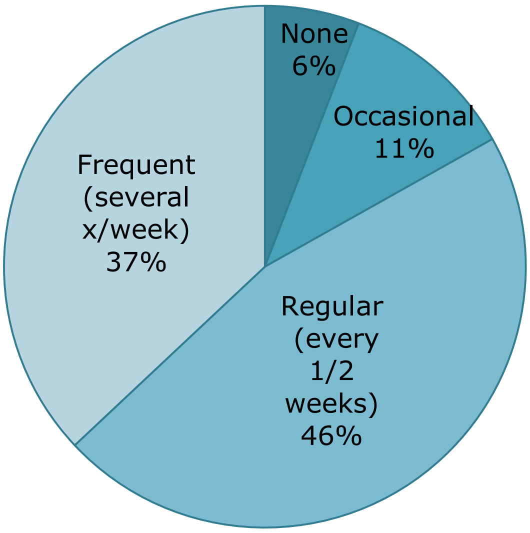


Figure 19. Therapy intensity needs at Discharge: (N=428)

6.5.8 NPCS Item 8: Vocational Rehabilitation

Figure 20 presents the results for Vocational Rehabilitation. Nearly half of the sample required either vocational assessment (20 percent) and a third required active vocational support.

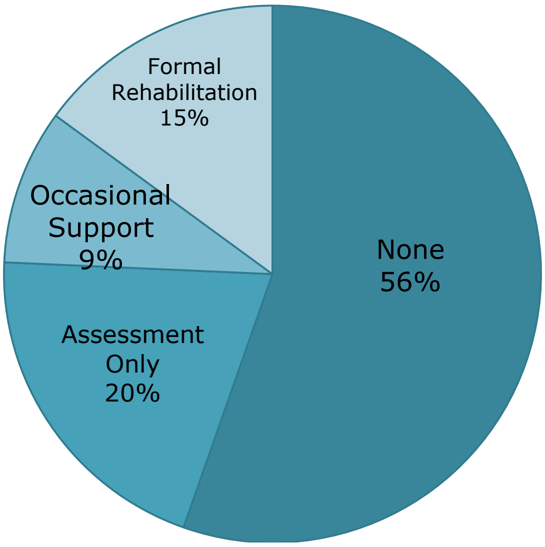


Figure 20. Needs for vocational rehabilitation at Discharge (N=428)

6.5.9 NPCS Item 9: Social Work/Case Management

Table 21 presents the results for Social Work/Case Management needs. Nearly 80 percent required social work support or case management, and nearly half required this input on a regular or frequent basis. For the majority, social worker input was sufficient, but 13 percent were identified as requiring more formal case management.

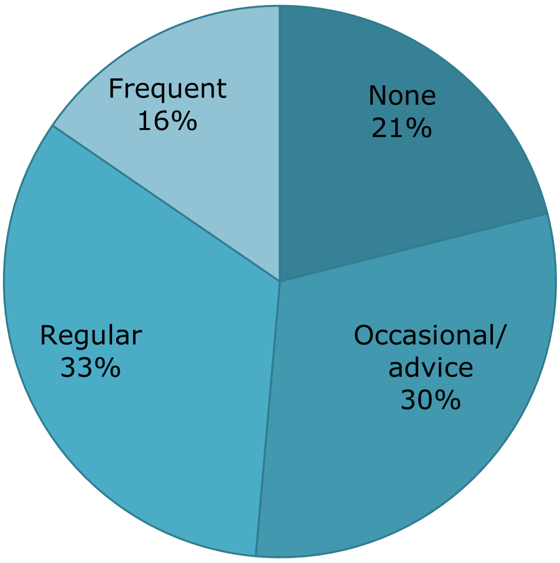


Figure 21. Amount of social work needs (N=428)

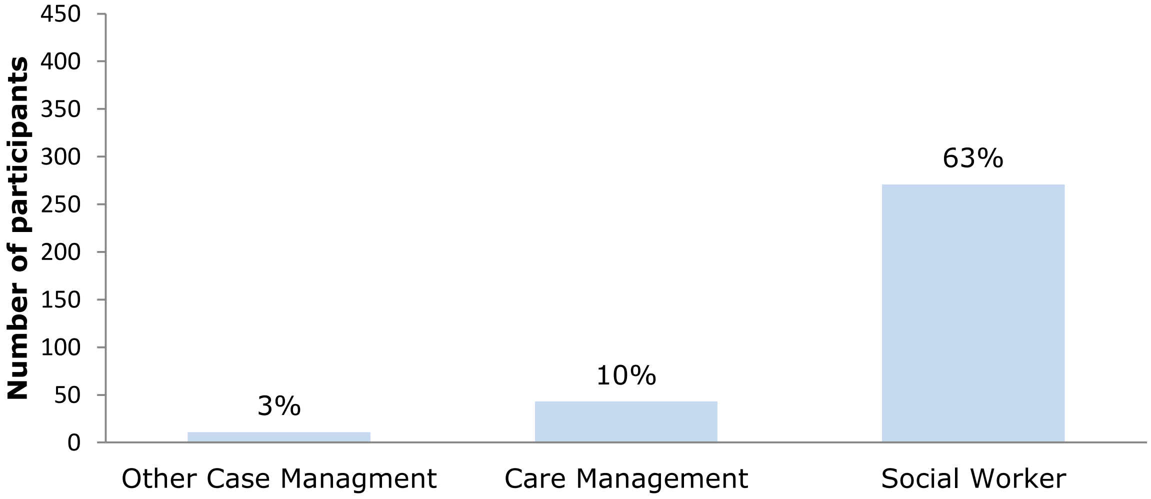


Figure 22. Type of Social Work needs at discharge (N=428)

6.5.10 NPCS Item 10: Family Carer Needs

Among the sample of 428 recruits at discharge, nearly half had identified needs for family/carer support. In 29 percent a carer assessment was recommended, whilst 20 percent required support – either on a time-limited or on-going basis. In the majority of cases, this type of support was expected to come from a social worker.

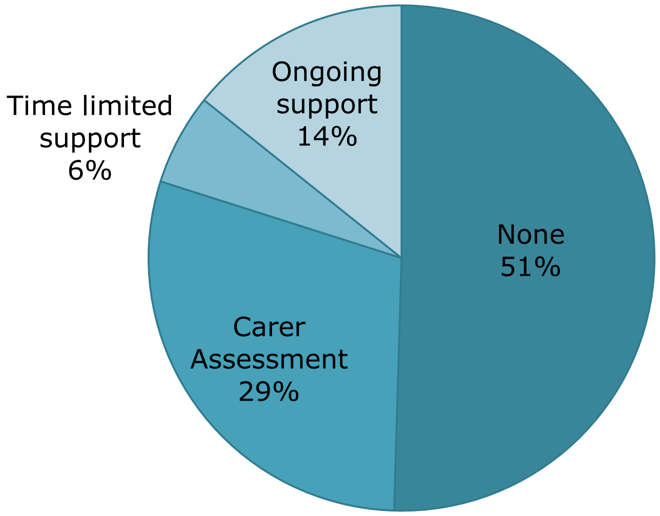


Figure 23. Needs for support for a family carer (N=428)

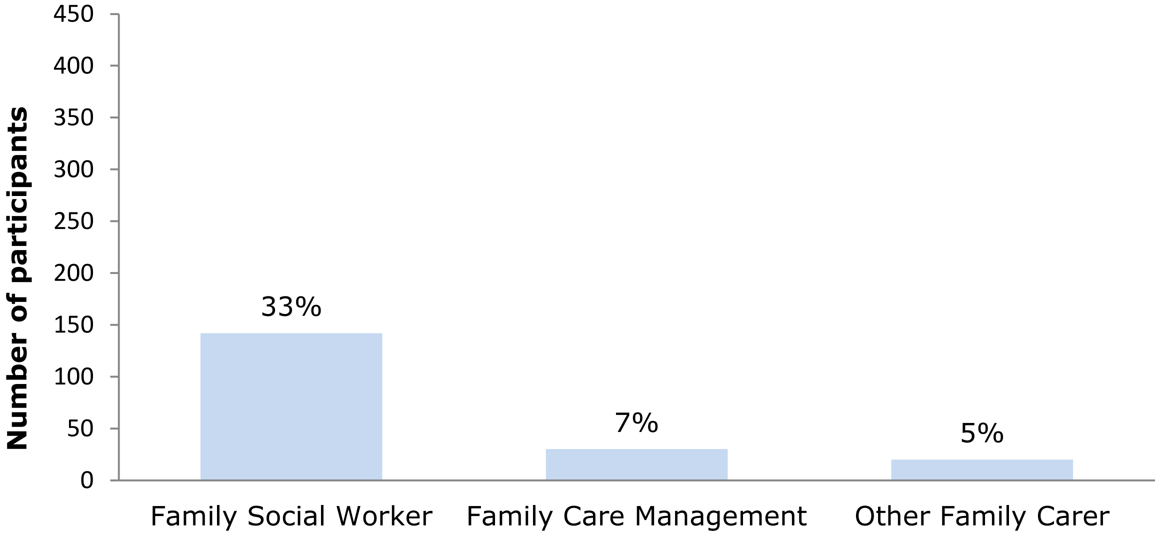


Figure 24. Source of support for family carer (N=428)

6.5.11 NPCS Item 11: Residential Respite Care Needs

Figure 25 presents the proportions of the recruitment sample who required residential respite care. The majority of the sample (84 percent) did not have respite needs at discharge, but 16 percent or so did require it, with 4 percent requiring it on a regular or frequent planned basis.

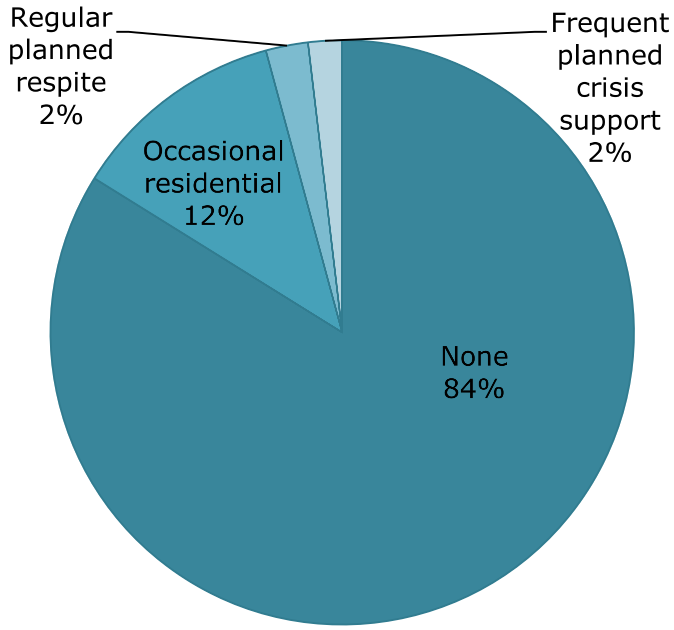


Figure 25. Requirements for residential respite care (N=428)

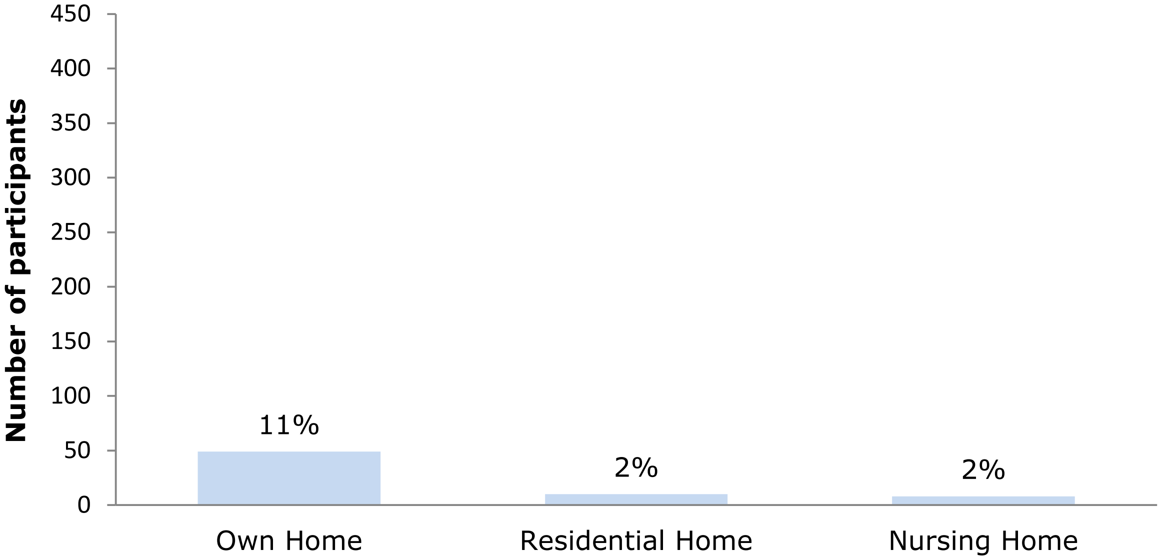


Figure 26. Type of respite care care eneeds at discharge (N=428)

6.5.12 NPCS Item 12: Day Respite Care Needs

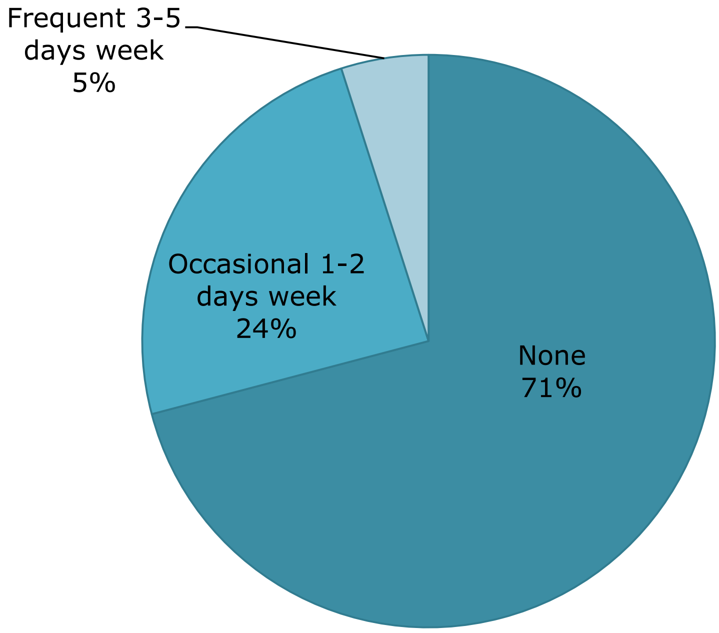


Figure 27. Day care needs (N=428)

6.5.13 NPCS Item 13: Advocacy Needs

Figure 28 presents the needs of participants for advocacy or support for decision-making in the community. Three quarters of the participants (76 percent) had no such needs but 13 percent were noted to require assessment of their mental capacity in the community, and 11 percent relied on a family advocate.

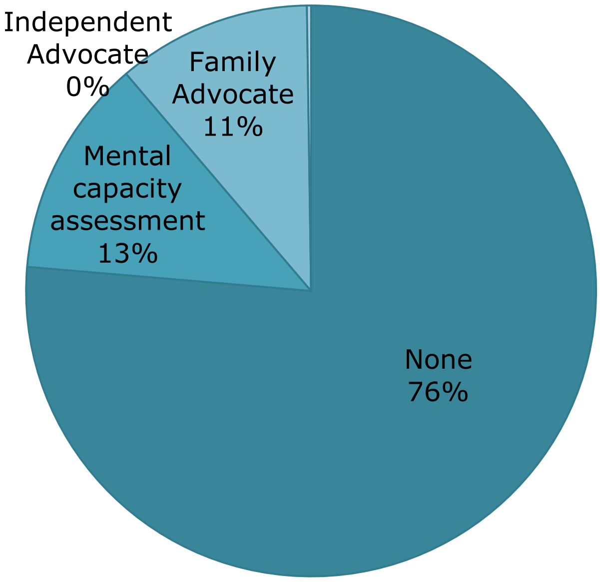


Figure 28. Needs for advocacy and support for decision-making (N=428)

6.5.14 NPCS Item 14: Equipment Needs

The participants' needs for specialised equipment are presented in Figures 29 and 30. Approximately one third (32 percent) required specialist or highly specialist bespoke equipment and a further 40 percent required off-the-shelf equipment. The most common types of equipment required were specialist seating/wheelchairs and other postural equipment, such as standing frames.

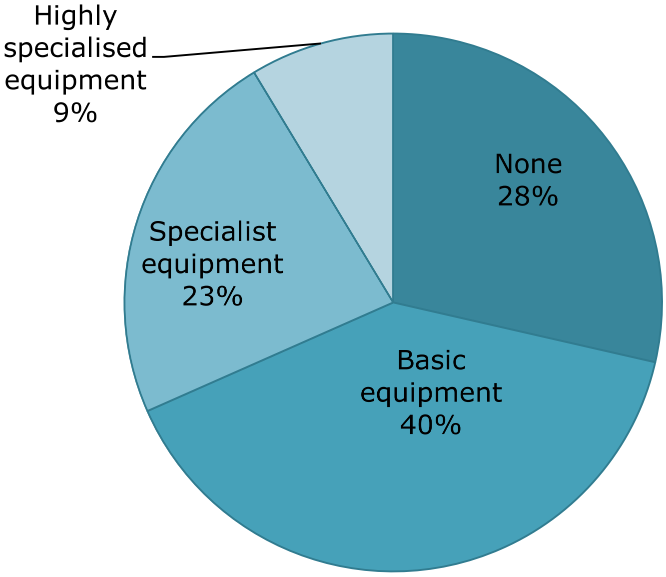


Figure 29. Equipment needed (N=428)

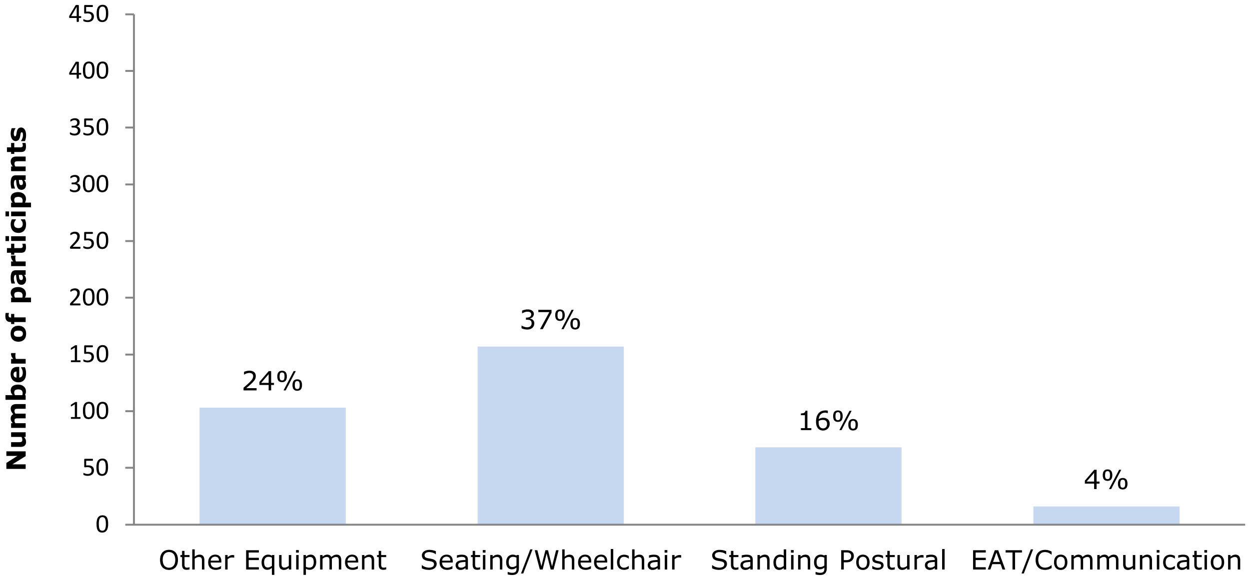


Figure 30. Types of Equipment needs at discharge (N=428)

6.5.15 NPCS Item 15: Accommodation Needs

Participants needs for special accommodation are illustrated in Figure 31 just over 60 percent of recruits had some needs for adapted or special accommodation at discharge. These needs most commonly related to home adaptations for physical disability, but 17 percent required a supported living environment or nursing home.

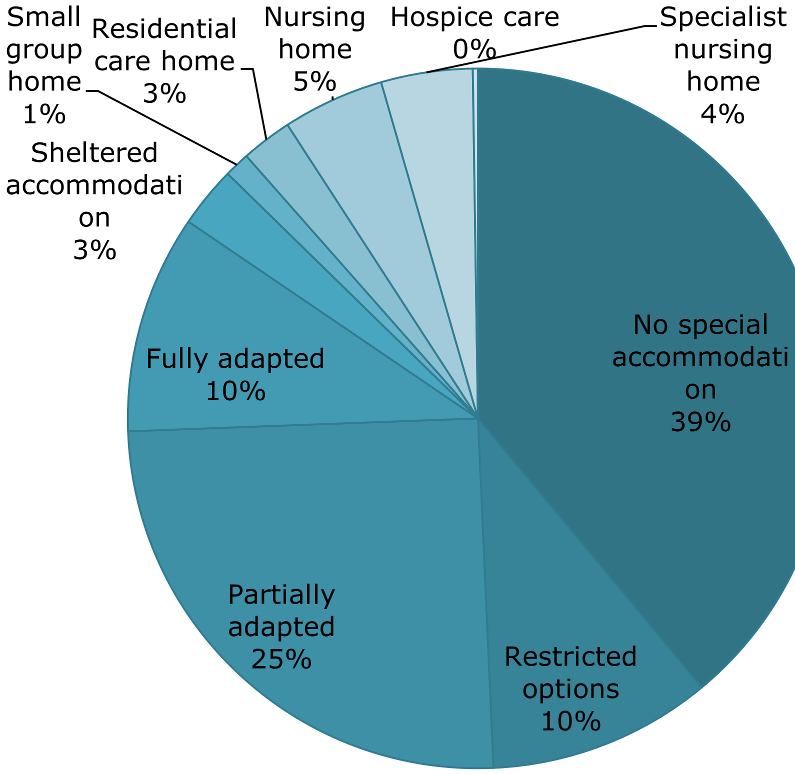


Figure 31. **Special accommodation needs (N=428)**

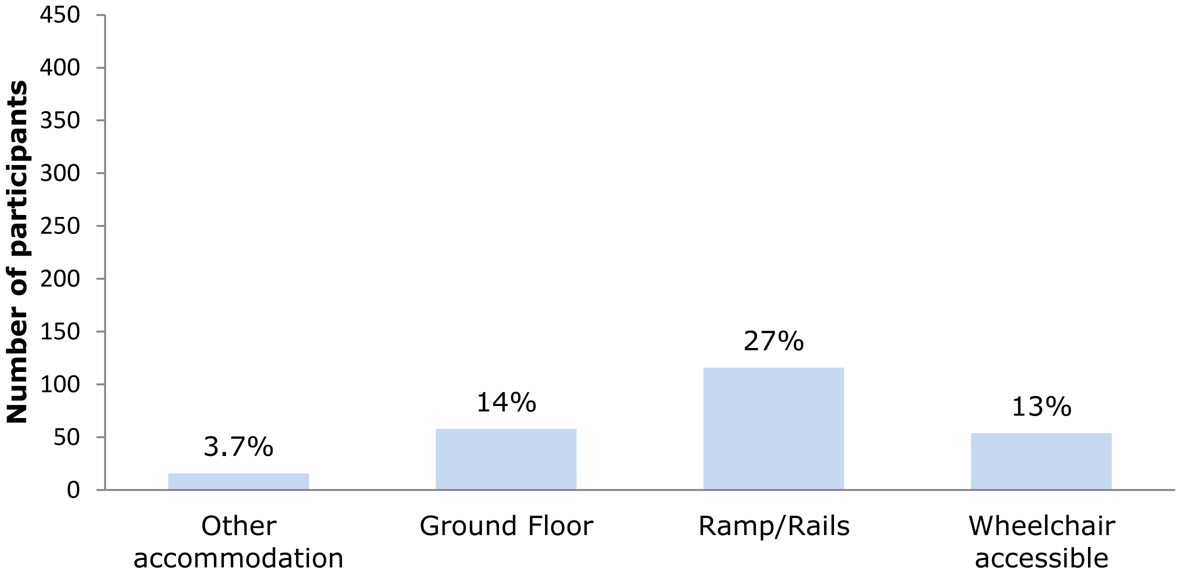


Figure 32. **Type of adaptation requirements at discharge (N=428)**

6.6 Limitations

The needs analysis in this chapter is based upon the 428 patients recruited at discharge from the nine services in the London Consortium. While this represents a reasonable capture of patients with complex needs discharged from Level 1 services, we did not capture the needs of people with LTNCs in general e.g. people discharged from Level 2 (local specialist) or Level 3 (general rehabilitation) services. Moreover, the data are confined to the one geographic area (London) which may not necessarily reflect service provision around the rest of the UK, which may be either better or worse.

6.7 Chapter summary

The frequency distributions of the 15 NPCS items confirm that the recruitment sample represents a group with substantial needs for healthcare, therapy and social/community support. For example, of this sample of 428 patients

- Two-thirds required specialist medical monitoring, most commonly from a consultant in rehabilitation medicine or neurology.
- Two thirds required assistance with personal care and a similar proportion required a personal enabler for community based activities.
- Over 90 percent required on-going multi-disciplinary community rehabilitation, and 44 percent required vocational rehabilitation.
- 80 percent required input from a social worker or case manager – and 50 percent required this on a regular basis (i.e. every 1-2 months).
- Half of the family carers needed either a carers assessment or on-going support.
- Two-thirds of the sample required equipment of some sort and 60 percent had some sort of accommodation needs, with 17 percent requiring a support living environment.

These data also provide support for the utility of the NPCS as a brief and practical assessment for assessing complex needs among a group with significant physical and cognitive impairments.

In Chapter 8, we will examine how well the participants' various needs were met at six and 12 months after discharge from specialist in-patient rehabilitation.

7 Where are they referred to for further rehabilitation and what kind of rehabilitation is prescribed?

7.1 Overview

The aim of this part of the study was to examine referral patterns for on-going community rehabilitation services, and to find out what types of follow-up service recommended by clinicians in LSNRC Units were accessed by patients. This chapter describes:

- The community services that patients were referred on to at the point of discharge from LSNRC Units.
- The number, types and geographic location of services that patients subsequently received after discharge.

7.2 Background

People with LTNCs have diverse needs for rehabilitation services following a hospital stay that can last for many months. Rehabilitation pathways for these patients can be complex and involve various professional groups within both in-patient and community settings, and the crossing of traditional organisational boundaries.

In order to shed light on the types and location of community services accessed by patients following discharge from LSNRC Units, an analysis of these services was carried out.

7.3 Procedure

Community rehabilitation teams (CRTs), along with other community services needed for continued rehabilitation and care planning, were identified by LSNRC clinicians at the point of patients' discharge from in-patient care. Information about the service(s) that each registered patient had been referred on to was passed to the research team, coded and entered onto a database by patient ID number.

To complement these data, at each phase of the research, participating patients and/or their family carers provided information about the types and amount of services received since discharge from hospital. These data were also coded and entered onto a supplementary database by patient ID number.

The two datasets were subsequently integrated to provide summary descriptive data on the types and extent of (a) clinician recommended services and (b) services actually received by patients. Postcode mapping software was used to illustrate the geographical distribution of patients in relation to services received, both at a national level and in greater detail across the Greater London area where the majority lived.

7.4 Results

7.4.1 Discharge destination at registration (Phase 0)

Of the 428 patients discharged from LSNRC Units and included on the LTNC register, 338 (79 percent) were discharged home, while the remaining 80 (21 percent) were referred to various residential settings for on-going medical, rehabilitation and/or nursing care (see Table 15).

Table 15. Destination of patients following discharge from LTNRC Units

Discharge destination	N	%
Home	338	79
Nursing home	52	12
On-going rehabilitation	15	4
Hospital	4	1
Other setting	19	4
TOTAL	**428**	**100**

These discharged patients were predominantly located in London and the surrounding area, though some were more widely dispersed across England and into Wales as shown in Figure 33.

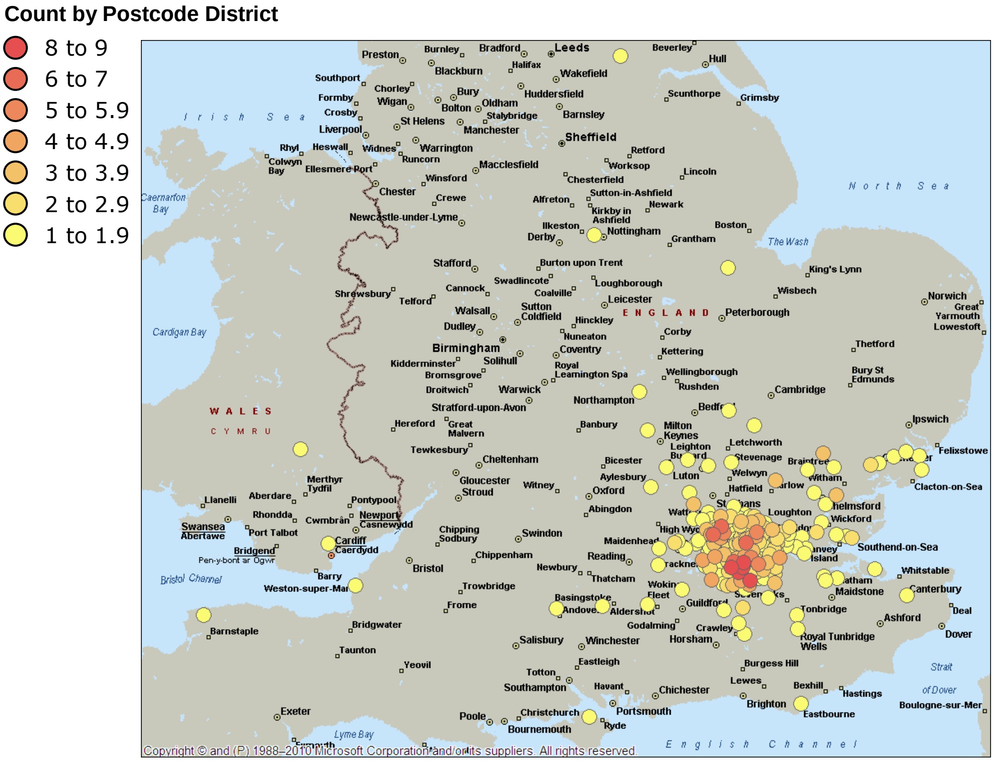


Figure 33. Map showing the geographical location of all participants discharged from LSNRC Units who were included on the LTNC register (N=428)

7.4.2 Referral to community services at registration (Phase 0)

Data on referral to services were missing in 35 cases, but were present for 393/428 (92 percent) of the registered patients. This group were referred for on-going rehabilitation to one or more community services.

In all, 470 referrals were made. The largest proportion of patients (N=324) were referred to one service, a number of others (N=61) had been referred to two services and the remaining few (N=8) to three.

Table 16 sets out the numbers of patients discharged from LSNRC Units and the types of community service they were respectively referred on to.

Table 16. LSNRC Units and types of services that patients were referred to on discharge

Patients discharged and referred (N=428)			Community rehabilitation referrals made (N=470)				
LSNRC Unit	**No record of referral**	**Referred to services**	**In-patient rehab**	**Community rehab teams**	**Out-patient services**	**Vocational rehab**	**Other services**
	N (%)	**N (%)**	**N (%)**	**N (%)**	**N (%)**	**N (%)**	**N (%)**
Blackheath (N=42)	7 (17%)	35 (83%)	4 (10%)	27 (64%)	2 (5%)	1 (2%)	6 (14%)
Edgeware (N=27)	5 (19%)	22 (81%)	0 (0%)	12 (44%)	6 (22%)	3 (11%)	8 (30%)
Homerton (N=37)	0 (0%)	37 (100%)	1 (3%)	33 (89%)	3 (8%)	0 (0%)	5 (14%)
King’s (N=58)	1 (2%)	57 (98%)	3 (5%)	52 (90%)	6 (10%)	3 (5%)	2 (3%)
Maudsley (N=15)	2 (13%)	13 (87%)	3 (20%)	8 (53%)	1 (7%)	2 (13%)	6 (40%)
Northwick Park (N=81)	3 (4%)	78 (96%)	10 (12%)	52 (64%)	9 (11%)	5 (6%)	15 (19%)
Putney (N=6)	6 (100%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)
Queen’s Square (N=64)	1 (2%)	63 (98%)	1 (2%)	46 (72%)	18 (28%)	7 (11%)	10 (16%)
Wolfson (N=98)	10 (10%)	88 (90%)	3 (3%)	76 (78%)	3 (3%)	10 (10%)	8 (8%)
TOTAL	**35 (8%)**	**393 (92%)**	**N=25**	**N=306**	**N=48**	**N=31**	**N=60**

With one exception, LSNRC Units referred from 81 to 100% of their patients to some form of community service. Those most often referred to across all centres were community rehabilitation teams (CRTs), amounting to 65 percent of all referrals, and indicating that the majority of patients required on-going multi-disciplinary input. Out-patient services received referrals for up to 28% of discharged patients.

To ascertain the relationship between patients' residential status after discharge and referral patterns, Table 17 sets out the types of community services patients were referred to in relation to their discharge destination.

Table 17. Patients' discharge destination in relation to services referred to

Patients discharged and referred (N=428)			Community rehabilitation referrals made (N=470)				
Discharge Destination	**No record of referral**	**Referred to services**	**In-patient rehab**	**Community rehab teams**	**Out-patient services**	**Vocational rehab**	**Other services**
	N (%)	**N (%)**	**N (%)**	**N (%)**	**N (%)**	**N (%)**	**N (%)**
Home N=339	17 (5%)	322 (95%)	5 (1%)	275 (81%)	44 (13%)	29 (9%)	43 (12%)
Nursing home (N=53)	15 (28%)	38 (72%)	2 (4%)	20 (38%)	3 (6%)	0 (0%)	15 (28%)
Rehabilitation (N=15)	0 (0%)	15 (100%)	15 (100%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)
Hospital (N=3)	1 (33%)	2 (67%)	2 (67%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)
Other (N=18)	2 (11%)	16 (89%)	1 (5%)	11 (58%)	1 (5%)	2 (11%)	2 (16%)
TOTAL	**35 (8%)**	**393 (92%)**	**N=25**	**N=306**	**N=48**	**N=31**	**N=60**

Four fifths of the patients who had been discharged home had been referred to community rehabilitation teams, with smaller proportions being referred to out-patient services, vocational rehabilitation and other services.

7.4.3 Community services accessed by participants following discharge

Of the 428 discharged patients, 306 (72 percent) completed at least one questionnaire during the following year and provided detailed information about the community services they had received.

A total of 102 different community services were accessed by these 306 participants. They spanned a range of different service types, as illustrated in Figure 34.

Services providing team based rehabilitation were the most prevalent and included those offering generic or intermediate rehabilitation (N=39), specialised rehabilitation for adults with LTNCs (N=22) and mental health or drug and alcohol services (N=7).

Single discipline services (N=9) were delivered either in out-patient departments or in the community and covered physiotherapy, occupational therapy, speech and language therapy, orthotics, psychiatry and psychology. Vocational rehabilitation was provided in one centre, four social services departments provided a range of services and one participant was accommodated in a supported living unit.

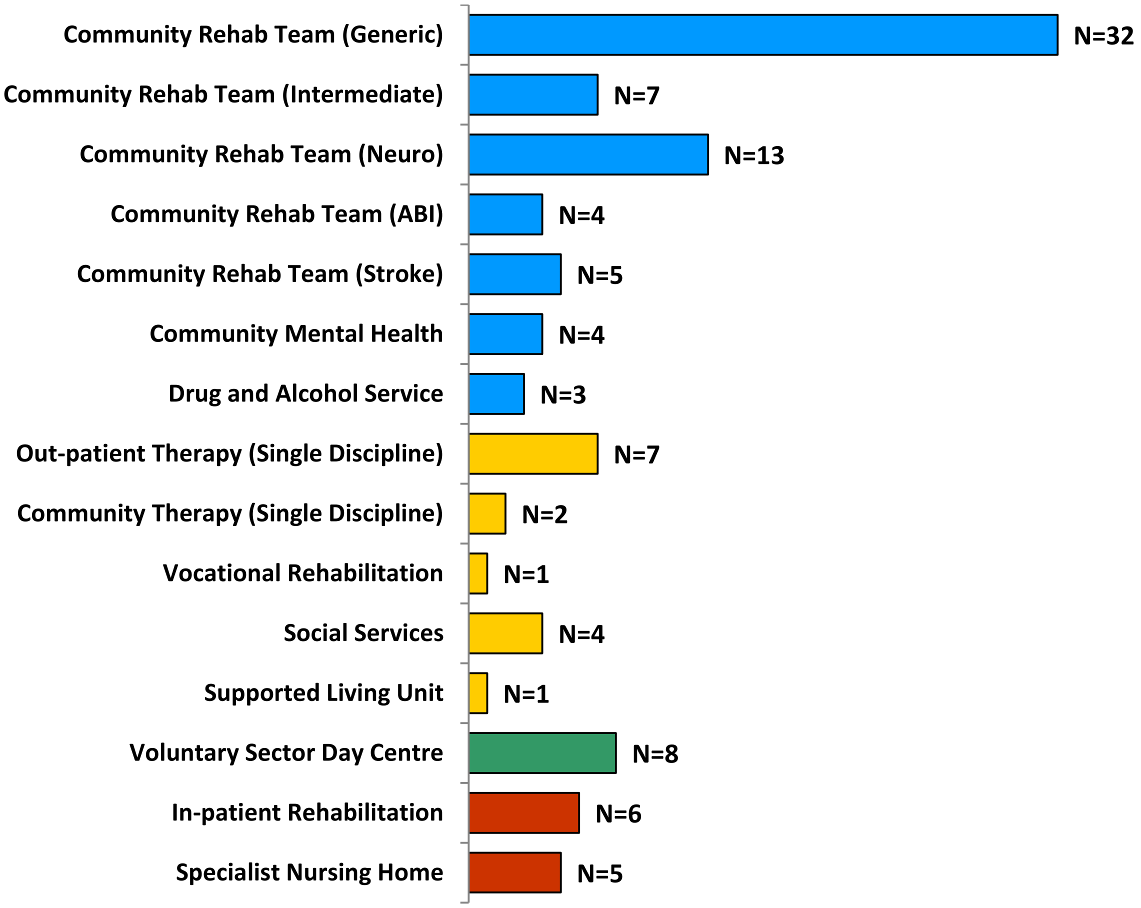


Figure 34. The range of community services (N=102) accessed by participants completing at least one questionnaire (N=306).

The voluntary sector predominantly provided day centre services (N=8). In a number of cases, participants had been discharged for on-going rehabilitation in local in-patient facilities (N=6), or were admitted to residential homes for specialist nursing care (N=5).

7.4.4 Geographical location of study participants and services

Figure 35 shows the geographical spread of

- LSNRC Units
- the 102 community services accessed
- the domicile of patients accessing services across the Greater London area.

This confirms a broad distribution of services, though some areas, particularly in South West London, appeared to have a relative dearth of community based services. Then again, this map does not feature community services that were not accessed by the present cohort.

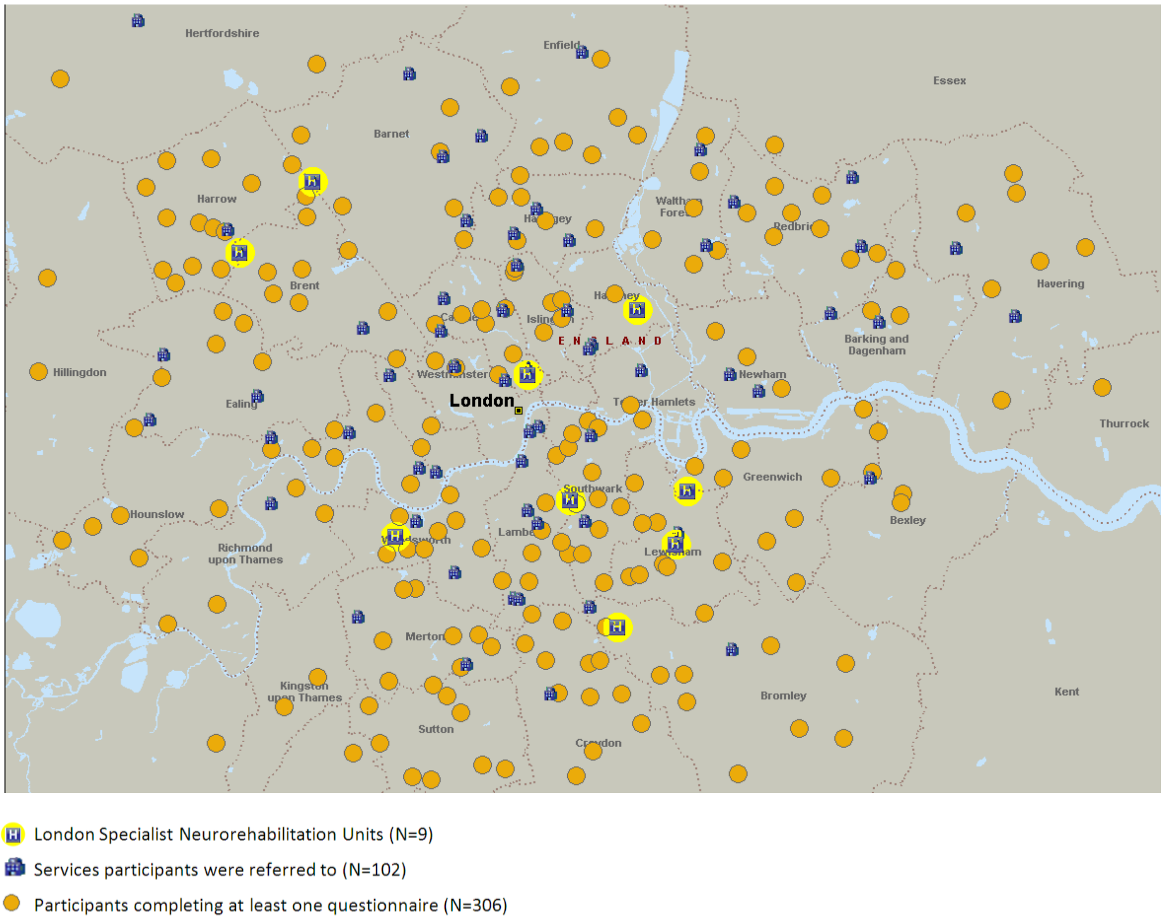


Figure 35. Greater London area map showing location of the nine LSNRC Units, the community rehabilitation services (N=102) accessed and the domicile of participants completing at least one questionnaire who lived in the area.

7.5 Chapter summary

- Four in every five patients returned home following discharge from LSNRC Units and almost all of them were referred on to community rehabilitation teams (CRTs) for on-going rehabilitation.
- Generic CRTs were by far the most prevalent services accessed by patients who completed at least one questionnaire.
- Given the complex types of LTNCs commonly cared for in LSNRC Units, there appeared to be a shortage of specialised CRTs offering on-going rehabilitation for conditions such as ABI and stroke.
- Only one Centre offered Vocational Rehabilitation, supporting the finding in Chapter 6 that, given the significant numbers of patients who needed it, there was a shortage of this type of service.
- Postcode mapping of services in relation to the domicile of patients in the Greater London area suggested that services were thinly spread in some parts of South London.

8 What type and amount of rehabilitation/ support (if any) have they received at six and 12 months post-discharge?

8.1 Overview

This chapter focuses specifically on the level and type of services patients received in the community after their discharge from specialist in-patient rehabilitation.

Descriptive data on health and social care needs, as described by the clinician-rated NPCS-Needs, were presented in Chapter 6 for the N=428 patients recruited to the study at discharge from hospital. In this chapter we examine the extent to which those needs were met for sub-samples of patients who responded at Phases 2 and 3 (six and 12 months respectively after discharge).

As not all patients responded at both Phase 2 (6 months) and Phase 3 (12 months), for both phases the met and unmet needs were calculated by comparing the NPCS-Gets scores with NPCS-Needs scores at Phase 0 for the relevant participants.

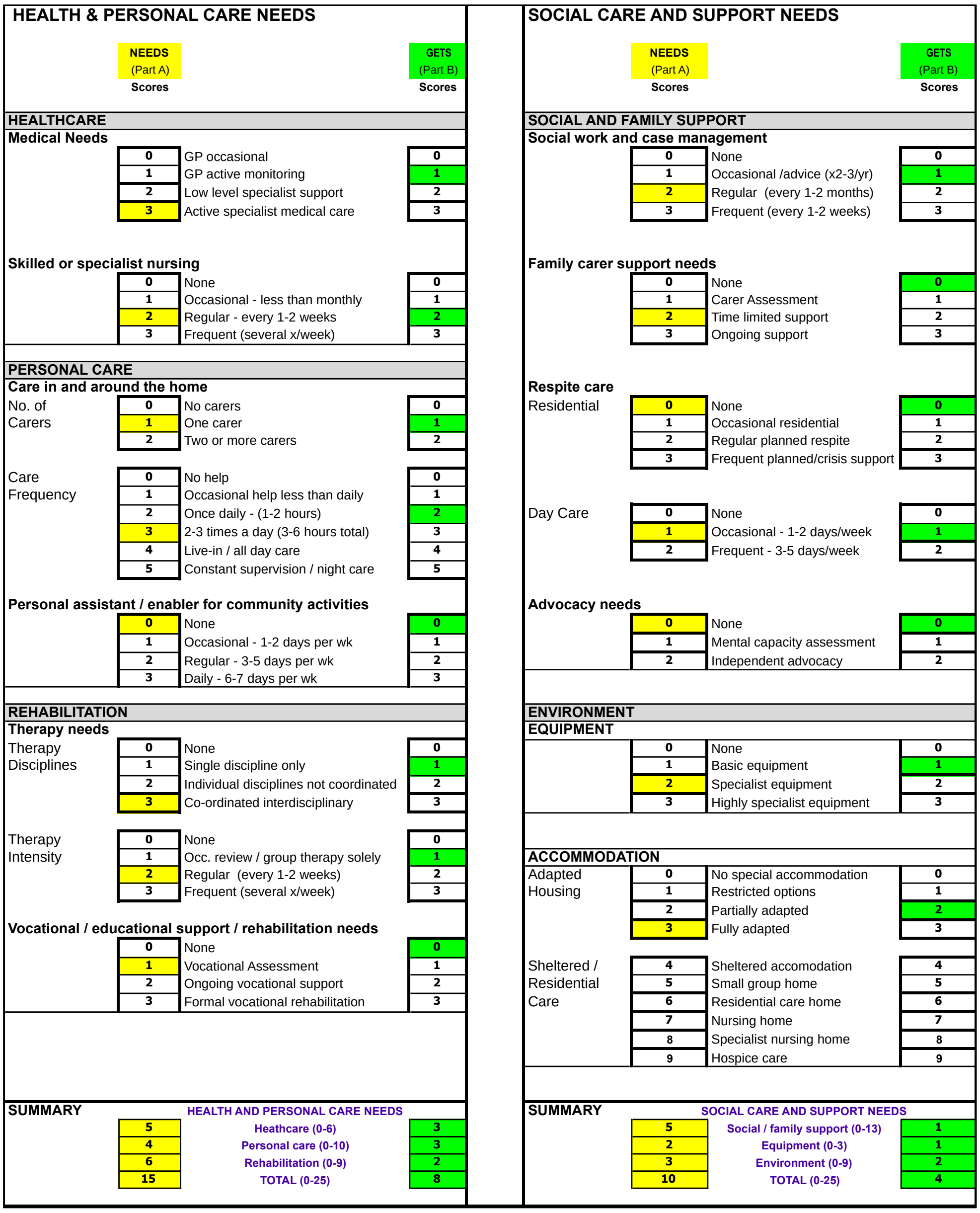
8.2 Study sample

- A total of N=212 participants returned the Phase 2 questionnaire at six months.
- A total of N=190 participants returned the Phase 3 questionnaire at twelve months.
- The number of patients responding at both time points is N=153.

8.3 Procedure

The NPCS represents a 15-item scale, in which item levels represent a hierarchical order of increasing needs (or provision) - (see Figure 36).

The NPCS-Needs were recorded by the treating team at discharge from hospital (Phase 0). The levels of service provision received during the first and second six-month periods after leaving hospital were captured by the NPCS-Gets, as recorded by the patients (or their proxy) at six and 12 months (Phases 2 and 3).



HEALTH & PERSONAL CARE NEEDS

HEALTHCARE

Medical Needs

NEEDS (Part A) Scores		GETS (Part B) Scores
0	GP occasional	0
1	GP active monitoring	[✓ 1]
2	Low level specialist support	2
[✓ 3]	Active specialist medical care	3

Skilled or specialist nursing

NEEDS		GETS
0	None	0
1	Occasional - less than monthly	1
[✓ 2]	Regular - every 1-2 weeks	[✓ 2]
3	Frequent (several x/week)	3

PERSONAL CARE

Care in and around the home

	NEEDS		GETS
No. of Carers	0	No carers	0
	[✓ 1]	One carer	[✓ 1]
	2	Two or more carers	2
Care Frequency	0	No help	0
	1	Occasional help less than daily	1
	2	Once daily - (1-2 hours)	[✓ 2]
	[✓ 3]	2-3 times a day (3-6 hours total)	3
	4	Live-in / all day care	4
	5	Constant supervision / night care	5

Personal assistant / enabler for community activities

NEEDS		GETS
[✓ 0]	None	[✓ 0]
1	Occasional - 1-2 days per wk	1
2	Regular - 3-5 days per wk	2
3	Daily - 6-7 days per wk	3

REHABILITATION

Therapy needs

	NEEDS		GETS
Therapy Disciplines	0	None	0
	1	Single discipline only	[✓ 1]
	2	Individual disciplines not coordinated	2
	[✓ 3]	Co-ordinated interdisciplinary	3
Therapy Intensity	0	None	0
	1	Occ. review / group therapy solely	[✓ 1]
	[✓ 2]	Regular (every 1-2 weeks)	2
	3	Frequent (several x/week)	3

Vocational / educational support / rehabilitation needs

NEEDS		GETS
0	None	[✓ 0]
[✓ 1]	Vocational Assessment	1
2	Ongoing vocational support	2
3	Formal vocational rehabilitation	3

SUMMARY

NEEDS	HEALTH AND PERSONAL CARE NEEDS	GETS
5	Heathcare (0-6)	3
4	Personal care (0-10)	3
6	Rehabilitation (0-9)	2
15	TOTAL (0-25)	8

SOCIAL CARE AND SUPPORT NEEDS

SOCIAL AND FAMILY SUPPORT

Social work and case management

NEEDS (Part A) Scores		GETS (Part B) Scores
0	None	0
1	Occasional /advice (x2-3/yr)	[✓ 1]
[✓ 2]	Regular (every 1-2 months)	2
3	Frequent (every 1-2 weeks)	3

Family carer support needs

NEEDS		GETS
0	None	[✓ 0]
1	Carer Assessment	1
[✓ 2]	Time limited support	2
3	Ongoing support	3

Respite care

	NEEDS		GETS
Residential	[✓ 0]	None	[✓ 0]
	1	Occasional residential	1
	2	Regular planned respite	2
	3	Frequent planned/crisis support	3
Day Care	0	None	0
	[✓ 1]	Occasional - 1-2 days/week	[✓ 1]
	2	Frequent - 3-5 days/week	2

Advocacy needs

NEEDS		GETS
[✓ 0]	None	[✓ 0]
1	Mental capacity assessment	1
2	Independent advocacy	2

ENVIRONMENT

EQUIPMENT

NEEDS		GETS
0	None	0
1	Basic equipment	[✓ 1]
[✓ 2]	Specialist equipment	2
3	Highly specialist equipment	3

ACCOMMODATION

	NEEDS		GETS
Adapted Housing	0	No special accommodation	0
	1	Restricted options	1
	2	Partially adapted	[✓ 2]
	[✓ 3]	Fully adapted	3
Sheltered / Residential Care	4	Sheltered accomodation	4
	5	Small group home	5
	6	Residential care home	6
	7	Nursing home	7
	8	Specialist nursing home	8
	9	Hospice care	9

SUMMARY

NEEDS	SOCIAL CARE AND SUPPORT NEEDS	GETS
5	Social / family support (0-13)	1
2	Equipment (0-3)	1
3	Environment (0-9)	2
10	TOTAL (0-25)	4

Legend: In this example score sheet, the level of Needs for each service are highlighted in yellow on the left, and the corresponding level of provision is highlighted in green on the right. Summary scores for each subscale are given at the bottom of each of the two domains.

