Cost-efficient service provision in neurorehabilitation: defining needs, costs and outcomes for people with long term neurological conditions

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A report prepared on behalf of the UK Rehabilitation Outcomes Collaborative (UKROC) steering group

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Overview of the report

Background

Long term neurological conditions (LTNCs) give rise to a complex interaction of medical, physical, cognitive, communicative and psychosocial problems, which cause disability for over 1 million people in the UK,[1] and present a substantial burden of care to both family members and the services that support them. Rehabilitation services help to keep people out of acute hospitals and support them in the community, or in their own homes, whilst optimising autonomy and quality of life.

By taking a systematic patient-centred approach to inform the provision of cost-effective neurorehabilitation services, this programme of research addressed key priorities in the NHS Improvement Plan, the National Service Framework (NSF) for LTNCs,[2] and the UKCRC (UK Clinical Research Collaboration) classification strategy.

The NSF for LTNCs in particular highlighted the need for specialist neurorehabilitation services for individuals with complex needs. However, at the onset of this programme there was no agreed definition of 'complex needs', or indeed what constitutes a 'specialist service'. Although many neurorehabilitation services in the UK routinely collected information on outcomes, there was no agreed common system for standardising information on patient needs, costs or outcomes, which could be used to compare different services and identify models that offer best quality and value for money.

Learning from established international models, we set out to provide the evidence to underpin the development of case-mix, accurate patient-level costing and funding models to inform tariff costs under Payment by Results (PbR).[3]

To reflect the full history of this seven-year programme of research, the main body of this report begins with a background chapter, followed by separate chapters setting out the five interconnected work streams that made up the programme. These ran concurrently and each one had specific objectives. The final chapters bring the outputs from each work stream together and present a synthesis of findings along with their implications for future rehabilitation service development.

Aims

Building on our previous applied health services research programmes, we aimed firstly, to develop the tools and data to determine the diverse rehabilitation needs of patients with LTNCs; and secondly, to inform the development of a nationally co-ordinated approach to needs-led commissioning and provision of specialist neurorehabilitation services.

Research questions

1. How can we measure individual rehabilitation needs and caseload complexity, and determine which patients need specialist services?
2. How are these needs currently provided for in the NHS and what do they cost?
3. How do we balance resources with outcome to optimise cost-efficiency, and which service models offer best quality and value for money in different neurorehabilitation settings?

Objectives of each work stream

1. To further develop, test and validate a set of standardised tools to measure individual rehabilitation needs and interventions across a range of different specialist service models and settings.
2. To define case-mix and the complexity of caseload in different services by applying the tools in a variety of neurorehabilitation settings and identifying the rehabilitation resources (medical, nursing and therapy time) that are currently provided to meet these needs.
3. To compare different international funding models and patient-level costing and case-mix methods for rehabilitation.
4. To develop patient level-costing protocols and apply these in different specialist rehabilitation settings to determine the differential treatment costs associated with different levels of caseload complexity in the UK.
5. To establish a nationwide database for centralised collation and analysis of case-episode data on needs, inputs, costs and person-centred outcomes from specialist neurorehabilitation services in the UK. Prospective data collection will inform tariff costs and provide ongoing benchmarking of quality, as well as evaluation of clinical benefits and cost-effectiveness.

Collaborating organisations

This research programme was undertaken in collaboration with key organisations:

- The Health and Social Care Information Centre (HSCIC)
- The British Society of Rehabilitation Medicine (BSRM)
- The Australasian Rehabilitation Outcomes Centre (AROC)

Outputs

The outputs of this programme to date have included the development of NHS-wide case-mix and costing models for use across the range of specialist neurorehabilitation services. The programme has provided:

- A valid set of tools to describe rehabilitation needs and a nationally standardised system for evaluation of needs inputs and outcomes.
- Accurate patient-level costing data which have underpinned development of commissioning currencies and tariff costs for specialist rehabilitation servicesunder PbR.
- A national centralised database, which provides practice-based evidence regarding high quality and cost-efficient service models to inform future planning of neurorehabilitation services.

Whilst the main focus of this programme has been on specialist neurorehabilitation, the principles and methodology could be extended to other areas of rehabilitation, and to other areas of healthcare e.g. specialist palliative care, where alternative commissioning currencies to fixed case episodes are similarly required.