Figure 36. Example of an NPCS score sheet rated for 'Needs' and 'Gets'

8.4 Analysis

In Chapter 5 we demonstrated that the NPCS performs at a scale level. We therefore examined overall difference between needs and provision of service by each of the six subscales and the two principal domains using Wilcoxon signed rank tests. Effect sizes for were calculated as: Wilcoxon z/√N; where N= the total number of participants in <u>both</u> groups.

We also performed an item level analysis:

- Simple descriptive statistics were used to describe the level of services provided in relation to needs
- To investigate the extent of met or unmet need at item level we calculated a **discrepancy score** obtained by subtracting the individual patient's needs at discharge from the services reported at six months and 12 months respectively. This discrepancy score revealed two groups of participants for each item:
    - **Unmet Needs** = NPCS Gets at 6 months <NPCS Needs at Phase 0
    - **Met (or exceeded) Needs** = NPCS Gets at 6 months ≥NPCS Needs at Phase 0

8.5 Results

8.5.1 Paired subscale analysis at six months

Table 18 shows the overall differences between NPCS-rated needs (Phase 0) and provision at 6 months (Phase 2) for each subscale and domain (N=212)

Table 18. Differences between NPCS-rated needs (at Phase 0) and provision at six months (Phase 2) for each subscale and domain (N=212).

	NPCS Needs at discharge (P0)		**NPCS gets at 6 months (P2)**		**Statistics**	
NPCS domains and subscales	Median (IQR)	Range	Median (IQR)	Range	Z value (P)	Effect size*
Healthcare (0-6)	2 (1-3)	0-6	2 (1-3)	0-6	-0.19 (0.85)	0.01
Personal (0-10)	4 (1-6)	0-10	4 (1-6)	0-10	-0.19 (0.85)	0.01
Rehabilitation (0-9)	5 (4-6)	0-9	4 (2-5)	0-9	-8.47 **(<0.001)**	0.41
Total Health Domain (range 0-25)	12 (9-14)	0-21	10 (6-13)	0-20	-4.76 **(<0.001)**	0.23
Social care (0-13)	3 (1-5)	0-13	1 (0-3)	0-11	-5.6 **(<0.001)**	0.29
Equipment (0-3)	1 (0-2)	0-3	1 (0-1)	0-3	-5.21 **(<0.001)**	0.26
Accommodation (0-9)	2 (0-2)	0-8	2 (0-2)	0-8	-0.52 (0.60)	0.03
Total Social Domain (range 0-25)	6 (3-9)	0-19	4 (2-6)	0-15	-5.6 **(<0.001)**	0.29

*Effect size for Wilcoxon calculated as z/√N, where N=total patients in both groups

Figure 37 illustrates the difference for the two principal domains.

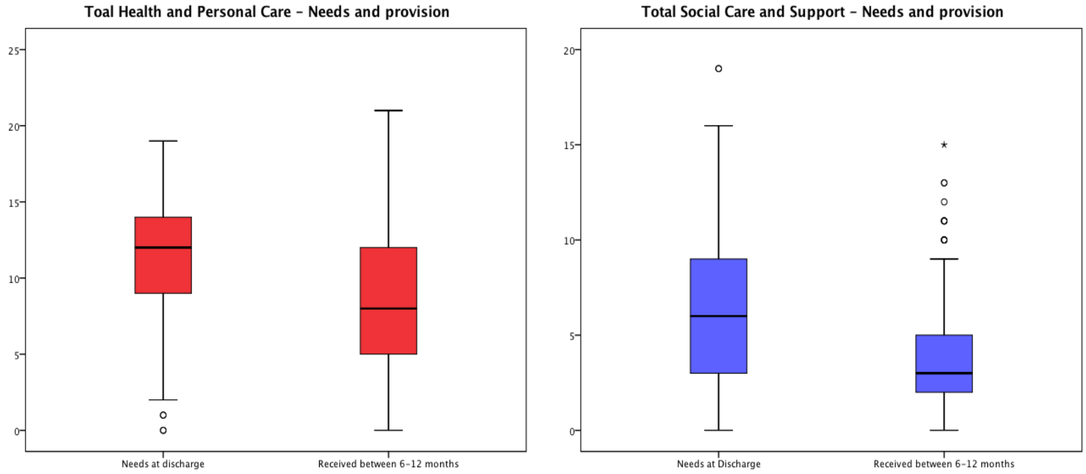


Figure 37. Box plots of the 'Health and personal care' and the 'Social care and support' domains for NPCS-Needs at Phase 0 and NPCS-Gets at 6 months (N=212)

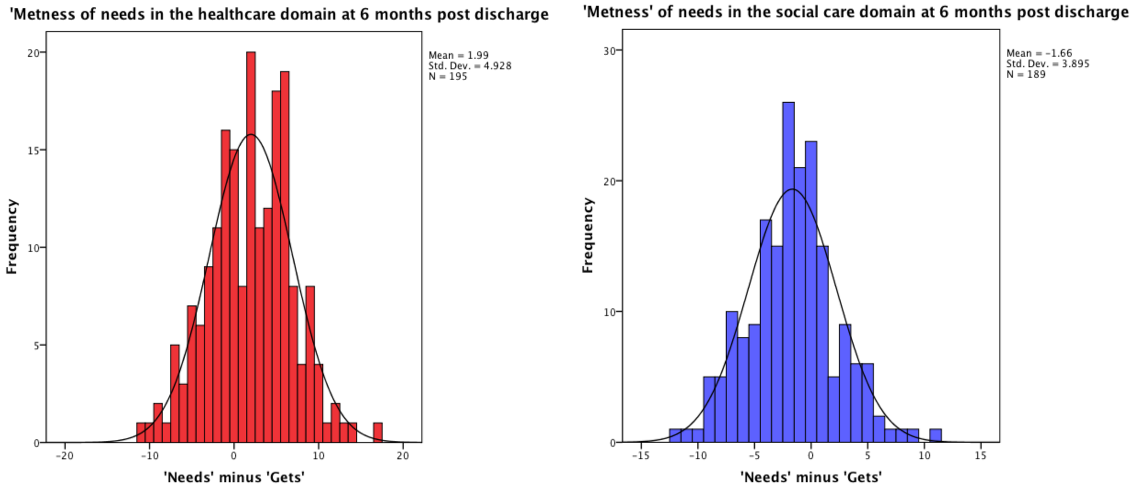


Figure 38. Histograms of the discrepancy scores ('Needs' minus 'Gets') for the NPCS 'Health and personal care' and the 'Social care and support' domains at 6 months post discharge (N=212)

There were statistically significant differences between needs and provision at 6 months for both the 'health and personal care domain (Wilcoxon z -4.76, p<0.001; Effect size (ES) 0.23) and the Social care and support domain (Wilcoxon z -5.6 p<0.001, ES 0.29).

However at subscale level, the data told a different story.

Within the Health and personal care domain, needs for medical and nursing care and personal were relatively well met; whereas needs for rehabilitation were significantly under-met (z -8.5 p<0.001, ES 0.41).

Within the social care and support domain, although needs for accommodation were relatively well met, there were significant unmet needs in both the social care (z -5.6, p<0.001, ES 0.29) and equipment (z -5.2, p<0.001, ES 0.26) subscales.

8.5.2 Item by item analysis at six months

In chapter 6, we examined the needs for rehabilitation and social care in an item-by-item analysis. It is therefore pertinent to examine service provision in relation to those needs at item level.

Firstly it was necessary to confirm that the needs of the patients responding at 6 months (N=212) were representative of those of the recruited sample (N=428). A detailed item-by-item breakdown of the scoring levels at Phase 0 for both the total (N=428) and the subsample (N=212) is given in Appendix 7. This analysis shows that:

- The evaluation NPCS-needs (i.e. the proportion of patients scoring each level score for each item) is very similar for P2 respondents (N=212) as for the recruited sample (N=428) in 14/15 of the NPCS items.
- The exception to this rule is the need for vocational rehabilitation (VR). Approximately 25% of the recruited group (N=428) were recorded at P0 to require vocational support or rehabilitation and a further 20% to require vocational assessment, leaving only 55% with no needs for VR input. However for the subsample of N=212, less than 10% required VR, and 5% required assessment, leaving 87% with no identified rehabilitation needs at Phase 0.

Therefore the 50% or so of patients who responded at 6 months may be said with some confidence to be representative of the total sample in respect of their needs for health and social care (with the possible exception of their needs for vocational rehabilitation).

To determine whether patients' needs for on-going rehabilitation had been met during the year following discharge from LSNRC Units, NPCS scores across the fifteen service-related domains were analysed.

Figure 39 summarises the proportions of individual met (or exceeded) and unmet needs across the 15 NPCS items at six months post discharge. Within the health and personal care domain, needs for medical, nursing care and basic personal care were met or exceeded in over 70% of cases. However, needs for a personal enabler were met less often (53%) and half had unmet need for therapy – both in terms of the number of disciplines required and intensity of input. Vocational needs were met for approximately two-thirds of the sample. However, as noted above, the needs of this particular group were low compared with the total recruited sample.

In the social care and support domain, fewer than half of the patients (44%) had their needs for social worker / case management support met. Needs for respite and advocacy support were relatively well met in this group, but over 75% of the sample had no identified needs in this area. Accommodation needs were met in 78% of the sample but 61% had unmet equipment needs.

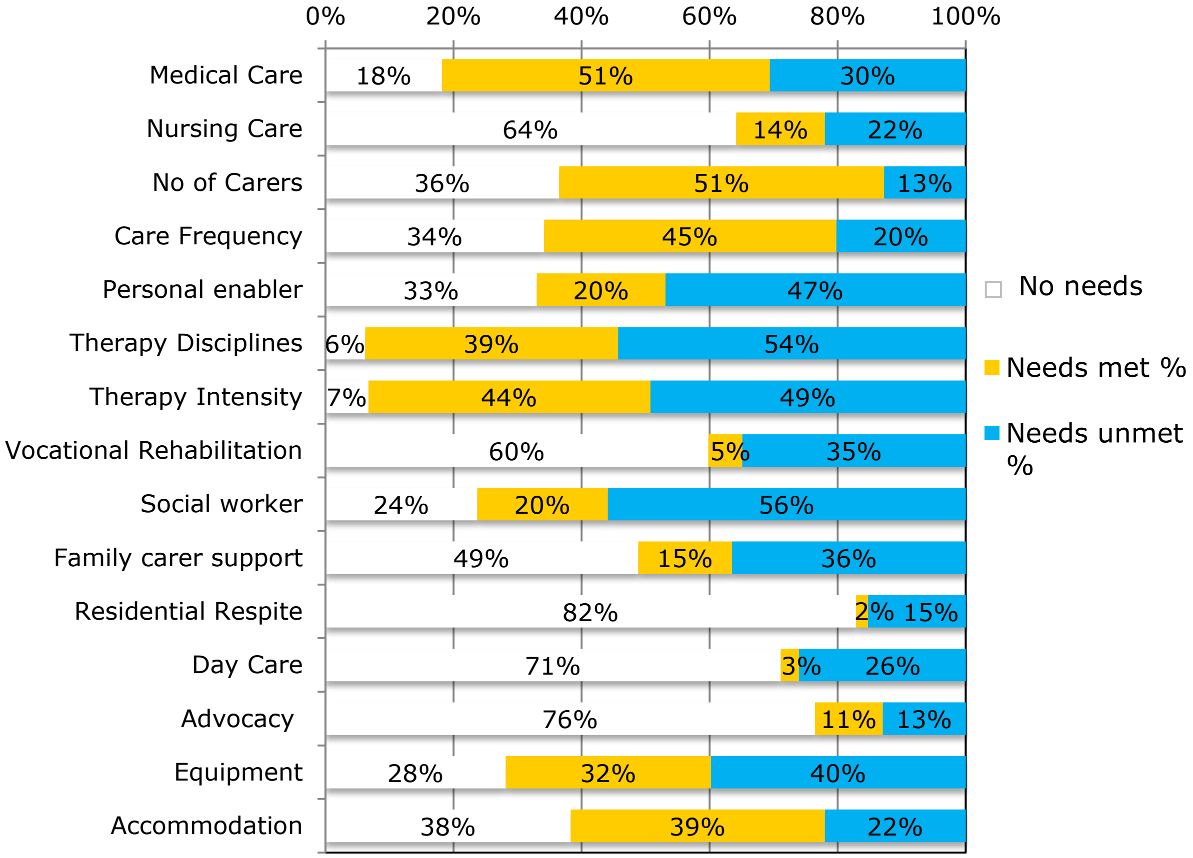


Figure 39. Proportions of patients' whose service needs were met (or exceeded) and unmet at six months after discharge from LSNRC Units (N=211)

Table 19 shows the difference between 'Needs' and 'Gets' at item level, tested by Wilcoxon signed rank tests. To allow for multiple tests, the threshold for significance was taken as 0.003.

The results mirrored the findings of subscale analysis, showing shortfalls in provision for items relating to rehabilitation, social support and equipment.

The exception was in Carer frequency, where support provided at 6 months exceeded the predicted need. This may suggest deterioration of independence for some patients after discharge, possibly as a result of the failure to meet needs for rehabilitation and social support.

Table 19. Item level statistical analysis of needs versus provision.

	Needs	Gets at 6 months	Wilcoxon signed rank tests		
			Z	p*	ES
Medical	2 (1-2)	2 (1-2)	-0.06	0.95	0.00
Nursing	0 (0-1)	0 (0-1)	-0.08	0.93	0.00
No of Carers	1 (0-1)	1 (0-1)	-2.04	0.04	-0.10
Care Frequency	2 (0-3)	3 (0-4)	-3.33	**<0.001**	-0.16
Personal enabler	1 (0-2)	0 (0-1)	-6.28	**<0.001**	-0.31
Therapy Disciplines	3 (2-3)	2 (1-2)	-7.67	**<0.001**	-0.37
Therapy Intensity	2 (2-3)	2 (1-2)	-5.81	**<0.001**	-0.28
Vocational Rehabilitation	0 (0-1)	0 (0-0)	-5.55	**<0.001**	-0.27
Social worker/Case management	1 (1-2)	0 (0-1)	-7.50	**<0.001**	-0.37
Family carer support	1 (0-1)	0 (0-1)	-2.54	0.01	-0.12
Respite - residential	0 (0-0)	0 (0-0)	-3.61	**<0.001**	-0.18
Respite Day care	0 (0-1)	0 (0-0)	-5.83	**<0.001**	-0.29
Advocacy needs	0 (0-0)	0 (0-0)	-1.96	0.06	-0.10
Equipment	1 (0-2)	1 (0-1)	-5.20	**<0.001**	-0.26
Accommodation	2 (0-2)	2 (0-2)	-.52	0.60	-0.03

*Adjusted probability to allow for multiple tests (N=15):
Threshold for significance is 0.05/15 = 0.003

8.5.3 Phase 3: Subscale analysis 12 months post discharge

Table 20 shows the overall differences between NPCS-rated needs (at Phase 0) and provision at 12 months (Phase 3) for each subscale and domain (N=190).

Figure 40 illustrates the difference for the two principal domains. The findings are similar to those at 6 months, with significant shortfalls in community rehabilitation, social support and equipment - except that the increase in care provision is no longer evident. As a result there is now a significant shortfall in provision for both the Health and the Social care domains, compared with Needs as assessed at discharge.

Table 20. Differences between NPCS-rated needs (at Phase 0) and provision at 12 months (Phase 3) for each subscale and domain (N=190)

	NPCS Needs at discharge		**NPCS gets at 12 months (N=190)**		**Statistics**	
NPCS domains and subscales	Median (IQR)	Range	Median (IQR)	Range	Z value (P)	Effect size*
Healthcare (0-6)	2 (1-3)	0-6	2 (1-3)	0-6	-0.39 (0.69)	0.02
Personal (0-10)	4 (1-6)	0-10	4 (1-5)	0-10	-1.2 (0.23)	0.06
Rehabilitation (0-9)	5 (4-6)	0-9	3 (0-4)	0-9	-9.63 **(<0.001)**	0.49
Total Health Domain (total range 0-25)	12 (8-14)	0-21	9 (5-12)	0-21	-6.6 **(<0.001)**	0.34
Social care (0-13)	2 (1-4)	0-11	2 (0-2)	0-11	-6.56 **(<0.001)**	0.34
Equipment (0-3)	1 (1-2)	0-3	1 (0-1)	0-3	-6.07 **(<0.001)**	0.31
Accommodation (0-9)	1 (0-2)	0-8	2 (0-2)	0-8	-1.48 (0.14)	0.08
Total Social Domain (total range 0-25)	5 (3-8)	0-18	3 (2-5)	0-15	-5.99 **(<0.001)**	0.31

*Effect size for Wilcoxon calculated as z/√N, where N=total patients in both groups

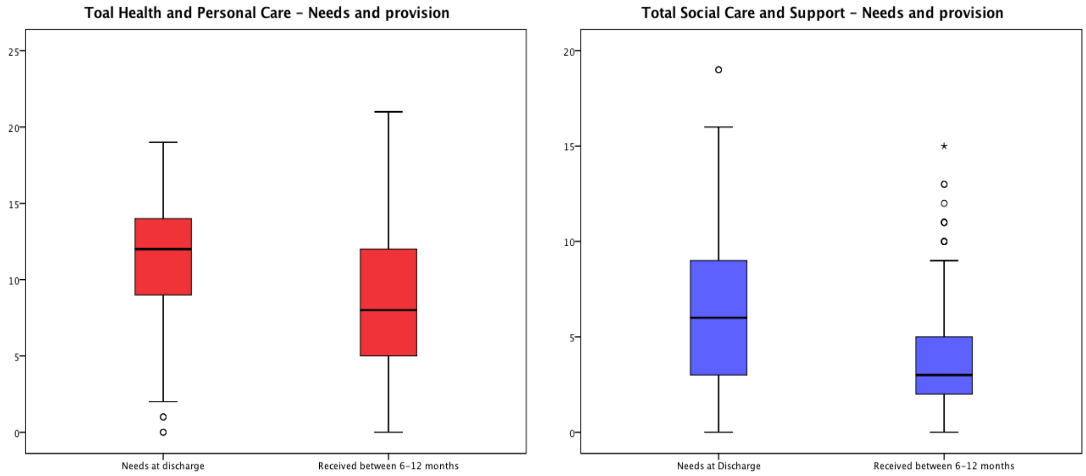


Figure 40. **box plots of the 'Health and personal care' and the 'Social care and support' domains for NPCS-Needs at Phase 0 and NPCS-Gets at 12 months (N=212)**

As Table 21 demonstrates, the differences in service provision cannot be accounted for by any difference in the level of dependency between the samples responding at 6 and 12 months.

For the patients (N=153) who responded at both occasions, there was a significant reduction in the provision of rehabilitation, social work support and equipment between 6 and 12 months post discharge, but no corresponding change in physical dependency (Barthel Index and NPDS) or care requirements (total weekly care hours, as estimated by the NPCNA).

Table 21. Wilcoxon rank tests for NPCS subscales and dependency ratings in the group (N=153) who responded at both 6 and 12 months

	NPCS score	**NPCS score**	**Statistics - Wilcoxon signed rank test**		
N=153	Median (IQR) 6 months	Median (IQR) 12 months	Z value	P value	Effect size*
NPCS Domains and subscales					
Healthcare (0-6)	2 (1-4)	2 (1-3)	-1.15	0.25	0.07
Personal (0-10)	4 (1-6)	4 (0-6)	-1.70	0.09	0.10
Rehabilitation (0-9)	4 (3-5)	3 (0-4)	-4.94	**<0.001**	0.28
Total Health Domain (0-25)	10 (6-13)	8 (5-12)	-4.24	**<0.001**	0.24
Social care (0-13)	1 (0-3)	2 (0-2)	-3.33	**0.001**	0.19
Equipment (0-3)	1 (0-2)	0 (0-1)	-2.56	**0.01**	0.15
Accommodation (0-9)	2 (0-2)	2 (0-2)	-1.62	0.11	0.09
Total Social Domain (0-25)	4 (2-6)	2 (3-5)	-2.34	**0.02**	0.13
Dependency ratings					
Total Barthel index	16 (12-19)	17 (12-20)	-1.68	0.09	0.10
Total NPDS	7 (2-17)	6 (2-18)	-1.52	0.13	0.09
Total Care Hours per week (NPCNA)	14 (3-40)	12 (0-41)	-1.86	0.10	0.11

8.5.4 Item by item analysis at 12 months

Figure 41 shows a similar analysis for met and unmet need in the subsample (N=190) who responded at 12 months.

Interestingly, the pattern of met and unmet needs across the fifteen service related domains was almost identical to that shown at six months, and the proportions of unmet needs varied by fewer than six percentage points across all services, with the exception of therapy disciplines, in which unmet need had increased by ten percent.

Needs for personal enablement, support and for equipment had also increased by six percent respectively.

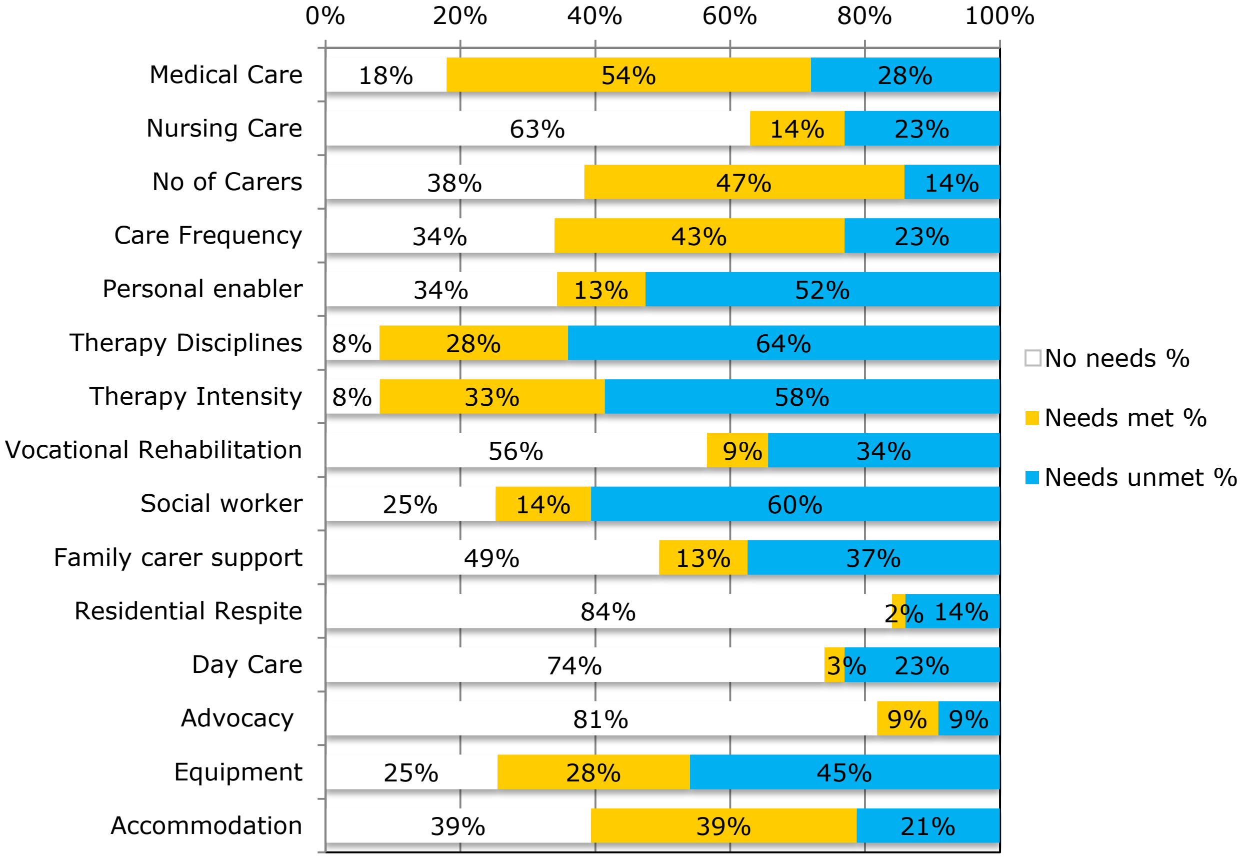


Figure 41. Proportions of patients' whose service needs were met/exceeded or unmet at twelve months after discharge from LSNRC Units (N=190).

Table 22 shows the difference between 'Needs' and 'Gets' at item level, tested by Wilcoxon signed rank tests. The findings are similar to those at 6 months. Again there is a trend towards provision of personal care in excess of predicted needs, although this no longer reached significance.

Table 22. Item level statistical analysis of needs versus provision

	Needs	**Gets at 12 months**	**Wilcoxon signed rank tests**		
			Z	**p***	**ES**
Medical	2 (1-2)	2 (1-3)	-0.83	0.40	-0.04
Nursing	0 (0-1)	0 (0-1)	-1.53	0.12	-0.08
No of Carers	1 (0-1)	1 (0-1)	-2.1	0.03	-0.11
Care Frequency	2 (0-3)	2 (0-4)	-2.01	0.04	-0.10
Personal enabler	1 (0-2)	0 (0-1)	-6.62	**<0.001**	-0.34
Therapy Disciplines	3 (2-3)	1 (0-2)	-8.86	**<0.001**	-0.46
Therapy Intensity	2 (2-3)	1 (1-2)	-8.20	**<0.001**	-0.42
Vocational Rehabilitation	0 (0-1)	0 (0-0)	-6.04	**<0.001**	-0.31
Social worker/Case management	1 (1-2)	0 (0-1)	-8.72	**<0.001**	-0.45
Family carer support	1 (0-1)	0 (0-1)	-2.20	0.03	-0.11
Respite - residential	0 (0-0)	0 (0-0)	-2.42	0.01	-0.13
Respite Day care	0 (0-1)	0 (0-0)	-2.93	**0.003**	-0.15
Advocacy needs	0 (0-0)	0 (0-0)	-2.28	0.02	-0.12
Equipment	1 (0-2)	0 (0-1)	-6.07	**<0.001**	-0.31
Accommodation	2 (0-2)	2 (0-2)	-1.48	0.14	-0.08

*Adjusted probability to allow for multiple tests (N=15):
Threshold for significance is 0.05/15 = 0.003

The interpretation of frequencies reported here for met (or exceeded) and unmet need, for each NPCS item needs to be considered cautiously. There are several points to bear in mind in considering these descriptive statistics.

- Firstly, an individual person's actual needs might have changed during the study due to changes in their physical condition. For example, a participant who has a fall or develops complications after six months might need more therapy or specialised equipment than was needed during the first six months. Thus simply subtracting their level of needed rehabilitation at twelve months from their level at six months could be misleading. Within the design of this study no provision was made for expert reassessment at either of the follow-up periods to determine whether the needs for input had changed.

- Secondly, even small numbers of individuals not getting their needs met constitutes a serious shortfall in services. For example only 15 percent of the sample reported any needs for residential respite care. However these participants almost certainly represent many of the most severely disabled among the sample and this respite care could be essential to the health and psychological well-being of their family/carer.

8.6 Limitations

While participant reports of services provided were obtained at six and 12 months the only clinical appraisal of each participant's needs was obtained at discharge. A person's needs for healthcare, rehabilitation and support services can change over time, sometimes dramatically, and it would have been preferable to obtain a second clinical NPCS rating at six or 12 months to strengthen these findings. While this was beyond the scope and resources of the present study it would be useful to build this in to future research involving the NPCS.

Of the original 428 participants recruited 212 responded at six months and 190 at 12 months with 153 of these participants responding at both time points. While statistical comparisons showed these groups to be similar to the original sample, with respect to demographic and diagnostic characteristics, it is possible that this attrition could have attenuated the sample's representativeness.

8.7 Chapter summary

In this chapter, we examined the extent to which health and social care needs, as assessed by the clinicians at discharge from in-patient rehabilitation (Phase 0) were and were not met during the first and second six month period after discharge.

- The sub-samples of patients responding at six and 12 months were shown to be representative of the total recruited sample (N=428) in respect of their needs for rehabilitation.
- At 6 months post discharge, the NPCS demonstrated significant gaps between needs and service provision, especially with respect to on-going community rehabilitation, equipment and social support. By contrast, needs for medical, nursing were relatively well met.
- Item level frequencies of met and unmet needs shown a similar overall picture with more than half the respondents not having their needs for therapy input and/or social worker/case management support met at six months and over 40 percent not having their needs for personal enablement and/or equipment met.

- Provision of support for personal care above the level of predicted need may suggest deterioration of independence for some patients after discharge, possibly as a result of the failure to meet needs for rehabilitation and social support.
- An almost identical pattern of met and unmet needs was seen at 12 months post discharge
- Findings must be interpreted with caution as needs may have changed since discharge from rehabilitation and were not formally reassessed either at six or 12 months.
- It is also important to remember that, even if need are met for the majority of patients, for the small number of individuals whose needs are not met, this can still constitute a serious shortfall in services.
- Therefore the group reporting dissatisfaction with their levels of rehabilitation service provision at 12 months were examined in more detail (see Chapter 14).

9 Where are they referred to for further rehabilitation and what kind of rehabilitation is prescribed?

9.1 Overview

In this chapter we examine the patient characteristics at baseline that may influence the amount of health and social services they receive after discharge from in-patient rehabilitation.

We report the results of multiple regression analyses that aimed to identify those variables that influence the level of rehabilitation services received by participants at six months after discharge into the community.

- The primary outcome variable in these analyses was the NPCS total score for participants at six months. This score represents a global summary of all aspects of healthcare, rehabilitation therapy and social support that participants and/or their carer had reported occurring within six months of re-entering the community.
- We chose six months, rather than 12 months, as the primary outcome time point for these analyses, because in previous work we have demonstrated a significant fall off in both health and social services between six and 12 months.

Specifically we examined the following question and hypothesis:

1. Which of the following variables predict the overall level of rehabilitation services received?
    - demographics
    - level of physical impairment
    - need for basic and special nursing care
    - social integration in the community
    - presence of cognitive/behavioural problems
2. Previous work has demonstrated a particular shortfall in rehabilitation and support needs for patients with cognitive / behavioural problems.[2] Therefore, we hypothesised in particular that people with cognitive/ behavioural problems are likely to receive lower levels of rehabilitation.

9.2 Study sample

Participants included in the following analyses were those participants with complete data sets at discharge (Phase 0) and at six months post-discharge (Phase 2). This meant the sample available for the regression analyses was typically a little smaller than the full six month sample of 212 due to missing data on some items.

9.3 Statistical analyses

Preliminary analysis of the total NPCS score distribution revealed that data were distributed within acceptable limits of normality (see Figure 42), so they were considered appropriate for parametric linear regression analysis.

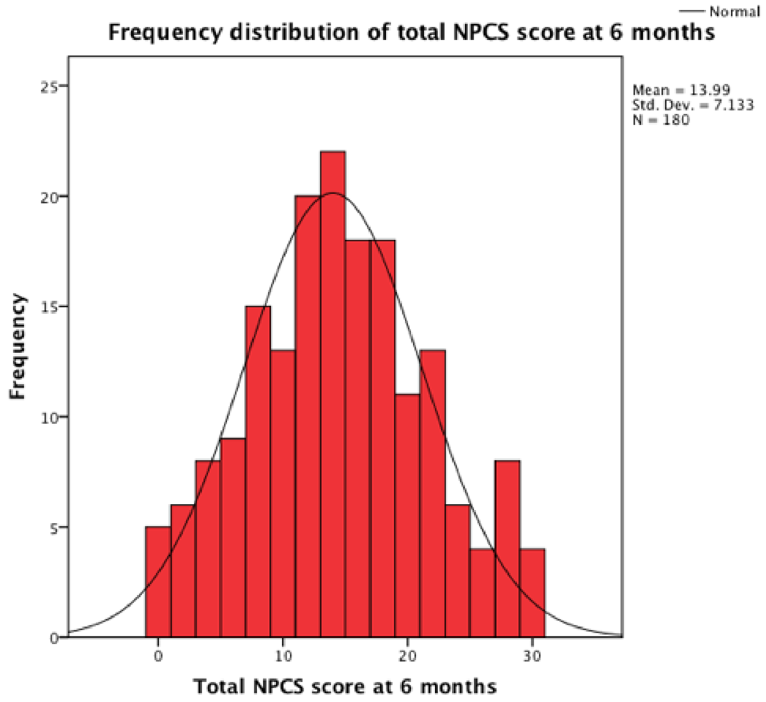


Figure 42. Frequency distribution of total NPCS score

1. Demographic variables: Characteristics of interest were: age, gender, ethnicity, marital status, education and diagnostic category. These were each entered as the predictor variable in separate univariate regression analyses with total NPCS score as the dependent variable. Age was treated as a continuous variable and the remaining five were all coded as 'dummy' or categorical variables.
2. Continuous variables for level of physical impairment, need for basic and special nursing care, and social integration in the community were all entered as the predictor variable in univariate regression analyses with the total NPCS score as the dependent variable and then the best predictors were entered into a stepwise multiple regression analysis. These three variables were identified by the relevant standardised psychometric scale as follows:
    - The level of physical impairment was identified through the Neurological Impairment Scale (NIS) scores - (NIS Motor and NIS Cognitive subscales) as rated by the clinicians at Phase 0.
    - Disability (dependency on assistance for basic and special nursing care) were identified from the two subscales of the Northwick Park dependency Score (NPDS) – NPDS-BCN (Basic Care Needs subscale) and NPDS-SNN (Special Nursing subscale) (as rated by self-report at baseline (Phase 1), shortly after discharge)

- Social integration was identified from the Community Integration Questionnaire (CIQ total score) rated by self report at Phase 1
- To determine whether people with cognitive behavioural problems received less rehabilitation a score representing the severity of participants' cognitive behavioural problems (CBP) was calculated by summing the three NPDS items that refer to problems regarding (i) safety, (ii) communication and (iii) behaviour. The total NPDS cognitive behavioural (NPDS-CB) score can range from 0 – 12. The distribution of NPDS-CB scores for participants at six months and the correlation between NPDS-CB score and NPCS score was calculated.

2. Participants were then divided into three groups:
    a) no CBPs (NPDS-CB score = 0),
    b) some CBPs (NPDS-CB = 1 – 3) and
    c) substantial CB problems (4 - 12).

A one way ANOVA was used to test for any differences in total NPCS across the three groups and a separate univariate regression analysis was then completed to see how well CBP at baseline predicted NPCS scores at 6 months.

9.4 Results

9.4.1 Demographic variables

None of the six demographic variables predicted a significant proportion of variance in the total NPCS score. These results are summarised in Table 23 below.

Table 23. Results of Univariate Regression Analyses of Demographic Variables as Predictors of Rehabilitation Received at Six Months (N=180)

Independent variable	F	R^2	p
Age	0.25	0.00	0.62
Gender	0.13	0.00	0.72
Ethnicity	0.04	0.00	0.99
Marital Status	1.37	0.02	0.25
Education	1.12	0.03	0.35
Diagnosis	1.74	0.06	0.11

9.4.2 Other variables

Table 24 below presents the results of the univariate regression analyses of baseline physical and cognitive impairment, care dependency and community integration as predictors of overall rehabilitation received in the first six months after discharge. Inspection of Table 24 shows that Basic Care Needs as measured by the NPDS-BCN scale was the best individual predictor of services received at six months accounting for some 39 percent of overall variance in NPCS Total score.

Table 24. Univariate Regression Analyses of Baseline Physical and Cognitive Impairment, Care Dependency and Community Integration as Predictors of Rehabilitation Received in First Six Months Post-Discharge.

Individual Predictor	β	CI (95%)	p	R^2
Neurological Impairment-Motor (NIS-Physical)	0.59	0.41 – 0.77	0.001	0.29
Cognitive – Behavioural Problems (NPDS-CB)	1.22	0.85 – 1.59	0.001	0.22
Basic Care Needs (NPDS-BCN)	0.36	0.28 – 0.43	0.001	0.39
Special Nursing Needs (NPDS-SNN)	1.00	0.69 – 1.32	0.001	0.21
Community integration (CIQ)	-0.61	-0.82 --0.40	0.001	0.21

In the stepwise model (see Table 25) Basic Care Needs remained the best single predictor accounting for 33 percent of the model variance. The addition of Motor and Cognitive Impairment (as measured by the NIS subscales) improved the predictive ability of the stepwise model by small but significant increments to a total R^2 of 40 percent.

Table 25. Stepwise Regression Analyses of Best Individual Predictor Variables of NPCS at 6 Months

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

Variables not included in model = SNN, CBP, CIQ

Table 26. Frequency Distribution of Scores on Cognitive-Behavioural Problems scale (NPDS-CB)

Score (0 – 12)	N	%	Σ %
0	66	37.1	37.1
1	35	19.7	56.7
2	16	9.0	65.7
3	17	9.6	75.3
4	9	5.1	80.3
5	9	5.1	85.4
6	8	4.5	89.9
7	8	4.5	94.4
8	5	2.8	97.2
9	3	1.7	98.9
10	0	0	98.9
11	2	1.1	100.0
12	0	0	100.0
Total	178	100	100.0

The Spearman correlation between the summed score for these three items (3-4 weeks post-discharge) and total NPCS score at six months is rho=0.43 (N=180, p<0.001).

If the 66 people scoring zero for NPDS-CB (see Table 26) are not included, the correlation increases to rho = 0.47. A linear regression (for the whole sample) using NPDS-CB at 3-4 weeks predicts 22 percent of variance in NPCS total scores at six months.

Participants were then divided into three categorical groups: 'No' CB problems (NPDS-CB=0) 'some' (NPDS-CB =1-3) and 'substantial CB' problems (NPDS-CB 4 - 12). Mean NPCS scores were calculated for these three groups as shown in Table 27.

Table 27. Mean NPCS Scores at Six Months for Baseline CBP Groups

CBP (0-12)	NPCS $\bar{X}$	N	Std. Dev.
0	11.00	55	6.65
1 - 3	12.98	60	5.21
4 -12	19.16	37	6.69
Total	13.77	152	6.88

A one-way ANOVA confirmed that these means were significantly different (F=20.41, df=2, p<0.001). A post-hoc Tukey test showed the significance resulted from the difference between the group scoring 4+ (substantial problems) and the other two groups.

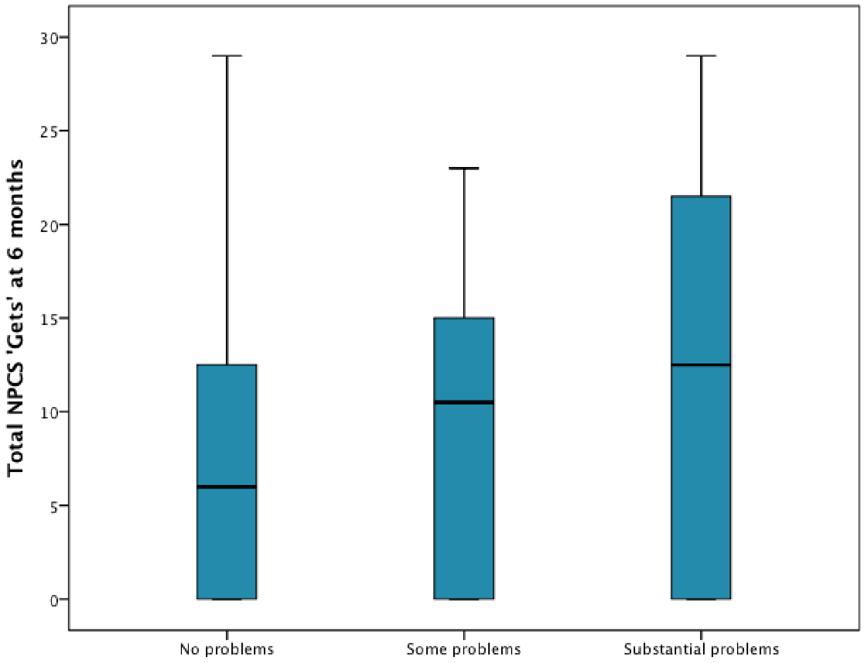


Figure 43. Box plot of NPCS Scores at Six Months Post-Discharge for CBP Groups

The distribution of NPCS 'Gets' scores at six months across patients without cognitive-behaviour problems versus those with some problems and those with substantial problems is compared in Figure 43. The correlation between overall cognitive-behaviour problems at Phase 1 (3 to 4 weeks) and at Phase 2 (6 months) is rho=0.79 (N=178, $p<0.01$).

A potential alternative method of estimating cognitive behavioural problems would be the clinician generated scores from discharge on the cognitive/behavioural items of the NIS i.e. NIS-Physical. However these predicted only 14 percent of variance in NPCS scores at six months.

This is not surprising as the impairment scores are quite different from the NPDS-CB scores. NIS cognitive scores simply rate the presence and severity of the impairment, whereas the NPDS-CB items are designed to evaluate the consequences of the CB problems in terms of needs for care.

9.5 Limitations

One limitation of the present study is that all of the variables employed in the regression analyses, apart from the NIS scores, came from participant self-report (i.e. patient or carer) and these are subjective. For example, scores representing cognitive/behavioural problems were based upon self-report on three items. This assumes a degree of objectivity and insight concerning one's own cognitive deficits that might be outside the abilities of some participants. Or a carer who is under severe stress might have difficulty acknowledging any positive aspects of the services received.

As far as possible we endeavoured to minimise any such potential sources of error through (a) a large sample, (b) assuring participants of confidentiality throughout, (c) telephone support for completing questionnaires, and (d) familiarising participants with all measures over three assessments.

9.6 Chapter summary

- We found no evidence that demographic variables including age, gender, marital status, education or diagnosis predicted how much rehabilitation/support people reported receiving at six months after discharge from hospital.
- The best single predictor of rehabilitation and support services received at six months was dependency or basic care needs as measured by the BCN scale of the NPDS which accounted for 33 percent of variance in total NPCS. Motor and cognitive impairment as measured by the NIS subscales improved the predictive ability of the model by small but significant increments to a total R^2=40 percent.
- We found no evidence to support the hypothesis that people with cognitive behavioural problems are likely to receive less rehabilitation. In fact people with high levels of CBPs had a significantly higher mean NPCS score than people with no CBPs or people with mild CBPs. Furthermore the NPDS-CB score is a reasonably good predictor of total NPCS score R^2=22 percent.
- The NPDS-CB scale was found to be a better predictor of the needs for health and social support than the NIS-cognitive subscale, as it is designed to evaluate the consequences of the CBP in terms of needs for care, as opposed to simply the severity of impairment.
- In other words, whether the disability is physical or cognitive – the more disabled patients receive greater levels of health and social services.

10 Is there a relationship between the quality and quantity of rehabilitation after discharge and outcomes with respect to disability and community integration?

10.1 Overview

This chapter examines the relationship between the levels of rehabilitation received after discharge from specialist rehabilitation services and two important outcomes at six months post-discharge, namely Community Integration and Carer Burden. Community integration is the extent to which the person with a LTNC participates in their local community and carer burden reflects the potential psychological distress and social strain on carers of supporting the person. In particular we test the hypothesis that individuals receiving higher levels of health and social services support achieve better outcomes, in terms of improved community integration and reduction of care burden, than those receiving little or no rehabilitation.

10.2 Study sample

Participants in the present analyses comprised all those remaining from the 428 Phase 0 recruits, who completed the survey questionnaires at six months (N=212). This represents a 50% attrition rate. These participants are described in detail in Chapter 3.

10.3 Measures

Dependent Variables

There were two outcome variables predicted in the present set of analyses:

1. Community Integration at six months measured by the CIQ.
2. Perceived Carer Burden at six months measured by the ZBI.

Independent Variables

The predictor variables included in this set of analyses included:

1. Neurological Motor Impairment at discharge measured by the NIS-M.
2. Neurological Cognitive Impairment at discharge measured by the NIS-C.
3. Physical disability (as measured by the NPDS-P - see section 10) at 4 weeks post-discharge
4. Cognitive Behavioural Problems (as measured by the NPDS-CB- see section 9.4.2) at 4 weeks post-discharge
5. Overall dependency for basic care and special nursing needs at 4 weeks post-discharge, as measured by the BCN, and SNN scales of the NPDS, as well as total NPDS.

6. Level of health and social support services received in the first six months post-discharge (i.e. NPCS).

10.4 Statistical Analyses

We examined the different individual components of the NPDS, to identify the most useful component to include in future multiple regressions.

- The Basic care needs (NPDS-BCN) comprises a physical (NPDS-P) and a cognitive/behavioural (NPDS-CB) component
- The Total NPDS is made up of the NPDS-BCN and the NPDS-SNN.

1. Non-parametric correlations were calculated between Community Integration (CIQ) at six months (Phase (P) 2) and:
    - Physical and cognitive impairment (NIS-M, NIS-C) at baseline (P0).
    - Physical (NPDS-P) and cognitive-behavioural problems (NPDS-CB), at baseline (P1) and at six months (P2).
    - Dependency scores (NPDS-BCN, NPDS-SNN, and total NPDS) at baseline (P1).
    - Community integration (CIQ) at baseline (P1).
    - Overall health and social services received (NPCS) at P2.
    - Carer burden (ZBI) at six months (P2).
2. Univariate regression analyses were completed for overall dependency (total NPDS), physical and cognitive impairment at baseline (NIS-M, NIS-C) and health and social services received at six months (NPCS) with community integration (CIQ-P2) at six months as the dependent variable.
3. A stepwise regression analysis was completed including NPDS, NIS- M, NIS-C and NPCS as the independent or predictor variables and CIQ-P2 as the dependent variable.
4. Non-parametric correlations were calculated between Carer Burden (ZBI) at six months and:
    - Baseline physical and cognitive impairment (NIS-M, NIS-C).
    - Physical (NPDS-P) and cognitive-behavioural problems (NPDS-CB), at baseline (P1) and at six months (P2).
    - Dependency scores (NPDS-BCN, NPDS-SNN, and total NPDS) at baseline (P1).
    - Overall health and social services received (NPCS–P2).
    - Community integration (CIQ–P2) at six months.
5. Univariate regression analyses were completed for the same set of variables as in 4 above using ZBI as the dependent variable.
6. A stepwise regression analysis predicting ZBI was completed entering the best predictor variables from the univariate analyses.

10.5 Results

10.5.1 Correlations with Community Integration (CIQ):

The Spearman correlations of the nine other variables with total CIQ at six months after discharge is presented in Table 28 below.

Community Integration at six months showed low, significant, negative correlations with baseline specialist nursing dependency, carer burden at six months and both motor and cognitive baseline neurological impairments.

The CIQ had moderate or strong negative correlations with basic care dependency and cognitive behavioural problems at baseline. There was a strong positive correlation between CIQ at baseline (3 to 4 weeks) and at six months.

Table 28. Spearman correlations between Community Integration (CIQ) at six months and measures of physical and cognitive impairment at baseline (NIS-M, NIS-C), basic and specialist nursing dependency (BCN, SNN) at baseline, cognitive behavioural problems at baseline (CBP), total rehabilitation (NPCS) and carer burden at six months (ZBI).

Variable	N	Spearman Rho*
Baseline measures		
Impairment (P0)		
NIS-Physical	190	-0.33
NIS-Cognitive	191	-0.33
CB problems (P1)		
NPDS-CB	165	-0.47
Physical disability (P1)		
NPDS-P	165	-0.58
Overall Dependency (P1)		
NPDS-BCN	165	-0.63
NPDS-SNN	165	-0.23
NPDS-total	165	-0.23
Community integration		
CIQ	142	0.73
At six months (P2)		
CB problems		
NPDS-CB	195	-0.47
Services received at 6 months		
NPCS	167	-0.46
Carer burden		
ZBI	135	-0.24

*All significant at p<0.001

10.5.2 Univariate Regression Analyses with Community Integration (CIQ) at 6 months as Dependent Variable:

Results of the univariate regression analyses with these variables as predictors of community integration at 6 months are shown in Table 29.

Table 29. Univariate Regression Analyses of measures of impairment, dependency carer burden and health and social care services received at 6 months as predictors with Community Integration (CIQ-P2) at 6 months as the dependent variable

Individual Predictor	B	CI (95%)	P	R^2
NIS-Physical at P0	-0.41	-0.56, 0.26	0.001	0.13
NIS-Cognitive at P0	-0.59	0.83, -0.34	0.001	0.10
NPDS-P at P1	-0.29	-0.36, -0.22	<0.001	0.28
NPDS-CB at P1	-1.03	-0.32, -0.73	<0.001	0.22
NPDS-BCN at P1	-0.27	-0.33, -0.21	<0.001	0.33
NPDS-SNN at P1	-0.47	-0.74, -0.21	0.001	0.07
NPDS-Total at P1	-0.23	-0.28, -0.18	<0.001	0.31
ZBI at P2	-0.07	-0.12, -0.28	0.002	0.07
NPCS at P2	-0.41	0.52, 0.29	<0.001	0.23

Inspection of Table 29 reveals that the strongest predictor variable for CIQ at 6 months was the NPDS BCN (R^2=33 percent, p<0.001) although the total NPDS (which includes both the BCN and SNN subscales) predicted a similar amount of variance, and either would be suitable for future analyses.

The NPDS-CB component was a stronger predictor of community integration than cognitive impairment (NIS-Cognitive).

The overall level of health and social services received after six months, was also a fairly strong negative individual predictor of Community Integration (R^2=23 percent, p<0.001).

However, it is possible that this is due to the strong relationship between disability and service provision as demonstrated in chapter 9 – and so this may simply reflect that more disabled patients have a poor level of community integration at six months. This possibility is explored further in the next section.

10.5.3 Stepwise Regression Analysis with Community Integration (CIQ) as Dependent Variable:

Results of the stepwise regression are presented in Table 30. Predictor variables entered into the model were Baseline NPDS (Phys, CB, BCN and SNN); NIS motor and cognitive and services received at six months (NPCS).

The NPDS-BCN again emerged as the best single negative predictor of CIQ, with a small additional gain in explained variance from NPCS. The remaining variables were excluded.

Table 30. Stepwise regression analysis of Physical and Cognitive impairment at Baseline (NIS-Physical-P1, NIS-Cognitive-P1) and services received at 6 months (NPCS-P2) as predictors with Community Integration (CIQ-P2) at 6 months as the dependent variable (N=91).

Stepwise Models	β	CI (95%)	p	R^2	ΔR^2
NPDS-BCN Phase2	-0.30	-0.38, -0.22	<0.001	0.32	0.31
NPDS-BCN Phase2	-0.22	-0.31, -0.13	<0.001	0.36	0.35
NPCS-Phase2	-0.23	-0.38, -0.08	0.003		

Excluded variables: NPDS-SNN, NPDS-P, NPDS-CB, NIS–Motor and NIS-Cognitive

10.5.4 Correlations with Carer Burden (ZBI):

Table 31 presents correlations of ZBI at six months with the nine other variables.

Inspection of Table 31 shows that ZBI correlates most strongly with self-reported Cognitive Behavioural Problems (NPDS-CB) at baseline and six months and with clinician rated cognitive impairment (NIS-C) at discharge.

Burden also showed a low negative correlation with CIQ at six months and modest positive correlations with both basic care dependency at baseline and NPCS at six months.

Table 31. Spearman correlations between Zarit Burden Inventory (ZBI) score at six months (Phase_2) and measures of physical and cognitive impairment and dependency, services received and community integration.

Variable	N	Spearman Rho
Baseline measures		
Impairment (P0)		
NIS-Physical	142	0.07
NIS-Cognitive	142	0.29**
Dependency (P1)		
NPDS-BCN	124	0.21*
NPDS-SNN	124	-0.06
CB problems		
NPDS-CB	124	0.32**
Community integration		
CIQ	110	-0.17
At six months (P2)		
CB problems		
NPDS-CB	145	0.33**
Services received at 6 months		
NPCS	124	0.20*
Community integration		
CIQ	135	-0.24**

* p<0.05, ** p<0.01

10.5.5 Univariate Regression Analyses with Carer Burden (ZBI) as Dependent Variable:

All the variables were examined as univariate predictors of ZBI at six months and the results are presented in Table 32.

Table 32 demonstrates that Cognitive Behavioural Problems reported by the patient or their carer at baseline (3 to 4 weeks) was the best single predictor of ZBI at six months, accounting for 11 percent of total variance.

This relationship between cognitive behavioural problems and carer burden was confirmed by the fact that the second best predictor was the clinician estimate of cognitive impairment at discharge (NIS-Cognitive at P0).

Table 32. Univariate Regression Analyses of physical and cognitive impairment at baseline, dependency at baseline, cognitive behavioural problems at baseline and six months, community integration at baseline and six months and received support/rehabilitation (NPCS) at six months with Carer Burden at 6 months as the dependent variable.

Individual Predictor	β	CI (95%)	p	R^2
NIS-Physical at P0	0.10	-0.46, 0.66	0.72	0.01
NIS-Cognitive at P0	1.41	0.54, 2.27	**0.01**	0.07
NPDS-P at P1	0.23	-0.06, 0.51	0.12	0.02
NPDS-CB at P1	2.00	0.96, 3.02	**0.001**	0.11
NPDS-BCN at P1	0.27	0.03, 0.51	**0.03**	0.04
NPDS-SNN at P1	-0.44	-1.37, 0.49	0.35	0.00
NPDS-total at P1	0.18	-0.03, 0.40	0.09	0.02
CIQ at P1	-0.80	-1.47, -0.14	**0.02**	0.05
NPCS at P2	0.49	0.03, 0.94	**0.04**	0.04

10.5.6 Stepwise Regression Analyses with Carer Burden (ZBI) as Dependent Variable:

Table 33 presents the results of the stepwise regression analysis. Predictor variables entered into the model were baseline NPDS (Phys, CB, BCN and SNN); NIS motor and cognitive, CIQ; and services received at six months (NPCS).

Inspection of Table 33 shows CBP (NPDS-CB) at baseline to be the best single predictor of ZBI with NPCS at six months improving the model significantly but only by a small margin (17% to 21%). It is notable that in the stepwise analysis CBP alone predicts 17 percent of variance in ZBI scores, whereas in the previous analysis reported in Table 32 this figure was only 11 percent. This is most likely to be due to different sample sizes (N=91 and N=124 respectively) that result from missing data.

Table 33. Stepwise regression analysis of Cognitive Behavioural Problems at baseline and received support/rehabilitation (NPCS) at six months with Carer Burden at 6 months as the dependent variable.

Individual Predictor	β	CI (95%)	p	R^2
NPDS-CB at P1	2.60	1.34, 3.83	0.001	0.17
NPDS-CB at P1	2.28	1.04, 3.53	0.001	0.21
NPCS_P2	0.53	0.03, 1.03	0.04	

Excluded variables: NIS_Motor_P1, NIS_Cognitive_P2, BCN_P1, SNN_P1, CIQ_P1

10.5.7 Correlations with Dependency as an outcome at 6 months

In view of the impact of dependency, on the two main outcomes we also examined dependency (total NPDS score) as a measure of outcome at 6 months in its own right.

The Spearman correlations of the other variables with total NPDS at six months after discharge is presented in Table 34 below.

Dependency at six months showed strong positive correlations with impairment at baseline; strong negative association with community integration and weaker positive correlations with carer burden at baseline. These relationships were retained with community integration and carer burden at six months. There was a strong positive association between services received and dependency at 6 months.

Table 34. Spearman correlations between Dependency (Total NPDS) at six months and measures of physical and cognitive impairment, community integration and carer burden at baseline; and with total rehabilitation (NPCS) community integration and carer burden at six months.

Variable	N	Spearman Rho
Baseline measures		
Impairment (P0)		
NIS-Physical	206	0.44**
NIS-Cognitive	207	0.47**
Carer burden (P1)		
ZBI	119	0.31*
Community integration		
CIQ	154	-0.58**
At six months (P2)		
Services received at 6 months		
NPCS	180	0.70**
Carer burden (P2)		
ZBI	96	0.30*
Community integration (P2)		
CIQ	140	-0.64**

**significant at $p<0.001$; *significant at $p<0.01$

10.5.8 Univariate Regression Analyses with Dependency (NPDS) at 6 months as Dependent Variable:

Results of the univariate regression analyses with these variables as predictors of dependency at six months are shown in Table 35.

Table 35. Univariate Regression Analyses of measures of impairment, dependency carer burden and health and social care services received at 6 months as predictors with Community Integration (CIQ-P2) at 6 months as the dependent variable

Individual Predictor	β	CI (95%)	p	R^2
NIS-Physical at P0	1.36	1.06, 1.67	<0.001	0.27
NIS-Cognitive at P0	1.80	1.28, 2.32	<0.001	0.18
CIQ at P1	-1.50	-1.8, -1.11	<0.001	0.28
ZBI at P1	0.19	0.04, 0.34	0.02	0.05
CIQ at P2	-1.41	-1.69, -1.14	<0.001	0.35
ZBI at P2	0.20	0.07, 0.33	0.003	0.06
NPCS at P2	1.28	1.06, 1.50	<0.001	0.42

Inspection of Table 35 reveals that the strongest predictor variable for NPDS at 6 months was the NPCS (R^2=42 percent, $p<0.001$). Motor impairment and community integration both at base line were also strong predictors, and an even stronger (negative) relationship was seen with community integration at six months.

10.5.9 Stepwise Regression Analysis with Community Integration (CIQ) as Dependent Variable:

Results of the stepwise regression are presented in Table 36. Predictor variables entered into the model were Baseline NIS motor and cognitive scores; baseline community integration (CIQ) and carer burden (ZBI); and services received at 6 months (NPCS).

Service received at six months emerged as the best single predictor of NPDS, with a small additional gain in explained variance from NIS motor and cognitive scores. The remaining variables were excluded.

Table 36. Stepwise regression analysis of Physical and Cognitive impairment at Baseline (NIS-Physical-P1, NIS-Cognitive-P1) and services received at 6 months (NPCS-P2) as predictors with Community Integration (CIQ-P2) at 6 months as the dependent variable (N=91).

Stepwise Models	β	CI (95%)	p	R^2	Δ R^2
Total NPCS Phase2	1.30	0.94, 1.66	<0.001	0.36	0.36
Total NPCS Phase2	0.98	0.58, 1.37	<0.001	0.43	0.42
NIS-Physical	0.79	0.31, 1.26	0.001		
Total NPCS Phase2	0.80	1.41, 1.19	<0.001	0.50	0.48
NIS-Physical	0.79	0.34, 1.24	0.001		
NIS Cognitive	1.12	0.46, 1.78	0.001		

Excluded variables: ZBI and CIQ

10.6 Limitations

While the longitudinal design is a strong feature of the present study the relationships among variables remain correlational. Hence while it is interesting to speculate about the nature of the relationships among these variables, such as services received and community integration, it is not legitimate to infer any causality.

10.7 Chapter summary

In this chapter we have examined the relationship between health and social services received and outcomes in terms of community integration, carer burden and overall dependency.

The strongest relationship seen was with overall disability or dependency, where services received explained 36 percent of the variance, which increased to 50 percent when baseline motor and cognitive impairment was included in the model.

A strong negative relationship was found between community integration and disability (again not unexpected), so that the NPDS-BCN was the strongest predictor, with services received at six months providing only small additional gains in explained variance.

There was little relationship between carer burden and overall dependency. Here cognitive behavioural problems were the major factor associated with carer burden at six months, with services received again adding only a small gain in explained variance.

For both community integration and carer burden, the direction of the relationship demonstrated increased levels of service provision in association with a worse condition. Although we had hypothesised that increased service provision would lead to a reduction in dependency and carer burden and improved community integration, we actually found the reverse – that is, higher levels of service provision were associated with increased dependency at six months.

Whilst at first sight counter-intuitive, it is logical to expect that the more disabled patients would require, and therefore receive, higher levels of care and support, especially as many patients are still undergoing treatment at six months post discharge.

In order to investigate this further, it is appropriate to examine these outcomes in relation to met and unmet needs for services, taking dependency into account. These issues are addressed further in the next chapter.

11 What are the longitudinal outcomes of community-based rehabilitation and their relationship to met and unmet needs for rehabilitation?

11.1 Overview

In this chapter, we examine the longitudinal outcomes to examine any changes in dependency, community integration and carer burden over the 12 months following discharge from rehabilitation. We also examine the impact of met and unmet needs for rehabilitation to test the hypothesis that, after controlling for baseline disability, individuals whose needs for healthcare, social support and rehabilitation are met achieve better long term outcomes in terms of improved community integration and reduction of care burden, than those whose needs are not met.

11.2 Study sample

Participants in the present analyses comprised all those recruits who completed the survey questionnaires at all three time-points (i.e. the ‘Best respondents sample) (N=134). The demographics for this sample were similar to those of the full recruited sample as shown in the table below:

Table 37. Demographics

Demographics	**Recruited sample (N=428)**	**Best respondents sample (N=134)**
Age (years)	Mean age 49.1 (sd15.2) range16-86	Mean age 50.2 (sd14) range16-82
M : F ratio	64% : 36%	64% : 36%
Married or living as a couple	51%	57%
Ethnicity	White – 72% Black - 14% Asian – 7%	White – 82% Black - 6% Asian – 6%
Education – highest level	None – 19% School – 36% Post school – 45%	None – 19% School – 32% Post school - 50%

11.3 Measures

11.3.1 Dependent variables

As in chapter 10, the two principal outcome variables were Community Integration ((measured by the CIQ) and Carer Burden (measured by the ZBI). We also examined change in dependency as measured by the total NPDS score and the total weekly care hours.

We were not so much interested in the total level of service provision offered, but in the extent to which service provision met the needs of the individual. We therefore examined discrepancy scores as predictor values that is service provided at six months (NPCS-Gets) minus the needs identified by the treating clinicians at P0 (NPCS-Needs).

11.4 Results

11.4.1 Correlations

Table 38 shows the relationship between 'metness of needs' at 6 months and outcome scores for dependency (NPDS), community integration (CIQ) and perceived carer burden (ZBI) at 1,6 and 12 months. Healthcare needs (which include rehabilitation) were more likely to be met in those who were more dependent or less-well integrated at baseline. On the other hand, social care needs were more likely to be met in those with higher baseline community integration.

Table 38. `Correlation matrix (Spearman rho) between discrepancy scores in NPCS 'Needs' and 'Gets' at 6 months and outcome scores in NPDS, CIQ and ZBI at 1, 6 and 12 months.

	Health care Discrepancy score at P2	Social care Discrepancy score at P2	NPDS score	CIQ score
At baseline				
NPDS score	0.09	-0.19		
CIQ score	0.03	0.24**	-0.60***	
ZBI score	0.05	0.02	-0.22**	
At 6 months				
NPDS score	0.20**	-0.13		
CIQ score	-0.15*	0.08	-0.67***	
ZBI score	0.08	-0.08	0.30***	-0.24**
At 12 months				
NPDS score	0.24**	0.17		
CIQ score	-0.24**	-0.07	-0.71***	
ZBI score	0.03	-0.16	0.27**	-0.28**

***Significant at p<0.001, **Significant at p<0.01, *Significant at <0.05

At both six and 12 months, there were moderately strong associations between the extent to which healthcare needs were met at six months and outcomes in terms of dependency (positive) and community integration (negative). In other words, those whose needs for healthcare services were met were more likely to be dependent and highly restricted in their social integration. There was also a very strong negative association between dependency and community integration. Therefore, dependency was entered as a covariate in the regression analyses later in this section.

Table 39 shows the Spearman rho correlations for NPCS discrepancy scores within the three subscales of the healthcare domain. Rehabilitation needs were most closely associated with CIQ and NPDS scores at both 6 and 12 months.

Table 39. Correlations (Spearman rho) between NPCS discrepancy scores within the subscales of the Health and personal care domain at 6 months with outcome scores in NPDS, CIQ and ZBI at 1, 6 and 12 months.

	Discrepancy scores at Phase 2		
	Medical and nursing Subscale	**Personal care Subscale**	**Rehabilitation Subscale**
At baseline			
NPDS score	0.007	-0.008	0.18
CIQ score	0.03	0.07	-0.08
ZBI score	-0.14	0.03	0.15
At 6 months			
NPDS score	0.08	0.11	**0.26****
CIQ score	-0.11	-0.07	**-0.22***
ZBI score	-0.02	0.05	0.08
At 12 months			
NPDS score	0.06	0.03	**0.28****
CIQ score	0.15	-0.09	**-0.27***
ZBI score	-0.03	-0.09	0.056

**Significant at $p<0.001$, *Significant at $p<0.01$

11.4.2 Change in dependency

We were also interested in the relationship between metness of needs and *change* in outcome score. As a group, this sample showed little change in any of the primary outcome variables between discharge from rehabilitation and 12 month follow-up.

Figure 44 shows the NPDS scores at each of the three time points and the distribution of NPDS change scores. There was no significant change between Phase 1 and 2 (Wilcoxon signed rank z=-1.1, p=0.25) or between Phase2 and 3 (Wilcoxon signed rank z=-1.1, p=0.25).

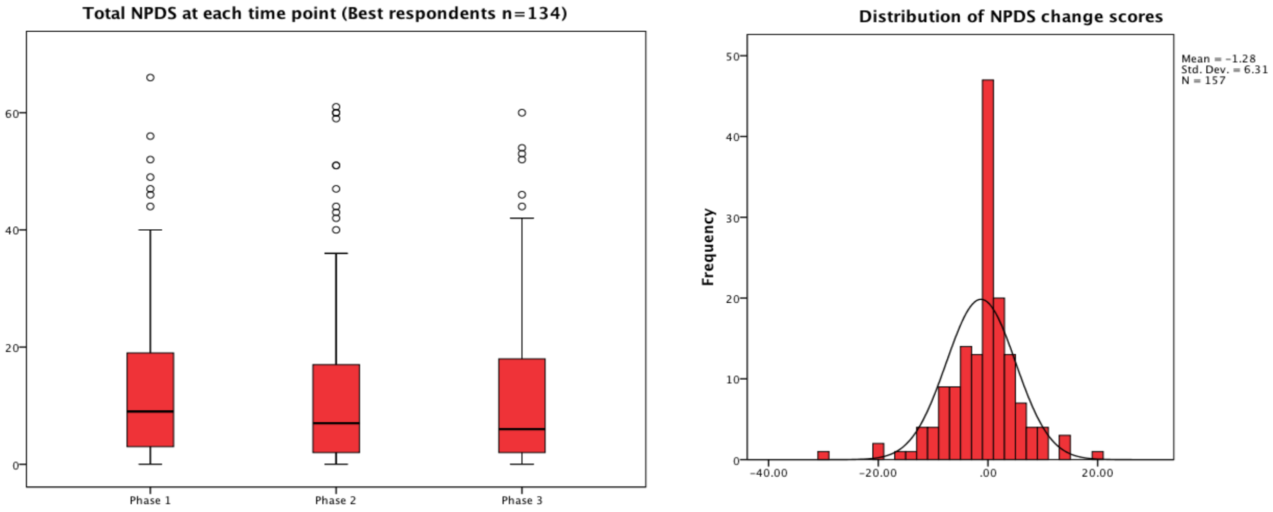


Figure 44. **NPDS scores at each of the three time points and the distribution of NPDS change scores**

Figure 45 shows the weekly care hours as estimated by the NPCNA at each of the three time points. Again there was no significant change between Phase 1 and 2 (Wilcoxon signed rank z=-0.43, p=0.66). Between Phase 2 and 3 there was a trend towards a reduction in care hours, but this did not reach statistical significance (Wilcoxon z=-1.86, p=0.06).

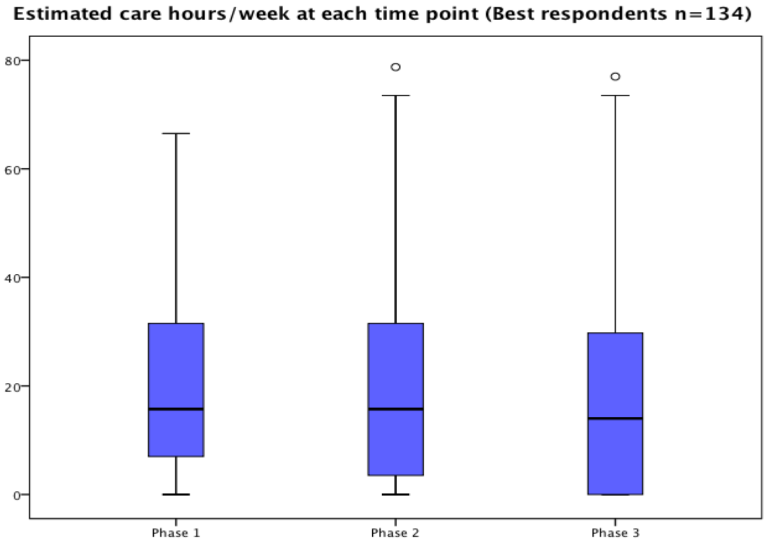


Figure 45. **Weekly care hours at each of the three time points.**

11.4.3 Change in Community integration

Figure 46 shows the CIQ at each of the three time points and the distribution of CIQ change scores between baseline and 12 months. In this instance there was a significant reduction in CIQ (indicating poorer integration) at six months (Wilcoxon signed rank z=-2.72, p=0.006), but by 12 months this had risen again (Wilcoxon z=-3.0, p=0.003), so that between baseline at discharge from in-patient rehabilitation (phase 1) and 12 months post discharge there was no difference (Wilcoxon z=-0.47, p=0.63).

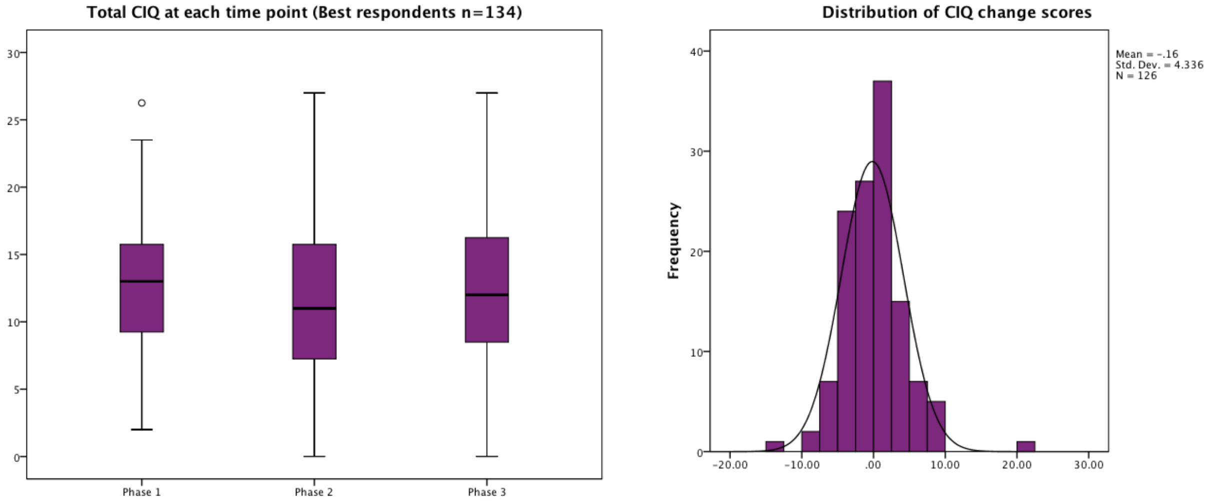


Figure 46. **Weekly care hours at each of the three time points**

11.4.4 Change in Carer Burden

Figure 47 shows the ZBI carer burden scores at each of the three time points and the distribution of ZBI change scores between baseline and 12 months. Once again there was no significant change between Phase 1 and 2 (Wilcoxon signed rank z=-0.41, p=0.68) or between Phase 2 and 3 (Wilcoxon signed rank z=-1.66, p=0.10).

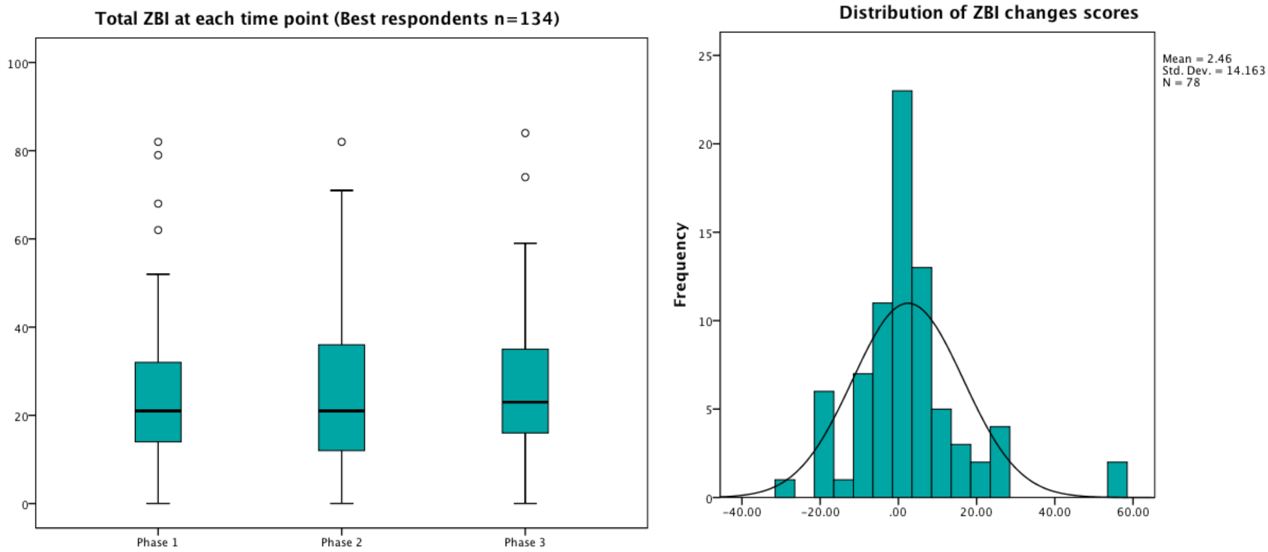


Figure 47. **ZBI carer burden scores at each of the three time points**

Table 40. Correlation matrix (Spearman rho) between discrepancy scores in NPCS 'Needs' and 'Gets' and change scores in NPDS, CIQ and ZBI

	Health care Discrepancy score	Social care Discrepancy score	NPDS change score	CIQ change score
Social care Discrepancy score	0.30***			
NPDS change score	0.17	0.09		
CIQ change score	-0.24*	-0.09	-0.33***	
ZBI change score	-0.04	-0.50	0.15	0.10

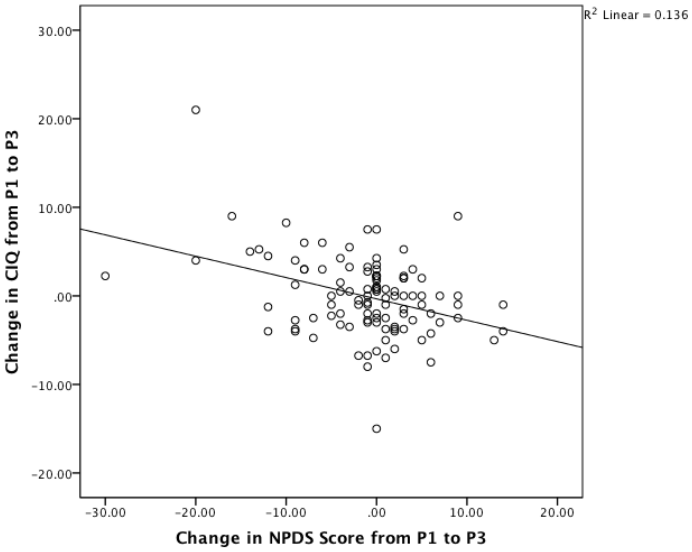
***Significant at p<0.001, **Significant at p<0.01, *Significant at <0.05

Table 40 shows the correlation matrix (Spearman rho) between discrepancy scores in NPCS 'Needs' and 'Gets' in the healthcare and social support domains and change scores in NPDS, CIQ and ZBI between baseline and 12 months.

There was a significant negative correlation between the CIQ change score and 'metness' of Healthcare needs – suggesting that the better health care needs were met, the worse the level of community integration. However, there was also a strong negative correlation between the NPDS and CIQ change scores, suggesting that decreasing dependency post discharge was associated with poorer community integration, which may have had a confounding effect.

Figure 48 shows a scatter plot of the relationship between change in CIQ and NPDS scores.

Figure 48. Scatter plot of the relationship between change in CIQ and NPDS scores



11.5 Multi-level modelling / linear regression

We therefore conducted further analysis using multi-level modelling, adjusting for the potential confounding variables of impairment and disability at baseline.

Again we examined the two principal outcomes - CIQ and ZBI at 12 months, in comparison with met and unmet needs in the Health and social care domains of the NPCS and also specifically within the rehabilitation subscale.

Due to the continuous nature of these variables, linear regression was used to examine the association of met needs on these outcomes. Due to the positively skewed distribution of the ZBI values, these were given a log transformation before analysis.

Exploratory analyses were performed using multilevel models, considering the clustering of patients within sites. However, these suggested almost no variability between sites in terms of patient outcomes, and thus more standard linear regression analyses were used for the analyses.

A series of four models were fitted to examine the effect of each of the met needs variables on the outcomes. These progressively adjusted for further factors, and details of the four models are listed below:

- unadjusted
- adjusted for baseline outcome score only
- adjusted for baseline outcome score and 3 other potential confounding variables (initial NPDS, baseline NIS cognitive and motor scores)
- adjusted for baseline outcome score, confounding variables and other needs met variables.

There was found to be a non-linear relationship between both baseline outcomes and their corresponding outcomes at 12 months. To allow for this, a quadratic (squared) term was included in the analysis in addition to the linear term.

11.5.1 Community Integration Questionnaire - 12 months

The first set of analyses examined how the difference between met and unmet needs at six months was associated with the CIQ score at 12 months.

A summary of the number of patients with met and unmet needs in each area is given in the Table 41. The patient numbers refer only to those with valid CIQ values at 12 months. A summary of the mean and standard deviation CIQ score at this time-point are also reported.

Table 41. Patients with met and unmet needs in the Health and social care domains and rehabilitation subscale of the NPCS related to the CIQ

Variable	Category	N (%)	CIQ (12 months) Mean (SD)
Health	Needs unmet	98 (63%)	13.2 (5.9)
	Needs met	57 (37%)	11.0 (5.8)
Social	Needs unmet	99 (74%)	12.1 (5.6)
	Needs met	34 (26%)	12.2 (5.0)
Rehabilitation	Needs unmet	124 (84%)	12.8 (5.6)
	Needs met	23 (16%)	9.6 (5.1)

Linear regression was used to examine the difference in CIQ at 12 months between patients with met and unmet needs. The analysis results from a series of models are summarised in Table 42. The figures reported are the regression coefficients for the needs variable, along with corresponding confidence intervals. These represent the mean difference in CIQ score for patients with met needs relative to patients with unmet needs.

Table 42. Adjusted and un-adjusted models for Linear regression of the difference in CIQ at 12 months

Variables	Model	N	Coefficient (95% CI)	P-value
Health	Unadjusted	155	-2.2 (-4.2, -0.3)	**0.02**
	Baseline adjusted	113	-1.2 (-2.9, 0.4)	0.13
	Covariate adjusted	108	-1.7 (-3.2, -0.1)	**0.04**
	Full model	77	-0.9 (-0.34, 1.7)	0.50
Social	Unadjusted	133	0.1 (-2.1, 2.2)	0.94
	Baseline adjusted	97	-0.3 (-2.1, 1.5)	0.76
	Covariate adjusted	93	-0.9 (-2.8, 1.0)	0.35
	Full model	77	-0.6 (-2.8, 1.6)	0.62
Rehabilitation	Unadjusted	147	-3.2 (-5.7, -0.7)	**0.01**
	Baseline adjusted	106	-2.8 (-4.9, -0.7)	**0.01**
	Covariate adjusted	102	-2.3 (-4.5, -0.3)	**0.03**
	Full model	77	-2.0 (-5.3, 1.3)	0.23

In keeping with the findings from simple correlations, results for the health needs measure suggested some evidence that those with met needs had lower CIQ scores than those with unmet needs. This difference was statistically significant when the baseline CIQ and potential confounders were adjusted for (model 3).

Here patients with met needs scored, on average, 1.7 units lower than those with met needs. However, this difference was no longer statistically significant after further adjusting for whether social and rehabilitation needs were met.

Whether or not social needs were met was not found to influence CIQ scores in any of the analyses.

The first three models for the rehabilitation variable suggested that those with their rehab needs met had lower scores than patients with their needs unmet. The size of differences varied by the specific analysis, but there was a difference of over two units in outcome between groups. The difference was not statistically significant after adjusting for the other met needs variables. However, this can be partly attributed to the smaller number of patients in that analysis rather than a substantially lower size of effect.

A summary of the results for all variables (from the full model) is given in Table 43.

Table 43. Met and unmet needs and baseline impairment and disability scores

Variables	Coefficient (95% CI)	P-value
Baseline CIQ (*) - linear term	2.7 (1.3, 4.0)	<0.001
- quadratic term	1.0 (0.2, 1.9)	
Initial NPDS (**)	-0.2 (-1.6, 1.1)	0.74
Baseline NIS Motor	-0.1 (-0.4, 1.3)	0.34
Baseline NIS Cognitive	-0.3 (-0.7, 0.0)	0.08
Met health needs	-0.9 (-0.34, 1.7)	0.50
Met social needs	-0.6 (-2.8, 1.6)	0.62
Met rehabilitation needs	-2.0 (-5.3, 1.3)	0.23

(*) Coefficients reported for a 5-unit increase in CIQ baseline score
(**) Variable analysed on the log scale

The results suggested that aside from the three met needs variables, there was no strong evidence that any of the 'confounding' variables were related to CIQ. There was slight evidence that higher NIS cognitive scores were associated with lower CIQ values, but this result was not quite statistically significant.

As might be expected CIQ values at baseline were significantly associated with CIQ values at 12 months.

11.5.2 Zarit Burden Interview - 12 months

Similar analyses examined how the difference between met and unmet needs at 6 months was associated with the ZBI score at 12 months.

A summary of the number of patients with met and unmet needs in each area is given in Table 44. The patient numbers refer only to those with valid ZBI values at 12 months. A summary of the mean and standard deviation ZBI score at this time-point are also reported.

Table 44. Patients with met and unmet needs in the Health and social care domains and rehabilitation subscale of the NPCS related to the ZBI

Variable	Category	N (%)	ZBI (12 months) Mean (SD)
Health	Needs unmet	54 (56%)	24.5 (20.7)
	Needs met	44 (44%)	26.6 (16.7)
Social	Needs unmet	66 (75%)	25.1 (19.7)
	Needs met	22 (25%)	24.6 (16.0)
Rehabilitation	Needs unmet	75 (82%)	25.1 (18.8)
	Needs met	17 (18%)	31.9 (20.6)

Linear regression was used to examine the difference in ZBI at 12 months between patients with met and unmet needs. The analysis results from a series of models are summarised in Table 45. As the ZBI was analysed on the log scale, the regression coefficients were transformed into ratios to give values with an easier interpretation. These are presented along with corresponding confidence intervals. These ratios represent the ratio of ZBI scores in patients with met needs relative to patients with unmet needs.

Table 45. Adjusted and un-adjusted models for Linear regression of the difference in ZBI at 12 months

Variables	Model	N	Ratio (95% CI)	P-value
Health	Unadjusted	99	1.58 (1.02, 2.45)	**0.04**
	Baseline adjusted	76	1.23 (0.85, 1.79)	0.26
	Covariate adjusted	73	1.33 (0.90, 1.97)	0.15
	Full model	53	1.65 (0.88, 3.07)	0.11
Social	Unadjusted	88	1.02 (0.60, 1.73)	0.12
	Baseline adjusted	68	1.17 (0.77, 1.77)	0.47
	Covariate adjusted	66	1.31 (0.84, 2.05)	0.23
	Full model	53	1.20 (0.67, 2.13)	0.54
Rehabilitation	Unadjusted	92	1.58 (0.88, 2.84)	0.12
	Baseline adjusted	69	1.06 (0.65, 1.73)	0.82
	Covariate adjusted	67	1.04 (0.63, 1.71)	0.87
	Full model	53	0.85 (0.42, 1.73)	0.65

The results suggested that, aside from one result in the unadjusted analyses, none of the three met needs variables were associated with the ZBI. A summary of the results for all variables (from the full model) is given in Table 46.

Table 46. Met and unmet needs and baseline impairment and disability scores

Variables	Ratio (95% CI)	P-value
Baseline ZBI (*) - linear term	1.60 (1.32, 1.94)	<0.001
- quadratic term	0.94 (0.89, 0.99)	
Initial NPDS (**)	1.06 (0.79, 1.43)	0.68
Baseline NIS Motor	1.01 (0.95, 1.08)	0.69
Baseline NIS Cognitive	1.09 (1.00, 1.18)	0.06
Met health needs	1.65 (0.88, 3.07)	0.11
Met social needs	1.20 (0.67, 2.13)	0.54
Met rehabilitation needs	0.85 (0.42, 1.73)	0.65

(*) Coefficients reported for a 5-unit increase in ZBI baseline score
(**) Variable analysed on the log scale

These results suggested slight evidence that NIS cognitive score was associated with the ZBI scores, although this result was not quite significant. A higher baseline score was associated increased ZBI scores. Neither the NPDS or NIS motor scores were associated with ZBI scores at 12 months.

11.6 Limitations

As noted previously, the relationships among variables are correlational and caution is due before inferring a causal relationship. Notwithstanding this caveat the negative correlation between 'metness of needs' and level of community integration remained even after baseline dependency and impairment were controlled for. Moreover this relationship was maintained throughout the three longitudinal phases of the study. It seems logical then to conclude that the most intensive services are directed towards the most disabled people who, not surprisingly, are the most socially isolated.

11.7 Chapter summary

In this chapter we examined the relationship between the extent to which health and social care needs were met and the outcomes, in terms of community integration and carer burden at 12 months.

Our initial exploration suggested a paradoxical relationship between the extent to which healthcare needs were met and community integration. Surprisingly, participants whose health and social care needs were well met were more likely to be highly dependent, poorly integrated into the community, and to have a carer with a high level of burden.

The relationship appeared to be confounded by a strong negative relationship between dependency and community integration, so baseline dependency and impairment were entered as confounder variables in our linear regression modelling.

The results of our analysis suggest that, after the relationship with dependency is taken into account, there is a still a negative relationship (albeit weaker) between 'metness of healthcare needs' - in particular rehabilitation - and community integration at 12 months. In other words the people whose healthcare and rehabilitation needs are best met are nonetheless the most socially isolated and marginalised. The consistency of the relationship throughout the three phases supports the view that this is a real relationship and not just a chance finding. The relationship was strongest for the rehabilitation subscale within the healthcare domain.

Perceived carer burden was not significantly associated with 'metness of needs', either in the health or social care domain.

12 What are the differential costs and cost-outcomes of different models of community neuro-rehabilitation?

Economic analysis: Service use and costs for people with long term neurological conditions in community rehabilitation

12.1 Background

There is limited evidence from the UK on the use of services and costs associated with complex and long-term neurological conditions (LTNCs). Even more limited is information on resource use for patients receiving community rehabilitation, although provision of this form of care has increased in recent years.[61] There was a reported increase (38 percent) in NHS spending on LTNC services between 2006-7 and 2009-10, a period following the introduction of the National Service Framework for Long-term Neurological conditions in 2005.[62]

Measuring the use of services by this patient group and calculating the related costs is important given that needs for care are likely to be substantial.[62] Health and social care resources are limited in their supply and demand is likely to exceed existing levels of service provision.[62]

The estimation and analysis of care costs allows us to determine whether resources are most used by those with the highest needs, and by linking costs with outcomes we can make assessments of cost-effectiveness.

The aims of the economic analyses presented in this chapter were to:

- Determine the differential costs and cost-outcomes of different models of community neuro-rehabilitation.
- Measure the use of services by patients six and 12 months following discharge from in-patient rehabilitation units.
- Calculate the costs of services used at six and 12 months.
- Identify demographic and clinical factors associated with service costs, using regression modelling.
- Estimate the costs of providing unmet community rehabilitation needs.

It was originally our intention to compare costs with change in clinical outcomes. However, as demonstrated in chapter 11, this cohort did not show significant functional change in any of the key measures. Instead we present a novel approach to costing met and unmet needs using the Needs and Provision Complexity Scale.

12.2 Methods

12.2.1 Service use

A version of the Client Service Receipt Inventory (CSRI)[55] specifically adapted for people with a LTNC was used to elicit data on all health and social care used by respondents. This questionnaire was originally developed for evaluations in the 1980s of closures of long-stay psychiatric hospitals and the care in the community programme of people with learning disabilities. Since then versions of the CSRI have been used in around 400 studies across numerous health and social care areas in the UK and internationally.

In this study the CSRI covered the six month periods prior to the six and 12-month post discharge time periods. Data were collected retrospectively from patients. While this may present some problems in terms of recall accuracy, it is the only feasible approach for collecting the breadth of service use data required of a study of rehabilitative care.

Information was collected on in-patient stays and residential care, contact with day care and community services, out-patient appointments, contacts with primary and secondary healthcare professionals, as well as services received by respondents at home.

Total health and social care costs were estimated by combining service use data with appropriate national unit costs.[63, 64] Costs were calculated in 2011/12 figures.

Informal care, which is a significant part of chronic conditions,[1] was also measured. Respondents stated how many hours per week family and friends provided care in specific areas due to their condition.

Alternative approaches exist for valuing informal care[65] and in this study we adopted the replacement cost method, where the cost of a relevant professional (here, a social services home care worker) is applied to the time spent providing care.[66]

12.2.2 Analyses

Missing service use items were replaced with median imputations derived from (a) total service contacts and (b) duration of those services used by patients across the sample. Given the number of services measured, substituting such values of service contacts and duration for missing values was found to be more appropriate than more sophisticated methods, such as multiple imputations. Service use patterns and mean costs were compared between the two time periods. Identification of potential cost predictors used univariate and multivariate analyses.

Cost data usually follow a skewed distribution due to a small number of patients having disproportionately high costs. To address this, two forms of models were constructed. First, linear regression models were used with confidence intervals around coefficients produced using non-parametric bootstrapping. This is a widely used Monte Carlo approach for estimating confidence intervals in situations where the distribution of the population sampled from is uncertain. It involves repeated sampling with replacement from the sample.

Second, to take account of the actual distribution of the cost data we used a general linear model with a log link and gamma distribution. Variables included in the models were gender, age, cognition challenges, motor problems, NPDS total score, dependency groups and NPCS needs score.

12.3 Results

A cohort of 500 consecutive patients were discharged over a 12-month period from the nine specialised rehabilitation units. Service use data were available at six- and 12-month follow-up for 211 and 182 patients respectively. The demographic characteristics of the populations responding at the different time points in the study are shown in Table 9 section 4.7.

12.3.1 Service use and costs

The reported frequencies of use of the different types of service collected via the CRSI are broadly in line with the frequencies reported using the NPCS which are detailed in Appendix 7.

Service use and costs in the six months prior to the six-month follow-up are reported in Table 47. One-quarter of patients were in-patients (on intensive care units, neurology, medical and specialist rehabilitation wards) at some stage during this period and these on average had a cumulative number of in-patient days in excess of one month (although this may have been due to more than one admission). In-patient care costs accounted for 39 percent of the total costs excluding informal care.

Approximately two-thirds of patients had contacts with GPs, but this service only accounted for one percent of total formal care costs. Nearly half the sample had contacts with neurologists (43%) and 18% with a rehabilitation doctor in a community or out-patient setting.

Outpatient therapy use was relatively high and accounted for 6 percent of formal care costs. A third of the sample had home-based therapy with 7 contacts per month on average. The costs of this therapy were greater than for the outpatient-based therapy.

Just 13% of patients had contact with a social worker. Under 10% reported the use of domestic home care and 15% accessed day-care services. Over half of the patients received care from family or friends and this was the most costly service due to the high number of care hours per week received, accounting for 53% of the total cost.

Table 47. Use and cost of services at six-month follow-up (N=211).

Service	N (%) of patients using services	Mean (SD) contacts for users only	Mean (SD) costs for users only (2011/12 £s)	Mean (SD) costs for whole sample (2011/12 £s)
In-patient & residential				
In-patient[1]	52 (25)	35.9 (50.1)	19,977 (28,409)	4923 (16,446)
Residential care[1]	22 (10)	140.9 (65.5)	26,524 (13,654)	2766 (9201)
Out-patient and community health care				
GP	135 (64)	4.3 (4.2)	210 (221)	135 (204)
Neurologist	90 (43)	1.9 (2.1)	257 (286)	109 (225)
Rehabilitation doctor	37 (18)	2.7 (3.8)	505 (1131)	87 (506)
Other doctor	53 (25)	2.7 (1.8)	437 (624)	110 (364)
Nurse	39 (19)	5.3 (12.3)	108 (190	20 (91)
Therapists[4]	87 (41)	15.6 (19.0)	1790 (2531)	738 (1845)
Mental health professionals	26 (12)	4.6 (4.7)	528 (458)	65 (235)
Dentist	54 (26)	3.1 (3.6)	198 (164)	51 (119)
Home-based /Social services				
Day care[2]	31 (15)	6.6 (3.9)	3432 (2035)	504 (1440)
Nurse[2]	20 (10)	5.5 (6.7)	615 (595)	58 (254)
Personal care[2]	24 (11)	34.7 (23.8)	5234 (5224)	595 (2401)
Social worker[2]	28 (13)	2.1 (1.7)	2115 (2122)	281 (1047)
Therapists[2,4]	73 (35)	6.9 (8.1)	3682 (4584)	1274 (3207)
Home care domestic help[2]	18 (9)	13.4 (15.6)	2877 (3461)	245 (1272)
Home care, day/night sitting service[2]	5 (2)	12.8 (11.7)	18,303 (21,147)	434 (4038)
Home care, other[2]	17 (8)	12.2 (16.1)	4672 (8987)	376 (2789)
Informal care[3]	120 (57)	56.7 (58.8)	25,339 (27,031)	14,411 (23,922)
Total formal care cost				**12,773 (19,371)**
Total cost (including informal care)				**27,184, (29,484)**

[1] Contacts measured in days, [2] Contacts per month [3] Contacts measured in hours per week

[4] Comprising physiotherapists, occupational therapists and speech and language therapists

Table 48 shows that by the 12-month follow-up there was a reduction in the use of many health and social care services. The proportion of people who were admitted to hospital decreased slightly to around one-fifth and the number of days in hospital for those who were admitted fell by over 50 percent. In-patient care accounted for 18% of the total formal care costs.

There continued to be relatively high levels of use of GPs and neurologists. Total formal care costs fell to an average of £8,907.

Most patients continued to receive informal care from family and friends and the mean number of hours per week for those receiving this actually increased slightly. Informal care at 12-month follow-up accounted for 62% of the total costs.

Table 48. Use and cost of services at 12-month follow-up (N=182).

	N (%) of patients using services	Mean (SD) contacts for users only	Mean (SD) costs for users only (2011/12 £s)	Mean (SD) costs for whole sample (2011/12 £s)
In-patient & residential				
In-patient[1]	36 (20)	14.6 (31.8)	8140 (16,664)	1610 (8017)
Residential care[1]	18 (10)	129.6 (77.8)	24,676 (15,182)	2441 (8730)
Out-patient and community health care				
GP	103 (57)	3.4 (3.3)	163 (204)	92 (173)
Neurologist	68 (37)	1.7 (1.2)	289 (305)	108 (233)
Rehabilitation doctor	15 (8)	2.0 (1.4)	419 (491)	35 (179)
Other doctor	41 (23)	2.7 (1.9)	359 (482)	81 (272)
Nurse	42 (23)	4.5 (8.6)	118 (224	27 (118)
Therapists[4]	58 (32)	17.0 (18.1)	2045 (2963)	652 (1918)
Mental health professionals	14 (8)	8.4 (8.8)	1413 (1728)	109 (597)
Dentist	38 (21)	2.9 (4.4)	168 (181)	35 (107)
Home-based /Social services				
Day care[2]	24 (13)	5.8 (4.0)	3124 (2189)	412 (1316)
Nurse[2]	14 (8)	13.3 (17.7)	3063 (6718)	236 (1978)
Personal care[2]	14 (8)	46.1 (31.8)	7736 (5361)	595 (2517)
Social worker[2]	7 (4)	3.6 (2.8)	4070 (3275)	157 (986)
Therapists[2,4]	45 (25)	5.4 (4.6)	3499 (3919)	865 (2455)
Home care domestic help[2]	18 (10)	9.8 (10.0)	3230 (3707)	319 (1492)
Home care, day/night sitting service[2]	6 (3)	20.1 (21.2)	27,603 (52,452)	910 (10,021)
Home care, other[2]	9 (5)	17.0 (14.6)	4521 (5643)	224 (1541)
Informal care[3]	98 (54)	59.2 (61.4)	27,007 (28,428)	14,542 (24,807)
Total formal care cost				**8907 (17,867)**
Total cost (including informal care)				**23,449 (29,589)**

[1] Contacts measured in days, [2] Contacts per month, [3] Contacts measured in hours per week

[4] Comprising physiotherapists, occupational therapists and speech and language therapists

12.3.2 Relationship between service costs and dependency level

Patients were categorised into four dependency groups based on their NPDS scores at one month after discharge, see Table 49.

Table 49. NPDS Dependency groups

	NPDS-P	NPDS-CB
Independent:	Total score ≤ 9	All three items score ≤ 1
Physical:	Total score ≥ 10	All three items score ≤ 1
Hidden:	Total score ≤ 9	One or more items score ≥ 2
Mixed:	Total score ≥ 10	One or more items score ≥ 2

From Figure 49 it can be seen that at 6–month follow-up costs were lowest for the independent group, similar for the physical and hidden groups and highest for the mixed group. As a proportion of total costs, informal care was highest for the physical and hidden groups. Total costs at 12-month follow-up followed a similar pattern (Figure 50).

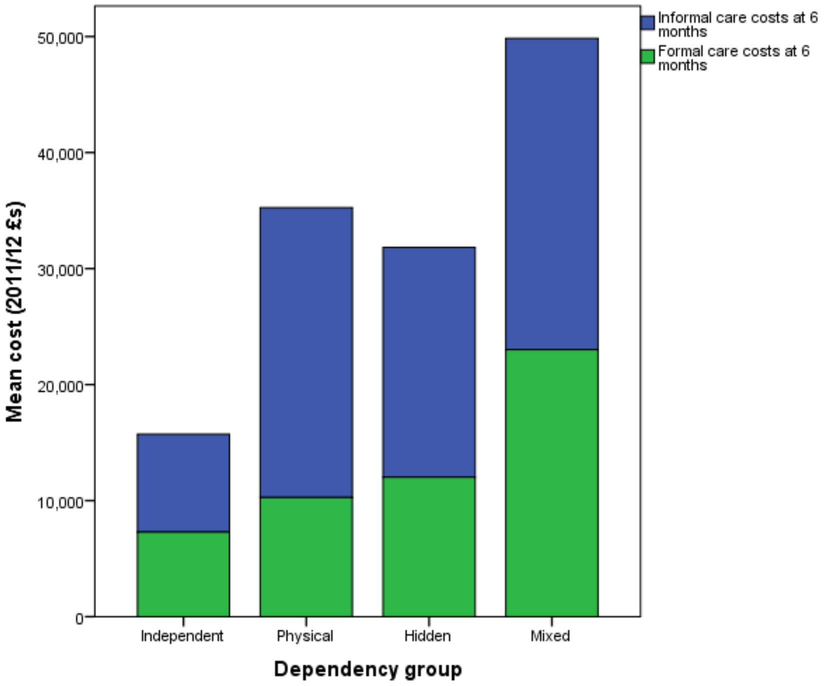


Figure 49. Formal and informal care costs at 6-months by dependency group.

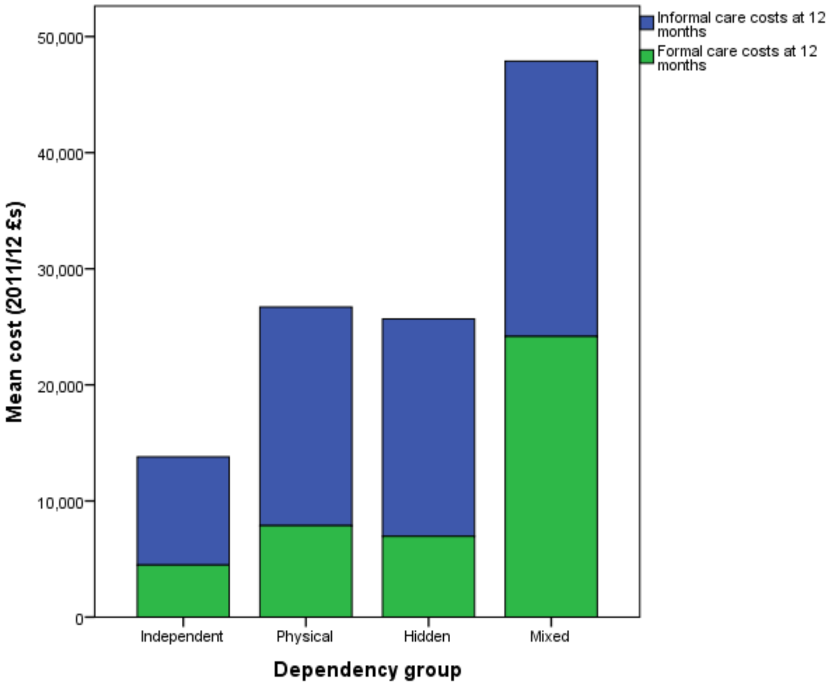


Figure 50. Formal and informal care costs at 12-months by dependency group.

The reduction in service costs between the two time points was apparent for all groups, especially those with mixed dependency (Figure 51).

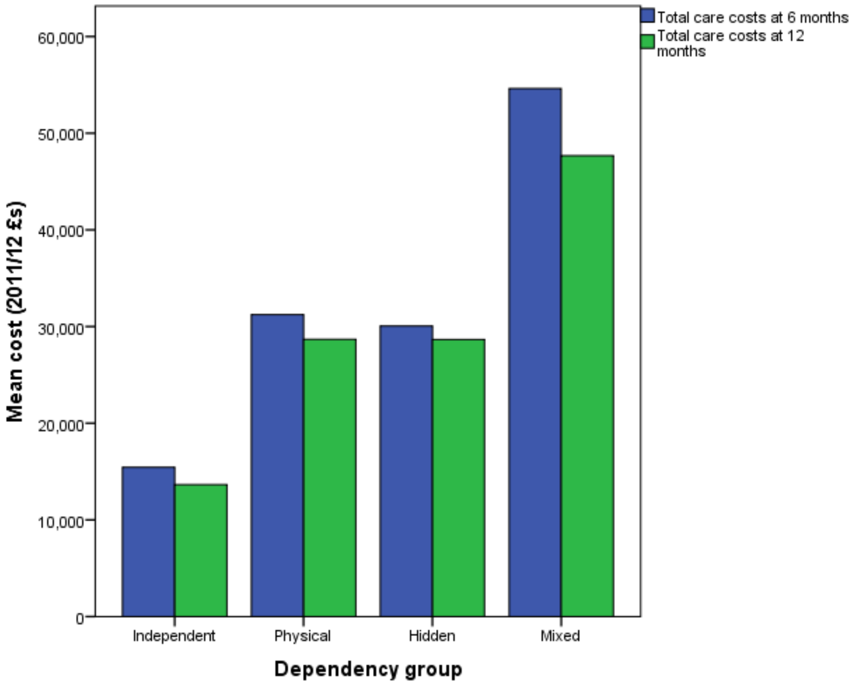


Figure 51. Total care costs by dependency group

12.3.3 Identification of factors associated with cost

The first bootstrapped regression model in Table 50 reveals that the NPDS was a significant predictor of total costs over the first six months following discharge. For every one-point increase on the NPDS costs were, on average, £494 higher. This model could explain 27% of variation in cost.