Scientific summary

Background

Long term neurological conditions (LTNCs) give rise to a complex interaction of medical, physical, cognitive, communicative and psychosocial problems, which present a substantial burden of care to both family members and the services that support them.

- The National Service Framework for LTNCs identified the need for specialist neurorehabilitation services for individuals with complex needs but, at the onset of this programme, there was no agreed definition of 'complex needs' - or indeed what constitutes a 'specialist service'.
- The Department of Health's clinical data systems did not include rehabilitation and there was no common system for standardising information information on patient needs, costs or outcomes, that could be used to compare different services and identify models that offer best quality and value for money.

Aims and research questions

Learning from established international models, we set out to provide the evidence to underpin the development of case-mix, accurate patient-level costing and funding models to inform tariff costs under the Department of Health's 'Payment by Results' Scheme.

Building on our previous applied health services research programmes, we aimed firstly, to develop the tools and data to determine the diverse rehabilitation needs of patients with LTNCs; and secondly, to inform the development of a nationally co-ordinated approach to needs-led commissioning and provision of specialist neurorehabilitation services.

Key research questions were:

1. How can we measure individual rehabilitation needs and caseload complexity, and determine which patients need specialist services?
2. How are these needs currently provided for in the NHS and what do they cost?
3. How do we balance resources with outcome to optimise cost-efficiency, and which service models offer best quality and value for money in different neurorehabilitation settings?

Workstreams and outputs from the programme

The programme had five interconnected work streams that ran concurrently. Each one had specific objectives and deliverables as set out in this report and detailed in chapters 1-3, but are summarised briefly below.

Workstream 1 – Measuring rehabilitation needs and complexity

Purpose: First of all, we required a set psychometrically robust tools to measure rehabilitation needs, inputs and outcomes that were fit for incorporation into a national clinical database, and were suitably adapted for the various settings in which they would be used.

Methods: Prior to the start of the programme, the rudimentary tools existed, but information was lacking about their validity, psychometric properties and utility for routine application in clinical settings. We used the Medical Outcomes Standards Framework to evaluate the instruments, to investigate their measurement properties and, where necessary, to adapt them. We explored different options for the evaluation of cost-efficiency.

Outputs: At the end of the programme, we have a fully validated set of tools to measure the following parameters at patient level. These are:

- Needs for rehabilitation - The Rehabilitation Complexity Scale and Patient Categorisation Tool
- Inputs provided to meet those needs - The Northwick Park nursing and therapy Dependency Scales, a Medical Activities Assessment
- Outcomes in terms of gains in independence - The UK Functional Assessment Measure and reduction of care needs (The Northwick Park Care Needs Assessment)
- Cost efficiency – the time taken to offset the initial costs of rehabilitation by reduction in the cost of ongoing care needs, as estimated by the Northwick Park Care Needs Assessment.

Workstream 2 – Current provision of rehabilitation resources

Purpose: It was then necessary to understand the services that were currently available to cater for patients at different levels of complexity, and the differential rehabilitation resource implications of providing for those needs.

Methods: We applied the tools developed in Workstream 1 in a variety of neurorehabilitation settings (including Level1 (tertiary) and Level 2 (Local) specialist rehabilitation services. We assessed caseload complexity across these different settings, and analysed the rehabilitation resources (ie inputs from medical, nursing and therapy staff) that were used by patients at different levels of complexity. We also examined the inputs from medical /surgical specialties other than rehabilitation medicine in hyper-acute rehabilitation settings.

Outputs: At the end of the programme, we have a clear picture of where these specialist rehabilitation services are currently provided in England, and the additional resource requirements for managing patients with more complex needs. This information was used to develop the weighted payment model in Workstream 4.

Workstream 3 – Learning from international costing and casemix methods

Purpose: In order to develop an appropriate casemix and costing methodology for use in the UK, we looked first the casemix models that have been developed in other countries to determine their applicability for use in the UK.

Methods: We conducted a review of the casemix and payment models that have been established in the US and Australia to see if any of them were directly transferable to the UK. Australia's health system provided the closest model to the UK National Health Service. Throughout the programme we worked in close collaboration with the Australasian Rehabilitation Outcomes Centre (AROC) to learn from their experience of developing a national database and casemix system for rehabilitation over the last decade.