The second model shows that the NIS motor score was positively associated with cost during the second six-month period. For every one-point increase on this scale, costs rise by £2023 on average. This model explained 31% of cost variations.

Table 50. Bootstrapped regression analysis to identify predictors of costs at 6-month and 12-month follow-up.

	0-6 months		**7-12 months**	
Variable	**Coefficient**	**95% CI**	**Coefficient**	**95% CI**
Female	-2867	-9638, 5132	4959	-5313, 13863
Age	-159	-431, 17	-111	-474, 248
NIS cognition	448	-1292, 2518	662	-588, 2332
NIS motor	529	-456, 1825	2023	757, 3078
NPDS total	494	172, 1206	89	-362, 595
Physical	12768	-4157, 26465	5370	-4156, 17207
Hidden	8932	-7761, 21840	10065	-2173, 21583
Mixed	16386	-5777, 29439	16832	-2800, 39574
NPCS needs	51	-324, 599	43	-868, 105
Constant term	19783		-4443	

The general linear models, using a gamma distribution and a log link, are shown in Table 51. (The confidence intervals indicate significance if they do not contain 1).

The model for the first 6 months shows that the NPDS score has a statistically significant impact on cost. These are increased by 2.1% for each unit increase on the scale. If the individual is physically dependent their costs are 80% higher than if their dependency group is 'independent'. Finally, costs are significantly higher with higher scores on the NPCS needs scale.

The second model indicates that costs in months 7-12 are significantly associated with the NIS motor score (each unit increase in this linked to a 14.1% increase in costs). Costs are also significantly increased for those in the 'hidden' dependency group.

Table 51. General linear model (with gamma distribution and log link) to identify predictors of costs at 6-month and 12-month follow-up.

	0-6 months		7-12 months	
Variable	**Exp**	**95% CI**	**Exp**	**95% CI**
Female	0.802	0.628, 1.023	1.108	0.641, 1.914
Age	0.990	0.979, 1.000	1.001	0.989, 1.014
NIS cognition	1.036	0.975, 1.100	1.061	0.969, 1.163
NIS motor	1.046	0.977, 1.120	1.141	1.040, 1.252
NPDS total	1.021	1.002, 1.041	1.008	0.975, 1.042
Physical	1.798	1.135, 2.850	1.295	0.853, 1.965
Hidden	1.517	0.632, 3.641	2.438	1.081, 5.498
Mixed	1.467	0.729, 2.953	1.182	0.496, 2.820
NPCS needs	1.001	1.000, 1.002	1.000	0.999, 1.001

Exp = exponentiated coefficient (indicating proportional impact on cost).

12.3.4 Creating a costing algorithm within the NPCS

The Needs and Provision Complexity Scale (NPCS) provides an ordinal scale for estimating met and unmet need. In addition, information collected during this project has supported development of a costing algorithm to express the impact of met and unmet needs directly in terms of cost.

Intuitive assumptions for each scoring level were made based on clinical experience and tested within a peer group of clinicians experienced in the planning and provision of community services. Costs were computed with reference to Curtis, 2011[64] and adjusted where necessary to reflect the costs of specialist care (with helpful further personal communication from Lesley Curtis). For example, specialist community rehabilitation team therapy staff were costed at Band 7 rather than Band 5 to reflect the costs of more experienced staff in these specialist teams, as identified in the community service profiles.

Applied in parallel, the Client Services Receipt Inventory (CSRI) provided information on the number and duration of contacts for each type of service. CSRI data were analysed within each of the NPCS items and scoring levels to ‘sense-check’ the costing assumptions.

The range of services provided varied considerably so we did not expect exact agreement, but statistically significant correlations were found between the CSRI- and NPCS-estimated total costs (Spearman rho 0.57, p<0.0001) and across all domains.

A summary of the costing assumptions and the estimated yearly costs (in 2011) attributed to each item level is given in Appendix 8.

12.3.5 Meeting the costs of unmet needs

Costing data derived as described above were computed into the database. In this section we describe an analysis of the costs of needs and provision, based on this computation.

Figure 52 shows the computed costs of needs within each subscale of the NPCS for the full sample of N=428. The costs of personal care (which includes formal and informal care) represent by far the largest cost within the community care setting. This is unsurprising given the extent of patients' disabilities, and is consistent with the costs from the CSRI.

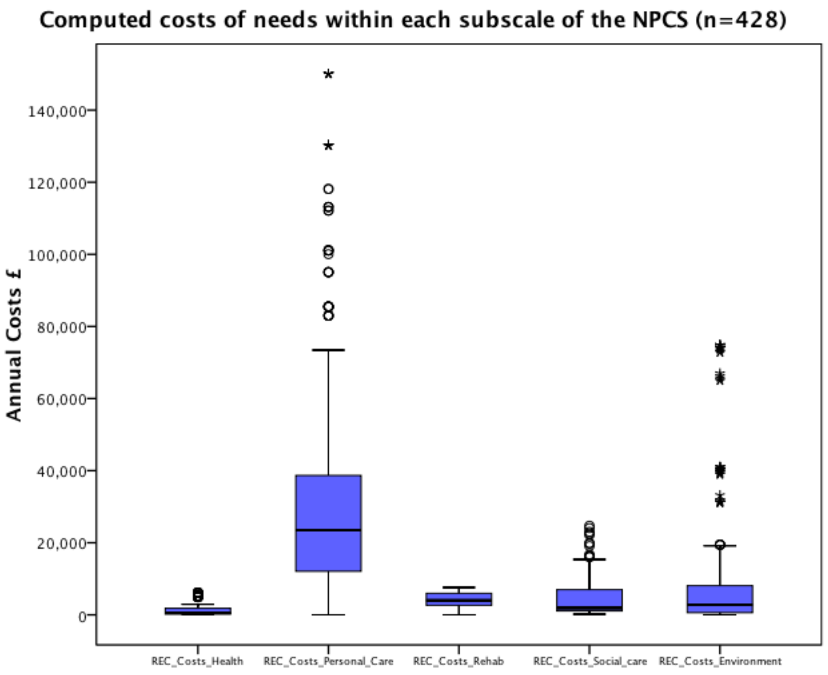


Figure 52. Comparative costs of needs within each subscale

Table 52 shows the comparative costs of Needs at Discharge from specialist rehabilitation compared with 'Gets' at 6 months. Table 53 shows the results of statistical analysis.

Table 52. Comparison of costs for 'Needs' (at discharge) versus 'Gets' at 6 months follow-up

NPCS Items	**Needs**		**Gets at 6 months**	
	Mean	***SD***	**Mean**	***SD***
Medical Care	**£523**	*£431*	**£539**	*£446*
Nursing Care	**£709**	*£1,426*	**£748**	*£1,501*
Personal Care	**£22,988**	*£33,063*	**£37,566**	*£52,972*
Personal enabler	**£11,481**	*£9,566*	**£6,032**	*£8,040*
Therapy	**£4,078**	*£2,167*	**£2,487**	*£2,059*
Vocational rehab	**£398**	*£576*	**£133**	*£377*
Social Worker	**£911**	*£588*	**£431**	*£637*
Family Carer support	**£311**	*£456*	**£237**	*£455*
Residential respite	**£509**	*£1,347*	**£169**	*£972*
Day Care	**£2,101**	*£3,568*	**£591**	*£2,050*
Advocacy	**£139**	*£267*	**£146**	*£301*
Equipment	**£738**	*£619*	**£496**	*£500*
Accommodation	**£8,110**	*£17,938*	**£12,834**	*£19,698*
Subscales				
Health	**£1,233**	***£1,499***	**£1,289**	***£1,642***
Personal care	**£33,378**	*£35,344*	**£43,692**	*£54,153*
Rehab	**£4,476**	*£2,297*	**£2,606**	*£2,118*
Social support	**£3,742**	*£4,726*	**£1,415**	*£2,704*
Environment	**£9,049**	*£18,366*	**£13,295**	*£19,815*
Domains				
Total Health and personal Care	**£40,437**	*£38,372*	**£47,481**	*£55,734*
Total social Care and Support	**£13,102**	*£19,396*	**£14,680**	*£19,871*

Table 53. Comparison of costs for 'Needs' (at discharge) versus 'Gets' at 6 months follow-up

NPCS Items	Mean Difference	95% Confidence Interval		Paired T-Test Significance		
		Lower	Upper	t	df	(2-tailed)
Medical Care	£15	-£60	£91	0.40	209	0.69
Nursing Care	£38	-£203	£280	0.31	207	0.75
Personal Care	£14,578	£8,759	£20,397	4.94	205	<0.001
Personal enabler	-£5,449	-£7,010	-£3,889	-6.89	206	<0.001
Therapy	-£1,565	-£1,935	-£1,195	-8.35	208	<0.001
Vocational rehab	-£263	-£347	-£179	-6.18	205	<0.001
Social Worker	-£480	-£580	-£380	-9.44	207	<0.001
Family Carer support	-£74	-£157	£10	-1.74	209	0.08
Residential respite	-£340	-£551	-£129	-3.18	205	0.002
Day Care	-£1,509	-£2,027	-£992	-5.75	202	<0.001
Advocacy	£7	-£38	£52	0.31	188	0.76
Equipment	-£243	-£328	-£158	-5.62	204	<0.001
Accommodation	£4,724	£1,610	£7,839	2.99	210	0.003
Subscales						
Health	£56	-£212	£323	0.41	207	0.68
Personal care	£10,313	£4,504	£16,122	3.50	202	0.001
Rehab	-£1,790	-£2,184	-£1,396	-8.96	203	<0.001
Social support	-£2,320	-£3,016	-£1,639	-6.67	182	<0.001
Environment	£4,246	-£1,074	£7,418	2.64	204	0.009
Domains						
Total Health and Personal Care	£8.566	£2,504	£14,629	2.79	194	0.006
Total Social Care and Support	£1,578	-£1,796	£4,951	0.92	180	0.36

N.B. Items in red indicate an under-spend Items in blue represent an over-spend

Overall, the results mirror the findings from analysis of the ordinal scale – namely that rehabilitation, social support and equipment in the community are significantly under-funded, compared with Needs. And, as a result personal care is over-provided and so is accommodation, suggesting that more people are in institutional care

More than that, however, by putting costs against these levels of under- and over-provision, we get some idea of the relative costs - and the cost-savings associated with providing the requisite levels of care. At item-by item level, if the under-spend on social care and rehabilitation is deducted from the significant over-spend on personal care and environment, the resulting overspend is £10,927 per annum, per patient.

This finding is also mirrored at subscale level: if the savings on rehabilitation and social support are deducted from the expenditure on personal care, the resulting saving is £6,196 per annum, and the total overspend across all five subscales is £10,497 per patient per annum.

Therefore, whether analysed at the level of the individual item, or more broadly on a subscale level, this analysis of NPCS-estimated costs suggest that the potential sums that commissioners may 'save' by not investing in rehabilitation and support are more than offset by the additional expenditure on personal care and institutional care.

Until recently, funding for health and social care within the NHS was completely separated, so this discrepancy may not have been felt at the level of commissioning. However, with the new Heath and Social Care Bill[67], funding for health and social services is more closely intertwined. It is therefore to be expected that these differences will impact more significantly on healthcare decisions in the future.

12.4 Limitations

The present study while innovative was not without its limitations.

- The quality of the CRSI data was dependent on the patient's/family's recall of service use over the previous 6 months period. This recall may have been imprecise, or at best an approximation. Where patients themselves reported on their service use, inaccuracies may have occurred because a significant proportion of patients have some degree of cognitive/communication problems. At the same time, the CSRI correlated well with the NPCS scores of service provision and CSRI responding was quite consistent at both six and 12 months.
- Another limitation was the attrition rate as acknowledged earlier. From the original cohort of 428 recruits, only 211 provided service use data at six months and 182 at 12 months. While statistical comparisons between on-going participants and drop-outs showed no demographic or clinical differences, apart from greater attrition for black participants, it remains possible that some systematic bias was operating.
- Although the majority of data fell within the expected range there were a small number of outliers with disproportionately high estimated costs. The exact reasons for this are unclear but were dealt with in part by bootstrapping. As this is the first study that we are aware of to attempt a detailed micro-level analysis of the cost of service provision in the community to people with LTNCs, it is important to replicate or extend this work elsewhere. This might help to confirm our supposition that these costs were due to a few severely disabled patients with excessively high care needs, as opposed to inaccurate reporting.

- A combination of approaches was used to develop the costing algorithm for the NPCS. CSRI data provided information on the number and duration of contacts for each type of service, but where CSRI data were insufficient, intuitive assumptions were made based on clinical experience and tested within a peer group of clinicians experienced in the planning and provision of community services. Whilst the costings so derived resonate with experience, they require further testing in other populations and settings and may well develop further over time.

12.5 Chapter summary

This analysis of costs has demonstrated the following key points.

- Around one-quarter of patients had further in-patient care at some stage during the first 6 months after discharge from rehabilitation and these inpatient care costs accounted for 39 percent of the total costs excluding informal care.
- The majority (over two thirds) had ongoing contact with GPs and specialist medical care, but these medical services accounted for only a small proportion of the total costs.
- One-third of patients also had frequent therapist contacts at home. These services were received seven times a month on average, reflecting the dependency of these patients.
- Over half of the patients received care from family or friends and this was the most costly service due to the high number of care hours per week received, accounting for 62 percent of the total cost.
- During the second 6 month period there was a reduction in usage of almost all formal services, and a relative increased reliance on informal care, which rose to 75% of the total cost
- The reported frequencies of use of the different types of service collected via the CRSI were broadly in line with the frequencies of reported using the NPCS
- Costs-analysis of met and unmet needs demonstrated a relative under-spend on rehabilitation, social care and equipment at 6 months, compared with predicted needs, and an over-spend on personal care and accommodation

The costing algorithm within the NPCS requires further testing and refinement, but the figures suggest that the potential sums that commissioners may 'save' by not investing in rehabilitation and support are more than offset by the additional expenditure on personal care and institutional care, and this over-spend may amount to a figure of over £10,000 per patient per annum.

However, it must be recognised that as the burden of caring for people with LTNCs falls largely on their families and informal carers, it is they that currently bear the brunt of those extra costs, rather than the State.

13 Community Rehabilitation Teams/Services

13.1 Background

Rehabilitation pathways for critical care patients may be complex, vary from place to place, and involve various professional groups, in-patient and community settings, and the crossing of traditional organisational boundaries. Thus, a fixed model of service delivery is not possible or practical, and responsibility for coordinating and delivering rehabilitation lies at the level of the organisation (acute and primary care trusts), rather than individual treatment teams.

To ensure continuity of care, healthcare professionals with the appropriate competencies should coordinate the patient's rehabilitation care pathway and similarly, rehabilitation goals should be reviewed, agreed, and updated throughout the patient's pathway.

As there is little comparative data on the configuration of the community rehabilitation services that take on patients with complex LTNCs following discharge from specialised neurorehabilitation units, an important component of this programme of research was to investigate the nature and scope of services that were available to participants in this study. However, the diverse nature of rehabilitation pathways and service delivery models operating nationally suggests that findings from this London cohort should be interpreted cautiously with regard to the NSF.

13.2 Procedure

A total of 124 services were identified by the research team from the referral information provided by LSNRC Units at the point of patients' discharge. Between phases 1 and 2, Community Service Profile Questionnaires were sent to each service and re-sent if responses had not been received after three to four weeks.

Initial response rates were poor, and up to three follow-up telephone calls were subsequently made to each service to identify barriers to completion. As a result of feedback received, the questionnaire was simplified and a shortened version (see Appendix 9) sent out in its place. This generated further responses.

13.3 Analysis

Services were classified by type and their location was mapped in relation to the services accessed by study participants. Questionnaire responses were entered onto an Excel spreadsheet and analysed using descriptive statistics. Responses to short answer questions were collated and summarised in narrative form.

13.4 Results

13.4.1 Services returning profiles

Members of staff from a third (36/124; 29%) of the community services contacted for information about the services they provided completed and returned questionnaires. The time between sending questionnaires out and receiving them back ranged from 2 to 24 weeks (median 9 weeks).

All these services had been accessed by study participants, and their geographic location in relation to the number of services described in Chapter 7 is highlighted by red pins in Figure 53.

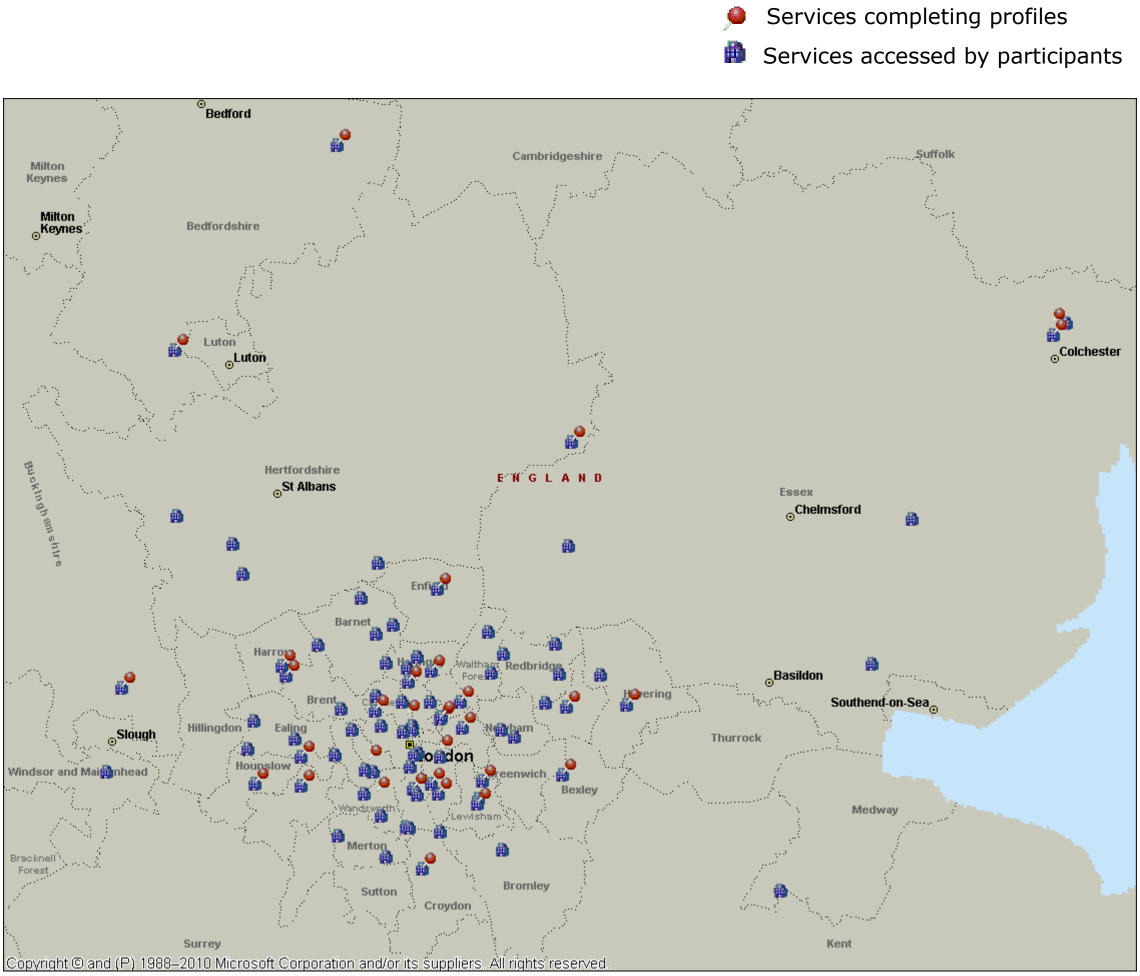


Figure 53. Distribution of community services in London and the surrounding area highlighting those for which service profiles were received (N=36).

Responding services were widely distributed across Greater London, with a few outliers in the surrounding counties.

13.4.2 Types of community services

In all, 36 services comprising 27 Community Rehabilitation Teams (CRTs) and nine other service types provided information about their service configuration.

Figure 54 gives a breakdown of these services. Comparison with figure 33 in Chapter 7 shows that almost all of the Neurological and ABI Community Rehabilitation Teams (CRTs) that were accessed by study participants provided information about their services, as did a third of both Generic and Intermediate CRTs and three-quarters of the Voluntary Sector/Support services.

Numbers of the other services were too small for meaningful comparison.

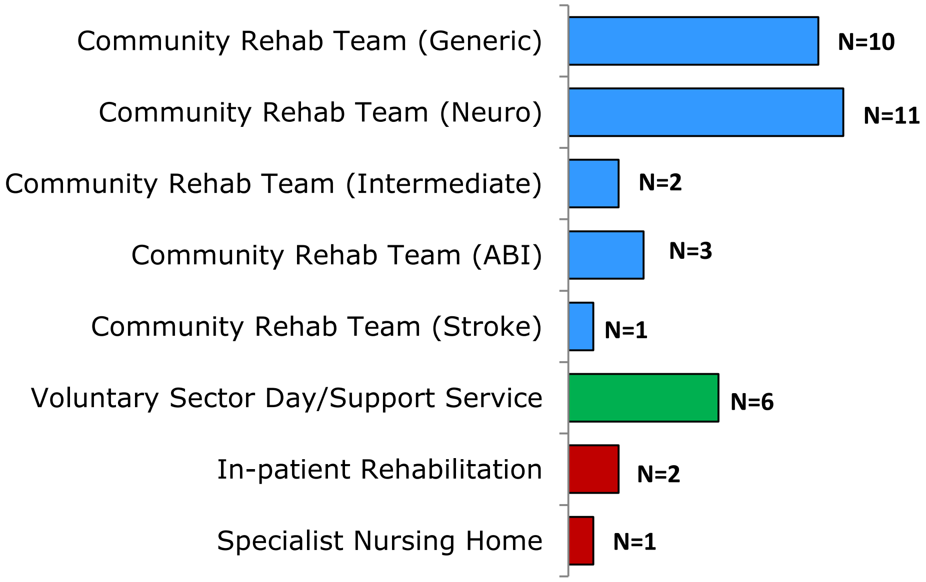


Figure 54. Breakdown of the types of community services from which service profiles were received (N=36).

Responses relating to each survey question are set out below, with figures and tables summarising findings where relevant. Findings for community rehabilitation teams are presented separately from those for the other more disparate types of community service.

Question 1 asked about the geographical location of the service and is covered under section 13.4.1.

Question 2. What area does the service cover?

Response choices were: 'Catchment restricted' or 'Unrestricted'. If restricted, respondents were asked to indicate whether this was by (a) PCTs, (b) Local Authority/Boroughs, (c) Other.

There were twelve non-responders. Three of the remaining 24 reported having unrestricted catchment areas (one voluntary sector day centre, one in-patient rehabilitation unit and one specialist nursing home), with 21 having catchments restricted by different administrative bodies.

As shown in Table 54 there was an even distribution of catchments restricted by different administrative bodies across the sample of CRTs, with Primary Care Trusts (PCTs) and Local Authority/Boroughs each being cited by six and a further three citing a combination of the two. Other services were spread across all three areas.

Table 54. Breakdown of services by restricted catchment areas

Type of service	Primary Care Trusts		Local Authority/ Boroughs		Local Authority/ Boroughs & PCTs	
	N	%	N	%	N	%
Community Rehabilitation Teams						
Generic (N=5)	3	(20%)	1	(7%)	1	(7%)
Neurological (N=8)	3	(20%)	3	(20%)	2	(13%)
Intermediate (N=1)	-	-	1	(7%)	-	-
ABI (N=1)	-	-	1	(7%)	-	-
TOTAL (N=15)	6	(40%)	6	(40%)	3	(20%)
Other services						
Voluntary Sector (N=5)	1	(17%)	3	(50%)	1	(17%)
In-patient Rehab (N=1)	1	(17%)	-	-	-	-
TOTAL (N=6)	2	(33%)	3	(50%)	1	(17%)

Question 3. How is the service funded and who by?

Response choices were: 'Case by case' or 'Block contract' with funding by:

(a) Healthcare (e.g. PCTs),

(b) Social services,

(c) Voluntary sector/charities.

Only three services answered the first part of this question: a Generic CRT citing a block contract and an in-patient service and voluntary sector day centre both citing case by case funding.

All but one of the remaining services subsequently gave information on funding sources, as shown in Table 55, which provides a breakdown of CRT and other service types by funding source.

The majority of both Generic and Neurological CRTs were funded through Healthcare (PCTs). Otherwise, individual CRTs were funded through a variety of sources, with numbers being too small to note any specific trends.

Similarly, other types of centre were funded from a variety of sources, either individually or in combination.

Table 55. Breakdown of service type by funding source

Type of service	Healthcare		Social Services		Healthcare and Social		Voluntary		Other combination	
	N	%	N	%	N	%	N	%	N	%
Community Rehabilitation Teams										
Generic (N=10)	8	(31%)	1	(4%)	1	(4%)	-	-	-	-
Intermediate (N=2)	1	(4%)	-	-	1	(4%)	-	-	-	-
Neurological (N=10)	9	(35%)	-	-	1	(4%)	-	-	-	-
ABI (N=3)	1	(4%)	1	(4%)	1	(4%)	-	-	-	-
Stroke (N=1)	1	(4%)	-	-	-	-	-	-	-	-
TOTAL (N=26)	20	(77%)	2	(8%)	4	(15%)				
Other services										
Voluntary sector (N=6)	-	-	2	(22%)	1	(11%)	2	(22%)	1	(11%)
In-patient service (N=2)	1	(11%)	-	-	-	-	-	-	1	(11%)
Nursing home (N=1)	-	-	-	-	1	(11%)	-	-	-	-
TOTAL (N=9)	1	(11%)	2	(22%)	2	(22%)	2	(22%)	2	(22%)

Question 4. What types of service model do you offer?

Choices given were:

(a) Home-based rehabilitation,

(b) Centre-based rehabilitation,

(c) Residential/in-patient rehabilitation,

(d) Other.

Ten CRTs and one Voluntary sector service did not respond to the question. Of the 17 CRTs that did respond, three-quarters offered Centre-based rehabilitation, with two services offering in-patient rehabilitation and one offering both. One Generic service also offered a community/workplace service (see Table 56).

None of the responding services offered home-based rehabilitation services.

Table 56. Breakdown of CRT type by service model offered

Type of service	Centre-based		Residential/ in-patient		Centre-based and Residential/ in-patient	
	N	%	N	%	N	%
Community Rehabilitation Teams						
Generic (N=6)	5	(29%)	-	-	1	(6%)
Intermediate (N=2)	1	(6%)	1	(6%)	-	-
Neurological (N=7)	7	(41%)	-	-	-	-
ABI (N=2)	-	-	-	-	2	(12%)
TOTAL (N=17)	13	(76%)	1	(6%)	3	(18%)
Other services						
Voluntary sector (N=5)	5	(63%)	-	-	-	-
In-patient service (N=2)	-	-	2	(25%)	-	-
Nursing home (N=1)	-	-	-	-	1	(13%)
TOTAL (N=8)	5	(63%)	2	(25%)	1	(13%)

Question 5a Who can access the service - What diagnoses do you take?

Diagnostic options were:

(a) Brain injury,

(b) Spinal Cord Injury,

(c) Peripheral Neuropathy,

(d) Progressive Neurological and

(e) Other conditions.

All services responded; over half of them taking patients with brain injuries (strokes, SAH, TBI and other ABIs), while the rest catered for progressive conditions, mental health problems or a mix of sudden onset and progressive conditions, as shown in Table 57.

Table 57. Breakdown of service type by diagnostic conditions catered for

Type of service	Any neurological condition		Brain[1] injury		Brain injury[1], Progressive and/or Other		Other conditions[2]	
	N	%	N	%	N	%	N	%
Community Rehabilitation Teams								
Generic (N=10)	3	(11%)	4	(15%)	3	(11%)	-	-
Intermediate (N=2)	2	(7%)	-	-	-	-	-	-
Neurological (N=11)	1	(4%)	5	(19%)	1	(4%)	4	(15%)
ABI (N=3)	1	(4%)	1	(4%)	1	(4%)	-	-
Stroke (N=1)	-	-	1	(4%)	-	-	-	-
TOTAL (N=27)	7	(26%)	11	(41%)	5	(19%)	4	(15%)
Other services								
Voluntary sector (N=6)	-	-	6	(67%)	-	-	-	-
In-patient service(N=2)	-	-	1	(11%)	1	(11%)	-	-
Nursing home (N=1)	-	-	1	(11%)	-	-	-	-
TOTAL (N=9)	-	-	8	(89%)	1	(11%)	-	-

[1] Stroke, SAH, TBI, Other ABI, [2] Progressive conditions (N=2) and Mental health (N=2)

Question 5b. Who can access the service - What is the target age group?

Target age groups were:

(a) Mainly younger adults (<65),

(b) Mainly older adults (>65),

(c) Children,

(d) Any.

Seven CRTs and three other centres did not respond. As shown in Table 58, half of the services catered for a mix of younger and older adults, with a quarter catering for mainly younger adults.

Table 58. Breakdown of service type by target age group for their services

Type of service	Mainly younger adults		Younger adults and children		Younger and older adults		Mainly older adults		Any age group	
	N	%	N	%	N	%	N	%	N	%
Community Rehabilitation Teams										
Generic (N=9)	1	(5%)	-	-	5	(25%)	1	(5%)	2	(10%)
Intermediate (N=2)	-	-	-	-	2	(10%)	-	-	-	-
Neurological (N=7)	2	(10%)	1	(5%)	3	(15%)	-	-	1	(5%)
ABI (N=2)	1	(5%)	-	-	1	(5%)	-	-	-	-
TOTAL (N=20)	4	(20%)	1	(5%)	11	(55%)	1	(5%)	3	(15%)
Other services										
Voluntary sector (N=5)	3	(50%)	-	-	2	(33%)	-	-	-	-
In-patient service (N=1)	-	-	-	-	-	-	-	-	1	(17%)
TOTAL (N=6)	3	(50%)	-	-	2	(33%)	-	-	1	(17%)

Question 6. What types of problem do you tackle?

Response choices were

(a) Physical disability,

(b) Cognitive/behavioural disability,

(c) Vocational rehabilitation.

One Generic CRT, three Neurological CRTs and one Voluntary Sector service did not answer this question.

The majority provided a mix of inputs designed to tackle physical, cognitive/ behavioural and vocational rehabilitation needs, with only a few services providing input for only one type of problem (physical or cognitive/behavioural), as shown in Table 59.

Table 59. Breakdown of CRT type by the types of problem addressed by their services

Type of service	Physical		Cognitive behavioural		Physical and cognitive behavioural		Physical, cognitive behavioural and vocational	
	N	%	N	%	N	%	N	%
Community Rehabilitation Teams								
Generic (N=9)	3	(13%)	-	-	3	(13%)	3	(13%)
Intermediate (N=2)	-	-	-	-	2	(9%)	-	-
Neurological (N=8)	-	-	2	(9%)	4	(17%)	2	(9%)
ABI (N=3)	-	-	-	-	1	(4%)	2	(9%)
Stroke (N=1)	1	(4%)	-	-	-	-	-	-
TOTAL (N=23)	4	(17%)	2	(9%)	10	(43%)	7	(30%)
Other services								
Voluntary sector (N=5)	-	-	1	(13%)	1	(13%)	3	(38%)
In-patient service (N=2)	-	-	-	-	2	(25%)	-	-
Nursing home (N=1)	-	-	-	-	1	(13%)	-	-
TOTAL (N=8)	-	-	1	(13%)	4	(50%)	3	(38%)

Question 7. What disciplines do you have on your team?

The choice of disciplines on the survey were:

(a) Physiotherapy,

(b) Occupational therapy,

(c) Speech and Language Therapy,

(d) Psychology,

(e) Social Work,

(f) Dietetics,

(g) Orthotics,

(h) Other

Only two Community Rehabilitation Teams did not respond to this question; both Neuro CRTs. The remaining 25 specified the diversity of disciplines in their respective teams.

Summary data indicating the number of teams in which each individual discipline was included is given in Figure 55.

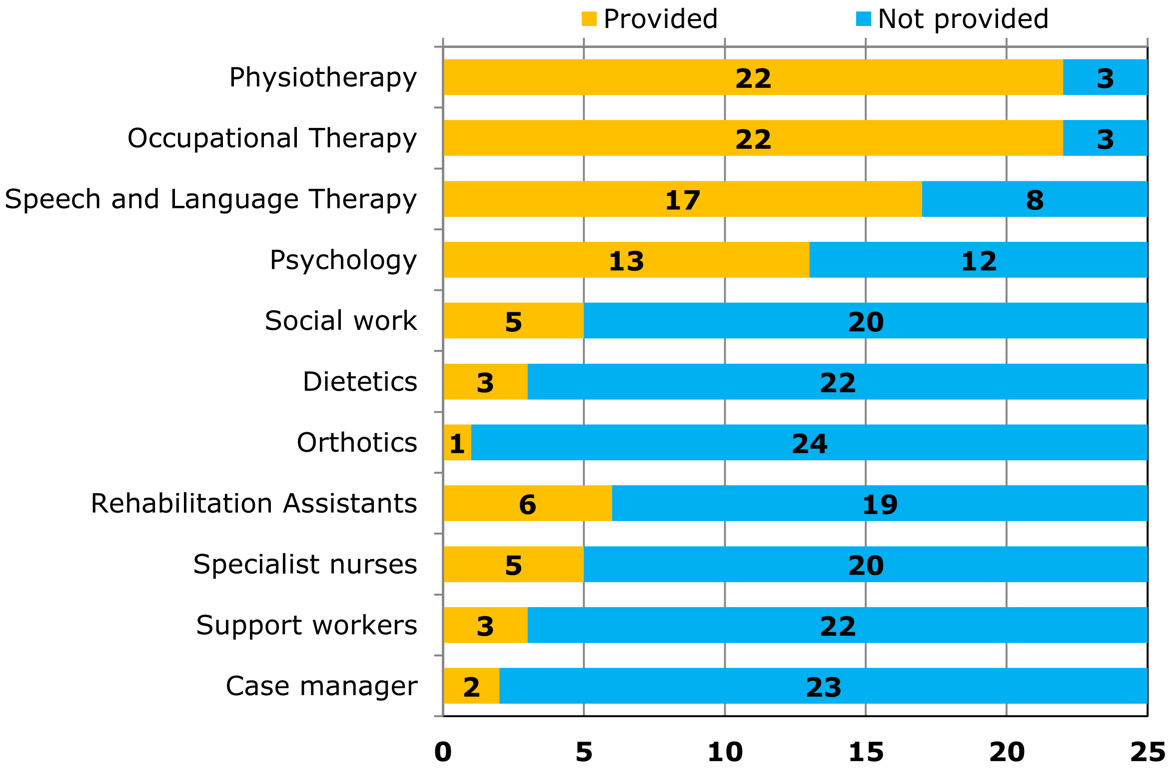


Figure 55. Number of disciplines provided and not provided by CRT teams responding to the survey (N=25)

Three core therapies; physiotherapy, occupational therapy and speech and language therapy were well represented, with psychology being available in half of the services surveyed.

However, social workers were only accessible in five out of the 25 services (20%) and case managers in two out of 25 (8%), indicating a potential shortfall in the support necessary for successful re-integration into the community.

Among the 'Other' disciplines cited that had not been suggested in the survey were rehabilitation assistants, specialist nurses (for Multiple sclerosis and Parkinson's disease), support workers, case managers and administrative/clerical workers. These disciplines were mentioned by only a few services and it is not known whether the low proportions reflect the situation more generally.

Two out of the nine other centres did not respond. As shown in Figure 56, the pattern of disciplines available in the remaining seven (two in-patient, one specialist nursing home and four voluntary sector day centres) varied from that found in CRTs, in that fewer of them had access to therapists.

In contrast, psychological input was offered in all but one. Two day centres provided support from volunteers, and one other offered music, yoga, cranio-sacral and exercise therapies.

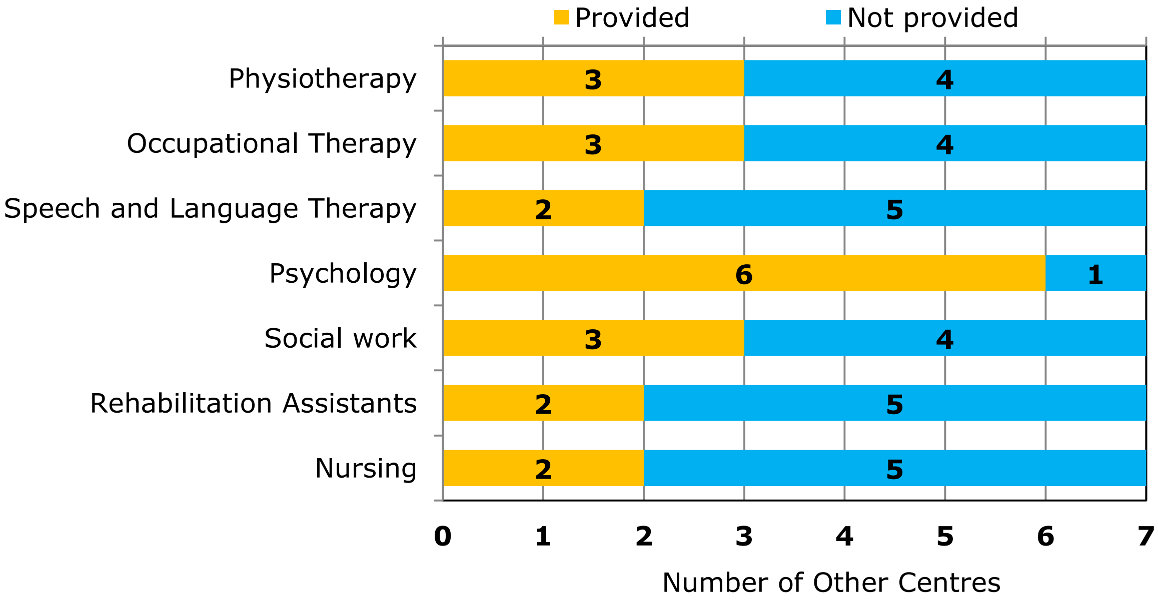


Figure 56. Number of disciplines provided and not provided by other teams responding to the survey (N=7)

Question 8. What medical input does your service have access to?

Respondents selected from three options to indicate the type of medical input their service had access to:

(a) Regular (how many sessions/week)

(b) As required from named doctor/practice

(c) No specific arrangements (work with patient's existing medical practitioner)

All but one voluntary sector service responded to the question. Table 60 gives a breakdown of their responses.

Table 60. Breakdown of service type by type of medical input

Type of service	Regular		As required from named doctor/ practice		No specific arrangements	
	N	%	N	%	N	%
Community Rehabilitation Teams						
Generic (N=10)	1	(4%)	2	(7%)	7	(26%)
Intermediate (N=2)	-	-	1	(4%)	1	(4%)
Neurological (N=11)	5	(19%)	2	(7%)	4	(15%)
ABI (N=3)	-	-	1	(4%)	2	(7%)
Stroke (N=1)	-	-	-	-	1	(4%)
TOTAL (N=27)	6	(22%)	6	(22%)	15	(56%)
Other services						
Voluntary sector (N=5)	1	(13%)	2	(25%)	2	(25%)
In-patient service (N=2)	2	(25%)	-	-	-	-
Nursing home (N=1)	-	-	1	(13%)	-	-
TOTAL (N=8)	3	(38%)	3	(38%)	2	(25%)

Half of the services had no specific arrangements for medical input. The remainder were equally divided between arrangements that were 'regular' or 'as required'.

Nonetheless, eighteen went on to complete the second part of this question, which asked services indicating that they had regular medical input to specify the types of medical professionals that they had access to.

Table 61 sets out the range of medical inputs available to patients attending these services. Across the 12 CRTs that responded, medical input ranged from one to four types of doctor, with primary care doctors and consultants in rehabilitation medicine being the most prevalent; each being cited by eight CRTs. Neuro-psychiatrists were the most prevalent type of doctor cited by five out of six of the other centres.

Table 61. Range of medical inputs provided through community services

Type of Service	Doctors per service	Types of doctor accessed by individual services				
		Primary care	Consultant in rehab medicine	Neuro-psychiatrist	Elderly care	Stroke doctor
Community Rehabilitation Teams						
Generic						
ID 5	1	-	✓	-	-	-
ID 7	3	✓	✓	✓	-	-
ID 26	1	-	-	-	-	✓
Intermediate						
ID 33	3	✓	✓	-	✓	-
Neurological						
ID 3	2	✓	-	✓	-	-
ID 8	2	✓	✓	-	-	-
ID 9	1	✓	-	-	-	-
ID 17	1	-	✓	-	-	-
ID 18	1	-	-	-	-	✓
ID 23	4	✓	✓	✓	-	✓
ID 31	2	✓	✓	-	-	-
ABI						
ID 1	2	✓	✓	-	-	-
Other services						
Voluntary						
ID 10	3	✓	✓	-	-	✓
ID 21	1	-		✓	-	-
ID 35	2	-	✓	✓	-	-
In-patient						
ID 6	1	-	-	✓	-	-
ID 13	2	✓	-	✓	-	-
Nursing home						
ID 11	3	✓	✓	✓	-	-
Total		11 (31%)	11 (31%)	8 (23%)	1 (3%)	4 (11%)

Question 9. Duration of input

Respondents were asked whether their programme length was:

(a) Time limited

(b) Flexible, based on individual need

(c) Other

Three CRTs did not answer, with the rest more or less equally divided between providing time limited and flexible services (see Table 62). The majority of other centres offered a flexible programme length.

Table 62. Breakdown of service type by programme length

Type of service	Time limited		Flexible		Other*	
	N	%	N	%	N	%
Community Rehabilitation Teams						
Generic (N=10)	2	(8%)	7	(29%)	1	(4%)
Intermediate (N=2)	2	(8%)	-	-	-	-
Neurological (N=8)	3	(13%)	2	(8%)	3	(13%)
ABI (N=3)	1	(4%)	2	(8%)	-	-
Stroke (N=1)	1	(4%)	-	-	-	-
TOTAL (N=24)	9	(38%)	11	(46%)	4	(17%)
Other services						
Voluntary sector (N=5)	1	(14%)	4	(57%)	-	-
In-patient service (N=1)	-	-	-	-	1	(14%)
Nursing home (N=1)	-	-	1	(14%)	-	-
Total (N=7)	1	(14%)	5	(71%)	1	(14%)

* One Generic, one Neuro and one in-patient rehabilitation service stated that their services were both time limited and flexible. One Neuro service was a 'rehab consortium with 12/24 weeks long term involvement with health funded continuing care clients' and another Neuro service commented that they were able to provide on-going support.

Services were also asked if they had a waiting list and if so, how long it was. Nine CRTs (six generic and three Neuro) responded and all stated a waiting list time of 1 week to 3 months.

Similarly, the four voluntary sector services responding to this question also cited a waiting list time of 1 week to 3 months.

Question 10. Do you feel you can cope adequately with the needs of your patient population, through your own service/other linked services?

Staff from fourteen CRTs, four voluntary sector services and one nursing home answered 'No' to this question.

Ten services reported constraints in the quality services they would have wished to offer. This was generally attributed to a high patient load alongside shortages in numbers of therapists.

This situation inevitably had the knock-on effect of increasing waiting list times, as well as limiting the frequency, intensity and duration of inputs available to patients. Indeed, one service referred to being unable to keep up with demand and working on a crisis management basis.

And seven services cited deficiencies in the range of disciplines available through their services as limiting their capacity to deliver the specialist multi-disciplinary input needed for people with diverse and complex neurological problems.

Valued services including psychology, vocational rehabilitation, dietetics, advocacy and support for relatives were all wanting, as were opportunities for patients to access hydrotherapy, gym facilities and leisure activities.

Also mentioned was the lack of a clear pathway from hospital to community services, which could compromise the potential benefits of early supported discharge from acute services to home. And a shortage of equipment was also referred to as being problematic.

Question 11. Do you consider yours to be a complex specialised community rehabilitation service?

Response choices were: 'Yes' or 'No'. If respondents answered 'Yes' they were asked to fill in a further set of questions before returning the survey to the research team.

All services responded to this question and almost three-quarters of the CRTs (N=19) and two thirds of the other centres (N=6) considered their services to be complex specialised.

The numbers and proportions of service types by the complexity of service they offered are set out in Table 63 below.

Table 63. Breakdown of service type by complexity of service offered

Type of service	Complex specialised service		Service not complex specialised	
	N	%	N	%
Community Rehabilitation Teams				
Generic CRT (N=10)	8	(30%)	2	(7%)
Intermediate CRT (N=2)	1	(4%)	1	(4%)
Neurological CRT (N=11)	7	(26%)	4	(15%)
ABI CRT (N=3)	2	(7%)	1	(4%)
Stroke CRT (N=1)	1	(4%)	-	-
TOTAL (N=27)	19	(70%)	8	(30%)
Other services				
Voluntary sector (N=6)	3	(33%)	3	(33%)
In-patient service (N=2)	2	(22%)	-	-
Nursing home (N=1)	1	(11%)	-	-
TOTAL (N=9)	6	(67%)	3	(33%)

Question 12. Complex community rehabilitation services

The 19 CRTs and 6 other complex specialised services responded to a further series of questions designed to provide more detailed information on what they offered

Firstly, they described the range of services, choosing from:

(a) Domiciliary visits

(b) Out-patient/day programmes

(c) Other services

Secondly, they indicated which regular coordinated multidisciplinary (MD) activities took place within their service. choosing from:

(a) Case notes

(b) Treatment planning meetings

(c) Outcome evaluation

(d) Goal setting

(e) Other MD activities

Table 64 sets out these activities by service type.

Table 64. Breakdown of service type by range of services offered

Type of service	Domiciliary visits		Out-patient/ day programme		Other services offered	
	N	%	N	%	N	%
Community Rehabilitation Teams						
Generic (N=7)	6	(38%)	4	(25%)		
Intermediate (N=1)	1	(6%)				
Neurological (N=6)	6	(38%)	4	(25%)	1	(6%)
ABI (N=1)	1	(6%)				
Stroke (N=1)	1	(6%)				
TOTAL (N=16)	15	(94%)	8	(50%)	1	(6%)
Other services						
Voluntary sector (N=2)	2	(50%)	1	(25%)	1	(25%)
In-patient service (N=1)			1	(25%)		
Nursing home (N=1)	1	(25%)	1	(25%)	1	(25%)
TOTAL (N=4)	3	(75%)	3	(75%)	2	(50%)

Fifteen CRTs, two voluntary sector services and one nursing home offered domiciliary visits. In contrast, only half of the services (eight CRTs and three other services) offered an out-patient and/or day programme with or without domiciliary visits.

In terms of other services provided, two CRTs respectively held splinting and other special clinics. One voluntary sector support service offered access to peer support groups and a specialist nursing home offered hydrotherapy.

Table 65. Breakdown of service type by multi- or inter-disciplinary team activity

Type of service	Case notes		Treatment planning meetings		Outcome evaluation		Goal setting	
	N	%	N	%	N	%	N	%
Community Rehabilitation Teams								
Generic (N=7)	7	(44%)	7	(44%)	6	(38%)	6	(38%)
Intermediate (N=1)	1	(6%)	1	(6%)	1	(6%)	-	-
Neurological (N=6)	6	(38%)	5	(31%)	6	(38%)	6	(38%)
ABI (N=1)	1	(6%)	1	(6%)	1	(6%)	1	(6%)
Stroke (N=1)	1	(6%)	1	(6%)	1	(6%)	1	(6%)
TOTAL (N=16)	16	(100%)	15	(94%)	15	(94%)	14	(88%)
Other services								
Voluntary sector (N=1)	1	(33%)	1	(33%)	-	-	-	-
In-patient service (N=1)	1	(33%)	1	(33%)	1	(33%)	1	(33%)
Nursing home (N=1)	1	(33%)	1	(33%)	1	(33%)	1	(33%)
TOTAL (N=3)	3	(100%)	3	(100%)	2	(66%)	2	(66%)

Eleven CRTs and six other services gave no information on regular MD activity within their respective services. As shown in Table 65, almost all of the remaining 19 services kept multi-disciplinary case notes, convened treatment planning meetings, participated in outcome evaluation and participated in goal setting.

One CRT referred to engaging in leadership and service development as another co-ordinated activity, while a voluntary support service referred to liaising with another multidisciplinary team.

A further series of questions asked about:

(a) The average number of patients requiring coordinated multi-disciplinary team input from two or more disciplines.

(b) The average number of disciplines that were involved with each patient within the service.

(c) Whether the intensity of rehabilitation provided was tailored to individual need or followed a set, pre-defined programme.

(d) How outcomes were measured and which standardised measures were used.

(e) The policy for on-going follow-up

Table 66 sets out responses to questions (a) to (c)

Eight out of the 16 centres responding to the question estimated that on average, more than three-quarters of their patients needed co-ordinated MD input from two or more disciplines. Five estimated that it was required by half to three-quarters of their intake, with two citing between a quarter and a half.

With three exceptions, fourteen CRTs and one other centre estimated that the average number of disciplines involved with each patient ranged from 2 to 3.

All but one CRT, as well as the three other centres responding to this question, provided rehabilitation that was tailored to individual need. The exception was an Intermediate CRT that provided a set pre-defined programme.

Table 66. Input needed from disciplines and intensity of rehabilitation provided

Type of Service	Patients needing MD input from two or more disciplines	Mean disciplines per patient	Rehabilitation tailored to individual need
Generic CRT			
ID 5	≥76%	2+	✓
ID 7	≥76%	2-3	✓
ID 24	≥76%	2-3	✓
ID 26	-	-	✓
ID 27	≥76%	2	✓
ID 32	26-50%	2	✓
ID 37	51-75%	2	✓
Intermediate CRT			
ID 33	≥76%	-	-
Neurological CRT			
ID 3	-	-	✓
ID 4	≥76%	2-3	✓
ID 8	51-75%	2-3	✓
ID 9	≥76%	3	✓
ID 18	26-50%	2	✓
ID 22	51-75%	2	✓
ID 23	51-75%	1-7	✓
ABI CRT			
ID 1	≥76%	2.5	✓
Stroke CRT			
ID 2	51-75%	2-3	✓
Voluntary sector			
ID 10	-	1-2	-
ID 35	-	-	✓
In-patient service			
ID 6	≥76%	5	✓
Nursing home			
ID 11	-	3-5	✓
TOTAL N=21			19 (90%)

Concerning measurement of outcomes, individual services indicated which (if any) among a list of four common rehabilitation outcome measures they used, and added any others not listed. Figure 57 shows the proportions using the listed measures out of the 16 CRTs and two other services (one in-patient service and one specialist nursing home) that responded.

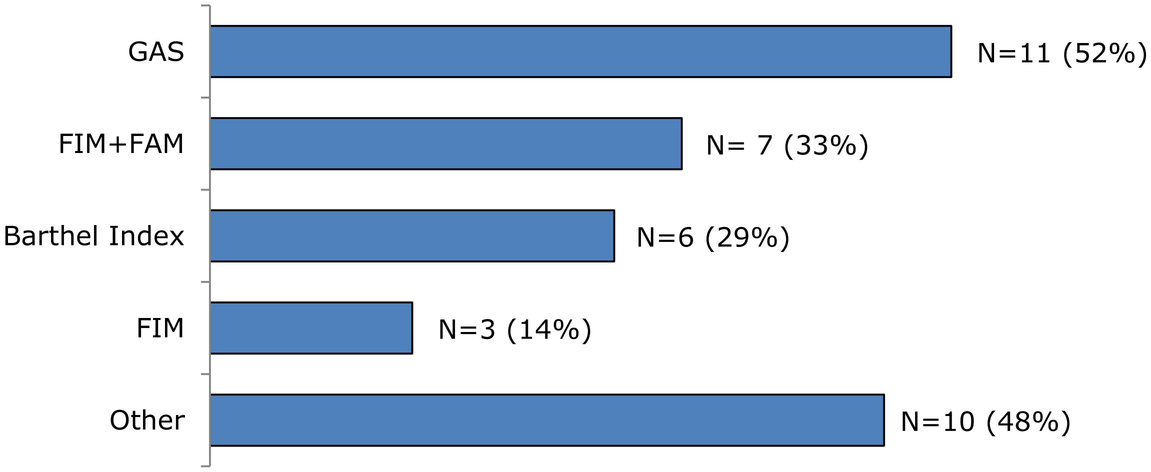


Figure 57. Proportions of services using listed rehabilitation outcome measures

Use of standardised measures was varied and there was some overlap, in that several centres used a multiplicity of measures. In individual terms, GAS was the most commonly used measure across the spectrum of services, being cited by three in five. Just over a third used the FIM+FAM, with fewer using the Barthel Index or the FIM alone.

The most prevalent combination of measures was GAS used with either the Barthel Index, the FIM, FIM+FAM or another measure (N=7) One Intermediate CRT and the Specialist Nursing Home used all the listed measures. A range of other outcome measures were cited, but there was little consistency across CRTs, which could have reflected their varied intake. Those used included:

- Care and Needs Scale (CANS)
- ED-5QL Quality of life measure
- Therapy Outcome Measure (TOMS)
- Canadian Occupational Performance Measure (COPM)
- Tinneti Gait and Balance Tool
- Berg Balance scale
- Brain Injury Community Rehabilitation Outcome Scale (BICRO)
- Beck Depression Inventory
- Beck Anxiety Inventory
- Patient satisfaction questionnaire

What is the policy for long term follow-up?

All but two of the seventeen community-based rehabilitation services and two in-patient services responding to this question, provided information about how patients were followed up after discharge.

- Eight cited self-referral or open access arrangements as being their usual practice for long term follow-up, while two cited referral via GPs or therapists.
- Six services offered follow-up assessment or review at set times, ranging from three months to one year after discharge.
- In contrast, six others operated a flexible approach, with patients being followed up or re-assessed at variable times according to need. This tended to be in cases where patients were deemed to be at risk of deterioration, such as those with progressive LTNCs or palliative care needs, for (unspecified) clinical reasons or where clear goals had been agreed.

Referral on to other out-patient or support services was mentioned by one in-patient and two out-patient services.

Routes of communication between services and patients or health and social care professionals included telephone contacts and the use of electronic patient record systems, all of which could act as a prompt to follow-up.

Question 13. Facilities, programmes and medical/nursing services

Lists of facilities that might currently have been provided by services as part of routine practice and included in its costs at the time of survey completion were listed for services to select from. These comprised:

(a) Specialist programmes

(b) Special facilities (including whether services were demonstration centres)

(c) Medical/nursing care services

Services were also asked to add any other categories that, in their view, characterised a specialist neuro-rehabilitation community service.

Lastly, they were asked to comment on any changes or threats to services that they might envisage as a result of impending changes to the NHS.

(a) Specialist programmes

No responses were forthcoming from 12 CRTs (four Generic, five Neuro, two ABI and one Intermediate) or from five other services (four voluntary sector Day Centres and one in-patient rehabilitation unit.

Figure 58 sets out the specialist programmes provided by two or more of the fifteen CRTs and three or more of the four other services that did respond to this question.

Only one service, a specialist nursing home, provided a specialist programme other than those listed in the survey and this was hydrotherapy (provided off site).

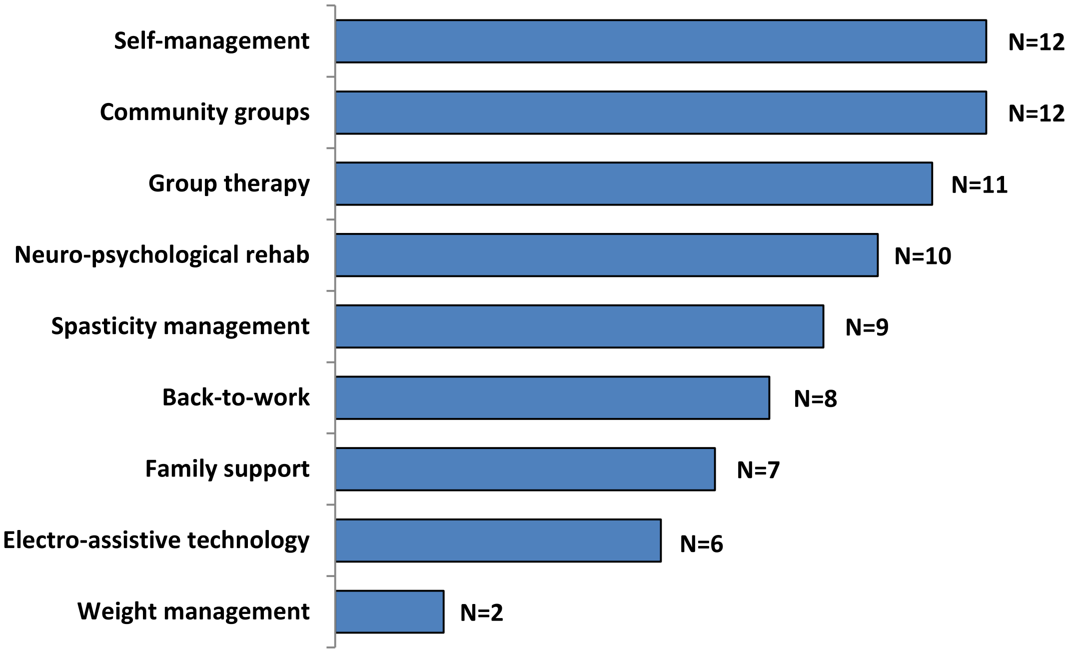


Figure 58. Provision of specialist programmes by community services as part of routine practice

(b) Special facilities and Demonstration Centres

Fifteen services (14 of the 27 CRTs and one specialist nursing home) responded to this question. The remaining 13 CRTs (four Generic, six Neuro, two ABI, one stroke and one Intermediate) and eight other service types did not respond.

The numbers providing special facilities are illustrated in Figure 59, which shows functional electrical stimulation and custom splints/orthoses as being the most commonly provided. Only four centres served as demonstration centres. The areas of expertise they covered are shown in Figure 60.

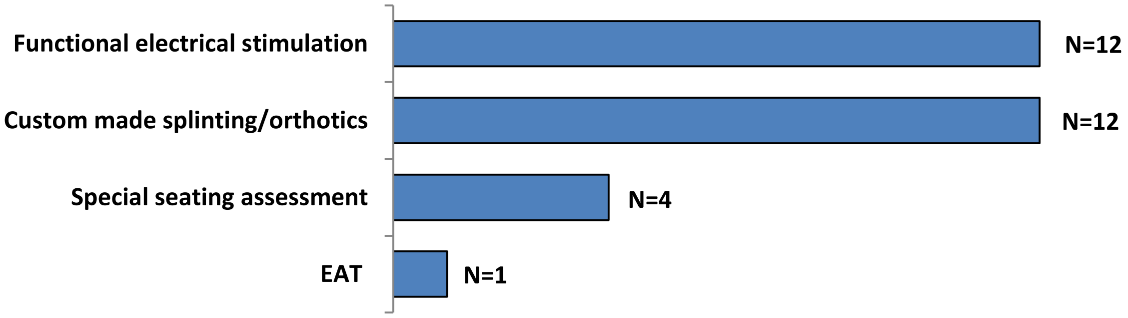


Figure 59. Provision of special facilities by community services as part of routine practice

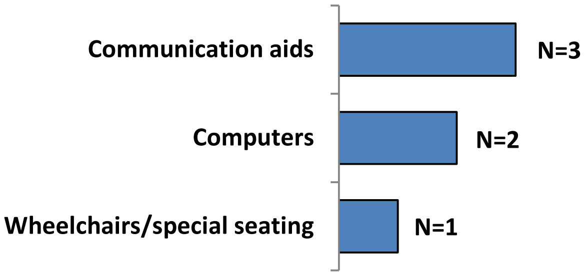


Figure 60. Areas of expertise covered by demonstration centres

(c) Medical/Nursing Services

Only a minority of services offered medical/nursing services as part of routine practice; six CRTs, one in-patient unit and one specialist nursing home. The proportions offering them are shown in Figure 61.

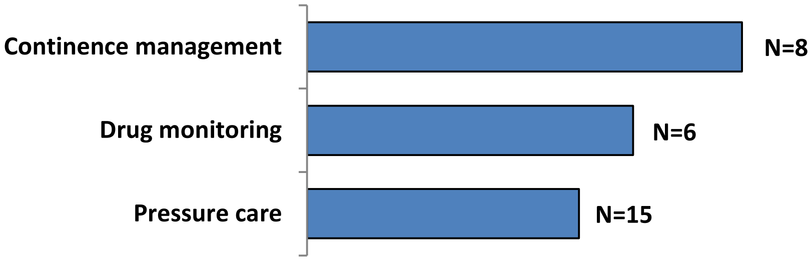


Figure 61. Provision of Medical/Nursing services as part of routine practice

Question 14. Are there any changes or threats to services that you identify as a result of impending changes to the NHS?

In all, sixteen services responded to this question. They comprised 13 CRTs, two Voluntary Sector services and one Specialist Nursing Home.

Four expressed uncertainty over the question, one describing the impending changes as 'a voyage into the unknown' and another being unsure about whether commissioning changes would present threats or opportunities.

Two others did not envisage changes impacting on their service. One remained confident that patient need would continue to drive the healthcare agenda, and that they would be able to continue providing holistic high quality rehabilitation. Another was encouraged by the current focus on maintaining health and well-being in the community from the QIPP LTC work stream, seeing this as integral to the service they offered.

On the other hand, funding cuts to healthcare, rehabilitation and social services, potential limitations to the time available for client contact and expectations that services would have to take on new responsibilities without additional resources were all cited as possible threats.

Recognition of gaps in the community stroke care pathway following early supported discharge, and the patchy nature of specialist rehabilitation, information and support across London only served to exacerbate worries such as these.

Similarly, proposals for structural reorganisation caused concerns that some services would be diluted, either through integration with other teams or through division into smaller units, and that this could limit their influence on service development.

Moreover, the prospect of services being downgraded aroused fears that vulnerable patients would suffer, particularly those with cognitive and communication difficulties who find it difficult to access support. This caused anxiety in staff committed to providing quality care.

13.5 Limitations

The results of the present chapter are tempered by the low response rate with only 36 (29%) out of 124 services responding despite 3-4 follow-up calls to each service that was mailed a questionnaire.

A further limitation was the wide variation in the time lag between the services receiving the survey and returning their completed responses. Both of these factors suggest that the services which did respond might be less than fully representative of all the services in London.

13.6 Chapter summary

- Despite persistent efforts to obtain information about their rehabilitation programmes, fewer than a third of the services contacted responded to our request to complete a Community Service Profile Questionnaire and this is clearly a limitation in terms of the generalisability of findings.

  Nonetheless, there was a fair representation of both CRTs and Voluntary Sector services among the responding sample, which was widely spread across Greater London and the surrounding area.
- Most restricted catchments were determined in equal measure by PCTs, Local Authorities or a combination of the two. The majority of services were funded through Healthcare, with some also receiving funding from Social Services and in a few cases from the voluntary sector.
- Centre-based rehabilitation was the predominant service model on offer, in some cases in combination with residential services. While over half offered a flexible programme length, almost a third were time limited.
- Overall, twice as many services catered for adults across the age groups as for younger adults alone, and over half catered specifically for people with brain injuries. Most had a multi-disciplinary focus in mainly addressing physical and cognitive behavioural problems in combination, with a few also offering vocational rehabilitation.

- Three core therapies (PT, OT and SALT) were well represented, with psychology being available in half of the services surveyed. However, there appeared to be a shortage of social workers and case managers across the board, indicating a potential shortfall in the support necessary for successful re-integration into the community.
- Half of the services had no specific arrangements for medical input. However, where this input was available, primary care doctors and consultants in rehabilitation medicine were the most prevalent, followed by neuro-psychiatrists.
- Seventy percent considered their service to be a complex specialised one, offering co-ordinated multi-disciplinary rehabilitation from two or more disciplines that was tailored to individual needs. Ninety percent of those responding to more detailed questions about their range of services on offer carried out domiciliary visits, with half offering out-patient and/or day programmes.
- Almost all kept case notes and held treatment planning meetings while about three-quarters engaged in outcome evaluation and goal setting. A variety of specialist programmes and facilities were offered as an adjunct to the core therapies available.
- Use of standardised outcome measures was varied, with Goal Attainment Scaling (GAS) being the most commonly used measure, followed by the Functional Independence Measure (FIM) alone or in combination with the Functional Assessment Measure (FAM).
- While a majority of these community-based services provided specialist multi-disciplinary care, some were under-staffed, and others felt under pressure to reduce waiting lists and increase throughput of patients at the expense of providing high quality holistic services in the longer term, especially for patients with complex needs. A shortage of accessible vocational rehabilitation, advocacy and psychology services was highlighted by some.

14 Patient and professional perceptions of barriers to the delivery of community rehabilitation services

14.1 Overview

Having investigated the level of health, rehabilitation and general support services needed and received by people with LTNCs, we then measured their perceived obstacles to accessing these services. We also carried out telephone interviews with a small sample of participants who expressed dissatisfaction with the services actually delivered, and where possible, the relevant services to further understand the causes of their dissatisfaction.

In particular we aimed to determine:

- The most frequent barriers or obstacles to accessing rehabilitation services in the community as perceived by all participants responding at six months.
- Satisfaction levels of participants at six months for the different service areas assessed by the NPCS.
- The perception of a small sample of participants who were 'very dissatisfied' with community rehabilitation services as to what exactly was the source of their dissatisfaction.
- The perception of the relevant service providers, for the same 'very dissatisfied' participants, as to what (if any) problems existed.

The quantitative results from the postal survey are reported first and then the results from the 20 telephone interviews of people who were not satisfied with the rehabilitation services they had received.

14.2 Quantitative data from postal survey

14.2.1 Sample

For the quantitative part of this study we analysed the results of the six items of the Services Obstacles Scale (SOS – see 3.4 Measurement tools). Participants comprised 196 participants who completed all six items of this scale at Phase 2 (six months).

In addition, we calculated frequency distributions for the six NPCS items that ask participants how satisfied they are with the provision of services from each of the six subscales.

14.2.2 Procedure

The procedure for the quantitative component (i.e. SOS Questionnaire) of this chapter is the same as reported earlier for the postal survey at Phase 2 (6 months). Details of the qualitative component (telephone interviews) are reported below in 14.3.1.

14.2.3 Results

The results of a principal component analysis of the six items of the SOS using the six months responses indicated that this is a robust, uni-dimensional scale. The first principal component accounted for 57% of variance and all six items loaded above 0.60 on the first component extracted. Cronbach's α for the six item scale was 0.84, reflecting a reliable scale.

Table 65 below presents the six items from the SOS ranked from the highest to the lowest, i.e. the most frequently endorsed item (obstacle) to the least frequently endorsed item (obstacle). The scale is scored from 1 (Strongly disagree) to 7 (Strongly agree).

Table 67. Services Obstacle Scale items in ranked order

Item (N= 212)	Mean	Median	Range	% Agree / Strongly Agree
For neurological problems there are very few services in my community.	4.27	4.0	1 - 7	35.8%
I don't know if there are good neurological rehabilitation services…..	4.18	4.0	1 - 7	28.6%
Lack of money to pay for medical, rehabilitation and injury related services is a major problem.	3.97	4.0	1 - 7	33.2%
I am dissatisfied with the amount of professional help and services being provided.	3.91	4.0	1 - 7	29.0%
Transportation is a major obstacle….	3.64	4.0	1 - 7	23.8%
I have little confidence in the quality of care now being provided.	3.44	3.0	1 - 7	20.3%

Inspection of Table 67 shows that the most frequently reported obstacles to services in the eyes of participants were the availability of services, knowledge about local services and financial barriers to accessing services.

The frequency distributions for the five NPCS items that asked participants if they were satisfied or not with the delivery of services in the different subscale areas of the NPCS are presented below in Table 68.

Table 68. Participants' satisfaction ratings at six months with the provision of services according to the subscale categories of the NPCS.

NPCS Global satisfaction rating (N=148-173)*	Too little %	Just right %	Too much %
Is this the right amount of medical/ nursing care for you?	19.7	80.3	0.0
Is this the right amount of personal care for you?	25.4	74.0	0.6
Is this the right amount of rehabilitation for you?	43.7	56.3	0.0
Is this the right amount of social/family support for you?	23.1	76.9	0.0
Is this the right amount of equipment /accommodation for you?	20.9	79.1	0.0

* The sample size ranged from 148-173 due to missing responses on individual items. Missing responses were common because participants often did not rate their satisfaction where they considered a specific item was not relevant to them.

Inspection of Table 66 demonstrates that a sizeable majority of participants were satisfied with the level of services provided for medical and nursing care, equipment and accommodation, social and family support and personal care.

The domains with the largest number of dissatisfied participants were rehabilitation (43.7 percent *Too little*) and Personal Care (25.4 percent *Too little*). It is also worth noting that virtually no participants used the response category *Too much* for any domain.

14.3 Interviews with people dissatisfied with their rehabilitation and their service provider's perspective on their complaints

In the second part of this chapter we report a small, qualitative study carried out to provide a human perspective to these statistics.

In particular, we sought to obtain first-hand accounts from people living with a LTNC of the problems they had encountered in getting access to good rehabilitation in the period after discharge.

We also sought, where possible, to balance this perspective with the views of the service provider to which the person had been referred at discharge.

14.3.1 Sample and Procedure

To identify participants who were dissatisfied with the rehabilitation they had received since discharge, we monitored the following item of the NPCS as data from Phase 2 (6 months) was entered.

Is this the right amount of rehabilitation for you?

Too little ☐ **Just right** ☐ **Too Much** ☐

This item follows, and relates to, the three NPCS items specifically addressing rehabilitation (i.e. therapy intensity, therapy frequency and vocational rehabilitation).

We attempted to contact all participants who selected the 'Too little' response option and invited them to participate in a brief structured interview. This was based upon the rehabilitation prescribed for them by the discharge clinician completing the NPCS (i.e. Needs) and the participants' own responses to the NPCS at six or twelve months (i.e. Gets).

We ceased recruiting new participants for interviews after 20 interviews had been completed. Seven people who participated in the postal survey and expressed dissatisfaction with the rehabilitation they had received declined to take part in this interview component when approached.

We also sought the permission of the 20 'dissatisfied' participants to contact the rehabilitation services that they had been referred to upon discharge, in order to obtain the provider's perspective on the delivery of prescribed services.

Ten participants gave permission for us to contact their rehabilitation services and this was achieved. A further six gave permission but the service provider either could not be contacted (after three calls), or in two instances, declined to participate for confidentiality reasons.

This left a final total of ten dissatisfied participants for whom we were also able to obtain some comments from their service provider to give a balanced picture.

Each 'dissatisfied' participant was called and asked specifically about the dissatisfaction they had indicated on their questionnaire, with a particular focus on the rehabilitation domain of the questionnaire. The NPCS was used as the focus for a brief structured interview centred around the person's responses. The call was recorded with the permission of participants and transcribed into text. Texts were then analysed using thematic analysis to discern the major recurrent themes[68].

The Community Rehabilitation Team was then contacted by a member of the research team for those participants who gave permission for their CRT to be contacted. The conversation with the CRT was structured and documented.

14.3.2 Results

Three main issues surrounding dissatisfaction with community rehabilitation services received by the participants emerged from a content analysis of the ten interviews. These were identified as:

- insufficient therapy
- communication breakdown
- lack of support and/or follow up

Each of these themes is illustrated below with verbatim quotes from participants. Where the service provider was available, and where relevant, we have also included their comments.

Insufficient Therapy

A common theme noted from the qualitative comments participants wrote on their survey responses, and one that featured in virtually every telephone interview, was that they considered that they would benefit from further rehabilitation. Moreover in almost every interview they specified a desire for more physiotherapy:

"…not enough physiotherapy….need it every day." (P1)

"…I would like assisted exercise…I would like physiotherapy once a week. I only had an eight week course with them [Physiotherapy and Speech and Language Therapy] which helped but I need more…" (P4)

All of the ten respondents claimed that they wanted more rehabilitation services in order to get better. While physiotherapy was the clear frontrunner, occupational therapy and various mental health services (psychology, psychiatry, counselling) were also mentioned by some interviewees.

In response, the CRT services on most occasions stated that the patients had been discharged from the service as they had reached and met their goals:

"We are a time limited service….in an ideal world, it would be great to keep seeing everyone – but we don't have enough therapists. Our role is to encourage independence." (CRT3**).**

Communication breakdown

In a number of cases there were marked differences between the patient and the CRT's perspectives on both the need for and value of on-going therapy. For example one patient commented:

"I feel totally abandoned by all the therapists…." (P2)

However the case notes at the CRT mentioned that the patient had been very difficult to contact for an initial appointment, and had then stated that she did not want to engage with the service, as she was grieving the loss of her mother. The CRT understood that her social worker would refer the client back to the service if and when she felt ready.

Another participant stated that:

"I am not in receipt of physiotherapy at present and my movement is deteriorating….." (P8)

The CRT's response to this was that the respondent had reached her therapy goals. However, she also did not seem aware that she could contact her GP about a further referral to the services.

Other examples of the communication breakdown between patient and CRT included one patient who was referred on to a gym that refused to work one-to-one with a client in a wheelchair and a man whose wife complained about the lack of physiotherapy in the home whose therapy had been stopped after a violent incident.

Lack of support and/or follow up

Some of the respondents felt that they had not been given enough support or further information once they had been discharged from the services:

"I am upset about the lack of support in returning to work…need to be on a program." (P6)

However, this patient had been referred to Workability for vocational support claimed her CRT worker

"….the biggest problem with community rehab services is that once you have reached your goals, you are discharged and just left to your own devices – no follow up and lack of info." (P10)

14.4 Limitations

The present study was an attempt to gain some perspective from both patients and service providers as to how things go wrong in the community after discharge and how some patients 'fall through the cracks'. It was a small, qualitative study comprising only 10 patients and its findings must be interpreted with this limitation in mind.

Future studies would do well to interview a larger number of dissatisfied patients as well as interviewing patients who were very satisfied with the services received. At the same time the 10 participants interviewed in the present study provided useful and at times moving accounts of their situation.

14.5 Chapter summary

In the present study we analysed two sections of the LTNC survey to provide a quantitative analysis of how satisfied most participants were at six months post-discharge with the rehabilitation they had received, and the barriers or obstacles they perceived to accessing those services.

We also identified 10 participants who were dissatisfied with rehabilitation services and interviewed them alongside an employee of the service provider they had been referred to on discharge. The purpose of this qualitative approach was to provide some understanding of the complexities in the referral process that are not apparent in the statistics.

In this sample of persons with LTNCs at six months after discharge from specialist rehabilitation, the major perceived obstacles to rehabilitation services were the availability of local services, knowledge about those services and how to access them and financial issues.

While most people expressed satisfaction with the levels of services provided, over 40% were dissatisfied with the amount of rehabilitation, and over 20 complained about levels of personal care, social/family support and equipment/accommodation provided.

The interviews with ten dissatisfied participants and service providers were transcribed and analysed using a thematic analysis approach. This revealed three patterns among this admittedly small group which were Insufficient therapy, Communication breakdown and Lack of support/follow-up.

15 Main discussion

The present research project aimed to pilot a register of people with LTNCs while simultaneously examining how well the needs of these people at discharge were subsequently met by services in their local community, and the costs of both paid and unpaid care.

In addition to the NSF for Long Term Conditions itself, the backdrop to this study was a report commissioned by SDO, which concluded that rehabilitation services had a weak evidence base, were difficult to access, poorly integrated and hospital-focused rather than focused on long-term outcomes such as participation in the community.[2]

A subsequent NIHR-SDO report on the impact of the NSF for LTNCs identified three models of best practice for promoting continuity of care in service delivery as follows:

1. Nurse specialists.
2. Community interdisciplinary neurological rehabilitation teams.
3. Day opportunities for support and meaningful activity.

However, that report also commented that it was 'clear that many do not have access to these services'.[18]

The present study builds upon these two existing reports in three important ways:

- First, the study provides the practical information and clinical measures essential for the development of a workable register for persons with LTNC. This register is necessary to ensure the 'continuity of care' highlighted in the Bernard report[18] as a major issue for disabled persons in the community.
- Second, notwithstanding a high attrition rate, the present study is the first detailed quantitative analysis of the specific health, rehabilitation and social support needs of a large cohort of people with an LTNC, measured against the extent to which each specific need is subsequently met in the year following discharge.
- Third, the study provides a detailed costing of both the professional and unpaid services delivered as well as costing the expense of unmet needs.

In more specific terms this project addressed the following eight research questions:

15.1 Does the LTNC register provide a practical tool to identify and monitor people with complex needs?

Setting up a national register of LTNCs was proposed by the LTNC Dataset Development group as a means to identify, from the diverse group of people with LTNCs, those individuals with complex needs, to define their need for services and to follow them through to avoid them becoming lost in the system.

At the start of the project, although the broad outline of the LTNC dataset had been developed by the NHS information Centre, it was still not yet clear what the level of uptake would be - either by patients or clinicians. In addition, there was no clearly developed set of tools for gathering and collating the data necessary for the register.

The sub-elements to this question therefore were:

- Can we develop a simple, manageable set of tools that would provide the data that would need to be collected to make the database useful and so warrant collection?
- Do patients with LTNC want to be registered and will they provide follow-up information reliably to make the data collected in the registry worthwhile from the commissioners' perspective?
- Will clinicians refer people to the dataset?
- How would the registry be managed and provided in the longer term?

15.1.1 Can we develop a simple manageable set of tools for a LTNC register?

In the course of this project we have identified a manageable set of tools for a LTNC register. We have also drawn up and tested questionnaires to support data collection, both by clinicians and by patients and/or their proxies to underpin such a register.

Using the World Health Organisation's International Classification of Functioning Disability and Health (ICF)[7] as a framework, we identified a simple set of tools that would provide information at the four different levels of function - impairment, disability and social participation.

Our proposed scheme for data collection is listed in Table 69.

Table 69. LTNC Registry data collection

	Clinician completed	**Patient completed**
At referral to registry		
Eligibility confirmation	Has an LTNC Has complex needs Requires integrated care planning (ICP)	Willing to be registered
	Name of referrer	Patient contact
At entry into registry		
Demographics	Age, gender,	Ethnicity
Details of LTNC	Diagnosis (ICD-10)	
Impairment	NIS	
Complex Needs	NPCS-Needs	
Contact details	Single point of contact responsible for registration	Patient or proxy – who will interact on patient's behalf
ICP	Date of last and next reviews	
At ICP review		
Details of review	Date of review, those present	
Disability		NPDS self-report or interview
Community integration		CIQ – self report or interview
Needs and provision	NPCS-Needs	NPCS gets
Review	Identification of unmet needs and plan to address them	
Next review	Planned review and who will be present	

NIS= Neurological Impairment Scale; **NPCS**: Needs and Provision Complexity Scale; **NPDS**: Northwick Park Dependency Scale; **CIQ**: Community Integration Questionnaire

For the purposes of this research project (in particular the health economic analysis), we also collected some more detailed costing information using the Client Service Receipt Inventory and Service Obstacles Scale. It is not envisaged, however, that these would form part of the on-going dataset.

15.1.2 Do patients want to be registered and will clinicians refer them?

The practicality of the register was tested by examining the extent to which (a) clinicians were willing and able to register patients, and (b) the extent to which patients were willing to be registered.

A limitation of this approach was that the pilot was conducted as part of a research study. It was therefore necessary to consent patients for the research prior to identifying whether they would be willing to be entered on a LTNC register. The research status of the project may have affected uptake in either direction.

- The research aspects required more extensive data collection than just the register, and this may have put some patients off.
- On the other hand, the fact that it was a research programme may have encouraged others to participate when they would not have done so otherwise.

Clinicians

So far as clinicians were concerned, the overall recruitment rate by the services themselves was 81 percent - however there was considerable variation from service to service (2 to 50%).

Feedback from the nine centres suggested that they did not find the paperwork especially onerous. The main reason for failure to recruit a centre's target number was systems failure. We did not specify to centres how recruitment should be managed, so that individual units developed their own processes for managing the project in the context of their own service.

A number of different models emerged. Recruitment was always most successful in those units where one person took personal responsibility for the registration of patients. In two of the units that individual was a dedicated researcher. However this is a resource that would typically not be available in everyday clinical practice. Experience from the high recruiting centres suggested that strong consultant leadership is the key to successful recruitment, at least until the LTNC register becomes a required part of normal practice.

In this study we did not examine other potential routes to registration, such as by GPs in primary care. The LTNC Dataset Development Group had already noted that some sort of incentive (e.g. QoF points) would probably be necessary to maximize uptake by GPs, given the pressures on their time.

Patients

Uptake from the patients' perspective was examined through a) their willingness to consent to recruitment for the project and b) their demonstration of involvement by responding to questionnaires at the three follow-up points.

As reported in Chapter 4, out of 467 patients approached 428 (92%) agreed to be recruited. Just 8% declined and it was not always clear for these decliners whether they were refusing to take part in the research study or the register.

The recruitment paperwork did include a specific question on whether the patient would be willing to have their details on a register. Unfortunately this question was not always completed by clinicians. For those patients for whom it was completed, 96 percent were willing to be registered. However, there may be some selection bias operating here, as all of these patients had already agreed to participate in the research.

Responding to questionnaires at the three follow-up time points was considered to be a more reliable indication of a willingness to be registered. Patients roughly fell into three groups in this respect: Twenty-nine percent did not respond at all, 31% responded at all three time points, leaving 40% who responded to at least one time point.

Although there was greater attrition for the non-white British group, it was not possible otherwise to predict from referral data, which patients were more likely to not subsequently respond. The non-respondents did not differ significantly from the 'best' respondents in terms of either demography, impairment, or needs for services at baseline.

The number of respondents dwindled over time, so that by 1 year post-discharge only 190 (44%) of the original 428 recruits responded to the questionnaire. However, there was evidence that those who continued to respond did so faster, and their responses were more reliable and complete. The findings and informal feedback suggest that familiarity with the questionnaires made it easier for them to respond, and some evidently valued the regular contact and opportunity to discuss their experiences (both good and bad) of on-going service provision.

In summary, we have developed a practical, psychometrically sound set of tools for inclusion in the LTNC register. Moreover, the findings suggest that it would be used by and appreciated by at least a third of patients in the form tested here using postal and telephone follow-up. However, this approach is labour intensive and it is possible that other approaches to data gathering, such as face-to-face interviews may be more successful.

On the other hand, the NSF recommends the identification of a single point of contact and annual Integrated Care Planning reviews. These would normally be held in face-to-face meetings with the patient and carer, and this might be the most appropriate point for the dataset information to be collected.

15.2 Does the NPCS provide a reliable, valid assessment of service provision in relation to need?

Prior to the start of the project, the LTNC Dataset Development group had developed the Needs and Provision Complexity Scale (NPCS) as a framework for measuring service provision in relation to need, and had done some early piloting of the tool in a number of different settings. However, it was not fully developed to the extent that validated tools existed to collect the information by clinician or patient report. Nor had it undergone psychometric evaluation.

In Chapter 6 of this report we presented a preliminary evaluation of the NPCS as a valid and reliable tool to measure needs and provision of services. Its scaling properties and repeatability (when self-reported by patients) were examined. Information gleaned from the use and costs of services in Chapter 12, supported the development of a costing algorithm for the NPCS to express the impact of met and unmet needs directly in terms of cost and so to evaluate the cost implications of any gaps in service provision.

Factor analysis generally provided support for a scale structure in two main domains ('Health and personal care' and 'social care and support'), and test-retest repeatability in a sample of 50 patients suggests that the self-complete version provides a reliable estimate of services provided.

Some interesting differences were observed in the factor structure of the NPCS-Needs as rated by the clinicians at baseline, and the 'NPCS-Gets' representing service provision as reported by the patients at six months post-discharge. The Needs scale showed high internal consistency, a pronounced general factor and two clear specific factors; whilst for the NPCS-Gets internal consistency was lower (although still acceptable) with less evidence of a single general factor underpinning the full NPCS. Instead it suggested that the healthcare and social care scales were two quite independent factors.

These differences need to be interpreted with some caution. Nevertheless, they suggest that whilst clinicians see both the healthcare and the social support items as a single bundle of the person's needs at discharge, the actual provision of healthcare and social support are quite independent. As noted in Chapter 6, this resonates with experience in that community-based health and social services are often disjointed – and therefore the NPCS may provide quite a good reflection of the reality of service provision as it is currently offered in the community.

So the NPCS has acceptable scaling properties as a measure of needs and provision, and as two principal domains of healthcare and social services, but can it tell us anything more than that? Can the individual items or subscales tell us more about specific gaps or shortfall of services?

Further evidence for its usefulness as a tool to describe individual needs and the extent to which these are met is presented in Chapter 8 (see below). The NPCS demonstrated clear discrepancies between the clinician-rated (Needs) and the patient-rated (Gets) scales. For example, showing that while needs for medical and nursing care are mostly well met, unmet needs in rehabilitation, social work support and equipment provision led to a possible increased use of personal care services, above the level predicted at discharge – and this also impacted significantly on the costs of on-going care, which were largely borne by the patients' families. Once again this finding resonates with experience and the reality of caring for patients with LTNC in the community.

In summary, this research has provided promising evidence for the NPCS, not only as an overall measure of needs and provision of services, but also as a simple practical tool which may be used at the level of the individual patient to describe specific shortfalls in service provision and associated costs - which may then be addressed as part of integrated care planning.

15.3 What are the needs of this group for on-going community-based rehabilitation and support?

In Chapter 6 we presented a detailed evaluation of the needs for health and social care services by this group of patients with complex needs arising from an LTNC. These were described using the NPCS. The frequency distributions of the 15 NPCS items confirmed that the recruitment sample represents a group with substantial needs for healthcare, therapy and social/community support. For example, of this sample of 428 patients:

- Two-thirds required specialist medical monitoring, most commonly from a consultant in rehabilitation medicine or neurology.
- Two-thirds required assistance with personal care, and a similar proportion required a personal enabler for community based activities.
- Over 90% required on-going multi-disciplinary community rehabilitation, and 44% required vocational rehabilitation.
- A total of 80% required input from a social worker or case manager – and 50% required this on a regular basis.
- Half of the family carers needed either a carer’s assessment or on-going support.
- Two-thirds of the sample required equipment of some sort and 60% had some sort of accommodation needs, with 17% requiring a support living environment.

These data also provide support for the utility of the NPCS as a brief and practical assessment for assessing complex needs amongst a group with significant physical and cognitive impairments.

15.4 Where are they referred to for further rehabilitation and what kind of rehabilitation is prescribed?

In Chapter 7 we examined referral patterns for on-going community rehabilitation services and analysed the location and types of services that had been accessed by patients who completed at least one questionnaire.

- Four in every five patients returned home following discharge from LSNRC Units and almost all of them were referred on to community rehabilitation teams (CRTs) for on-going rehabilitation. Generic CRTs were by far the most prevalent services accessed by patients who completed at least one questionnaire.
- Given the complex types of LTNCs commonly cared for in LSNRC Units, there appeared to be a shortage of specialised CRTs offering on-going rehabilitation for conditions such as ABI and stroke. Moreover, only one Centre offered Vocational Rehabilitation, supporting the finding in Chapter 6 that, given the significant numbers of patients who needed it, there was a shortage of this type of service.

- Postcode mapping of services in relation to the domicile of patients in the Greater London area suggested that services were thinly spread in some parts of South London.

In Chapter 13, we examined the configuration of the community rehabilitation services that took on patients with complex LTNCs by means of a Community Service Profile Questionnaire that was sent to all 124 services that patients were referred to at discharge by LSNRC Units.

- Despite persistent efforts to obtain information about their rehabilitation programmes, fewer than half of the services contacted responded to our request to complete a questionnaire. Nonetheless, CRTs and Voluntary Sector services were well represented among the responding sample, which was also geographically diverse.
- Centre-based rehabilitation was the predominant service model on offer - in some cases combined with residential services. More services catered for adults across the age groups than for younger adults alone, and over half catered specifically for people with brain injuries.
- Most had a multi-disciplinary focus, with three core therapies (PT, OT and SALT) being well represented and supplemented by psychology in half of the services surveyed. Medical input mainly came from primary care doctors, consultants in rehabilitation medicine and neuro-psychiatrists. However, an apparent shortage of social workers and case managers may have compromised the input needed for successful re-integration into the community.
- Seventy percent considered their service to be a complex specialised one, offering co-ordinated multi-disciplinary rehabilitation from two or more disciplines that was tailored to individual needs. Domiciliary visits, along with out-patient and/or day programmes were offered by some.
- Almost all kept case notes and held treatment planning meetings, while about three-quarters engaged in outcome evaluation and goal setting. A variety of specialist programmes and facilities were offered as an adjunct to the core therapies available.
- While a majority of these community-based services provided specialist multi-disciplinary care, some were under-staffed, and others felt under pressure to increase throughput of patients at the expense of providing high quality holistic services in the longer term, especially for patients with complex needs.

15.5 What type and amount of rehabilitation (if any) have they received at six months post-discharge?

In Chapter 8, we examined the extent to which health and social care needs (as assessed by the clinicians at discharge from in-patient rehabilitation) were and were not met during the first and second six month period after discharge.

The sub-samples of patients responding at six and 12 months were shown to be representative of the total recruited sample (N=428) in respect of their needs for rehabilitation. At 6 months post discharge, the NPCS demonstrated significant gaps between needs and service provision, especially with respect to on-going community rehabilitation, equipment and social support. By contrast, needs for medical, and nursing care were relatively well met.

Within the 15 items of the NPCS, the frequencies of met and unmet needs showed a similar overall picture, with more than half the respondents not having their needs for therapy input and/or social worker/case management support met at six months, and over 40 percent not having their needs for personal enablement and/or equipment met. Provision of support for personal care above the level of predicted need at six months suggests a deterioration of independence for some patients after discharge from in-patient rehabilitation, possibly as a result of the failure to meet needs for rehabilitation and social support highlighted above. An almost identical pattern of met and unmet needs was seen at 12 months post discharge.

A limitation of this study was that the patients were not reviewed by a clinician at the six and 12 months assessments. Therefore we have no re-evaluation of their needs for services at these points and comparison is only made with the needs at discharge from patient rehabilitation.

It is also important to remember that, even if needs are met for the majority of patients, for the small number of individuals whose needs are not met, this can still constitute a serious shortfall in services. Therefore the group reporting dissatisfaction with their levels of rehabilitation service provision at 12 months were examined in more detail (see Chapter 14).

15.6 Which variables influence the quantity and quality of rehabilitation that different patients get?

In Chapter 9, we examined the patient characteristics at baseline that may influence the amount of health and social services they receive after discharge from in-patient rehabilitation. We used multiple regression analyses to identify those variables that influence the level of rehabilitation services received by participants at six months. The variables explored were those which may be expected to impact on needs for rehabilitation and uptake of services – namely demographics, physical impairment, needs for care and nursing, social integration and the presence of cognitive behavioural problems.

As previous work has suggested, and given a particular shortfall in rehabilitation and support needs for patients with cognitive / behavioural problems, we hypothesised that people with cognitive/behavioural problems were likely to receive lower levels of rehabilitation.

In fact, we found no evidence that demographic variables including age, gender, marital status, education or diagnosis predicted how much rehabilitation/support people reported receiving at six months after discharge from hospital. The best single predictor of rehabilitation and support services received at six months was dependency, as measured by the basic care needs scale of the NPDS, which accounted for 33 percent of variance in total NPCS scores. Motor and cognitive impairment (measured by the NIS-Physical subscale) improved the predictive ability of the model by small but significant increments to a total R^2=40 percent.

We found no evidence to support the hypothesis that people with cognitive behavioural problems are likely to receive less rehabilitation. In fact people with high levels of CBPs had a significantly higher mean NPCS score than people with no CBPs or people with mild CBPs. Furthermore, the NPDS-CB score is a reasonably good predictor of total NPCS score (R^2=22 percent). Not surprisingly, the NPDS-CB scale was found to be a better predictor of the needs for health and social support than the NIS-cognitive subscale, as it is designed to evaluate the consequences of the CBP in terms of needs for care, as opposed to simply the severity of impairment, and these were the main predictor variables for service provision.

In other words, whether the disability is physical or cognitive – the more disabled patients receive greater levels of health and social services.

15.7 Is there a relationship between the quality and quantity of rehabilitation after discharge and outcomes with respect to disability and community integration?

In Chapters 10 and 11, we explored the relationship between the levels of rehabilitation received after discharge from specialist rehabilitation services and three important outcomes - namely dependency (disability), community integration and perceived carer burden. We examined this relationship both at six and 12 months.

The findings were broadly similar at both time points and were, at first sight, paradoxical. The overall level of health and social services received was a strong negative predictor of community integration at six months and a positive predictor of dependency and perceived carer burden. This suggested that better service provision led to poorer community integration, but the relationship appeared to be confounded by a strong negative relationship between dependency and community integration.

We therefore delved a little further into this relationship by using linear regression modelling to explore outcomes in relation to met and unmet need for services, taking dependency level into account by including it as a covariate.

The results suggested that, after the relationship with dependency is taken into account, there was a still a negative relationship (albeit weaker) between 'metness' of healthcare needs and community integration at 12 months. The consistency of the relationship throughout the three phases supported the view that this was a real relationship and not just a chance finding. The relationship was strongest for the rehabilitation subscale within the healthcare domain.

At first sight it may seem surprising that having one's needs for healthcare and rehabilitation met is associated with poorer outcomes in terms of both independence and community integration, but at a practical level this is perhaps less surprising. Rehabilitation is a goal-orientated process, and therapy interventions will normally be withdrawn once rehabilitation goals have been met. Community rehabilitation services are quite thinly spread and rationing of services is a common feature, as described in Chapter 13. In this context, it is to be expected that therapy teams will attempt to focus their efforts on those patients who have the greatest needs for support – whether at the level of basic self-care or social integration.

Perceived carer burden was not significantly associated with 'metness of needs', either in the health or social care domain. As in other studies[69] carer burden was most strongly associated with cognitive behavioural problems. The interventions most likely to be relevant in this context would be respite care (day care or residential). In the item level analyses in Chapter 8, we highlighted that respite care needs were identified only in a small minority of cases (15 percent), but when present there were significant shortfalls in provision at both six and 12 months.

It is therefore possible that a relationship does exist, but that the numbers of patients requiring / using respite services in this sample were too small to demonstrate a statistical relationship. On the other hand, provision of suitable respite services for people with LTNC can be problematic as we have highlighted in a related project,[11] and this may lead to poor uptake of services, even when they are made available.

15.8 What are the differential costs and cost-outcomes of different models of community neuro-rehabilitation?

In Chapter 12 we explored the costs of services used within the first and second six-month period following discharge from in-patient rehabilitation. We examined the demographic and clinical factors associated with service costs and assessed the cost of services required to meet unmet need.

Within the first six months, in-patient care costs accounted for 39 percent of the total costs excluding informal care. Approximately two-thirds of patients had contacts with GPs, but this service only accounted for one percent of total formal care costs. Nearly half the sample had contacts with neurologists and therapists (physiotherapists, occupational therapists and/or speech and language therapists) in a community or out-patient setting. One-third of patients also had therapist contacts at home. Not surprisingly, those services received at home occurred with a relatively high frequency of contact. The average cost of formal care across the whole sample was £12,773. Over half of the patients received care from family or friends and this was the most costly service due to the high number of care hours per week received, accounting for 53 percent of the total cost. When informal care costs were accounted for the mean cost rose to £27,184.

During the second six-month period, there was a reduction in the use of many health and social care services. The proportion of people who were admitted to hospital decreased slightly to around one-fifth, and the number of days in hospital for those who were admitted fell by over 50 percent. In-patient care now accounted for 18 percent of the total formal care costs. There continued to be relatively high levels of use of GPs and neurologists. Total formal care costs fell to an average of £8,907. Most patients continued to receive informal care from family and friends and the mean number of hours per week for those receiving this actually increased slightly. There was increased reliance on informal care during this second six-month period, so that at the 12-month follow-up it now accounted for 62 percent of the total costs. The total mean cost had reduced slightly to £23,449.

Formal and informal costs were examined within four groups representing levels of dependency: a) independent, b) mainly physical disability, c) mainly hidden disability and d) mixed. The total costs were highest for the mixed group. However, as a proportion of total costs, informal care was highest for the physical and hidden groups.

Bootstrapped regression models were used and demonstrated that a significant predictor of total cost over the first 6 months following discharge was the NPDS total score (with a one-point increase in these associated with an average cost increase of £494). Over the second 6 month period costs were shown to be increased for higher NIS motor scores (a one-point increase in this associated with costs that were higher by an average of £2023).

We examined the cost implications of met and unmet need using the NPCS costing algorithm. The results demonstrated that the sums commissioners save through under-investment in rehabilitation and social support, are exceeded approximately two-fold by the additional costs of personal care. Of course, a substantial proportion of the excess care costs fall to the family carers, but if these informal care arrangements break down, then the burden of cost reverts to the State. These findings emphasise the important of joined up health and social care funding for patients with complex needs for rehabilitation and support.

15.9 Limitations of the Present Research

There were a number of limitations to the present research project which need to be borne in mind when considering the major findings and their implications. Notably, the study included some participants with perceptual, cognitive and/or behavioural difficulties and relied to a certain extent on self-report. For example, some participants will have had impaired memory, or limited insight, and found completing the measures taxing.

15.9.1 Representation and generalisability of findings:

Geographic distribution

The representativeness of the sample of people with LTNCs in our study is one important consideration. Our geographic analysis in Chapter 7 demonstrated that the study population and the providers that we surveyed were widely distributed across London and were therefore probably appropriately representative of experience in the London Region, but they might not be fully representative of experience in other part of the UK.

In particular, there may be differences in rural areas in terms of the availability and provision of healthcare, rehabilitation and social services. However, it is unlikely that the provision of services in more remote or less populated regions is likely to be any better, and indeed might well be somewhat worse. Thus any concerns identified about unmet needs in the present study sample are still likely to have national relevance.

Attrition

There was also considerable attrition of the responder group, so that by 12 months only 44% of the original 428 patients provided information. This is hardly surprising, given the extent of physical and cognitive impairments prevalent in the sample and the many competing demands on their time and energy that participants face in their daily lives, but it occurred despite our strenuous efforts to maintain good telephone contact with all recruits.

It was reassuring that statistical comparisons between the respondent and non-respondent groups showed almost no differences in terms of demographic variables, diagnostic groupings or impairment at baseline. The notable exception, however, was that Black British recruits were more likely to be lost. This group, may also be more disadvantaged in their access to services, so this could have led to a slightly over-optimistic impression of the levels of service provision.

Centre –by-centre variation in recruitment

Recruitment rates varied quite markedly between the nine centres. Across the whole cohort a total of 109 people (19%) were never approached about the study, and the proportion of these varied widely across different services. Similarly, of those approached, the proportion who declined varied from 0-25%. Feedback from the centres suggests that this variation was not due to differences in the patients themselves, but to differences in recruitment practice, and this may have led to some bias in the final mix in the recruitment study cohort.

15.9.2 Response format

Although three different modes of responding (mail, internet, phone) could potentially be used by participants in the present study we did not attempt to analyse for any possible differences across data collection methods. This was because participants overwhelmingly preferred pencil-and-paper or postal responding to the survey (84%). Moreover, the distinction was not a

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clear one in many cases as, for example, postal responses with missing data were typically telephoned to complete the missing items. Nonetheless, it is conceivable that participants who only used the internet, could be different in some systematic way from those who preferred post or telephone responding, and this is a limitation of the present study.

Timing of questionnaire completion

A further limitation arises from the lack of precision about exactly when participants completed the questionnaire booklet at each phase of the study. For example, at Phase 1 participants were expected to complete and return their questionnaires within just 3-4 weeks after discharge from hospital – effectively to provide baseline information to their condition/community integration against which to compare change over the following year. In fact the average time between send-out and receipt of questionnaires was 47 days (i.e. nearly 7 weeks) again with substantial variation, which means that some patients will already have had have had several weeks to adapt to life in the community by the time we received their baseline data, and others will have had only very little time.

15.9.3 Changing need

As noted above, the patients were not reviewed by a clinician at the six and 12 months. Therefore, for our comparison of met and unmet needs, we did not re-evaluate their needs for services at these points and could only compare provision with the needs described at discharge from patient rehabilitation. This comparison works reasonable well for the first 6 month time point, as the quantification of service provided reflects provision over the whole of the intervening period, but it would have been useful to have a formal re-clinical evaluation of needs for the second 6 month period.

As it is, we know the level of service provision dropped off somewhat in the second period. But we do not know whether this is in response to reduced needs, or whether services were withdrawn due to teams having limited resources and needing to focus their attention on the next patients coming through. The qualitative feedback we received in Chapter 14 suggested that the latter might be the case, at least for some but we cannot be certain.

Despite these recognised problems, this study represents a unique analysis of experience in a sizeable sample of people with complex neurological disabilities as they re-entered the community following in-patient rehabilitation. This hard-to-reach group of patients has been under-investigated in the past. The findings resonate with clinical experience and we have no reason to believe that the limitations highlighted above would invalidate the conclusions that we have drawn from our findings.

15.9.4 Sampling of People Dissatisfied with Services

Finally, in an effort to shed light on what can go wrong in the provision of services to people with a LTNC living in the community - we attempted to interview 20 participants whose questionnaire responses reflected marked unhappiness with their rehabilitation and support since leaving in-patient rehabilitation. We also attempted, with the participant's permission, to interview the relevant service provider to garner their perspective on the extent of met or unmet needs. While illuminating, this study within a study has one serious limitation in that we did not attempt to interview 20 participants who were very satisfied with services.

15.10 Directions for Future Research

There are a range of issues arising from the present research that merit further investigation and analysis.

The present study has demonstrated that register for people with LTNCs would be workable and would have applicability for at least a proportion of people with LTNCs. If such a register were to be implemented then it would be important to evaluate or audit the register once it is established. The immediate issues to focus on include:

- register uptake by clinicians and patients
- retention of patients on the register
- data quality
- practical issues around maintaining contact with patients in the community
- the costs involved in establishing and maintaining a national register.

In the longer term two important issues to examine will be the impact of the register upon clinical and community care and the research output of the register. The primary purpose of the register would be to monitor the implementation of the 'backbone' quality requirement of the NSF for LTNC – namely integrated care planning (ICP) and the allocation of a single named point of contact. If the QIPP programme for Long Term Conditions develops a 'year or care' tariff for providing the single point of contact and annual ICP review, then the register could form the basis of a commissioning dataset for counting this activity.

In this study we have performed preliminary psychometric analysis of the NIS and NPCS. While both instruments displayed sound psychometric properties in the present study further psychometric work is necessary. For example the inter-rater reliability of the NPCS for evaluation of Needs remains to be established. Inter-rater reliability of the NIS has been evaluated in a single centre, but this could now be extended to a multicentre evaluation.