Once the UK dataset was sufficiently established, we conducted a comparative case-mix adjusted analysis on data collected in Australia and the UK, using the data elements that were common to both datasets.

Outputs: By the end of the programme, we had a clear understanding of the differences between the two countries, both in the populations served and the way that rehabilitation services are provided. These differences confounded direct comparison, and our findings demonstrated that a casemix classification based on the Functional Independence Measure (which underpins casemix in Australia and the US) was not fit for purpose within the UK health system. This confirmed the need to take a different approach to development of a casemix and costing model for specialist rehabilitation the UK.

Workstream 4 – Costing rehabilitation programmes in the UK

Purpose: The purpose of this part of the programme was to obtain accurate costing of specialist rehabilitation services in England, and to determine the differential costs of treating patients with different levels of complexity. The aim was to establish a costing and payment model that is fair both to providers and commissioners, that would take account of the increased costs of managing complex patients (but only while they remain complex) and at the same time reward efficiency.

Methods: We developed a pragmatic patient-level costing methodology for specialist rehabilitation services, and applied this in different settings to quantify rehabilitation service costs. Using data from Workstream 3, we developed a weighted costing model that reflected the differential treatment costs associated with different levels of caseload complexity.

Outputs: At the end of the programme, we had developed a novel commissioning currency in the form of a multi-level weighted payment model based on serial Rehabilitation Complexity scores. The commissioning currency was mandated for use by NHS England in April 2012. We also developed a set of indicative tariffs adjusted for caseload complexity, and supplied NHSE England with an evaluation of the cost impact of implementing them – both overall and at the level of the individual provider.

Workstream 5 – National Database Development

Purpose: The final workstream involved the establishment of a nationwide database for centralised collation and analysis of patient episode data from specialist neurorehabilitation services (Levels 1 & 2) in the UK. In addition to providing the commissioning dataset for NHS England, the purpose of the database was to provide national benchmarking data on quality and outcomes, and a dataset that will, in future, be large enough to interrogate in order to identify the approaches that work best for different groups of patients.

Methods: The UK Rehabilitation Outcomes Collaborative (UKROC) dataset was established in 2010. In order to be commissioned as a Level 1 or 2 specialist rehabilitation service, all providers must be registered with UKROC, and reporting the full dataset. Analysis of the data collected up to April 2014 provided comparative data on outcomes and cost efficiency across the different service models, and explored the predictors of efficiency and cost-efficiency.

Outputs: Since April 2012, the UKROC database it has provided the commissioning dataset NHS England. Only activity submitted to UKROC is counted for reimbursement. UKROC provides sign-posting information to NHS England to support the designation of services into the different service levels described within the Department of Health's Specialised Services definition set.

By the end of the programme, UKROC now collates data from all designated Level 1 (n=15) and Level 2 (n=48) specialist rehabilitation services in England. It also has more limited data from other services such as slow-stream rehabilitation and specialist nursing homes. A total of over 22,000 case episodes has been recorded, and the dataset is now growing at a rate of nearly 5000 cases per year. Quality benchmarking reports are now provided for all services at quarterly intervals.

Our multicentre analysis of 4 year's data confirmed the cost-efficiency of rehabilitation for patients with complex needs. The initial costs of rehabilitation were effectively recouped by savings in on-going costs of care within 19 months of discharge. Patients who were highly dependent on admission, were the most cost-efficient to treat, recouping the costs of rehabilitation in just 13.6 months.

Conclusions and impact

This programme represents a substantial body of research, which has improved our understanding of the rehabilitation needs of patients with complex disability, the resources that are required to manage them, and the outcomes that may be expected. It has also provided the Department of Health with critical information about the costs of rehabilitation services, currencies to provide fair reimbursement for cost-efficient intervention, and the scale of cost savings that may be derived from timely rehabilitation interventions.

This programme has evolved though a time of great change in the NHS. The Health and Social Care Act 2012 introduced the most radical re-organisation and restructuring of the commissioning / funding in the entire history of the NHS. This has provided both opportunities and challenges, as described in Chapter 2.