A key concern for future research in neurological rehabilitation is the question of the effectiveness of rehabilitation. Although the evidence base for effectiveness of community rehabilitation services has extended somewhat since the Gladman report[2] (see Chapter 2) it remains limited. More recent systematic reviews[70, 71] have found support for comprehensive rehabilitation programmes for acquired brain injury with respect to three outcomes: (i) psychosocial problems, (ii) community integration, and (iii) employment.

A major limitation in many of the published evaluations of effectiveness has been failure to describe the nature and dose of rehabilitation interventions, and in particular to relate that to the need for intervention. Although this study did not attempt trial the effectiveness of community rehabilitation services, it has developed a new measure (the NPCS) that could facilitate a proper evaluation of community rehabilitation services by providing a simple practical tool for recording multidisciplinary health and social care interventions in relation to individual needs. The NPCS allows a precise characterisation of interventions in terms of both the type and amount needed and delivered. We believe that this elucidation of met and unmet needs will make a useful contribution to future evaluations of the effectiveness of community-based services.

Another avenue for future research concerns the demands and burden of caring for a person with an LTNC. The present study confirms earlier research findings from our group that the strongest predictor of carer burden is the presence of cognitive-behavioural problems exhibited by the person cared for[72]. Our previous work has also identified some of the difficulties in the provision of suitable respite care with poor utilisation of services even when they are available.[11]

In this study, self-reported needs for residential respite stood at 16% and day respite at 29%. Where respite was cited as a need, the majority of those who wanted it would have preferred to receive it in the home, suggesting a clear need to develop more accessible domiciliary respite services. Given the severity of disabilities faced by many participants, it is vital to ensure that these services are delivered by staff who are trained to deal with adults with complex problems, and who have insight into their psychosocial needs; issues that were also emphasised in our previous work and that merit further research.

Finally, we have presented an economic evaluation of services provided, their relative costs and the factors that best predict the costs of on-going care in the community. It would now be appropriate to extent this analysis to other areas of the country outside London. A novel element of this research has been development of a preliminary costing algorithm for the NPCS, and its application to evaluate the relative costs of met and unmet need. The findings resonate with clinical experience and work is now underway to validate further the assumptions underpinning in the costing algorithm.

16 Conclusion

Our findings suggest that a register in the form tested here would be used and appreciated by at least a third of patients. However, this method of postal/telephone follow-up is labour intensive, and may fail to capture some of the most vulnerable patients. Integrated care planning reviews should normally involve face-to-face meetings with the patient and/or carer and this may offer an appropriate route to data collection for the register.

Our survey of community rehabilitation service providers confirmed a diverse array of community-based services that were accessed by the sample. The majority were multi-disciplinary, with Physiotherapy, Occupational therapy, Speech and language therapy and psychology as the core disciplines, and they offered a range of specialist interventions.

Amongst the major challenges faced by these services were that, although many of them strived to follow the principles of holistic care enshrined in the NSF, they were constantly under pressure to function and rapid response 'quick fix' teams.

Several teams presented passionate support for their model of high quality rapid intervention stroke care. Others noted lost opportunities to provide slow stream rehabilitation and meaningful longer term support to patients with complex cognitive and communicative needs, which were diminishing steadily over time, leaving vulnerable patients unsupported.

The NPCS forms a simple practical tool to capture met and unmet needs and so assist clinical teams to identify and address any gaps in service provision at either an individual or population level.

The costing algorithm for the NPCS developed in the course of the project also provides a rough estimate of the costs associated with met and unmet needs. In this study we have demonstrated how this may be used, not only to quantify the cost of providing for unmet needs, but also for estimating the scale of potential savings that might result.

Although we hypothesised that outcomes (dependency, community integration and perceived carer burden) would be better when needs for rehabilitation and support were well-met, we actually demonstrated the opposite relationship in our population level analysis of this sample.

Whilst at first sight surprising, this finding has some clinical logic. Given the scarcity of community rehabilitation services, therapy teams will naturally tend to focus their efforts on those patients who have the greatest needs for support.

However, at an individual level, failure to meet needs for rehabilitation, social support and equipment provision in this sample was demonstrably associated with increased requirements for personal care.

Costs-analysis suggested that ‘savings’ arising from the under-spend on rehabilitation and support were more than offset by the over-spend on personal care and accommodation – on average by over £10,000 per person per year. However, as the burden of caring for people with LTNCs fell largely on their families and informal carers, it is they that bear the brunt of those extra costs, rather than the State.

17 Recommendations

1. Our findings confirm that a LTNC Registry would be appropriate for and appreciated by a proportion of patients with LTNC, but that this proportion may be smaller than previously assumed. About one-third of this population engaged with our pilot ‘register’. This figure may be useful to local developers planning to set up such a registry.
2. Although we have developed an array of tools to collect data for such a registry by a variety of methods (including postal / online questionnaire, telephone interview), we suggest that face-to-face interview at the time of integrated care planning reviews would be the most practical method of information gathering to ensure that data collection is complete.
3. We propose the following simplified dataset (see Table 70), which could be feasibly collected through a combination of patient/carer-completed and clinician completed tools in the course of a clinical review meeting

Table 70. LTNC Registry data collection

	Clinician completed	**Patient/carer completed**
At referral to registry		
Eligibility confirmation	Has an LTNC Has complex needs Requires integrated care planning (ICP)	Willing to be registered
	Name of referrer	Patient contact
At entry into registry		
Demographics	Age, gender,	Ethnicity
Details of LTNC	Diagnosis (ICD-10)	
Impairment	NIS	
Complex Needs	NPCS-Needs	
Contact details	Single point of contact responsible for registration	Patient or proxy – who will interact on patient’s behalf
ICP	Date of last and next reviews	
At ICP review		
Details of review	Date of review, those present	
Disability		NPDS self-report or interview
Community integration		CIQ – self report or interview
Needs and provision	NPCS-Needs	NPCS gets
Review	Identification of unmet needs and plan to address them	
Next review	Planned review and who will be present	

NIS= Neurological Impairment Scale; **NPCS**: Needs and Provision Complexity Scale; **NPDS**: Northwick Park Dependency Scale; **CIQ**: Community Integration Questionnaire

4. The NSF for LTNC advocated joined up health and social services support. As highlighted in Chapter 5, whilst clinicians view health and social services as a single bundle of needs at discharge, the experience of patients and their families in the community is that these are currently quite separate – and this resonates also with experience in the community teams. Bringing together these two aspects of care is one of the principal aims of the new Health and Social Care Bill. Our findings support the need for this.
5. Tested for the first time in this study, the NPCS provides a robust but simple practical tool with which to compare met and unmet needs across a wide range of health and social care. It may be used for planning either at the population or the individual level, not only to highlights the gaps in service provision, but also to provide a crude estimate of the potential costs and cost savings of filling those gaps - and so helping to identify those developments with potential to provide value for money.
6. A major weakness of previous evaluations of the effectiveness of community rehabilitation has been the failure to evaluate interventions in relation to the prescribed needs for service input. On other words they may test 'met unneed' as much as 'unmet need' . The NPCS provides for the first time a tool to evaluate services provided in relation to the needs for those services. We recommend that this approach be adopted in future evaluations.
7. Although originally developed and tested in the context of LTNC, it is not condition specific, and now merits further exploration in the wider context of community services provision.
8. This study was confined to the London region for pragmatic reasons. Further work is now required to match provision to need in other parts of the country and to provide more detailed analysis of the costs and cost-benefits of meeting unmet needs, so to determine future priorities for investment in service development.

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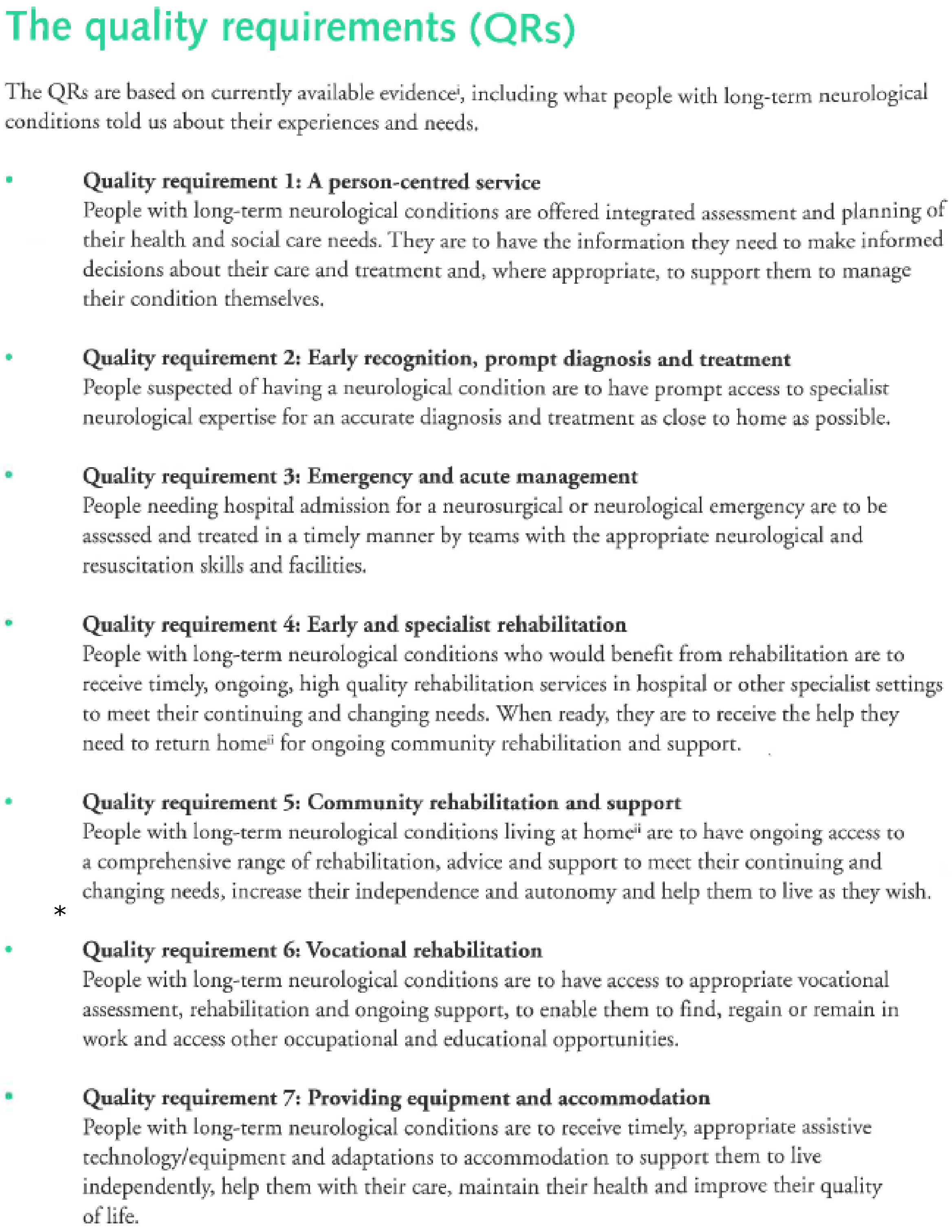
Appendix 1: NSF Quality Requirements



The quality requirements (QRs)

The QRs are based on currently available evidence[i], including what people with long-term neurological conditions told us about their experiences and needs.

- **Quality requirement 1: A person-centred service**
  People with long-term neurological conditions are offered integrated assessment and planning of their health and social care needs. They are to have the information they need to make informed decisions about their care and treatment and, where appropriate, to support them to manage their condition themselves.

- **Quality requirement 2: Early recognition, prompt diagnosis and treatment**
  People suspected of having a neurological condition are to have prompt access to specialist neurological expertise for an accurate diagnosis and treatment as close to home as possible.

- **Quality requirement 3: Emergency and acute management**
  People needing hospital admission for a neurosurgical or neurological emergency are to be assessed and treated in a timely manner by teams with the appropriate neurological and resuscitation skills and facilities.

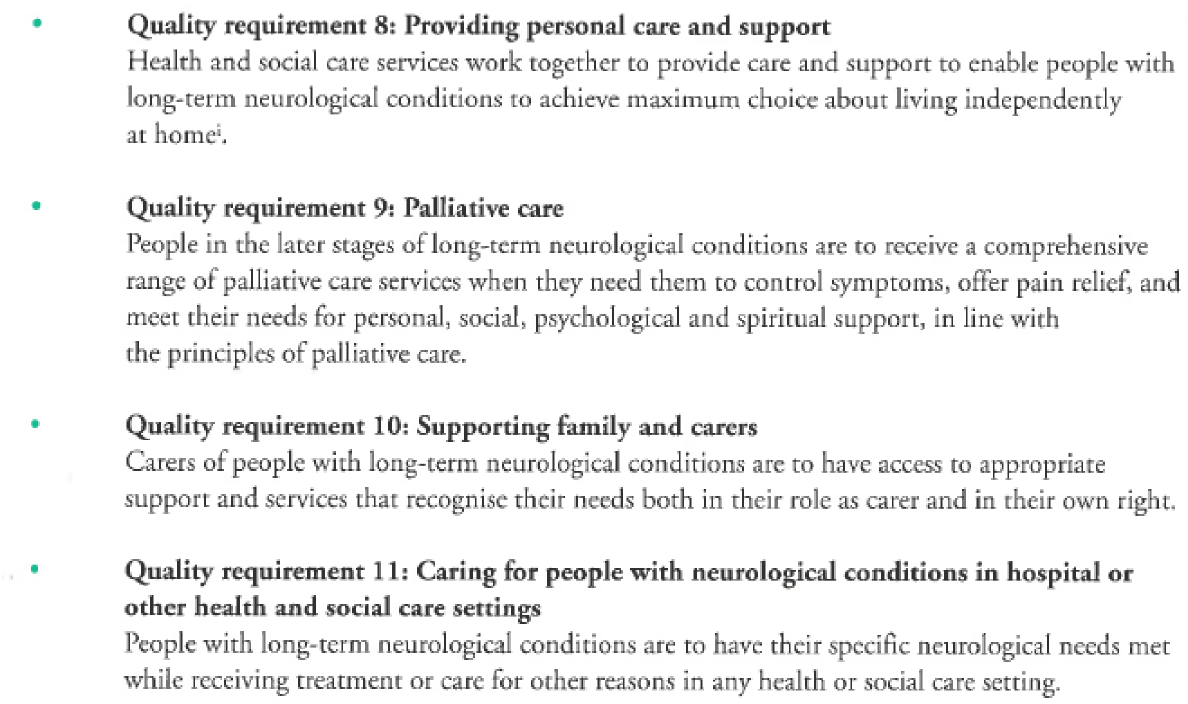
- **Quality requirement 4: Early and specialist rehabilitation**
  People with long-term neurological conditions who would benefit from rehabilitation are to receive timely, ongoing, high quality rehabilitation services in hospital or other specialist settings to meet their continuing and changing needs. When ready, they are to receive the help they need to return home[ii] for ongoing community rehabilitation and support.

- **Quality requirement 5: Community rehabilitation and support**
  People with long-term neurological conditions living at home[ii] are to have ongoing access to a comprehensive range of rehabilitation, advice and support to meet their continuing and changing needs, increase their independence and autonomy and help them to live as they wish.

*

- **Quality requirement 6: Vocational rehabilitation**
  People with long-term neurological conditions are to have access to appropriate vocational assessment, rehabilitation and ongoing support, to enable them to find, regain or remain in work and access other occupational and educational opportunities.

- **Quality requirement 7: Providing equipment and accommodation**
  People with long-term neurological conditions are to receive timely, appropriate assistive technology/equipment and adaptations to accommodation to support them to live independently, help them with their care, maintain their health and improve their quality of life.



- **Quality requirement 8: Providing personal care and support**
  Health and social care services work together to provide care and support to enable people with long-term neurological conditions to achieve maximum choice about living independently at home[i].

- **Quality requirement 9: Palliative care**
  People in the later stages of long-term neurological conditions are to receive a comprehensive range of palliative care services when they need them to control symptoms, offer pain relief, and meet their needs for personal, social, psychological and spiritual support, in line with the principles of palliative care.

- **Quality requirement 10: Supporting family and carers**
  Carers of people with long-term neurological conditions are to have access to appropriate support and services that recognise their needs both in their role as carer and in their own right.

- **Quality requirement 11: Caring for people with neurological conditions in hospital or other health and social care settings**
  People with long-term neurological conditions are to have their specific neurological needs met while receiving treatment or care for other reasons in any health or social care setting.

Appendix 2: Literature review search terms

1. ((integrate$ adj3 care) or (integrate$ adj3 healthcare) or (integrate$ adj3 health care)).ti,ab.
2. (integrat$ adj3 working).ti,ab.
3. (integrat$ adj3 provision).ti,ab.
4. (integrat$ adj3 provider organisation$).ti,ab.
5. (integrat$ adj3 assessment$).ti,ab.
6. (integrat$ adj3 team$).ti,ab.
7. (integrat$ adj3 management).ti,ab.
8. (integrat$ adj3 primary adj3 community).ti,ab.
9. (integrat$ adj3 rehabilitation).ti,ab.
10. (integrat$ adj3 health adj3 social).ti,ab.
11. (integrat$ adj3 servic$).ti,ab.
12. (structured care or structured healthcare or structured health care).ti,ab.
13. structured service.ti,ab.
14. ((care adj2 pathway) or (care adj2 path way)).ti,ab.
15. (joint$ adj3 working).ti,ab.
16. joined-up partnership$.ti,ab.
17. (partnership$ adj3 working).ti,ab.
18. (joint service$ adj3 development$).ti,ab.
19. partnership project$.ti,ab.
20. (joint$ adj3 service$).ti,ab.
21. joined-up service$.ti,ab.
22. ((joint$ adj3 care) or (joint$ adj3 healthcare) or (joint adj3 health care)).ti,ab.
23. (joined-up care or joined-up health care or joined up health care).ti,ab.
24. ((co-ordinat$ adj3 care$) or (co-ordinat$ adj3 health care$) or (co-ordinat$ adj3 healthcare$)).ti,ab.
25. ((coordinat$ adj3 care$) or (coordinat$ adj3 health care$) or (coordinat$ adj3 healthcare$)).ti,ab.
26. (co-ordinat$ adj3 service$).ti,ab.
27. (coordinat$ adj3 service$).ti,ab.

28. (contin$ adj3 service$).ti,ab.

29. ((contin$ adj3 care) or (contin$ adj3 healthcare) or (contin$ adj3 health care)).ti,ab.

30. ((progression adj3 care) or (progression adj3 healthcare) or (progression adj3 health care)).ti,ab.

31. ((inter-organisation$ or inter-organization$) adj3 (care or healthcare or health care or service$ or team$ or work$ or collaboration$ or co-ordinat$ or cordinat$)).ti,ab.

32. ((interorganisation$ or interorganization$) adj3 (care or healthcare or health care or service$ or team$ or work$ or collaboration$ or co-ordinat$ or cordinat$)).ti,ab.

33. (multidisciplinary adj3 (care or healthcare or health care or service$ or team$ or work$ or collaboration$ or co-ordinat$ or coordinat$)).ti,ab.

34. (multiprofessional adj3 (care or healthcare or health care or service$ or team$ or work$ or collaboration$ or co-ordinat$ or coordinat$)).ti,ab.

35. (multi-disciplinary adj3 (care or healthcare or health care or service$ or team$ or work$ or collaboration$ or co-ordinat$ or coordinat$)).ti,ab.

36. (multi-professional adj3 (care or healthcare or health care or service$ or team$ or work$ or collaboration$ or co-ordinat$ or coordinat$)).ti,ab.

37. (multi-agency adj3 (care or healthcare or health care or service$ or team$ or work$ or collaboration$ or co-ordinat$ or coordinat$)).ti,ab.

38. (inter-agency adj3 (care or healthcare or health care or service$ or team$ or work$ or collaboration$ or co-ordinat$ or coordinat$)).ti,ab.

39. (inter-professional adj3 (care or healthcare or health care or service$ or team$ or work$ or collaboration$ or co-ordinat$ or coordinat$)).ti,ab.

40. (interdisciplinary adj3 (care or healthcare or health care or service$ or team$ or work$ or collaboration$ or co-ordinat$ or coordinat$)).ti,ab.

41. (inter-disciplinary adj3 (care or healthcare or health care or service$ or team$ or work$ or collaboration$ or co-ordinat$ or coordinat$)).ti,ab.

42. (collaborat$ adj3 service$).ti,ab.

43. multidisciplinary assessment$.ti,ab.

44. single assessment$.ti,ab.

45. care trust$.ti,ab.

46. strategic collaboration$.ti,ab.

47. provider partnership$.ti,ab.

48. (pool$ adj3 budget$).ti,ab.

49. joint commissioning.ti,ab.

50. integrated commissioning.ti,ab.

51. exp "delivery of health care, integrated"/

52. exp ambulatory care/

53. (ambulatory care or ambulatory health care or ambulatory healthcare).ti,ab.

54. (ambulatory service$ or ambulatory health service$).ti,ab.

55. case management.ti,ab.

56. care management.ti,ab.

57. case management/

58. managed care program$.ti,ab.

59. patient care plan.ti,ab.

60. patient care team/

61. care team$.ti,ab.

62. or/1-61

63. motor neuron disease/

64. motor neuron disease.ti,ab.

65. motor neurone disease.ti,ab.

66. MND.ti,ab.

67. parkinson disease/

68. parkinson disease.ti,ab.

69. ms.ti,ab.

70. multiple sclerosis.ti,ab.

71. exp multiple sclerosis/

72. degenerative neurologic$ disease$.ti,ab.

73. degenerative neurologic$ condition$.ti,ab.

74. long term neurologic$ disease$.ti,ab.

75. long-term neurologic$ disease$.ti,ab.

76. long term neurologic$ condition$.ti,ab.

77. long-term neurologic$ condition$.ti,ab.

78. LTNC$.ti,ab.

79. epilepsy/

80. epilepsy.ti,ab.

81. epileptic.ti,ab.

82. cerebral palsy/

83. or/63-82
84. 62 and 83
85. 84
86. 2006$.ed.
87. 85 and 86
88. or/63-78
89. or/79-82
90. 89 not 88
91. 90 and 62
92. 91
93. limit 92 to yr="2006 - current"
94. 87 or 93
95. limit 94 to English language
96. limit 95 to yr="2007 - current"

Appendix 3: Literature review tabulated studies

Summary of quantitative studies for Brain Injury

Author(s)	Design	Subjects	Intervention	Results
Colantonio et al, (2010)	Retrospective cohort study	306	Data were collected using the Problem Checklist (PCL) from the Head Injury Family Interview (HIFI). Using Bonferroni correction, group differences between women and men	More men reported difficulty setting realistic goals and restlessness whereas significantly more women reported headaches, dizziness and loss of confidence. Men reported sensitivity to noise and sleep disturbances as significantly more problematic than women, whereas for women, lack of initiative and needing supervision were significantly more problematic in daily functioning
Douglas et al (2006)	Repeated measure design	25	Assessment involved a semi structured interview, global subjective QOL rating and administration of standardised measures: SF-12v2, Neurobehavioral Functioning Inventory, Instrumental-Expressive Social Support-Scale, and Community Integration Questionnaire.	Adults who participated regularly over 6 months reported positive and statistically significant changes in social integration and mental health.
Gary et al, (2009)	Post injury Outcomes	Several studies	Research studies that reported data for African Americans and Hispanics with TBI, outcomes from both primary and secondary analyses including paediatric patients with TBI and caregivers.	African Americans and Hispanics have worse functional outcomes and community integration and are less likely to receive treatment and be employed than Whites post-TBI. Emerging research detects racial and ethnic differences in marital stability, emotional/neuro-behavioural complications and QOL outcomes
Kim and Colantonio (2010)	Systematic review	10 studies	Evidence for post-acute traumatic brain injury (TBI) rehabilitation interventions used to enhance community integration (CI) relevant to occupational therapy.	Of 10 studies, 7 found that post-acute TBI rehabilitation benefits CI; all effective studies involved occupational therapy or involved interventions occupational therapists can deliver.

Summary of quantitative studies for Brain Injury (continued)

Author(s)	**Design**	**Subjects**	**Intervention**	**Results**
Mascialino et al, (2009)	Outcome one year post injury	360	Objective measures of community integration have found that in the first year after injury, minority groups with traumatic brain injury (TBI) exhibit lower levels of community integration than White participants. The objective of this study was to determine if this discrepancy persists beyond one year post injury, and if assessing subjective components of community integration helps understand these differences	Participation Objective Participation Subjective (POPS) indicated minority status predicted levels of transportation use ($p < 0.01$), with white participants reporting less use, after controlling for demographic and injury variables. Subjective indicators, minority status predicted levels of dissatisfaction with community, civic, life and leisure participation ($p < 0.01$), and total levels of participation ($p < 0.0125$), with White participants reporting significantly less dissatisfaction
Mosconi et al, (2011)	Survey	234 families	Two postal self-administered survey questionnaires were carried out: one targeted families of patients with severe brain injury to evaluate their objective and subjective burdens and needs; the other focused on the viewpoints of volunteer associations helping people with severe brain injury. Issues explored were quality of discharge from hospital (information received, family participation, etc.), needs of the family (work, financial resources, spare time, relationships with friends and other relatives), and the viewpoint of volunteer associations.	54 percent of sample of patients with severe brain injury reported involvement and informed in the hospital discharge process; about 17 percent had not been involved at all and only about one-third of families received satisfactory support during the discharge phase. Few families received any help from community social services (10 percent). Almost two-thirds of families had experienced financial difficulties and, in many cases, one family member had to change his/her work situation. Families' social relationships, travelling, hobbies, and spare time were significantly reduced. The 57 volunteer associations who returned the survey (84 percent response rate) confirmed that their members had experienced the same difficulties.

Summary of quantitative studies for Brain Injury (continued)

Author(s)	**Design**	**Subjects**	**Intervention**	**Results**
Sander et al, (2009)	Outcomes	151	Participants were 151 persons with mild to severe TBI (38 percent Black; 38 percent Hispanic; 24 percent White) recruited from consecutive admissions to the Neurosurgery service of a county Level I trauma center. A large number of participants had low income and low education. Community integration was assessed using the Community Integration Questionnaire (CIQ), Craig Handicap Assessment and Reporting Technique--Short Form (CHART-SF), and Community Integration Measure (CIM).	Age, education, and income, race/ethnicity contributed significantly to the variance in CIQ Total score, Home Integration Scale, and Productive Activity Scale scores. Blacks had lower CIQ Total scores compared to Whites. Black and Hispanic participants had lower scores than Whites on the Home Integration Scale, and Blacks had lower scores than Whites and Hispanics on the CIQ Productive Activity Scale. Low income (<=$20,000) was related to lower scores on the CIQ and CHART-SF Social Integration Scales, and scores on the CIM Total, Belonging, and Independent Participation scales.
Smith et al, (2006)	RCT	41	community rehabilitation service vs. more traditional out-patient service of carers	Dependent variables were level of met family need, a measure of family dysfunction, carer psychopathology, and carer emotional acceptance. The community sample fared significantly better on all measures except carer psychopathology.
Trexler et al, (2010)	RCT	22	A prospective randomised controlled trial of resource facilitation (RF) on return to work, participation in home and community activities, and depression compared with standard care.	Participation increased significantly for both groups (F = 60.65, P < .0001), but the interaction between groups and time demonstrated greater improvement for the RF group relative to controls (F = 9.11, P < .007). Also, 64 percent of the RF group was employed at follow-up compared with 36 percent of the control group P < .0001). No significant differences were found between groups on measures of depression

Summary of quantitative studies for Brain Injury (continued)

Author(s)	**Design**	**Subjects**	**Intervention**	**Results**
Winstanley et al, (2006)	Cohort	134	Measures: Relative measures included General Health Questionnaire-28 (psychological distress), Family Assessment Device (family functioning), and BIOS Family Needs Questionnaire (perceived adequacy of support). The degree of impairment and level of participation of the person with TBI were assessed by the Mayo-Portland Adaptability Inventory and Sydney Psychosocial Reintegration Scale, respectively	The overall model accounted for substantial proportions of the variance in psychological distress and family functioning. Importantly, the distress experienced by relatives was not due to the direct impact of the neurobehavioral impairments, but the effect of these impairments was mediated by the degree of community participation achieved by the person with TBI.

Summary of quantitative studies for Stroke

Author(s)	Design	Subjects	Intervention	Results
Bjorkdhal et al (2006)	RCT	58 stroke	Home vs. rehabilitation clinic (hospital)	No significant differences between the groups on any of assessments. An earlier improvement on some measures (including Assessment of Motor and Process Skill) for the home group. For both groups there was a greater improvement on the activity level than on the impairment level. The costs of the home group were less than half of the costs of the day clinic group
Egan,M, et al (2010)	pre-test-post-test evaluation	35 stroke survivors and 26 carers	The community reintegration and physical and emotional well-being of the stroke survivors and their care partners, measured before and, four months following service provision.	Post-test results demonstrated a small improvement in community reintegration among the stroke survivors but no significant change in community reintegration on the part of the caregivers and no alteration in physical and emotional health among either stroke survivors or care partners.
Ellis et al (2010)	Meta-analysis	6 trials involving 4759 participants	Investigating the impact of a stroke liaison worker versus usual care.	No significant overall difference for subjective health status (standardised mean difference (SMD) -0.03, 95 percent confidence interval (CI) -0.11 to 0.04, P = 0.34) or extended activities of daily living (SMD 0.04, 95 percent CI -0.03 to 0.11, P = 0.22). No overall significant effect for the outcome of carer subjective health status (SMD 0.04, 95 percent CI -0.05 to 0.14, P = 0.37). Patients with mild to moderate disability (Barthel 15 to 19) had a significant reduction in dependence (odds ratio (OR) 0.62, 95 percent CI 0.44 to 0.87, P = 0.006). This would equate to 10 fewer dependent patients (95 percent CI 17 fewer to 4 fewer) for every 100 patients seen by the stroke liaison worker. Similar results were seen for the outcome of death or dependence for the sub-group with Barthel 15 to 19 (OR 0.55, 95 percent CI 0.38 to 0.81, P = 0.002). This risk difference equates to 11 fewer dead or dependent patients (95 percent CI 17 fewer to 4 fewer) for every 100 patients seen by the stroke liaison worker

Author(s)	Design	Subjects	Intervention	Results
Ferrarello et al (2011)	Systematic review and meta-analysis	15 RCTs involving 700 participants with follow-up data.	active physiotherapy intervention, compared with placebo or no intervention, at least 6 months after stroke	Significant effect of the intervention (Effect size (ES) 0.29, 95 percent CI 0.14 to 0.45). The efficacy of the intervention was evident when short- and long-distance walking were considered as separate outcomes, with weighted mean difference of 0.05 m/s (95 percent CI 0.008 to 0.088) and 20 m (95 percent CI 3.6 to 36.0), respectively. Also, ADL improvement was greater, though non-significantly, in the intervention group. No significant heterogeneity was found.
Harrington et al (2010)	RCT	243 stroke patients	standard care vs. service and education intervention	Significant between-group changes in Subjective Index of Physical and Social Outcome (SIPSO) physical at nine weeks (median (95 percent confidence interval (CI)), 1 (0, 2): P = 0.022) and at one year (0 (-1, 2): P = 0.024). (WHOQol-Bref psychological (6.2 (-0.1, 9.1): P = 0.011) at six months. Mean cost per patient was higher in the intervention group.
Kim,J.W. & Moon,S.S. (2007)	Survey	123 family caregivers	Needs of family caregivers caring for stroke patients assessed by the Family Needs Questionnaire (FNQ) compared with two rehabilitation phases and among three different treatment settings.	Family caregivers in the acute rehabilitation phase perceived the need for health information as more important than those in the post-acute phase. Also, were less satisfied with community network support and family support than those in the post-acute phase. Comparative treatment settings, family caregivers in out-patient clinic services showed the lowest satisfaction of their needs in four areas (health information, emotional support, instrumental support, and professional support) compared with those in in-patient facilities or day hospitals
Roth et al (2011)	prospective population-based	112	Race and gender differences in 1-year stroke outcomes - from the national Reasons for Geographic and Racial Differences in Stroke (REGARDS). A primary family caregiver was also enrolled and interviewed for each stroke survivor.	African American stroke survivors were less likely to be living with their primary family caregivers than white participants. Analyses that controlled for age, education, and whether the stroke survivors lived with their primary family caregivers indicated that African Americans and women showed significantly greater deficits on multiple 1-year outcome measures compared to whites and men, respectively.

Summary of primary qualitative research papers

Authors	**Main aims of study**	**Data collection method**	**Type of service/setting(s) involved**
Doig et al. (2008)	To explore therapists' opinions about the rehabilitation approaches that they perceived contributed to positive outcomes for people with acquired brain injury in community-based rehabilitation settings in order to develop a set of practice principles for clinicians working in this area.	Semi-structured interviews with therapists working with people with acquired brain injury	Community based services - Australia
Reed et al. (2010)	Using a phenomenological approach, to explore stroke survivors' needs and their perceptions of whether a community stroke scheme met these needs.	Semi-structured interviews with stroke survivors	Specialist community stroke scheme – United Kingdom (UK)
Rotondi et al. (2007)	To determine the expressed needs of persons with traumatic brain injury (TBI) and their primary family caregivers.	Semi-structured interviews	Paralleled transitions in settings, treatments, and responsibilities (i.e. acute care, in-patient rehabilitation, return home, and living in the community) – US
Sample et al. (2007)	Examined systems of care for individuals with brain injury, from the providers' perspective, in two Colorado communities, one rural and one small urban, from 1998 to 2001	Interview	Service providers: Medical, rehabilitation, community, and school service - US
Suddick & De, Souza (2006)	Investigated therapists' experiences and perceptions of the reasoning behind the team approach in neurological rehabilitation, the structure and composition of the team within which they worked and the team working process.	Semi-structured interviews with occupational therapists and physiotherapists from	Rehabilitation centre; community team; and a stroke unit based within the UK.
White et al. (2009)	To explore the experiences of community-dwelling stroke survivors and feedback about the health system and transition to home	Interview	Community rehabilitation after stroke – Australia

Summary of non-primary qualitative research papers

Authors	Main aims of study	Data collection method	Type of service/setting(s) involved
Bernard (2010)	To review the existing literature and reports what helps and hinders integrated services	Literature review on evidence of best models of integrated service provision for long term neurological conditions	Models of best practice integrated services delivery - nurse specialists, community interdisciplinary neurological rehabilitation teams (CINRTs) and certain types of day opportunities
Nyein et al. (2007)	Describes the setup of brain injury rehabilitation services in the United Kingdom within the context of the National Health Service.	Policy; academics; experts and models of best practice	National service delivery programme for rehabilitation

Summary of expert opinion papers based on high level guidance

Authors	Main aims of document	Type(s) of data collection used
Welsh Assembly Government (2010) Task and Finish Group on Care Pathways for Long Term Neurological Conditions	This report by the Welsh Neuroscience Expert Group Care Pathways sub-group outlines a process for the development of care pathways to support children, young people and adults with long term neurological conditions. The aim of these pathways is to help people with long term neurological conditions manage their condition, maintain independence and achieve the best possible quality of life through an integrated process of education, information sharing, assessment, care planning and service delivery.	Policy documents; National Service Framework for Long Term Conditions for England. Examples of evidence based on good practice.

Appendix 4: Protocol – participant recruitment

Secure Storage Device: DATABASE C_PERSONAL INFORMATION

- Upon receipt of recruitment paperwork – details entered onto the DATABASE A_LTNC Register (Excel) and 2 separate Excel files called DATABASE B Recruitment and DATABASE C_PERSONAL INFORMATION
- Data entered into DATABASE A_LTNC Register
    - Participant ID
    - Who consented
    - Date of Consent
    - Date of Discharge
    - Date of recruitment paperwork receipt
- Data entered into DATABASE B Recruitment
    - Participant ID
    - Diagnosis
    - Date of Birth
    - Discharge Destination
    - Referral for on-going rehab
    - Contact details of rehab support provider
    - PCT
    - Significant needs
    - Whether they require integrated care planning
    - Named point of contact for care planning in Community
    - Neurological Impairment Scale (NIS)
    - Needs and Provision Complexity Scale (NPCS)
- Data entered into DATABASE C_ PERSONAL INFORMATION (Secure Storage Device)
    - Participant ID
    - DOB
    - Name, address and contact details
    - Family member contact details
    - GP Details
- Once all of the above has been entered, place paperwork in filing cabinet according to site.

[2]**Participant Follow up**

Directory:

..\..\Project Databases\DATABASE A_LTNC REGISTER.xlsm

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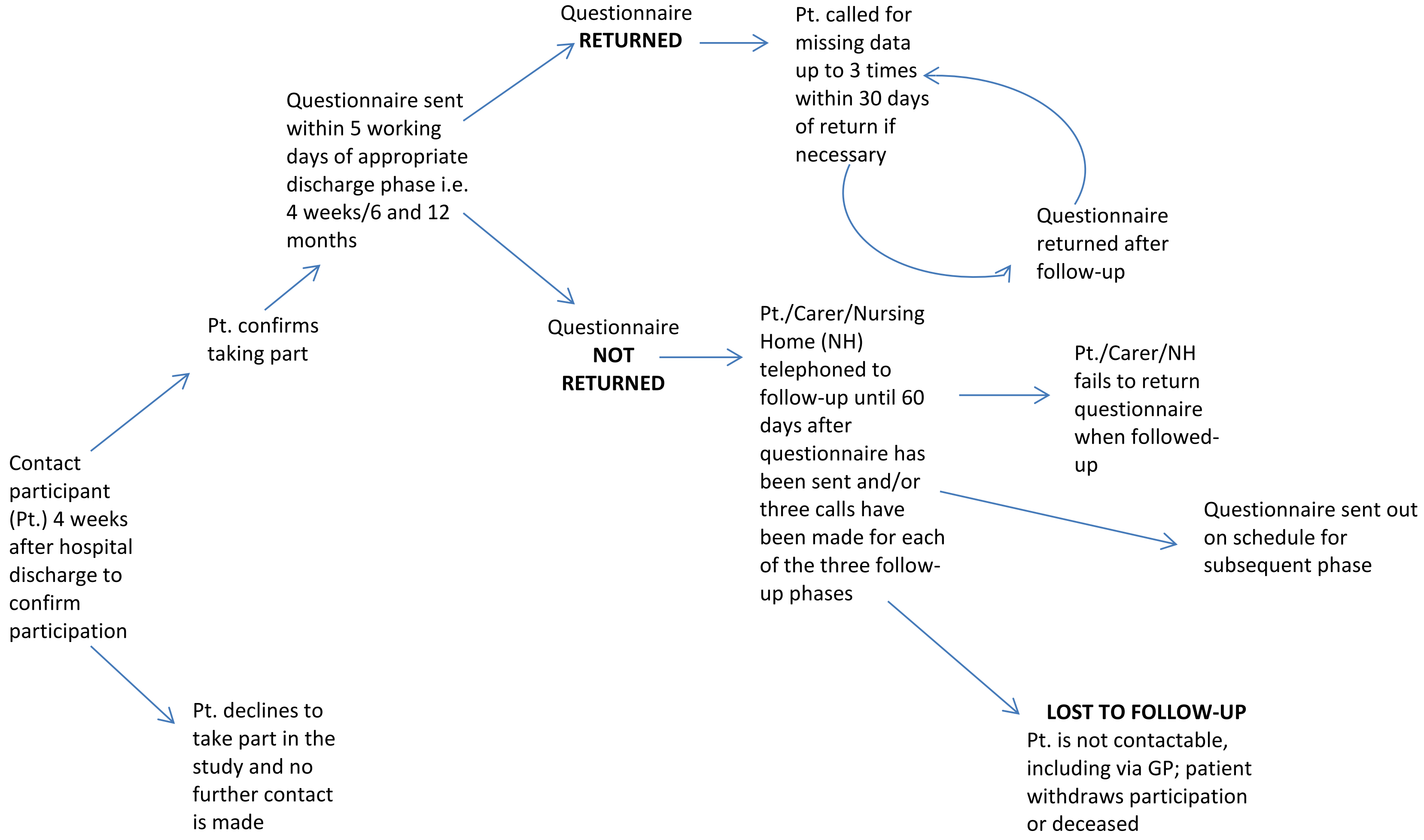
[2] **Procedure implemented as of September 2010 – prior to this date, no formal system used. Follow up – carried out on an ad hoc basis.**

- At four weeks post discharge date a phone call to participant to confirm participation in study would be made. Using DATABASE A, the study co-ordinator (at that time) would look at the register and identify participants who needed to be called.
- If participant refused to be part in the study they would not be contacted again and this was noted on the register.
- If participant agreed, then follow instructions as per protocol for contact with participants.

Appendix 5: Protocol – participant recruitment and follow-up



Contact participant (Pt.) 4 weeks after hospital discharge to confirm participation

Pt. confirms taking part

Pt. declines to take part in the study and no further contact is made

Questionnaire sent within 5 working days of appropriate discharge phase i.e. 4 weeks/6 and 12 months

Questionnaire **RETURNED**

Pt. called for missing data up to 3 times within 30 days of return if necessary

Questionnaire returned after follow-up

Questionnaire **NOT RETURNED**

Pt./Carer/Nursing Home (NH) telephoned to follow-up until 60 days after questionnaire has been sent and/or three calls have been made for each of the three follow-up phases

Pt./Carer/NH fails to return questionnaire when followed-up

Questionnaire sent out on schedule for subsequent phase

LOST TO FOLLOW-UP

Pt. is not contactable, including via GP; patient withdraws participation or deceased

Appendix 6: Questionnaire booklet

Appendix 4: Questionnaire Booklet

Evaluation of Community Rehabilitation Services for People with Long-Term Neurological Conditions

Research Team:

Christine O'Connell
Research Administrator
christine.o'connell@kcl.ac.uk
0207 848 5537

KING'S College LONDON

University of London

RESEARCH PROJECT ON COMMUNITY REHABILITATION SERVICES FOR PEOPLE WITH A LONG-TERM NEUROLOGICAL CONDITION (LTNC)

Thank-you very much for agreeing to take part in this London-wide study that was prompted by the publication of the Government's National Service Framework for Long-Term Conditions.

The information that you provide will help us to:

- Identify gaps in community rehabilitation services
- Identify which groups of patients get good rehabilitation and which groups miss out
- Examine how effective rehabilitation services are and how satisfied the service users are with these services

In this booklet you will find a number of questionnaires that we would like you to fill out. There are quite a few questionnaires to complete but you do not have to do them all in one go. You are welcome to take a break when you want to - or do the questionnaires in 2-3 sittings.

The Questionnaires will ask you about:

Part 1: The general details of the person with the Long Term Neurological Condition.

Part 2: Asks about which parts of your daily life you require help or support for.

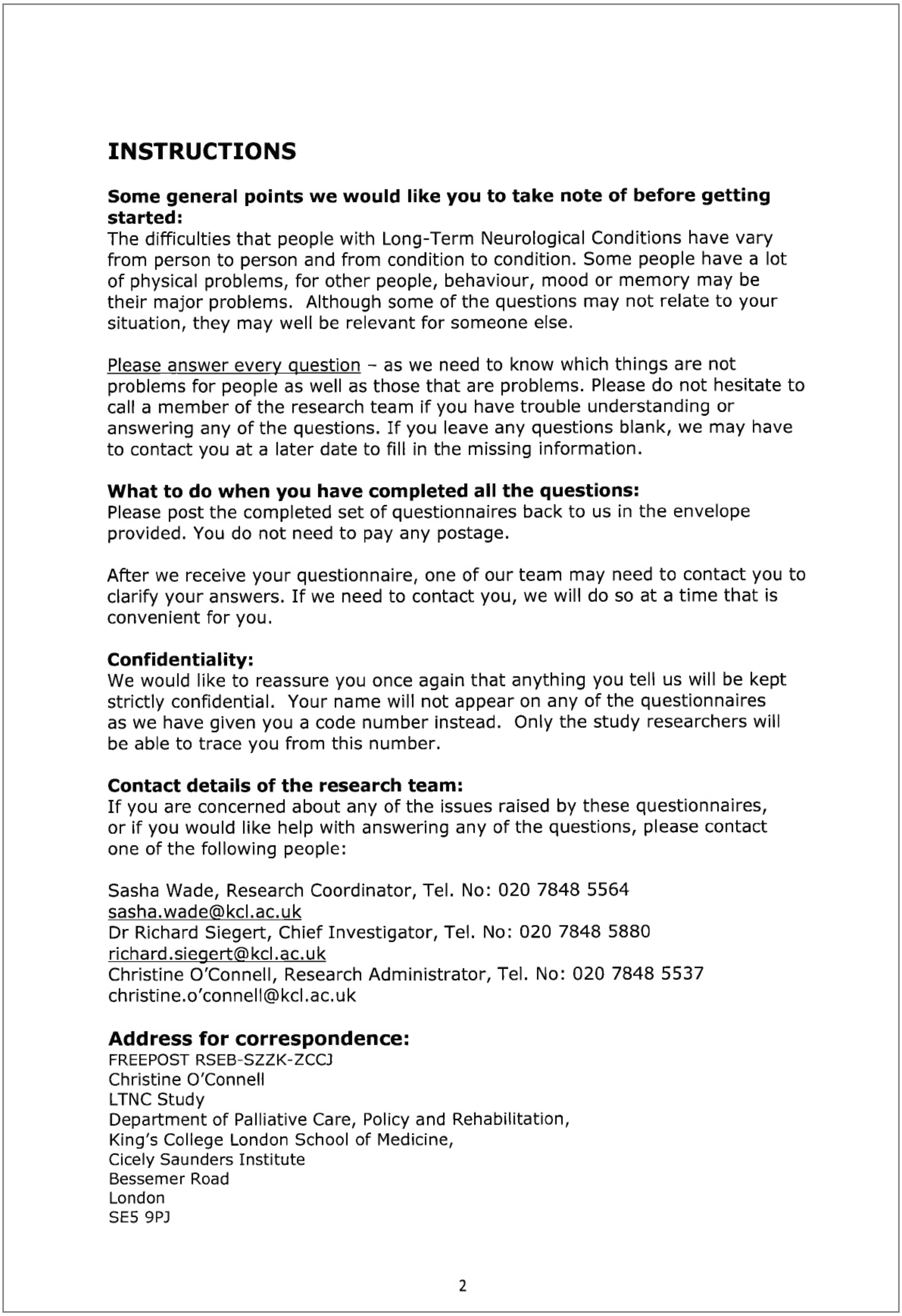
Part 3: Asks about your current need for rehabilitation and what services you are receiving.

Part 4: Asks about your involvement in your local community.

Part 5: Asks about the types of services you have used, and how much you have used them.

Part 6: Asks about things that may be preventing you from accessing services.

Part 7: Asks about carer experiences and must be completed by the carer.



INSTRUCTIONS

Some general points we would like you to take note of before getting started:
The difficulties that people with Long-Term Neurological Conditions have vary from person to person and from condition to condition. Some people have a lot of physical problems, for other people, behaviour, mood or memory may be their major problems. Although some of the questions may not relate to your situation, they may well be relevant for someone else.

Please answer every question – as we need to know which things are not problems for people as well as those that are problems. Please do not hesitate to call a member of the research team if you have trouble understanding or answering any of the questions. If you leave any questions blank, we may have to contact you at a later date to fill in the missing information.

What to do when you have completed all the questions:
Please post the completed set of questionnaires back to us in the envelope provided. You do not need to pay any postage.

After we receive your questionnaire, one of our team may need to contact you to clarify your answers. If we need to contact you, we will do so at a time that is convenient for you.

Confidentiality:
We would like to reassure you once again that anything you tell us will be kept strictly confidential. Your name will not appear on any of the questionnaires as we have given you a code number instead. Only the study researchers will be able to trace you from this number.

Contact details of the research team:
If you are concerned about any of the issues raised by these questionnaires, or if you would like help with answering any of the questions, please contact one of the following people:

Sasha Wade, Research Coordinator, Tel. No: 020 7848 5564
sasha.wade@kcl.ac.uk
Dr Richard Siegert, Chief Investigator, Tel. No: 020 7848 5880
richard.siegert@kcl.ac.uk
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christine.o'connell@kcl.ac.uk

Address for correspondence:
FREEPOST RSEB-SZZK-ZCCJ
Christine O'Connell
LTNC Study
Department of Palliative Care, Policy and Rehabilitation,
King's College London School of Medicine,
Cicely Saunders Institute
Bessemer Road
London
SE5 9PJ

PART ONE: GENERAL DETAILS OF THE PERSON WITH A LONG-TERM NEUROLOGICAL CONDITION (LTNC)

ID Number:	☐☐☐☐	
Gender:	Male ☐	Female ☐
Date of Birth:	☐☐/ ☐☐ / ☐☐☐☐ Day Month Year	
Filled in by:	Carer ☐	Person with LTNC ☐
Do you have internet access?	Yes ☐	No ☐
Do you use email or any social networking sites?	Yes ☐	No ☐

Are you currently (please tick one box):

☐ Married

☐ Living as a couple

☐ Divorced

☐ Separated

☐ Single and never married

☐ Civil partnership

☐ Dissolved civil partnership

☐ Widowed

☐ Other **(please state)**

....

Please tick one box to indicate the ethnic group you identify with:

☐ White British

☐ White Irish

☐ White Other

☐ Black Caribbean

☐ Black African

☐ Black Other

☐ Asian Indian

☐ Asian Pakistani

☐ Asian Bangladeshi

☐ Asian Other

☐ Chinese

☐ Other **(please state)**

....

What is your highest level of Education?

☐ GCSE (or O Levels)	☐ Bachelor's Degree
☐ A levels	☐ Higher Degree
☐ Post school diploma or professional qualification e.g. NVQ	☐ None

---

Are you currently (please tick one box):

☐ In full-time work

☐ Part-time work

- ☐ More than half time
- ☐ Half-time or less

☐ Self-employed	☐ Long-term sick or disabled
☐ Retired	☐ Student <u>or</u> on a training scheme
☐ Unemployed	☐ Looking after children/homemaker

What benefits (if any) do you currently receive?

☐ Disability Living Allowance:

- ☐ care component
- ☐ mobility component

	Work related benefits
☐ Attendance Allowance	☐ Statutory Sick Pay
	☐ State Pension
☐ Housing Benefit/Cost (or	☐ Employment and Support Allowance (or incapacity benefit)
☐ Council Tax Benefit	☐ Jobseeker's Allowance (or Unemployment Benefit)
	☐ Occupational Pension
☐ Child Benefit	☐ Working Tax Credit
☐ Child Tax Credit	☐ Income Support/Pension Credit
☐ Other **(please state):**	

....

Do you have a key worker/point of contact who you can consult about your care?

Yes ☐ No ☐

If yes, please describe who and from what organisation:

....

PART TWO: Dependency of the person cared for on others for support with daily activities

These questions are about how able you are to look after yourself. From what you tell us we can work out:

- ***The time it takes*** *to support someone who cannot manage without help from others*
- ***The number of people needed*** *to assist with some activities*
- ***What it would cost*** *if all this care were to be provided from outside*

Please answer every question, even if you can manage some things alone.

2A: Moving around in general

Please tick one box in each section. If you are not sure which of two or more answers to select, please select the one nearest the bottom of the list.

MOBILITY ... How do you move around indoors?

☐ Without any help
☐ Without any help apart from a walking aid - e.g. a stick or frame
☐ With **one person** helping or watching over you
☐ With **more than one person** helping
☐ Use a wheelchair independently - including turning corners
☐ Use a wheelchair pushed by someone else
☐ Don't move around at all or are bed-bound

TRANSFERS ... How do you move from bed to chair and back?

☐ On your own without any help
☐ With help or supervision from **one person**
☐ With help from **two people**
☐ You use a hoist
☐ You do not move from bed to chair

STAIRS ... How do you climb stairs at home?

☐ Without any help
☐ With someone carrying yourwalking aid or providing encouragement
☐ With physical help from someone
☐ Use a stair lift
☐ Never climbs stairs
☐ You do not have stairs – e.g. lives in a bungalow

2B: Personal care – washing, bathing, dressing and skin care

Please <u>tick one box</u> to show how much help is needed <u>for each of the three activities</u> below.

- ***If you are not sure which of two or more answers to choose***, *please select the one nearest the bottom of the list.*
- ***Washing and grooming*** *includes washing your hands and face, cleaning teeth, brushing hair and shaving or putting on makeup.*
- ***Bathing or showering*** *includes getting to the bath or shower room, transferring in and out, washing and drying yourself.*
- ***Dressing*** *includes putting on shoes and socks, tying laces, putting on a splint or prosthesis.*
- ***'Setting things up'*** *refers to getting things ready, such as running the basin or bath, or putting things out, such as wash things or clothes.*

	Washing and grooming	**Bathing or showering**	**Dressing**
No help needed, manages on your own	☐	☐	☐
Help/Supervision needed:			
To set things up only	☐	☐	☐
Incidental help (e.g. buttons, shoelaces)	☐	☐	☐
From **one person** and takes **under ½ hour**	☐	☐	☐
From **one person** and takes **over ½ hour**	☐	☐	☐
From **two people** and takes **under ½ hour**	☐	☐	☐
From **two people** and takes **over ½ hour**	☐	☐	☐

AVOIDING PRESSURE SORES:

How much help do you need to relieve skin pressure (e.g. turning, shifting position)

- When in bed or when sitting in a chair?

☐ Not applicable – don't need to do anything to relieve skin pressure
☐ Skin is intact and you can relieve pressure independently
☐ Need prompting (reminding) only to relieve pressure
☐ **Skin is intact** but you need physical help from **one person** to change your position
☐ **Skin is intact** but you need physical help from **two people** to change your position
☐ **Skin is marked or broken** and you need help from **one person** to change your position
☐ **Skin is marked or broken** and you need help from **two people** to change your position

2C: Eating and drinking

Please <u>tick one box</u> in each section.

EATING FOOD

How much help do you need with eating food?

☐ **No help needed** - able to eat independently with or without special cutlery

Need some help or supervision/prompting:

☐ **To set up only** - e.g. cutting up food or spreading butter

☐ From **one person** and takes **under ½ hour**

☐ From **one person** and takes **over ½ hour**

☐ **Fed through a tube** – e.g. a gastrostomy or nasogastric tube

DRINKING FLUIDS

How much help do you need with drinking?

☐ **No help needed** - able to pour your own drink and drink it independently

Need some help or supervision/prompting:

☐ But able to drink independently if a cup is left within reach

☐ From **one person** and takes **under ½ hour**

☐ From **one person** and takes **over ½ hour**

☐ **Receive fluids through a tube** - e.g. a gastrostomy or nasogastric tube

TUBE FEEDING

If you're fed through a gastrostomy or nasogastric tube, how much help is needed?

☐ **Not applicable** - not tube fed

☐ Fed through a tube **but can manage this independently**

Need some help or supervision:

☐ To set up a feed just **once a day**

☐ To set up a feed **twice a day**

☐ To set up a feed **three times a day**

☐ Need extra flushes **during the day** in addition to flushes before/after feeds

☐ Need extra flushes **during the day and night** in addition to before/after feeds

---

2D: Emptying the bladder and continence of urine

Please tick one box in each section.

- ***If you are not sure which of two or more answers to choose*** *as far as the number of people needed to help and the time taken are concerned, please select the one nearest the bottom of the list.*

- ***Using the toilet includes*** *getting there, transferring onto the toilet seat, cleaning yourself, adjusting clothes and washing hands afterwards. Also includes managing a bottle without spilling it if one is used, using a bed-pan, commode, catheter, pads, or any other continence equipment*

HELP TO EMPTY BLADDER

Do you need help when emptying your bladder?

☐ **No help needed** can manage everything independently

Need some help or supervision:

☐ Have a catheter or convene which is emptied for you
☐ Help for set up only - e.g. copes if bottles are within reach
☐ Help from **one person** and takes **under ¼ hour**
☐ Help from **one person** and takes **over ¼ hour**
☐ Help from **two people**

FREQUENCY:

If you need help for emptying your bladder, how many times a day do you go?

Day-time	**Night-time**
☐ **No help** needed	☐ **No help** needed
☐ **Up to four times** a day	☐ **Up to four times** a night
☐ **Five or more times** a day	☐ **Five or more times** a night

BLADDER ACCIDENTS

A bladder accident is leakage of urine that requires a change of clothes/bedding.

It includes leaks from a catheter or convene, or accidental spillage from a bottle

Do you have bladder accidents?

☐ **Never** have bladder accidents
☐ Have **occasional accidents** - less than once a week
☐ Have **accidents once or twice** a day
☐ Have **accidents more than twice** a day

2E: Using the toilet to open the bowels and control of the bowels

Please tick one box in each section.

- ***If you are not sure which of two or more answers to choose*** *as far as the number of people needed to help and the time taken are concerned, please go with the one nearest the bottom of the list.*
- ***Using the toilet*** *includes getting there and transferring onto the toilet seat, cleaning yourself, adjusting clothing and washing hands afterwards.*
- *Also includes dealing with a colostomy bag hygienically if they use one or using pads, bed-pan etc.*

HELP TO OPEN YOUR BOWELS

Do you need help using the toilet to open your bowels?

☐ **No help needed** can manage everything independently

Need some help or supervision

☐ For set up only - e.g. giving an enema or suppositories

☐ From **one person** and takes **under ¼ hour**

☐ From **one person** and takes **over ¼ hour**

☐ From **two people** and takes **under ¼ hour**

☐ From **two people** and takes **over ¼ hour**

FREQUENCY

If you need help to open your bowels, how many times a day do you go?

☐ No help needed

☐ **Once a day** or less often

☐ **More than once** a day

BOWEL ACCIDENTS

A bowel accident is leakage of faeces or soiling requires a change of clothes/bedding.

Do you have bowel accidents?

☐ **Never** have bowel accidents

☐ Do not have accidents provided someone gives you a regular enema or suppositories to remain continent

☐ Have **occasional accidents** – weekly or less often but not everyday

☐ Have **more frequent accidents** - one or more times a day

2F: Special nursing needs that require input from a nurse or trained carer?

Please tick any that apply

Do you have any of the following needs for trained nursing?

☐ A **tracheostomy** and/or ventilation support - either invasive or non-invasive

☐ An **open pressure sore** or a **wound** requiring dressings once a week or more often

☐ **Splints or a brace** requiring time and experience to apply

☐ An **additional medical or surgical problem** causing a significant temporary increase in nursing needs

☐ You or other family members receive regular **psychological support** or counselling

☐ Need **more than two interventions at night**

☐ A need for **one-to-one special nursing care** from a nurse or trained carer

2G: Taking medication

Please tick one box only in this section

How much help do you need to take medication
- including remembering to take it, opening bottles etc?

☐ **Not applicable** - not taking any medication

☐ **No help needed** - able to take all medication independently

☐ **Able to help yourself** if tablets are left out in the morning

☐ Require help for **medication to be given**

Which times per day does any medication need to be given?

☐ Morning ☐ Mid-morning ☐ Mid-day ☐ Afternoon ☐ Evening ☐ Bed-time

Or alternatively say how many times a day: ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 or more

2H: Making a snack / meal

Please tick one box only in this section

How much help do you need to make a snack or meal

☐ **Not applicable** – entirely gastrostomy fed

☐ **Able to make a snack and drink** at home independently

☐ **Able to help yourself** if a snack is left out in the kitchen

☐ Need meals or drinks **putting in front of you**

2I: Help with domestic duties

Do you require help with the following domestic duties?

	Do not need help	Can do some things	Unable to do anything	Could manage but other people do it
a) Light housework	☐	☐	☐	☐
b) Heavy housework	☐	☐	☐	☐
c) Shopping	☐	☐	☐	☐
d) Laundry	☐	☐	☐	☐

2J: Communication, safety, behaviour and other activities needing support

These questions ask about problems that affect the communication, safety and/or your behaviour.

- **Please answer them all,** even if they do not seem to apply in your case.

Please <u>tick one box only</u> in each section.

COMMUNICATION

How well are you able to communicate about your needs?

☐ Able to communicate about all your needs

☐ Able to communicate basic needs **without help** – may have some speech difficulties

☐ Able to communicate basic needs **with a little help**, or by using a communication aid or chart

☐ Able to **respond to direct questions** about basic needs

☐ Responds **only to gestures** –signs or miming – and visual clues

SAFETY

How much help do you need to remain safe?

☐ Always know where you are, the time of day and are aware of personal safety

☐ Require some **help with safety**, but could safely be left for **more than 2 hours** and **could call for help** in emergency

☐ Require **help to maintain safety**.
Could **not be left safely for 2 hours** and **could not call for help** in an emergency

☐ Requires **constant supervision** or checks at least once an hour

BEHAVIOUR

How much of a problem is your behaviour

☐ **No problem behaviours** and act in a socially appropriate way

☐ Need **verbal and/or physical prompting** for daily activities

☐ Need **persuasion to participate** in care, activities or rehabilitation

☐ Need a **structured programme** designed to improve your behaviour

☐ Disruptive, may show **physical/verbal aggression** to others which you cannot always control

☐ **Inclined to wander out of the house** on a regular basis

PART THREE: CARE AND SUPPORT REQUIREMENTS

Today's Date: Day ☐☐ **Month** ☐☐ **Year** ☐☐☐☐

PART 3 – Current Rehabilitation and Support Services

- In Part 3 we want to know about the care and support you currently receive.
- We will ask you about 12 areas where you could be getting support from either the NHS or social services.
- We are also interested in whether you think that this support is the right amount for you at the moment, or if you think that you need more support or less support in order to for you to be happy and lead a good life.

For each of the questions below we want to know about:

1. The level of care and support you are receiving (either received **within the last 6 months**, or has been arranged for you)
2. Whether this care and support is the right amount, or whether you think you would benefit from more or less care than what you are currently receiving.

If more than one option applies please choose the one nearest the bottom of the list

For example:
If the you are under regular follow-up by your GP, and were seen within the last 6 months,
But you also need occasional review by a specialist,
You would mark as follows:

	Yes	**No**
Do you receive regular medical care?	☐	☐

If 'yes':

Requires medical monitoring/ intervention:	**Tick one**
a) Regular visits to GP for monitoring/treatment	☐
b) Require occasional advice/review from specialist doctor (e.g. 1-2 visits per year)	☐
c) Require regular treatment from specialist doctor (e.g. 3 or more visits per year)	☐

This section is about how much medical and nursing care you receive

1. MEDICAL CARE
We want to know about **care received from a doctor (GP or specialist) for investigation, monitoring or treatment**
- Specialist Medical input may be from any medical specialty

	Yes	No
Do you receive **regular medical care?**	☐	☐

If 'yes':

This includes:	Tick any
a) Regular visits to GP for monitoring/treatment	☐
b) Require occasional advice/review from specialist doctor (e.g. 1-2 visits per year)	☐
c) Require regular treatment from specialist doctor (e.g. 3 or more visits per year)	☐

Which type(s) of specialist doctor?	Tick any
Neurologist	☐
Rehab doctor	☐
Psychiatrist	☐
Palliative Care	☐
Other, please specify:	☐

2. SPECIAL NURSING SUPPORT
We want to know about **the level of support / intervention from specially trained or skilled nurses.**
E.g. for wound care, bladder / bowel management / medication monitoring / specialist advice/support/counselling)

	Yes	No
Did you receive **support from a trained/specialist nurse** in the last 6 months:	☐	☐

If 'Yes':

Support received:	Tick one
a) Occasionally (e.g. once a month or less often)	☐
b) Regularly (e.g. every 1 - 2 weeks)	☐
c) Frequently (e.g. every day or several times a week)	☐
d) 2-12 hours per day	☐
e) 12-24 hours per day	☐

Which type(s) of nurse?	Tick any
District nurse	☐
Specialist nurse in:	
a) Neurology	☐
b) Mental Health	☐
c) Palliative Care	☐
d) Other, please specify: ………………………………………………………………………………………………………	☐

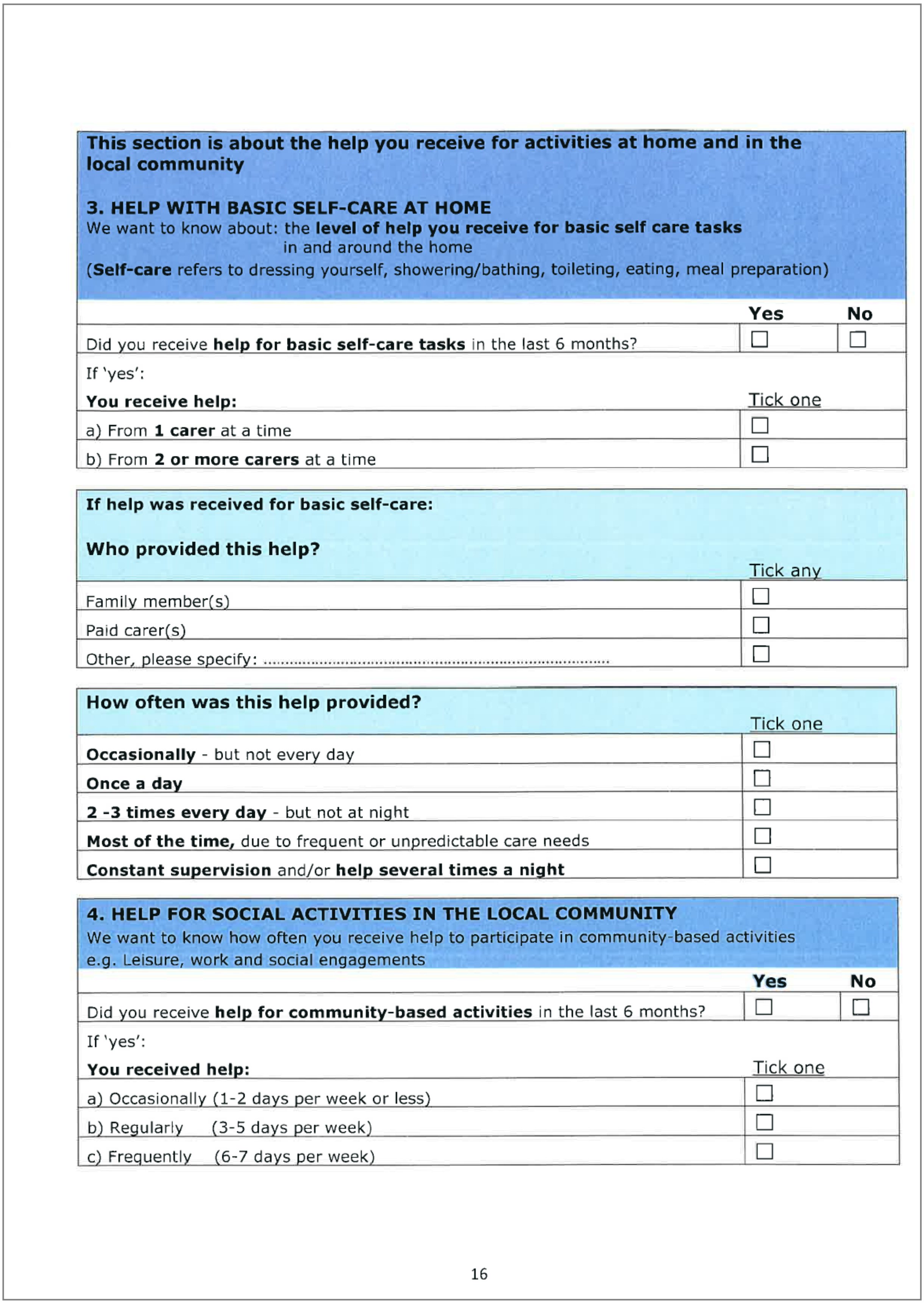
Questions 1-2: Is this the right amount of Medical/Nursing care for you?	
Too little	☐
Just right	☐
Too much	☐

If not the right amount, what do you need?

………

………

………



This section is about the help you receive for activities at home and in the local community

3. HELP WITH BASIC SELF-CARE AT HOME

We want to know about: the **level of help you receive for basic self care tasks** in and around the home

(**Self-care** refers to dressing yourself, showering/bathing, toileting, eating, meal preparation)

	Yes	No
Did you receive **help for basic self-care tasks** in the last 6 months?	☐	☐

If 'yes':

You receive help:	Tick one
a) From **1 carer** at a time	☐
b) From **2 or more carers** at a time	☐

If help was received for basic self-care:

Who provided this help?

	Tick any
Family member(s)	☐
Paid carer(s)	☐
Other, please specify:	☐

How often was this help provided?	Tick one
Occasionally - but not every day	☐
Once a day	☐
2 -3 times every day - but not at night	☐
Most of the time, due to frequent or unpredictable care needs	☐
Constant supervision and/or **help several times a night**	☐

4. HELP FOR SOCIAL ACTIVITIES IN THE LOCAL COMMUNITY

We want to know how often you receive help to participate in community-based activities e.g. Leisure, work and social engagements

	Yes	No
Did you receive **help for community-based activities** in the last 6 months?	☐	☐

If 'yes':

You received help:	Tick one
a) Occasionally (1-2 days per week or less)	☐
b) Regularly (3-5 days per week)	☐
c) Frequently (6-7 days per week)	☐

Questions 3-4: Is this the right amount of Personal care for you?	
Too little	☐
Just right	☐
Too much	☐

If not the right amount, what do you need?

....

....

....

This section is about the amount and types of therapy/rehabilitation you receive

5. THERAPY

We are interested in how many different types of therapist you see, and how often you see them.
e.g. physiotherapy, occupational therapy ; psychology, speech and language therapy

	Yes	No
Did you receive **therapy** in the last 6 months?	☐	☐

If 'yes':

Therapy input received from:	Tick one
a) A **single discipline** only (e.g. physio or occupational therapy)	☐
b) More than one discipline - but **working separately**, rather than as a team	☐
c) More than one discipline - **working together in a coordinated team**	☐

Which therapy disciplines did you see?	Tick any
Physiotherapist	☐
Occupational therapist	☐
Speech and language therapist	☐
Dietician	☐
Orthotics / Prosthetics	☐
Psychologist	☐
Counsellor	☐
Psychiatrist	☐
Other, please specify:	☐

If therapy was received: **How often did you see the therapist(s)?**	Tick one
a) Occasionally (one hour per month) or **therapy in group sessions only**	☐
b) Regular individual sessions - every 1-2 weeks	☐
c) Frequent individual sessions - several times per week	☐

6. SUPPORT TO RETURN TO WORK OR EDUCATION

We want to know about any **vocational support received to return to** full-time or part-time **work or education**.

e.g. disability employment officer, work retraining, access to work scheme

	Yes	**No**
Did you receive **help/support to return to work/education** in the last 6 months?	☐	☐

If 'yes':

Help received:	Tick one
a) Just for work-related/educational assessment/advice (1-2 sessions)	☐
b) Ongoing work-related/education support e.g. access to work scheme	☐
c) A formal vocational programme for work-related or educational support e.g. work preparation, work retraining, supported placements	☐

Questions 5-6: Is this the right amount of rehabilitation for you?	
Too little	☐
Just right	☐
Too much	☐

If not the right amount, what do you need?

……

……

……

This section is about the level of social support you receive

7. SOCIAL WORK AND CASE MANAGEMENT

We want to know about your **social work and case management:**

	Yes	No
Did you receive **social work or case management** in the last 6 months?	☐	☐
If 'yes': **Help / support received:**	Tick one	
a) Available for advice when required	☐	
b) 1-2 appointments	☐	
c) 3 or more appointments	☐	

8. FAMILY SUPPORT

We want to know about the **support received for any family carer**

	Yes	No
Did you receive **support for any family carer** in the last 6 months?	☐	☐
If 'yes': **Carer Support received:**	Tick one	
a) An assessment only - to see what support may be needed	☐	
b) Some short term carer/family support e.g. for skills training	☐	
c) Ongoing carer/family support e.g. for emotional support	☐	

This section is about respite care, which is to give family carers a break

This may be either in a **residential or a day care setting**

9. RESPITE CARE

A) We want to know about requirements for respite care in a residential setting e.g. a nursing home or hospice

	Yes	No
Did you receive **residential respite care** in the last 6 months?	☐	☐
If 'yes': **Residential respite care received:**	Tick one	
a) Once	☐	
b) Twice	☐	
c) 3 or more times	☐	

What type of residential respite care?	Tick any
Home-based live-in care	☐
Residential home	☐
Nursing home	☐
Specialist nursing home	☐
Hospice	☐
Other, please specify:	☐

B) We want to know about **requirements for day care** e.g. in a day care centre

	Yes	No
Did you receive **day care** in the last 6 months?	☐	☐

If 'yes':

Day Care received:	Tick one
a) Occasionally e.g. 1-2 days per week	☐
b) Frequently e.g. 3-5 days per week	☐

What type of day care?	Tick any
Community day centre	☐
Specialist day centre	☐
Hospice	☐
Other, please specify:	☐

10. ADVOCACY NEEDS

An advocate is someone who may represent the interests and rights of someone who lacks the mental capacity to make decisions for themselves.
In many cases this role is provided by the family - occasionally an independent advocate is required.

	Tick one
In the last 6 months:	
a) **No independent advocate** required	☐
b) **Received assessment for mental capacity** to make decisions regarding care	☐
c) Lacks mental capacity but **family support all decision making**	☐
d) Lacks mental capacity and **received an independent advocate**	☐

Questions 7-10: Is this the right amount of social/family support for you?

Too little	☐
Just right	☐
Too much	☐

If not the right amount, what do you need?

……

……

……

This section is about aids and equipment, or adapted accommodation

11. SPECIAL EQUIPMENT

We want to know about your **aids and equipment**

	Yes	No
Did you receive **aids or equipment** in the last 6 months?	☐	☐

If 'yes':

Aids / equipment received:	Tick one
a) Basic off-the-shelf equipment e.g. kitchen aids, commode, bed hoist	☐
b) Special equipment - requiring professional assessment /provision (e.g. Special wheelchair)	☐
c) Highly specialist /specially-made equipment requiring prescription (e.g. Environmental control systems, communication aids, ventilator)	☐

What type(s) of equipment?	Tick any
Basic lifting/handling equipment	☐
Seating/wheelchair	☐
Standing/postural support	☐
Electronic assistive technology	☐
Communication aid	☐
Assisted ventilation	☐
Other, please specify:	☐

12. ACCOMMODATION

a) If ABLE to live in your own home:

We want to know your requirements for adapted accommodation.

	Yes	No
Do you have **adapted accommodation?**	☐	☐

If 'yes':

Your adapted accommodation is:	Tick one
a) Ground floor accommodation or reliable lift access	☐
b) Minor adaptations (e.g. hand rails, ramps)	☐
c) Fully adapted accommodation (e.g. fully wheelchair accessible)	☐

OR b) If UNABLE to live in your own home:

We want to know about supported accommodation or residential care.

	Yes	No
Do you live in **supported accommodation or residential care?**	☐	☐

If 'yes':

Your supported accommodation or residential care is a:	Tick one
a) Supervised living arrangement e.g. small group home	☐
b) Sheltered living accommodation e.g. warden controlled	☐
c) Residential care home setting	☐
d) Nursing home	☐
e) Specialist nursing home	☐
f) Hospice care	☐

Questions 11-12: Is this the right amount of equipment/accommodation for you?	
Too little	☐
Just right	☐
Too much	☐

If not the right amount, what do you need?

....

....

....

13. PRIVATE SERVICES

Are you currently paying for any private rehabilitation or medical services?

Please circle:

Yes No

If so, what services?

....

....

14. WAITING LIST

Are you on a waiting list for any rehabilitation or support services?

Please circle:

Yes No

If so, what services?

....

....

When are they expected to start? ....

....

PART FOUR: COMMUNITY INVOLVEMENT

Please note, in questions 1-6, 'you', refers to the person with a LTNC and not their carer
Please circle the letter beside the best answer.

1. Who usually does the shopping for groceries or other necessities in your household?		
a) You alone	b) You and someone else	c) Someone else

2. Who usually prepare meals in your household?		
a) You alone	b) You and someone else	c) Someone else

3. In your home who usually does the everyday housework?		
a) You alone	b) You and someone else	c) Someone else

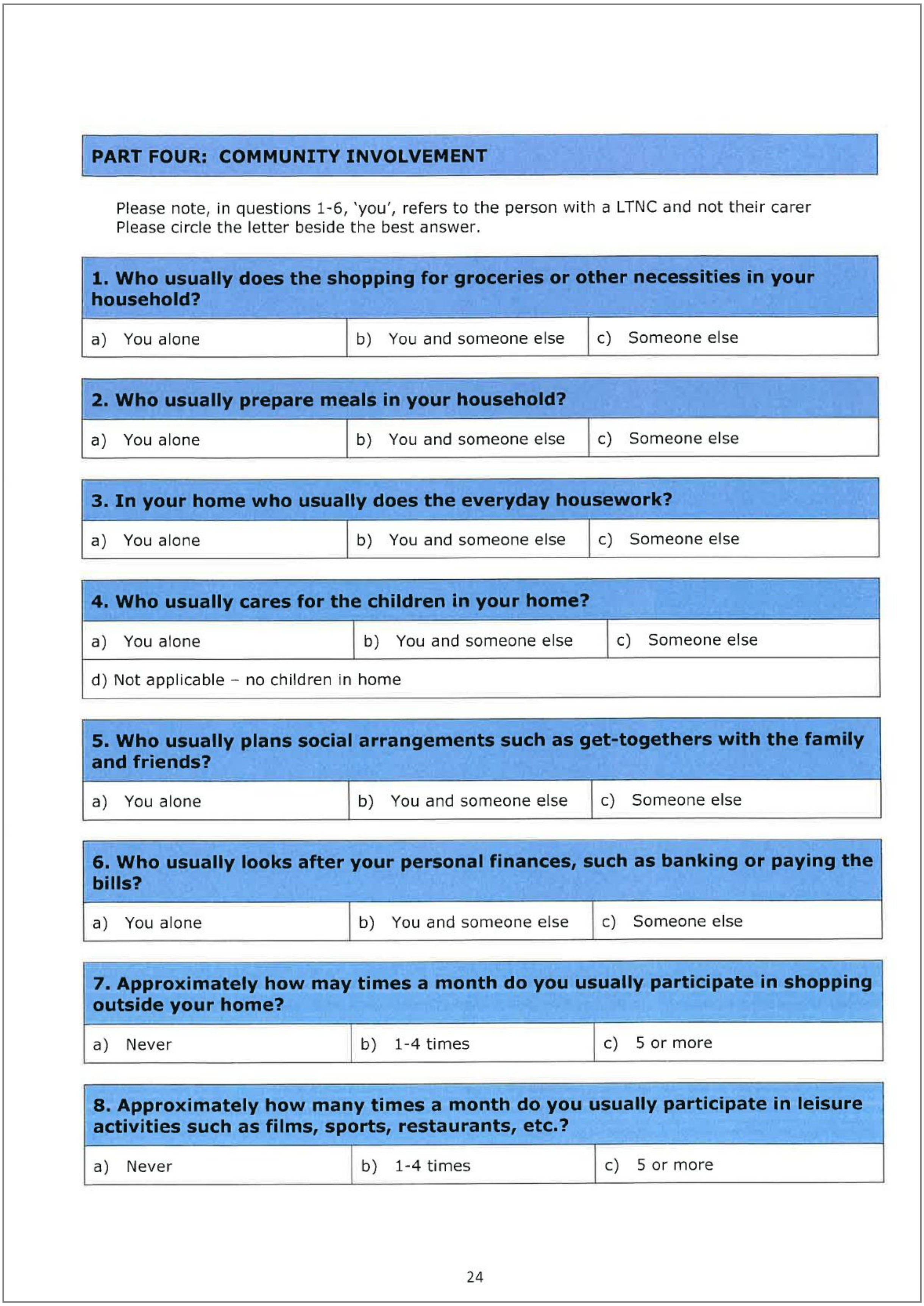
4. Who usually cares for the children in your home?		
a) You alone	b) You and someone else	c) Someone else
d) Not applicable – no children in home		

5. Who usually plans social arrangements such as get-togethers with the family and friends?		
a) You alone	b) You and someone else	c) Someone else

6. Who usually looks after your personal finances, such as banking or paying the bills?		
a) You alone	b) You and someone else	c) Someone else

7. Approximately how may times a month do you usually participate in shopping outside your home?		
a) Never	b) 1-4 times	c) 5 or more

8. Approximately how many times a month do you usually participate in leisure activities such as films, sports, restaurants, etc.?		
a) Never	b) 1-4 times	c) 5 or more



PART FOUR: COMMUNITY INVOLVEMENT

Please note, in questions 1-6, 'you', refers to the person with a LTNC and not their carer
Please circle the letter beside the best answer.

1. Who usually does the shopping for groceries or other necessities in your household?

a) You alone	b) You and someone else	c) Someone else

2. Who usually prepare meals in your household?

a) You alone	b) You and someone else	c) Someone else

3. In your home who usually does the everyday housework?

a) You alone	b) You and someone else	c) Someone else

4. Who usually cares for the children in your home?

a) You alone	b) You and someone else	c) Someone else
d) Not applicable – no children in home		

5. Who usually plans social arrangements such as get-togethers with the family and friends?

a) You alone	b) You and someone else	c) Someone else

6. Who usually looks after your personal finances, such as banking or paying the bills?

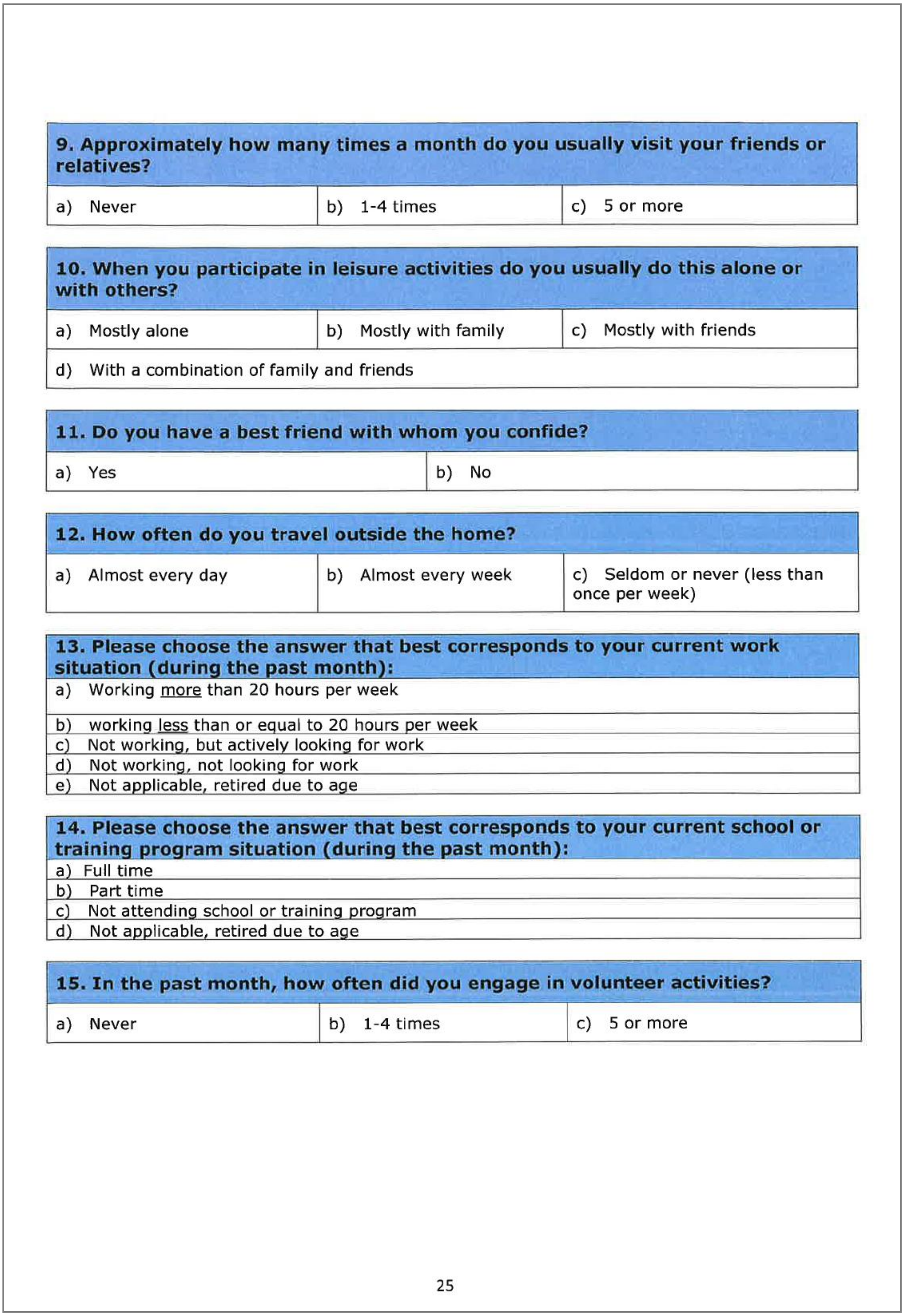
a) You alone	b) You and someone else	c) Someone else

7. Approximately how may times a month do you usually participate in shopping outside your home?

a) Never	b) 1-4 times	c) 5 or more

8. Approximately how many times a month do you usually participate in leisure activities such as films, sports, restaurants, etc.?

a) Never	b) 1-4 times	c) 5 or more



9. Approximately how many times a month do you usually visit your friends or relatives?		
a) Never	b) 1-4 times	c) 5 or more

10. When you participate in leisure activities do you usually do this alone or with others?		
a) Mostly alone	b) Mostly with family	c) Mostly with friends
d) With a combination of family and friends		

11. Do you have a best friend with whom you confide?	
a) Yes	b) No

12. How often do you travel outside the home?		
a) Almost every day	b) Almost every week	c) Seldom or never (less than once per week)

13. Please choose the answer that best corresponds to your current work situation (during the past month):
a) Working more than 20 hours per week
b) working less than or equal to 20 hours per week
c) Not working, but actively looking for work
d) Not working, not looking for work
e) Not applicable, retired due to age

14. Please choose the answer that best corresponds to your current school or training program situation (during the past month):
a) Full time
b) Part time
c) Not attending school or training program
d) Not applicable, retired due to age

15. In the past month, how often did you engage in volunteer activities?		
a) Never	b) 1-4 times	c) 5 or more

PART FIVE: The services you receive

Client Services Receipt Inventory for Person with a Long-Term Neurological Condition

- We are interested to know how much you have used **Health and Social Services** during the past 6 months (i.e. since you were discharged from inpatient rehabilitation services);
- The Questions are grouped according to the 'type' of service used:
  - (a) In-patient or other residential services
  - (b) Day care or community services
  - (c) Out-patient appointments or consultations
  - (d) Services received at home
- Your answers will allow us to work out the cost of providing this care to individuals and from this we can work out the cost to society in general.

Health and Social Services received by you in last 6 months:

Section 1: In-patient or other residential services

In the past 6 months, have you stayed in a hospital or other residential care setting?

1. ☐ Yes 2. ☐ No **If you answered 'No', please go to section 2**

If you answered 'Yes', please state the total number of days that you stayed in any of the following wards or settings during the past 6 months and indicate if this service was paid for privately.

		Please tick box if paid for privately
A. Intensive care unit	………….. days	☐
B. Neurology ward	………….. days	☐
C. Medical ward	………….. days	☐
D. Specialist rehabilitation ward or unit	………….. days	☐
E. Other ward (please state) …………………………………………………	………….. days	☐
F. Other ward (please state) ………. …………………………………………	………….. days	☐
G. Hospice	………….. days	☐
H. Nursing or residential home	………….. days	☐
I. Respite care setting	………….. days	☐
J. Other residential setting (please state)	………….. days	☐

…………………………………………………………………………………

Section 2: Day care or community services

In the past 6 months, have you spent time in a day care or community setting?

1. ☐ Yes 2. ☐ No **If you answered 'No', please go to section 3**

If you answered 'Yes', please state the average number of times per month that you attended any of the following:

K. Day hospital	.... attendances per month
L. Community rehabilitation unit	.... attendances per month
M. NHS day care	.... attendances per month
N. Palliative day care	.... attendances per month
O. Social services day centre	.... attendances per month
P. Voluntary organisation day / resource centre	.... attendances per month
Q. Support groups or societies	.... attendances per month
R. Other day setting (please state)	.... attendances per month

Section 3: Out-patient clinic or surgery based appointments

In the past 6 months, have you had any face to face appointments or consultations with professionals in a hospital out-patient department or other type of clinic / surgery?

1. ☐ Yes 2. ☐ No **If you answered 'No'**, please go to section 4

If you answered 'Yes', please state the number of visits made to any of these professionals over the past 6 months, the average time for a visit in minutes, and indicate if the service was paid for privately.

Please tick box if paid for privately

A. General practitioner (GP)	.... visits	.... minutes	☐
B. Neurologist	.... visits	.... minutes	☐
C. Rehabilitation consultant	.... visits	.... minutes	☐
D. Psychiatrist	.... visits	.... minutes	☐
E. Other doctor (please state) e.g. Palliative care	.... visits	.... minutes	☐
F. Other doctor (please state)	.... visits	.... minutes	☐
G. General practice nurse	.... visits	.... minutes	☐
H. Nurse specialist	.... visits	.... minutes	☐
I. Community mental health nurse	.... visits	.... minutes	☐
J. Other nurse (please state)...................................	.... visits	.... minutes	☐
K. Physiotherapist	.... visits	.... minutes	☐
L. Occupational therapist	.... visits	.... minutes	☐
M. Speech therapist	.... visits	.... minutes	☐
N. Other therapist (please state) e.g. dietician	.... visits	.... minutes	☐
O. Psychologist	.... visits	.... minutes	☐
P. Counsellor	.... visits	.... minutes	☐
Q. Mental health worker	.... visits	.... minutes	☐
R. Dentist	.... visits	.... minutes	☐
S. Other*	.... visits	.... minutes	☐
T. Other*	.... visits	.... minutes per visit	☐

* For example, osteopath, homeopath, acupuncturist etc.

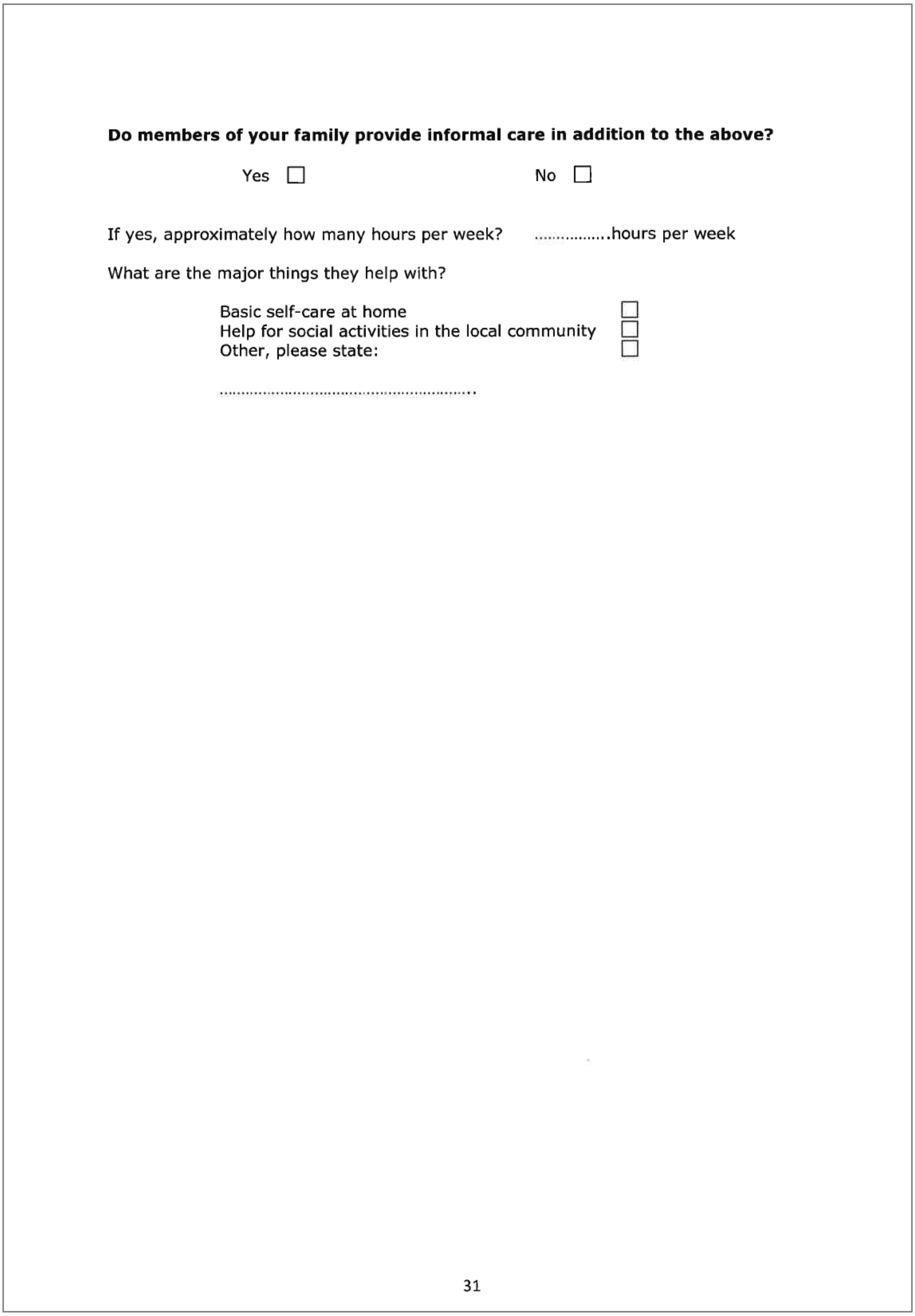
Section 4: Home based services

In the past 6 months, have you had any home based services?

1. ☐ Yes 2. ☐ No **If you answered 'No'**, please go on to the next page,

If you answered 'Yes', please fill in the average number of visits per month, and the average time a visit took. Please then indicate whether services were paid for privately by ticking the relevant box.

Please note: Some services are timed in minutes / visit, others in hours / visit			**Please tick box if paid for privately**
A. Qualified general nurse	……. visits per month	……. minutes per visit	☐
B. Community mental nurse	……. visits per month	……. minutes per visit	☐
C. Help with personal care	……. visits per month	……. minutes per visit	☐
D. Physiotherapy	……. visits per month	……. minutes per visit	☐
E. Occupational therapy	……. visits per month	……. minutes per visit	☐
F. Speech therapy	……. visits per month	……. minutes per visit	☐
G. Social worker	……. visits per month	……. minutes per visit	☐
H. Domestic help	……. visits per month	……. hours per visit	☐
I. Day time sitting service	……. visits per month	……. hours per visit	☐
J. Overnight sitting service	……. visits per month	……. hours per visit	☐
K. Other service (please state) ………………………………………………………… ……….	……. visits per month	…… hours ….. mins per visit	☐
L. Other service (please state) ………………………………………………………… ……….	……. visits /per month	…… hours ….. mins per visit	☐
M. Meals on wheels	…….times per month		



Do members of your family provide informal care in addition to the above?

Yes ☐ No ☐

If yes, approximately how many hours per week? …………….hours per week

What are the major things they help with?

Basic self-care at home ☐
Help for social activities in the local community ☐
Other, please state: ☐

………………………………………………..

PART SIX: Services Obstacle Scale

This section asks about the types of obstacles or barriers that may prevent you from accessing the services you need.

DIRECTIONS: Use the following scale in responding to items 1 - 6 below:

1. **DISAGREE *strongly***
2. **DISAGREE**
3. **DISAGREE *slightly***
4. **NEITHER AGREE NOR DISAGREE**
5. ***slightly* AGREE**
6. **AGREE**
7. ***strongly* AGREE**

1. I am dissatisfied with the amount of professional help and services being provided.

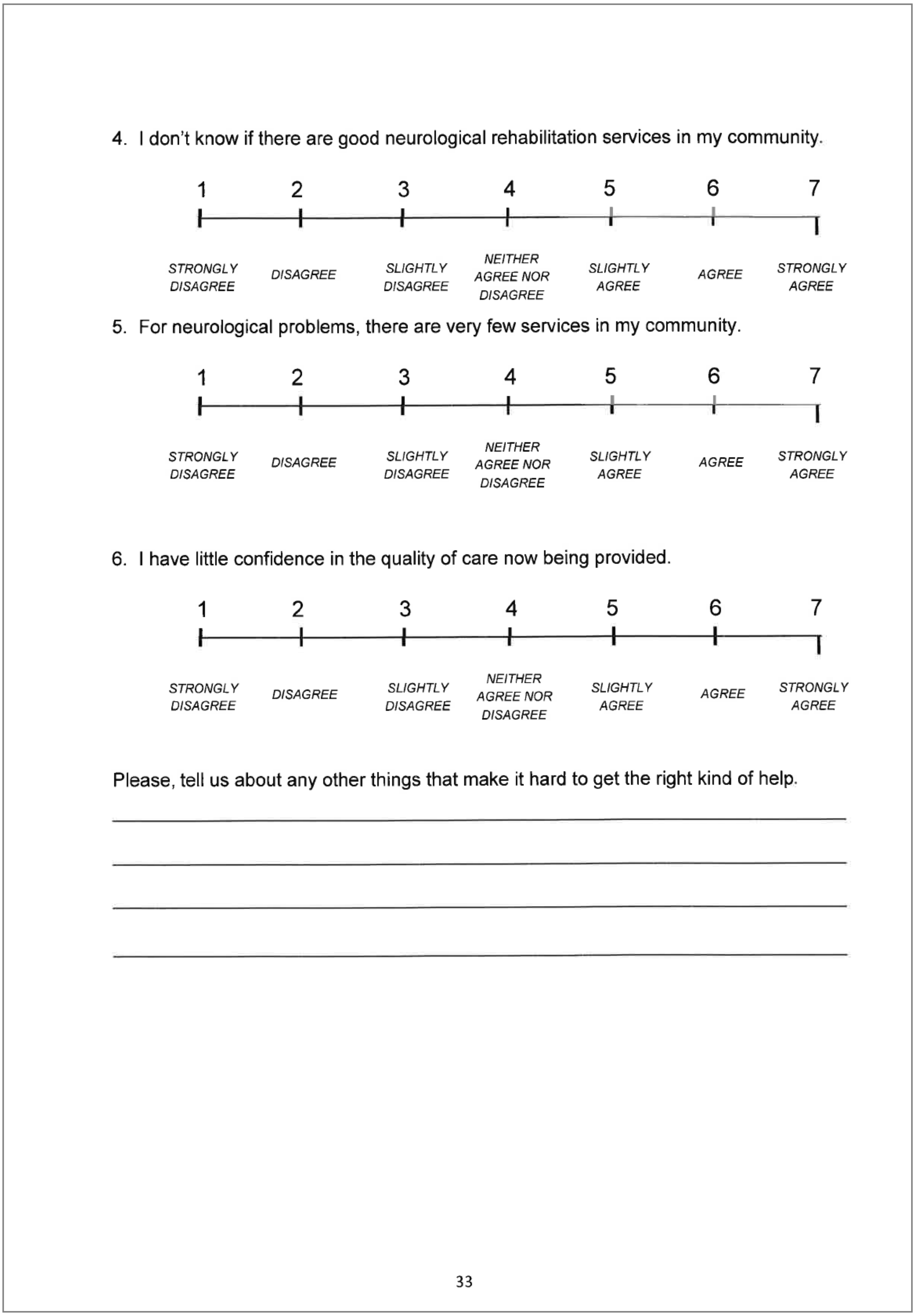
1	2	3	4	5	6	7
STRONGLY DISAGREE	*DISAGREE*	*SLIGHTLY DISAGREE*	*NEITHER AGREE NOR DISAGREE*	*SLIGHTLY AGREE*	*AGREE*	*STRONGLY AGREE*

2. Transportation is a major obstacle toward getting enough help.

1	2	3	4	5	6	7
STRONGLY DISAGREE	*DISAGREE*	*SLIGHTLY DISAGREE*	*NEITHER AGREE NOR DISAGREE*	*SLIGHTLY AGREE*	*AGREE*	*STRONGLY AGREE*

3. Lack of money to pay for medical, rehabilitation, and injury related services is a major problem.

1	2	3	4	5	6	7
STRONGLY DISAGREE	*DISAGREE*	*SLIGHTLY DISAGREE*	*NEITHER AGREE NOR DISAGREE*	*SLIGHTLY AGREE*	*AGREE*	*STRONGLY AGREE*



4. I don't know if there are good neurological rehabilitation services in my community.

1	2	3	4	5	6	7
STRONGLY DISAGREE	*DISAGREE*	*SLIGHTLY DISAGREE*	*NEITHER AGREE NOR DISAGREE*	*SLIGHTLY AGREE*	*AGREE*	*STRONGLY AGREE*

5. For neurological problems, there are very few services in my community.

1	2	3	4	5	6	7
STRONGLY DISAGREE	*DISAGREE*	*SLIGHTLY DISAGREE*	*NEITHER AGREE NOR DISAGREE*	*SLIGHTLY AGREE*	*AGREE*	*STRONGLY AGREE*

6. I have little confidence in the quality of care now being provided.

1	2	3	4	5	6	7
STRONGLY DISAGREE	*DISAGREE*	*SLIGHTLY DISAGREE*	*NEITHER AGREE NOR DISAGREE*	*SLIGHTLY AGREE*	*AGREE*	*STRONGLY AGREE*

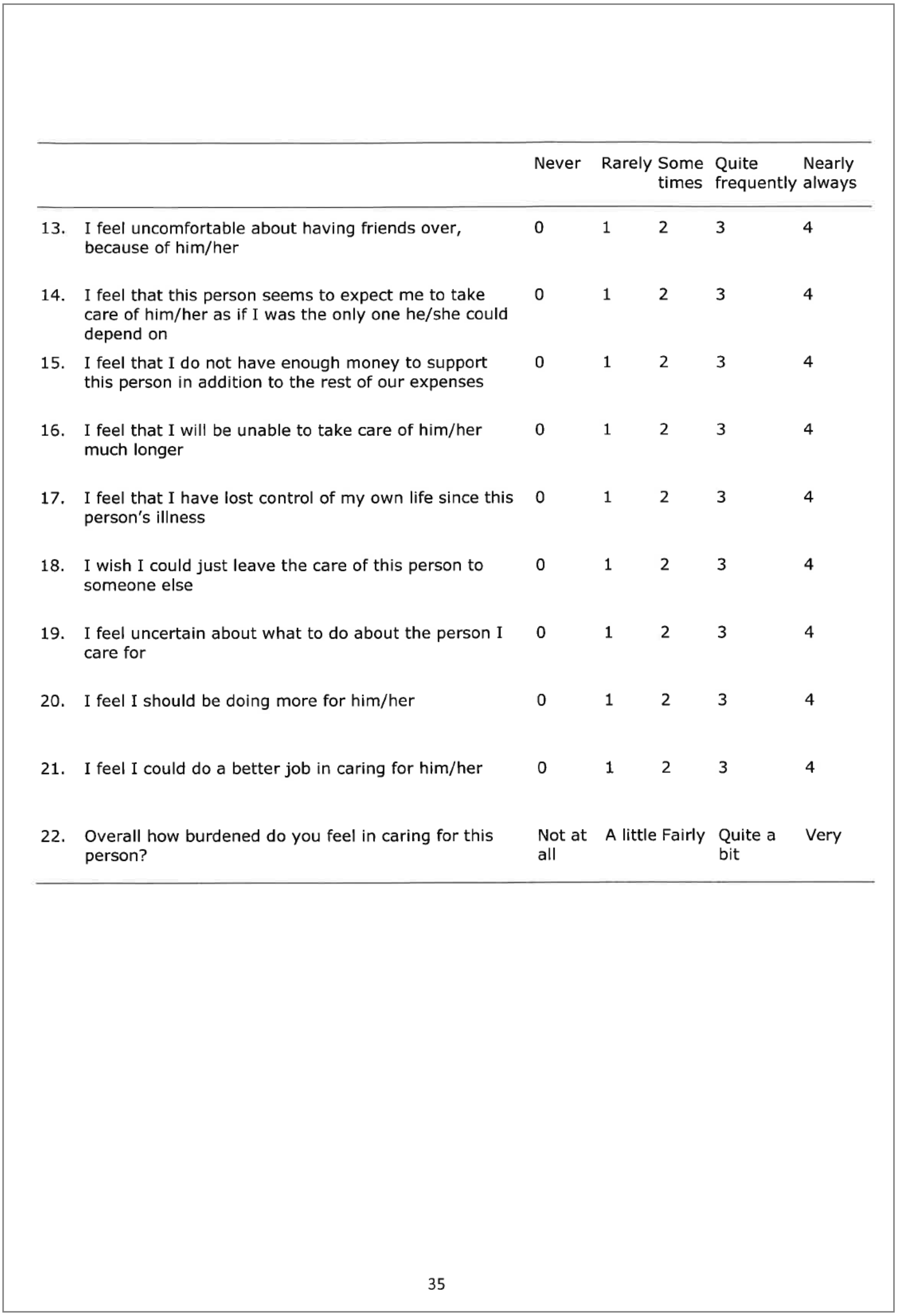
Please, tell us about any other things that make it hard to get the right kind of help.