Throughout the programme we have shared our results through peer-reviewed publications, and presentations to reach a wide audience of stakeholders. The findings and developments produced in the course of this programme have been integrated into the commissioning strategy for specialised rehabilitation services as this has progressed over the seven-year life-time of this programme. They have had major impact on national policy in this area.

Data provided by this programme on service configuration has been used by the British Society of Rehabilitation Medicine (BSRM) to drawn up its standards for neurorehabilitation services. These standards have in turned been taken up and used in the NHS-England Service specification for the designation of services. Our data has supported the development of tariffs and commissioning for specialist rehabilitation.

Early findings from this work highlighted deficiencies in the provision of specialist rehabilitation. There was insufficient service capacity to meet demand and many services had inadequate staffing and resources to manage their caseload. The demonstration that rehabilitation was highly cost-efficient led to an increase in commissioning and, throughout the course of the programme, we have seen a gradual increase in service provision, with corresponding increase in the complexity of caseload managed.

From the end of this programme, funding for the UKROC database has been included in the NHSE commissioning portfolio for 2015/16 and going forward. This contracting arrangement confirms the value that NHSE England places on the outputs of this programme grant for the purposes of commissioning and national benchmarking.

Following a successful new topic proposal to HQIP in 2011, a National Clinical Audit has been developed to evaluate specialist rehabilitation following Trauma. The project will link the UKROC and TARN (Trauma Audit and Research Network) Databases to support tracking of patients as they move from the Major Trauma centres to the Specialist Level 1 and 2 Rehabilitation services.

The programme was centred on specialist neurorehabilitation services, but the approach is relevant for wider application. In the course of this programme we have worked with groups in other areas of healthcare, including the Expert Working Panels involved in casemix and tariff development for palliative care and complex neurological disability in Children. These collaborations have led to two further successful applications for NIHR-funded programmes in those fields.

Recommendations for future research

Although the programme has delivered its key targets, this is still a time of major change and development within the NHS. There is still much to be done, working in continued collaboration with NHSE, Monitor and the HSCIC:

Key recommendations for further research and development include:

1. Further development of datasets, tariffs and commissioning currencies for community-based services, including:
    a. Slow-stream rehabilitation in specialist nursing homes and neuro-rehabilitation services. Although this programme touched on these areas there is still uncertainty about the optimum resources required to manage such patients, and the most appropriate tools for outcome evaluation.
    b. Long-term care and support for patients with complex disabilities, both in home-based settings and institutional care (specialist nursing homes).
    c. Specialist community rehabilitation including home-based programmes, day-centre and outreach services.

2. Development of a national clinical registry for patient with prolonged disorders of consciousness to identify patients, monitor progress and interventions, and to record outcomes, including emergence into consciousness and long term prognosis. The UKROC dataset provides the obvious repository for such information, but will require further development to accommodate this information.

These and other developments will be the subject of a follow-on grant application to continue this important and highly productive applied programme of health services research and development.

Plain English summary

- Following illness or injury, the majority of patients will make a good recovery, but a small number will be left with complex disability, requiring treatment in specialist rehabilitation services.
- Patients with complex needs are more expensive to treat, but there is evidence that rehabilitation can provide value for money by helping them to regain independence and so reducing the costs of long-term care.
- At the outset of this programme the Department of Health had no systematic way of recording information about rehabilitation services. It did not know where the services were, how many patients were treated, or how much the rehabilitation programmes cost.
- This programme established a national clinical database to collect information on the rehabilitation needs of patients with complex disability, the types of rehabilitation they receive, and the outcomes in terms of improved independence and cost-efficiency.
- The UK Rehabilitation Outcomes Collaborative (UKROC) database now collates data from all Level 1 and 2 in-patient specialist rehabilitation in England, and routinely provides comparative information on service quality and outcomes. The data confirm that rehabilitation is highly cost-efficient, effectively paying for itself within 19 months of discharge.
- We also established a system for accurately identifying the cost of rehabilitation, and paying for it in a fair manner that takes account of the higher costs of managing complex patients but and at the same time rewards efficient practice. This is now used by NHS England to pay for in-patient specialist rehabilitation.
- Future research will focus on equivalent developments for community-based rehabilitation services.