PART SEVEN: The challenges and rewards of taking on a caring role

Please ask your carer to fill in this section.
The following is a list of statements that reflect how people sometimes feel when taking care of another person.

After each statement, please indicate how often you feel that way: Never, rarely, sometimes, quite frequently or nearly always. There are no right or wrong answers.

		Never	Rarely	Some times	Quite frequently	Nearly always
1.	I feel that the person I care for asks for more help than he/she needs	0	1	2	3	4
2.	Because of the time I spend with him/her, I do not have enough time for myself	0	1	2	3	4
3.	I feel stressed between caring for him/her and trying to meet other responsibilities for my family or work	0	1	2	3	4
4.	I feel embarrassed over his/her behaviour	0	1	2	3	4
5.	I feel angry when I am around the person I care for	0	1	2	3	4
6.	I feel that he/she currently affects my relationship with other family members or friends in a negative way	0	1	2	3	4
7.	I am afraid of what the future holds for the person I care for	0	1	2	3	4
8.	I feel he/she is dependent upon me	0	1	2	3	4
9.	I feel strained when I am around the person I care for	0	1	2	3	4
10.	I feel that my health has suffered because of my involvement with the person I care for	0	1	2	3	4
11.	I feel that I do not have as much privacy as I would like, because of the person I care for	0	1	2	3	4
12.	I feel that my social life has suffered because I am caring for this person	0	1	2	3	4



		Never	Rarely	Some times	Quite frequently	Nearly always
13.	I feel uncomfortable about having friends over, because of him/her	0	1	2	3	4
14.	I feel that this person seems to expect me to take care of him/her as if I was the only one he/she could depend on	0	1	2	3	4
15.	I feel that I do not have enough money to support this person in addition to the rest of our expenses	0	1	2	3	4
16.	I feel that I will be unable to take care of him/her much longer	0	1	2	3	4
17.	I feel that I have lost control of my own life since this person's illness	0	1	2	3	4
18.	I wish I could just leave the care of this person to someone else	0	1	2	3	4
19.	I feel uncertain about what to do about the person I care for	0	1	2	3	4
20.	I feel I should be doing more for him/her	0	1	2	3	4
21.	I feel I could do a better job in caring for him/her	0	1	2	3	4
22.	Overall how burdened do you feel in caring for this person?	Not at all	A little	Fairly	Quite a bit	Very

Appendix 7: Needs at discharge and care received at six months for the NPCS domains

Table 7.1a: Medical Needs at Discharge (Time 1) and Medical Care Received at 6 Months (Time 3)

	Recruitment needs of all 428 participants recruited at Time 1		Recruitment needs of those who responded at Time 3 (N=212)		Medical care received by participants who responded at Time 3 (N=212)	
	N	**%**	**N**	**%**	**N**	**%**
GP OCCASIONAL	84	19.6	39	18.4	44	21.0
GP ACTIVE MONITORING	84	19.6	40	18.9	30	14.3
LOW LEVEL SPECIALIST MONITORING	174	40.7	88	41.5	87	41.4
ACTIVE SPECIALIST	86	20.1	45	21.2	49	23.3
TOTAL	428	100.0	212	100.0	210	100.0

Table 7.1b: Met and Unmet Medical Care Needs at Time 3 (Time 3 Gets – Time 1 Needs)

	Difference Score	N	%
UNMET NEEDS	*-3*	*6*	*2.9*
	-2	*19*	*9.0*
	-1	*39*	*18.6*
	Total Unmet Needs	**64**	**30.5**
MET NEEDS	*0*	*74*	*35.2*
	Total Met Needs	**74**	**35.2**
EXCEEDED NEEDS	*+1*	*48*	*22.9*
	+2	*21*	*10.0*
	+3	*3*	*1.4*
	Total Exceeded Needs	**62**	**34.3**

Table 7.2a: Nursing Needs at Discharge (Time 1) and Nursing Care Received at 6 Months (Time 3)

	Recruitment needs of all 428 participants recruited at Time 1		Recruitment needs of those who responded at Time 3 (N=212)		Nursing Care received by participants who responded at Time 3 (N=212)	
	N	**%**	**N**	**%**	**N**	**%**
NONE	254	59.3	136	64.2	133	63.6
OCCASIONAL	75	17.5	38	17.9	40	19.1
REGULAR (EVERY 1/2 WEEKS)	50	11.7	17	8.0	13	6.2
FREQUENT (SEVERAL X/WEEK)	49	11.4	21	9.9	23	11.0
TOTAL	428	100.0	212	100.0	209	100.0

Table 7.2b: Met and Unmet Nursing Care Needs at Time 3 (Time 3 Gets – Time 1 Needs)

	Difference Score	N	%
UNMET NEEDS	*-3*	*9*	*4.3*
	-2	*12*	*5.7*
	-1	*25*	*12.0*
	Total Unmet Needs	**46**	**22.0**
MET NEEDS	*0*	*108*	*51.7*
	Total Met Needs	**108**	**51.7**
EXCEEDED NEEDS	*+1*	*37*	*17.7*
	+2	*11*	*5.3*
	+3	*7*	*3.3*
	Total Exceeded Needs	**55**	**26.3**

Table 7.2c: IS THIS THE RIGHT AMOUNT OF MEDICAL/NURSING CARE FOR YOU?

	N	%
TOO LITTLE	34	16.0
JUST RIGHT	138	65.1
TOO MUCH	0	0.0
TOTAL	172	21.1
MISSING	40	18.9
TOTAL	212	100.0

Table 7.3a: Number of Carers Needed at Discharge (Time 1) and Number of Carers Received at 6 Months (Time 3)

	Recruitment needs of all 428 participants recruited at Time 1		Recruitment needs of those who responded at Time 3 (N=212)		No. Carers received by participants who responded at Time 3 (N=212)	
	N	**%**	**N**	**%**	**N**	**%**
NONE	157	36.7	77	36.3	57	26.9
ONE	219	51.2	110	51.9	133	62.7
TWO OR MORE	52	12.1	25	11.8	22	10.4
TOTAL	428	100.0	212	100.0	212	100.0

Table 7.3b: Met and Unmet Nursing Care Needs at Time 3 (Time 3 Gets – Time 1 Needs)

	Difference Score	N	%
UNMET NEEDS	*-2*	*1*	*0.5*
	-1	*27*	*12.7*
	Total Unmet Needs	**28**	**13.2**
MET NEEDS	*0*	*139*	*65.6*
	Total Met Needs	**139**	**65.6**
EXCEEDED NEEDS	*+1*	*44*	*20.8*
	+2	*1*	*0.5*
	Total Exceeded Needs	**45**	**21.2**

Table 7.4a: Carer Frequency Needs at Discharge (Time 1) and Carer Frequency Received at 6 Months (Time 3)

	Recruitment needs of all 428 participants recruited at Time 1		Recruitment needs of those who responded at Time 3 (N=212)		Carer Frequency received by participants who responded at Time 3 (N=212)	
	N	**%**	**N**	**%**	**N**	**%**
NO HELP	139	32.5	71	33.5	57	27.5
OCCASIONAL HELP (<DAILY)	36	8.4	13	6.1	22	10.6
ONCE DAILY	70	16.4	41	19.3	19	9.2
2/3 TIMES A DAY (3-6 HOURS)	107	25.0	47	22.2	50	24.2
LIVE-IN/ALL DAY CARE	46	10.7	26	12.3	25	12.1
CONSTANT/NIGHT	30	7.0	14	6.6	34	16.4
TOTAL	428	100.0	212	100.0	207	100.0

Table 7. 4b: Met and Unmet Carer Frequency Needs at Time 3 (Time 3 Gets – Time 1 Needs)

	Difference Score	N	%
UNMET NEEDS	*-5*	*1*	*0.5*
	-4	*1*	*0.5*
	-3	*9*	*4.3*
	-2	*16*	*7.7*
	-1	*16*	*7.7*
	Total Unmet Needs	**43**	**20.8**
MET NEEDS	*0*	*69*	*33.3*
	Total Met Needs	**69**	**33.3**
EXCEEDED NEEDS	*+1*	*53*	*25.6*
	+2	*21*	*10.1*
	+3	*16*	*7.7*
	+4	*4*	*1.9*
	+5	*1*	*0.5*
	Total Exceeded Needs	**95**	**45.9**

Table 7.5a: Personal Enabler Needs at Discharge (Time 1) and Personal Enabler Received at 6 Months (Time 3)

	Recruitment needs of all 428 participants recruited at Time 1		Recruitment needs of those who responded at Time 3 (N=212)		Personal Enabler received by participants who responded at Time 3 (N=212)	
	N	**%**	**N**	**%**	**N**	**%**
NONE	139	32.5	69	32.5	123	59.1
OCCASIONAL (1-2/WEEK)	146	34.1	73	34.4	64	30.8
REGULAR (3-5/ WEEK)	94	22.0	47	22.2	13	6.3
DAILY	49	11.4	23	10.8	8	3.8
TOTAL	428	100.0	212	100.0	208	100.0

Table 7.5b: Met and Unmet Personal Enabler Needs at Time 3 (Time 3 Gets – Time 1 Needs)

	Difference Score	N	%
UNMET NEEDS	*-3*	*12*	*5.7*
	-2	*30*	*14.4*
	-1	*57*	*27.4*
	Total Unmet Needs	**99**	**47.6**
MET NEEDS	*0*	*85*	*40.9*
	Total Met Needs	**85**	**40.9**
EXCEEDED NEEDS	*+1*	*16*	*7.7*
	+2	*6*	*2.9*
	+3	*2*	*1.0*
	Total Exceeded Needs	**24**	**11.5**

Table 7.5c: Is this the Right Amount of Personal Care for you?

	N	%
TOO LITTLE	43	20.3
JUST RIGHT	125	59.0
TOO MUCH	1	0.5
TOTAL	169	79.7
MISSING	43	20.3
TOTAL	212	100.0

Table 7.6a: Therapy Needs at Discharge (Time 1) and Therapy Received at 6 Months (Time 3)

	Recruitment needs of all 428 participants recruited at Time 1		Recruitment needs of those who responded at Time 3 (N=212)		Therapy received by participants who responded at Time 3 (N=212)	
	N	**%**	**N**	**%**	**N**	**%**
NONE	26	6.1	14	6.6	42	19.9
SINGLE DISCIPLINE ONLY	39	9.1	16	7.5	49	23.2
MULTIPLE DISCIPLINES NOT CO-ORDINATED	144	33.6	66	31.1	68	32.2
MULTIPLE DISCIPLINES WORKING AS CO-ORDINATED TEAM	219	51.2	116	54.7	52	24.6
TOTAL	428	100.0	212	100.0	211	100.0

Table 7.6b: Met and Unmet Therapy Needs at Time 3 (Time 3 Gets – Time 1 Needs)

	Difference Score	N	%
UNMET NEEDS	*-3*	*14*	*6.6*
	-2	*39*	*18.5*
	-1	*61*	*28.9*
	Total Unmet Needs	**114**	**54.0**
MET NEEDS	*0*	*78*	*37.0*
	Total Met Needs	**78**	**37.0**
EXCEEDED NEEDS	*+1*	*12*	*5.7*
	+2	*4*	*1.9*
	+3	*3*	*1.4*
	Total Exceeded Needs	**19**	**9.0**

Table 7.7a: Therapy Intensity Needs at Discharge (Time 1) and Therapy Intensity Received at 6 Months (Time 3)

	Recruitment needs of all 428 participants recruited at Time 1		Recruitment needs of those who responded at Time 3 (N=212)		Therapy Intensity received by participants who responded at Time 3 (N=212)	
	N	**%**	**N**	**%**	**N**	**%**
NONE	25	5.9	14	6.6	42	20.0
OCCASIONAL REVIEW	47	11.0	21	10.0	45	21.4
REGULAR (EVERY 1/2 WEEKS)	197	46.1	96	45.5	75	35.7
FREQUENT (SEVERAL X/WEEK)	158	37.0	80	37.9	48	22.9
TOTAL	427	100.0	211	100.0	210	100.0

Table 7.7b Met and Unmet Therapy Intensity Needs at Time 3 (Time 3 Gets – Time 1 Needs)

	Difference Score	N	%
UNMET NEEDS	*-3*	*12*	*5.7*
	-2	*30*	*14.4*
	-1	*61*	*29.2*
	Total Unmet Needs	**103**	**49.3**
MET NEEDS	*0*	*67*	*32.1*
	Total Met Needs	**67**	**32.1**
EXCEEDED NEEDS	*+1*	*32*	*15.3*
	+2	*5*	*2.4*
	+3	*2*	*1.0*
	Total Exceeded Needs	**39**	**18.7**

Table 7.8a: Vocational Rehabilitation Needs at Discharge (Time 1) and Vocational Rehabilitation Received at 6 Months (Time 3)

	Recruitment needs of all 428 participants recruited at Time 1		Recruitment needs of those who responded at Time 3 (N=212)		Vocational Rehab received by participants who responded at Time 3 (N=212)	
	N	**%**	**N**	**%**	**N**	**%**
NONE	237	55.4	126	86.5	179	86.5
ASSESSMENT ONLY	87	20.3	41	5.3	11	5.3
OCCASIONAL SUPPORT	40	9.3	18	4.3	9	4.3
FORMAL REHABILITATION	64	15.0	27	3.9	8	3.9
TOTAL	428	100.0	212	100.0	207	100.0

Table 7.8b: Met and Unmet Vocational Rehabilitation Needs at Time 3 (Time 3 Gets – Time 1 Needs)

	Difference Score	N	%
UNMET NEEDS	*-3*	*17*	*5.8*
	-2	*16*	*14.4*
	-1	*40*	*27.4*
	Total Unmet Needs	**73**	**47.6**
MET NEEDS	*0*	*121*	*40.9*
	Total Met Needs	**121**	**40.9**
EXCEEDED NEEDS	*+1*	*5*	*7.7*
	+2	*6*	*2.9*
	+3	*2*	*1.0*
	Total Exceeded Needs	**39**	**11.6**

Table 7.8c: Is this the Right Amount of Rehabilitation for you?

	N	%
TOO LITTLE	69	32.5
JUST RIGHT	89	42.0
TOO MUCH	0	0.0
TOTAL	158	74.5
MISSING	54	25.5
TOTAL	212	100.0

Table 7.9a: Social Work/Case Management Needs at Discharge (Time 1) and Social Work/Case Management Received at 6 Months (Time 3)

	Recruitment needs of all 428 participants recruited at Time 1		Recruitment needs of those who responded at Time 3 (N=212)		Social Work received by participants who responded at Time 3 (N=212)	
	N	**%**	**N**	**%**	**N**	**%**
NONE	90	21.0	50	23.6	137	65.6
OCCASIONAL	130	30.4	73	34.4	27	12.9
REGULAR	142	33.2	65	30.7	30	14.4
FREQUENT	66	15.4	24	11.3	15	7.2
TOTAL	428	100.0	212	100.0	209	100.0

Table 7.9b: Met and Unmet Social Work/Case Management Needs at Time 3 (Time 3 Gets – Time 1 Needs)

	Difference Score	N	%
UNMET NEEDS	*-3*	10	*4.8*
	-2	39	*18.7*
	-1	70	*33.5*
	Total Unmet Needs	**119**	**56.9**
MET NEEDS	*0*	*62*	*29.7*
	Total Met Needs	**62**	**29.7**
EXCEEDED NEEDS	*+1*	24	*11.5*
	+2	1	*.5*
	+3	3	*1.4*
	Total Exceeded Needs	**28**	**13.4**

Table 7.10a: Family Carer Needs at Discharge (Time 1) and Family Carer Received at 6 Months (Time 3)

	Recruitment needs of all 428 participants recruited at Time 1		Recruitment needs of those who responded at Time 3 (N=212)		Family Carer received by participants who responded at Time 3 (N=212)	
	N	**%**	**N**	**%**	**N**	**%**
NONE	216	50.5	104	49.1	146	69.2
RECEIVED ASSESSMENT	126	29.4	59	27.8	28	13.3
TIME LIMITED SUPPORT	25	5.8	15	7.1	5	2.4
ON-GOING SUPPORT	61	14.3	34	16.0	32	15.2
TOTAL	428	100.0	212	100.0	211	100.0

Table 7.10b: Met and Unmet Family Carer Needs at Time 3 (Time 3 Gets – Time 1 Needs)

	Difference Score	N	%
UNMET NEEDS	*-3*	*20*	*9.5*
	-2	*18*	*8.5*
	-1	*39*	*18.5*
	Total Unmet Needs	**77**	**36.5**
MET NEEDS	*0*	*93*	*44.1*
	Total Met Needs	**93**	**44.1**
EXCEEDED NEEDS	*+1*	*18*	*8.5*
	+2	*9*	*4.3*
	+3	*14*	*6.6*
	Total Exceeded Needs	**41**	**19.4**

Table 7.11a: Residential Respite Needs at Discharge (Time 1) and Residential Respite Received at 6 Months (Time 3)

	Recruitment needs of all 428 participants recruited at Time 1		Recruitment needs of those who responded at Time 3 (N=212)		Residential Respite received by participants who responded at Time 3 (N=212)	
	N	**%**	**N**	**%**	**N**	**%**
NONE	358	83.8	175	82.5	199	96.1
OCCASIONAL	51	11.9	27	12.7	3	1.4
REGULAR	10	2.3	7	3.3	3	1.4
FREQUENT	8	1.9	3	1.4	2	1.0
TOTAL	427	100.0	212	100.0	207	100.0

Table 7.11b: Met and Unmet Residential Respite Needs at Time 3 (Time 3 Gets – Time 1 Needs)

	Difference Score	N	%
UNMET NEEDS	*-3*	*3*	*1.4*
	-2	*5*	*2.4*
	-1	*24*	*11.6*
	Total Unmet Needs	**32**	**15.5**
MET NEEDS	*0*	*170*	*82.1*
	Total Met Needs	**170**	**82.1**
EXCEEDED NEEDS	*+1*	*2*	*1.0*
	+2	*2*	*1.0*
	+3	*1*	*0.5*
	Total Exceeded Needs	**5**	**2.4**

Table 7.12a: Day Care Needs at Discharge (Time 1) and Day Care Received at 6 Months (Time 3)

	Recruitment needs of all 428 participants recruited at Time 1		Recruitment needs of those who responded at Time 3 (N=212)		Day care received by participants who responded at Time 3 (N=212)	
	N	**%**	**N**	**%**	**N**	**%**
NONE	302	70.9	151	71.2	186	91.2
OCCASIONAL	103	24.2	48	22.6	15	7.4
FREQUENT	21	4.9	13	6.1	3	1.5
TOTAL	426	100.0	212	100.0	204	100.0

Table 7.12b: Met and Unmet Day Care Needs at Time 3 (Time 3 Gets – Time 1 Needs)

	Difference Score	N	%
UNMET NEEDS	*-2*	*9*	*4.4*
	-1	*46*	*22.5*
	Total Unmet Needs	**55**	**27.0**
MET NEEDS	*0*	*139*	*68.1*
	Total Met Needs	**139**	**68.1**
EXCEEDED NEEDS	*+1*	*9*	*4.4*
	+2	*1*	*0.5*
	Total Exceeded Needs	**10**	**4.9**

Table 7.13a: Advocacy Needs at Discharge (Time 1) and Advocacy Received at 6 Months (Time 3)

	Recruitment needs of all 428 participants recruited at Time 1		Recruitment needs of those who responded at Time 3 (N=212)		Advocacy received by participants who responded at Time 3 (N=212)	
	N	**%**	**N**	**%**	**N**	**%**
NONE	326	76.3	159	75.0	152	76.8
MENTAL CAPACITY ASSESSMENT	53	12.4	28	13.2	4	2.0
FAMILY ADVOCATE	47	11.0	24	11.3	33	16.7
INDEPENDENT ADVOCATE	1	0.2	1	0.5	9	4.5
TOTAL	427	100.0	212	100.0	198	100.0

Table 7.13b: Met and Unmet Advocacy Needs at Time 3 (Time 3 Gets – Time 1 Needs)

	Difference Score	N	%
UNMET NEEDS	*-2*	*8*	*4.0*
	-1	*19*	*9.6*
	Total Unmet Needs	**27**	**13.6**
MET NEEDS	*0*	*138*	*69.7*
	Total Met Needs	**138**	**69.7**
EXCEEDED NEEDS	*+1*	*12*	6.1
	+2	*17*	8.6
	+3	*4*	2.0
	Total Exceeded Needs	**33**	**16.7**

Table 7.13c: Is this the Right Amount of Social/Family Support for you?

	N	%
TOO LITTLE	36	17.0
JUST RIGHT	119	56.1
TOO MUCH	0	0.0
TOTAL	155	73.1
MISSING	57	26.9
TOTAL	212	100.0

Table 7.14a: Equipment Needs at Discharge (Time 1) and Equipment Received at 6 Months (Time 3)

	Recruitment needs of all 428 participants recruited at Time 1		Recruitment needs of those who responded at Time 3 (N=212)		Equipment received by participants who responded at Time 3 (N=212)	
	N	**%**	**N**	**%**	**N**	**%**
NONE	122	28.6	59	27.8	87	42.4
BASIC EQUIPMENT	170	39.8	80	37.7	77	37.6
SPECIALIST EQUIPMENT	98	23.0	51	24.1	38	18.5
HIGHLY SPECIALIST EQUIPMENT	37	8.7	22	10.4	3	1.5
TOTAL	427	100.0	212	100.0	205	100.0

Table 7.14b: Met and Unmet Equipment Needs at Time 3 (Time 3 Gets – Time 1 Needs)

	Difference Score	N	%
UNMET NEEDS	*-3*	*5*	*2.4*
	-2	*18*	*8.8*
	-1	*59*	*28.8*
	Total Unmet Needs	**82**	**40.0**
MET NEEDS	*0*	*91*	*44.4*
	Total Met Needs	**91**	**44.4**
EXCEEDED NEEDS	*+1*	*30*	*14.6*
	+2	*2*	*1.0*
	Total Exceeded Needs	**32**	**15.6**

Table 7.15a: Accommodation Needs at Discharge (Time 1) and Accommodation Received at 6 Months (Time 3)

	Recruitment needs of all 428 participants recruited at Time 1		Recruitment needs of those who responded at Time 3 (N=212)		Accommodation received by participants who responded at Time 3 (N=212)	
	N	**%**	**N**	**%**	**N**	**%**
NO SPECIAL ACCOMODATION	166	39.0	80	37.7	84	40.0
RESTRICTED OPTIONS	44	10.3	24	11.3	8	3.8
PARTIALLY ADAPTED	107	25.1	62	29.2	71	33.8
FULLY ADAPTED	43	10.1	19	9.0	18	8.6
SHELTERED ACCOMODATION	12	2.8	4	1.9	3	1.4
SMALL GROUP HOME	5	1.2	3	1.4	3	1.4
RESIDENTIAL CARE HOME	10	2.3	5	2.4	10	4.8
NURSING HOME	20	4.7	6	2.8	8	3.8
SPECIALIST NURSING HOME	18	4.2	9	4.2	5	2.4
HOSPICE CARE	1	0.2	0	0	0	0
TOTAL	426	100.0	212	100.0	210	100.0

Table 7.15b: Met and Unmet Accommodation Needs at Time 3 (Time 3 Gets – Time 1 Needs)

	Difference Score	N	%
UNMET NEEDS	*-8*	1	.5
	-6	1	.5
	-5	1	.5
	-4	1	.5
	-3	8	3.8
	-2	16	7.6
	-1	18	8.6
	Total Unmet Needs	**46**	**21.9**
MET NEEDS	*0*	*107*	*51*
	Total Met Needs	**107**	**51**
EXCEEDED NEEDS	*+1*	24	11.4
	+2	26	12.4
	+3	3	1.4
	+5	3	1.4
	+8	1	0.5
	Total Exceeded Needs	**57**	**27.1**

Table 7.13c: Is this the Right Amount of Equipment/Accommodation for you?

	N	%
TOO LITTLE	31	14.6
JUST RIGHT	117	55.2
TOO MUCH	0	0.0
TOTAL	148	69.8
MISSING	64	30.2
TOTAL	212	100.0

Appendix 8: NPCS costing computation – intuitive estimation of costs per year

Score	**Brief Descriptor**	**Costs per year based on:**	**Annual cost**
MEDICAL CARE NEEDS			
M 0	**GP occasional**	3 standard visits to GP per year	£93
M 1	**GP active**	6 standard visits to GP per year	£186
M 2	**Low level specialist**	4 standard visits to GP per year plus 2 consultant hospital outpatient visits per year	£462
M 3	**Active specialist**	4 standard visits to GP per year plus 4 consultant outpatient visits per year, with uplift for investigations estimate £500 per year	£1,300
SKILLED NURSING NEEDS			
N 0	**None**	Nil	£0
N 1	**Occasional**	District nurse home visit x 8 per year (allow 1 hour for visit inc travel time)	£584
N 2	**Regular**	District nurse home visit x 30 per year (allow 45 mins per visit inc travel time)	£1,643
N 3	**Frequent**	District nurse home visit x 100 per year (allow 40 mins per visit inc travel time, as intervention is likely to be quick)	£4,818
PERSONAL CARE			
Number of carers – multiplier for care frequency			
CN 0	**None**	Nil	**0**
CN 1	**1 carer**	x1 multiplier for care frequency	X1
CN 2	**2 carers**	x2 multiplier for care frequency	X2
Care frequency			
CF 0	**None**	Nil	**0**
CF 1	**Occasional need**	5 hours per week care assistance from standard carer (plus any standard uplift for travel time/costs etc)	£5,270
CF 2	**Regular help x1/day**	10 hours per week care assistance from standard carer (i.e. 1.5 hours per day) plus any standard uplift for travel time/costs etc)	£11,440
CF 3	**Regular help 2-3 x/ day**	18 hours per week care assistance from standard carer (i.e. 2-3 hours per day) plus any standard uplift for travel time/costs etc)	£20,592
CF 4	**Live-in care**	Live in carer with sleep-in care at night plus cover for the 4 hours that a living carer would normally have off per day	£55,328
CF 5	**Constant care**	Live in carer with waking night time care	£100,048

PERSONAL ASSISTANT / ENABLER

PA 0	**None**		0
PA 1	**Occasional**	Skilled care worker 8 hours/week	£12,064
PA 2	**Frequent**	Skilled care worker 12 hours/week	£18,096
PA 3	**Daily**	Skilled care worker 20 hours/week	£30,160

THERAPY NEEDS

Therapy Disciplines: - required to be actively involved in treatment (i.e. at least 1 hr per month)			
TD 0	**None**	Nil	0
TD 1	**Single discipline only**	x1 multiplier for therapy intensity	x1
TD 2	**Individual disciplines**	x2 multiplier for therapy intensity – assumes 2 disciplines	x2
TD 3	**Co-ordinated team**	x3 multiplier for therapy intensity – assumes 3 disciplines	x3
Therapy Intensity: - Overall intensity of trained therapy intervention required			
TI 0	**None**	Nil	0
TI 1	**Occasional review**	6 sessions (1 hour) therapy time per year (if training carers, their time is already counted above)	£846
TI 2	**Regular intervention**	10 sessions therapy time per year (time-limited course over 6-12 weeks)	£1410
TI 3	**Frequent intervention**	16 sessions of community team per year (time-limited course over 6-12 weeks)	£2256

VOCATIONAL /EDUCATIONAL SUPPORT NEEDS

VR 0	**None**	Nil	0
VR 1	**Vocational Assessment**	4 sessions therapy time stat (community team based on outreach visits)	£564
VR 2	**On-going vocational support**	6 sessions therapy time per year (likely to be in a time-limited course over 6-12 weeks)	£846
VR 3	**Formal vocational rehab**	12 sessions therapy time per year	£1692

SOCIAL WORK AND CASE MANAGEMENT

S 0	**None**	Nil	
S 1	**Occasional advice**	8 social worker or contacts per year (mainly telephone contact allow 30 mins per contact)	£848
S 2	**Regular intervention**	12 social worker sessions (of ½ hr) per year Likely to be for a limited period	£1,272
S 3	**Frequent intervention**	18 social worker sessions (of ½ hr) per year Likely to be for a limited period	£1,908

FAMILY / CARER SUPPORT

FC 0	**None**	Nil	0
FC 1	**Carer Assessment required**	1 hour social worker or case manager contact stat	£212
FC 2	**Time-limited family/carer support**	6 sessions (of ½ hr) per year	£636
FC 3	**On-going family/carer support**	12 sessions (of ½ hr) per year	£1,272

RESPITE NEEDS

RESIDENTIAL RESPITE			
RR 0	**None**	Nil	0
RR 1	**Occasional**	10 days nursing home care per year (£1378 per week as likely to have complex needs)	£1,969
RR 2	**Regular planned**	3 weeks nursing home care per year (£1378 /wk as likely to have complex needs)	£4,134
RR 3	**Frequent with back-up support**	6 weeks nursing home care per year (£1378 /wk as likely to have complex needs)	£8,268
DAY CARE			
RD 0	**None**	Nil	0
RD 1	**Occasional**	Day centre attendance x 60 per year	£5,520
RD 2	**Frequent**	Day centre attendance x 135 per year	£12,420

ADVOCACY NEEDS

AD 0	**None**	Nil	0
AD 1	**Capacity Assessment**	2 sessions of senior social worker stat	£424
AD 2	**Independent advocacy**	IMCA services – 8 sessions per year – allowing for direct contact and indirect time	£784

SPECIALIST EQUIPMENT

E 0	**None**	Nil	0
E 1	**Basic equipment**	Estimate £625 per year – including set-up maintenance/replacement	£526
E 2	**Specialist equipment**	Estimate £1250 per year including set-up maintenance/replacement	£1,250
E 3	**Highly specialist equipment**	Estimate £2000 per year including set-up maintenance/replacement	£2,000

ACCOMMODATION NEEDS

HOME LIVING ARRANGEMENTS			
AC 0	**None**	Nil	
AC 1	**Restricted options**	Any additional cost of ground floor flat or flats with lift access, over and above ordinary rental costs. Estimated £1200 pa	£1,200
AC 2	**Partially adapted**	One off cost for adaptation e.g. £2500 stat	£2,500
AC 3	**Fully adapted**	One off cost for adaptation e.g. £7500 stat	£7,500
SHELTERED AND RESIDENTIAL CARE			
AC 4	**Sheltered living**	Warden controlled accommodation Assume also requires adapted accommodation with more space - estimated £755 per week	£39262
AC 5	**Small group home**	These arrangements tend to be fairly expensive because of need for staff supervision Estimated £1231 per week	£64012
AC 6	**Residential care home**	Basic residential care home rates estimated £768/week	£39936
AC 7	**Nursing home**	Standard nursing home estimated £ 741 per week	£38532
AC 8	**Specialist nursing home**	Specialist nursing home estimated £1378 per week (range £1000-2000)	£71656
AC9	**Hospice care**	Inpatient hospice care - £320 per day = £2240 per week Required for limited period - assume 8 weeks	£17,920

Appendix 9: Short Community Rehabilitation Questionnaire

Name of service

Address

Contact person – Phone – e-mail

1	**Where is the service?**	***Post-code and location (Borough)***
2.	**What area does it cover?**	***Catchment Restricted / Unrestricted?*** *If restricted – how* ☐ *PCT(s) – which……………………………….* ☐ *Local Authority/ Borough(s)……………………* ☐ *Other………………………………………..*
3.	**How is the service funded?**	***Case by case / Block contract*** *Who by? (tick any)* ☐ *Healthcare (e.g. PCTs)…………………………..* ☐ *Social services………………………………….* ☐ *Voluntary sector/ charity………………………………..*
4	**What types of service model do you offer:**	*(Tick any)* ☐ *Home-based rehab (visiting pts in their home)* ☐ *Centre-based rehab (Pts come to you)* ☐ *Residential / in-patient rehab (Pt stays overnight)* ☐ *Other*
5.	**Who can access the service?**	*What diagnoses do you take? (Tick any)* ☐ *Brain Injury – Stroke/SAH/TBI/Other ABI* ☐ *Spinal Cord Injury* ☐ *Peripheral Neuropathy* ☐ *Progressive Neurological* ☐ *Other* *…………………………………………………………….* *What is the target age group (Tick one)* ☐ *Main younger adults (e.g. <65)* ☐ *Mainly older adults (e.g. >65)* ☐ *Children* ☐ *Any*

6.	**What types of problem to you tackle**	*(Tick any)* ☐ *Physical disability* ☐ *Cognitive / behavioural disability* ☐ *Vocational rehabilitation*	
7.	**What disciplines do you have on your team?**	*(Tick any)* ☐ *Physiotherapy* ☐ *O/T* ☐ *SLT* ☐ *Psychology*	☐ *Social worker* ☐ *Dietetics* ☐ *Orthotics* ☐ *Other*
8.	**What medical input does your service have access to?**	*Tick one* ☐ *Regular (how many sessions / week)* ☐ *As required from named doctor / practice* ☐ *No specific arrangement (just work with the pt's existing medical practitioner)* *If regular medical input – please specify type:* ☐ *Primary care (e.g. GP)* ☐ *Specialist* ○ *Consultant in Rehab medicine* ○ *Neuro-psychiatrist* ○ *Geriatrician* ○ *Stroke doctor* ○ *Other…………………………………*	
9.	**Duration of input**	*Is the programme length* ☐ *Time limited – how long……………………* ☐ *Flexible, base on individual need* ☐ *Other………………………………………..* *Do you have a waiting list?* *If so – how long?*	

10	*Do you feel you can cope adequately with the needs of your patient population, through your own service / other linked services* ☐ *Yes* ☐ *No* *If no – what is missing?*
11.	*Do you consider yours to be a complex specialised community rehabilitation service?* ☐ *Yes* ☐ *No* ***If yes,*** *please continue to fill in the remaining questions and return via post/email to address below* ***If no,*** *many thanks for your help, you do not need to complete the remaining questions. Please return this questionnaire via post/email to the address below.*

Complex Community Rehabilitation Services

a) Please tick **all** the elements that are currently in place within your rehabilitation service
b) Please **add any other** features that you believe would distinguish a specialist neuro-rehab community service from a district specialist service

Range of services offered by your service	☐ Out-patient /day programme ☐ Domiciliary visits ☐ Other…….
Coordinated multi- or inter-disciplinary activity within your service	Regular multi- or interdisciplinary activity in: ☐ Multidisciplinary Case notes ☐ Multidisciplinary treatment planning meetings ☐ Multidisciplinary Goal setting ☐ Multidisciplinary Outcome evaluation ☐ Other (specify)
On average, how many of your patients require coordinated multi-disciplinary team input from 2+ disciplines?	

On average, how many disciplines within your service are involved with each patient?	
Is the intensity of rehabilitation provided…	☐ Tailored to individual need Or ☐ A set, pre-defined program
How are outcomes measured? **Please state any standardised measures used** ☐ Barthel ☐ FIM ☐ FIM-FAM ☐ Goal Attainment Scaling ☐ Other (e.g. COPM ____________________) **What is the policy for ongoing follow-up?**	

13. Facilities, programmes and medical/nursing services

Please tick **any** of the following special facilities, programmes or medical/surgical care that are **currently provided as part of your neuro-rehabilitation service, and included in its costs** (NB Having ready access to services provided and charged by other departments does not count for this purpose). Please **add any other categories** that characterize a specialist neuro-rehab community service.

Specialist Programmes provided by your unit as part of routine practice	**Special Facilities** provided by your unit as part of routine practice	**Medical/Nursing Services** provided by your unit as part of routine practice
☐ Specialist spasticity management ☐ Electro-assistive technology ☐ Group therapy programmes ☐ Behavioural / cognitive / neuropsychology rehabilitation programmes ☐ Formalised family support ☐ Weight management	☐ Functional electrical stimulation ☐ Custom-made splinting /orthotics ☐ EAT ☐ Special seating assessment ☐ Other (please specify) ____________________________	☐ Pressure care ☐ Continence management ☐ Drug monitoring ☐ Other (please specify) ___________________

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programmes ☐ Back to work programmes ☐ Self-management programmes ☐ Community groups e.g. fatigue management, exercise groups ☐ Other…….	**Is your service a Demonstration centre for** ☐ EAT ☐ Communication aids ☐ Computers ☐ Wheelchairs/special seating ☐ Other________	

14. Comments

Are there any changes or threats to services that you identify as a result of impending changes to the NHS?

Thank you for your help – now please return to:

Bernadette Khoshaba

Department of Palliative Care, Policy and Rehabilitation

King's College London

Cicely Saunders Institute

Bessemer Road

London SE5 9PJ

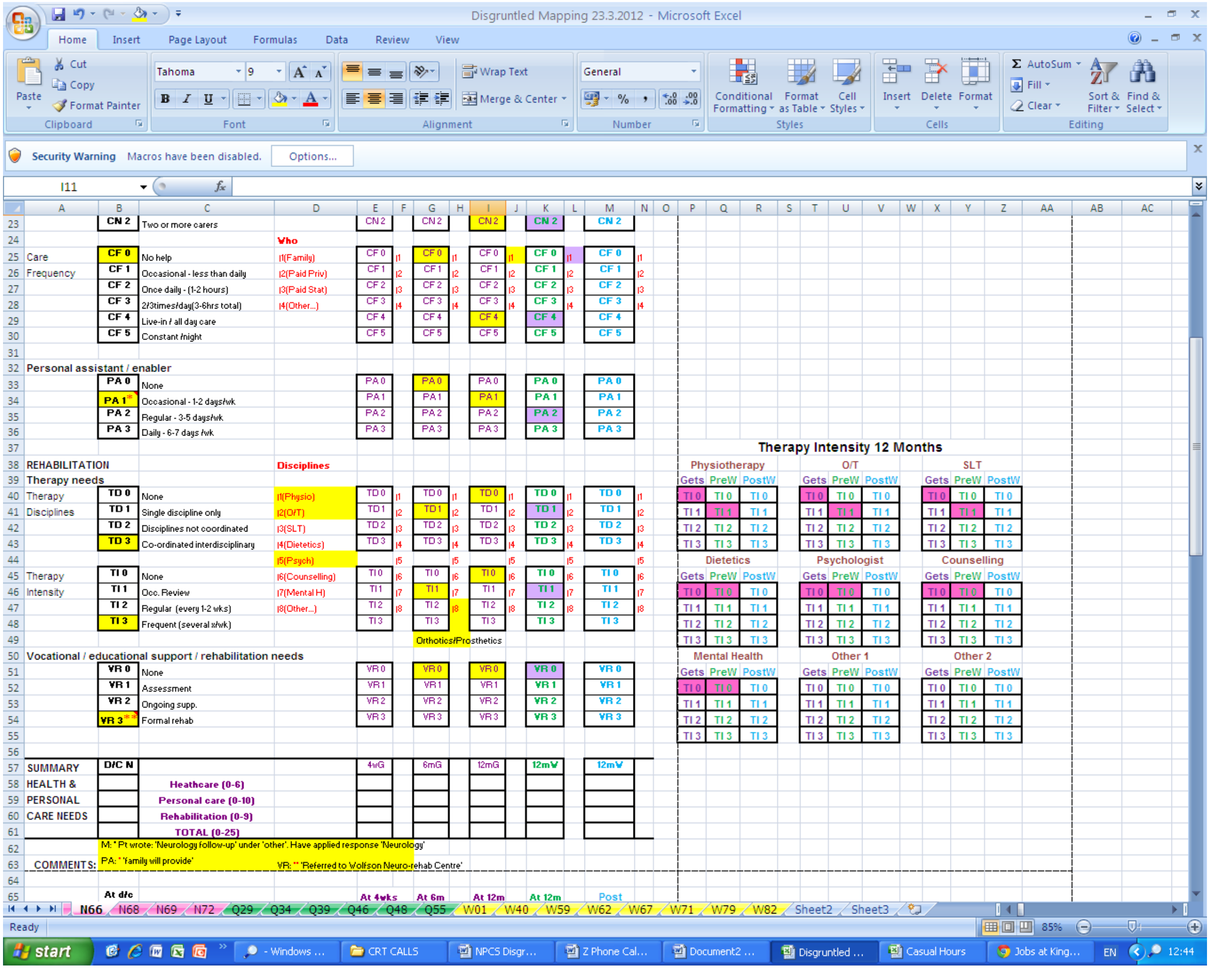
Tel: 0207 848 5143

Fax: 0207 848 5517

Email: Bernadette.khoshaba@kcl.ac.uk

Appendix 10: Protocol for obtaining information from dissatisfied participants

- A portion of these participants were randomly selected for follow up.
- The information about the services that the participant was receiving was mapped from the NPCS questionnaire onto the 'GETS' column on the NPCS score sheet.
- There was a particular focus on the Rehabilitation domain of services and because of this, therapy intensity fields were created on the score sheet for each individual therapy the participants may have been receiving (see below).



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	A	B	C	D	E	F	G	H	I	J	K	L	M	N
23		CN 2	Two or more carers		CN 2		CN 2		CN 2		CN 2		CN 2	
24				Who										
25	Care	CF 0	No help	I1(Family)	CF 0	I1	CF 0	I1	CF 0	I1	CF 0	I1	CF 0	I1
26	Frequency	CF 1	Occasional - less than daily	I2(Paid Priv)	CF 1	I2	CF 1	I2	CF 1	I2	CF 1	I2	CF 1	I2
27		CF 2	Once daily - (1-2 hours)	I3(Paid Stat)	CF 2	I3	CF 2	I3	CF 2	I3	CF 2	I3	CF 2	I3
28		CF 3	2/3times/day(3-6hrs total)	I4(Other...)	CF 3	I4	CF 3	I4	CF 3	I4	CF 3	I4	CF 3	I4
29		CF 4	Live-in / all day care		CF 4		CF 4		CF 4		CF 4		CF 4	
30		CF 5	Constant /night		CF 5		CF 5		CF 5		CF 5		CF 5	
31														
32	Personal assistant / enabler													
33		PA 0	None		PA 0		PA 0		PA 0		PA 0		PA 0	
34		PA 1*	Occasional - 1-2 days/wk		PA 1		PA 1		PA 1		PA 1		PA 1	
35		PA 2	Regular - 3-5 days/wk		PA 2		PA 2		PA 2		PA 2		PA 2	
36		PA 3	Daily - 6-7 days /wk		PA 3		PA 3		PA 3		PA 3		PA 3	
37														
38	REHABILITATION			Disciplines										
39	Therapy needs													
40	Therapy	TD 0	None	I1(Physio)	TD 0	I1	TD 0	I1	TD 0	I1	TD 0	I1	TD 0	I1
41	Disciplines	TD 1	Single discipline only	I2(O/T)	TD 1	I2	TD 1	I2	TD 1	I2	TD 1	I2	TD 1	I2
42		TD 2	Disciplines not coordinated	I3(SLT)	TD 2	I3	TD 2	I3	TD 2	I3	TD 2	I3	TD 2	I3
43		TD 3	Co-ordinated interdisciplinary	I4(Dietetics)	TD 3	I4	TD 3	I4	TD 3	I4	TD 3	I4	TD 3	I4
44				I5(Psych)		I5		I5		I5		I5		I5
45	Therapy	TI 0	None	I6(Counselling)	TI 0	I6	TI 0	I6	TI 0	I6	TI 0	I6	TI 0	I6
46	Intensity	TI 1	Occ. Review	I7(Mental H)	TI 1	I7	TI 1	I7	TI 1	I7	TI 1	I7	TI 1	I7
47		TI 2	Regular (every 1-2 wks)	I8(Other...)	TI 2	I8	TI 2	I8	TI 2	I8	TI 2	I8	TI 2	I8
48		TI 3	Frequent (several x/wk)		TI 3		TI 3		TI 3		TI 3		TI 3	
49							Orthotics/Prosthetics							
50	Vocational / educational support / rehabilitation needs													
51		VR 0	None		VR 0		VR 0		VR 0		VR 0		VR 0	
52		VR 1	Assessment		VR 1		VR 1		VR 1		VR 1		VR 1	
53		VR 2	Ongoing supp.		VR 2		VR 2		VR 2		VR 2		VR 2	
54		VR 3**	Formal rehab		VR 3		VR 3		VR 3		VR 3		VR 3	
55														
56														
57	SUMMARY	D/C N			4wG		6mG		12mG		12mW		12mW	
58	HEALTH &		Heathcare (0-6)											
59	PERSONAL		Personal care (0-10)											
60	CARE NEEDS		Rehabilitation (0-9)											
61			TOTAL (0-25)											
62		M: * Pt wrote: 'Neurology follow-up' under 'other'. Have applied response 'Neurology'												
63	COMMENTS:	PA: * 'family will provide'		VR: ** 'Referred to Wolfson Neuro-rehab Centre'										
64														
65		At d/c			At 4wks		At 6m		At 12m		At 12m		Post	

Therapy Intensity 12 Months

Physiotherapy			O/T			SLT		
Gets	PreW	PostW	Gets	PreW	PostW	Gets	PreW	PostW
TI 0	TI 0	TI 0	TI 0	TI 0	TI 0	TI 0	TI 0	TI 0
TI 1	TI 1	TI 1	TI 1	TI 1	TI 1	TI 1	TI 1	TI 1
TI 2	TI 2	TI 2	TI 2	TI 2	TI 2	TI 2	TI 2	TI 2
TI 3	TI 3	TI 3	TI 3	TI 3	TI 3	TI 3	TI 3	TI 3

Dietetics			Psychologist			Counselling		
Gets	PreW	PostW	Gets	PreW	PostW	Gets	PreW	PostW
TI 0	TI 0	TI 0	TI 0	TI 0	TI 0	TI 0	TI 0	TI 0
TI 1	TI 1	TI 1	TI 1	TI 1	TI 1	TI 1	TI 1	TI 1
TI 2	TI 2	TI 2	TI 2	TI 2	TI 2	TI 2	TI 2	TI 2
TI 3	TI 3	TI 3	TI 3	TI 3	TI 3	TI 3	TI 3	TI 3

Mental Health			Other 1			Other 2		
Gets	PreW	PostW	Gets	PreW	PostW	Gets	PreW	PostW
TI 0	TI 0	TI 0	TI 0	TI 0	TI 0	TI 0	TI 0	TI 0
TI 1	TI 1	TI 1	TI 1	TI 1	TI 1	TI 1	TI 1	TI 1
TI 2	TI 2	TI 2	TI 2	TI 2	TI 2	TI 2	TI 2	TI 2
TI 3	TI 3	TI 3	TI 3	TI 3	TI 3	TI 3	TI 3	TI 3

Information from the 'Right questions was then mapped from the questionnaire onto the 'Pre-call WANTS' column on the NPCS score sheet for all domains and onto the additional individual therapy intensity fields. This was done based on information extrapolated from the questionnaire and before a phone-call was made to the participant.

- Because the right amount questions were only asked in relation to overall groups of services (e.g. Personal Care) and not specified by domains within those groups (e.g. number of carers; care frequency; personal assistant), the WANTS information from the questionnaire could not easily be mapped onto the NPCS score sheet.

- The following rules were therefore used when mapping onto the score sheet based on information from the questionnaire for the WANTS column.
    - If the participant ticks 'just right' then the participants 'WANTS' should match their 'GETS' on the NPCS score sheet.
    - If the participant ticks 'too little' and elaborates on the specific area they are dissatisfied with and stipulates how much they would like in their comments, this should be recorded by highlighting the appropriate cell on the score sheet in the 'WANTS' column.
    - When the participant ticks 'too little' and does not elaborate in the comments box or just elaborates by saying they want 'more' rehabilitation, consistently go up by one level on each of the areas of care within that domain
    - When the participant is unclear about which aspect of their care they are referring to e.g. 'I need a break from caring for her', consistently go up by one level on each of the areas of care within that domain.
    - If 'GETS' is at highest overall but they have specified 'too little', keep at same level.

Appendix 11: Outcome of call with participants

Comments:

QUESTION 1 – To determine the accuracy of information provided by the participant:

One of your patients, (NAME), has informed us that they are currently receiving rehabilitation in the form of (NAME DISCIPLINES) at a level of (NUMBER) sessions per week. Can you confirm that this is correct?

Comments:

TYPE OF RESPONSE	**THERAPY 1:** ______________	**THERAPY 2:** ______________	**THERAPY 3:** ______________
Agree – Information is correct			
Disagree – information is incorrect re: disciplines			
Disagree – Information is incorrect re: intensity			
Disagree – Patient is not affiliated with this service			
Other – Elaborate			

QUESTION 2 – The CRT opinion regarding the patient's feelings of disgruntlement

(NAME) feels they are receiving too little rehabilitation and would benefit from additional rehabilitation in the form of (FREQUENCY/DISCIPLINES DESIRED). In your opinion, would this level of care be of benefit?

Comments:

TYPE OF RESPONSE	**THERAPY 1** ______	**THERAPY 2:** ______	**THERAPY 3:** ______
Perhaps – but we are a time limited service			
Perhaps – but we do not have the resources			
Perhaps – issue with referral			
Unlikely – the patient needs to further their rehab success independently			
Unlikely – the patient was discharged as they had met all rehab goals			
Unlikely- due to extent of neurological			
Other			

QUESTION 3 – To determine any other issues which are felt to be challenges to providing an optimal service or to service-user satisfaction

Is there anything else you would like to add regarding challenges faced by your service in terms of meeting the requirements of your patients and ensuring their satisfaction with what you are providing as a service?

Comments:

Appendix 12: Key questions formed the basis for the telephone conversation with service providers

QUESTION 1 – To determine the accuracy of information provided by the participant:

"One of your patients, (NAME), has informed us that they are currently receiving rehabilitation in the form of (DISCIPLINES) at a level of (NUMBER) sessions per week. Can you confirm that this is correct?

***QUESTION 2* – The CRT opinion regarding the patient's feelings of dissatisfaction**

(NAME) feels they are receiving too little rehabilitation and would benefit from additional rehabilitation in the form of (FREQUENCY/DISCIPLINES DESIRED). In your opinion, would this level of care be of benefit?

***QUESTION 3* – To determine any other issues which are felt to be challenges to providing an optimal service or to service-user satisfaction**

Is there anything else you would like to add regarding challenges faced by your service in terms of meeting the requirements of your patients and ensuring their satisfaction with what you are providing as a service?

The responses from participants and services were tabulated and compared for similarities and differences. A narrative review of findings was prepared by two researchers in collaboration.