

Specialist rehabilitation for neurological conditions: literature review and mapping study

Report for the National Co-ordinating Centre for NHS Service Delivery and Organisation R & D (NCCSDO)

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Executive summary

For the wider aims and the quality requirements of the National Service Framework (NSF) for Long-Term Neurological Conditions to be met, commissioners and providers of services for those with long-term neurological conditions will need to ensure that the services they commission and deliver represent the best value for money and so will require information about effectiveness and cost-effectiveness. This is not simple, because of the range of conditions covered by the NSF, its long-term scope and the diversity of services.

The purposes of this study were to identify and describe existing models of specialist neurological rehabilitation services provided to people with long-term neurological conditions and to examine the evidence base for their effectiveness and cost-effectiveness.

There were two stages to the study:

- 1 a mapping exercise to identify models of 'specialist' neurological rehabilitation for people with neurologically based activity limitation in the UK, and
- 2 a systematic review of the national and international literature on specialist neurological rehabilitation, its organisation and delivery.

Stage 1 Mapping

For the mapping exercise 205 local experts from three groups (23 commissioners, 139 service providers and 43 service users) in four strategic health authorities (North West, North East, East Midlands and South Central), were interviewed mostly by telephone using a semi-structured interview guide and asked in detail about the specialist neurological services they commissioned, delivered or received. Interviews lasted for up to 40 minutes. Some service providers preferred to respond to questions electronically and completed and returned questionnaires by e-mail.

From the detailed responses, a taxonomy of service models was developed and used to identify similar service models elsewhere.

Findings from the mapping exercise

- 1 Not all relevant rehabilitation expertise was found in specialist services; generic services could also deliver high-quality rehabilitation.
- 2 Most statutory specialist services were centred on cities, with apparently poor provision in rural areas.
- 3 People with stroke generally had greater access to acute services than for other neurological conditions (e.g. traumatic brain injury) but stroke services targeted at community reintegration and participation were less well developed.

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- 4 Services for people with hidden disabilities, such as cognitive impairment, were lacking in the statutory sector.
- 5 The hub-and-spoke model through community hospitals (for progressive neurological conditions) appeared to be one potential solution for rarer conditions.
- 6 Non-statutory services 'filled in the gaps' that statutory services did not meet.
- 7 Clinician expertise and person-centredness were noticed and valued by users.
- 8 Service users had difficulty accessing services.
- 9 Services were not considered (by service users) to be joined up.
- 10 Services were focused primarily on hospital or acute provision, rather than towards the long-term, psychological function or participation outcomes.

Stage 2 Literature review

An extensive, systematic literature review was conducted and a total of 5104 articles considered for inclusion, 4728 from electronic databases and 376 references from hand searching of grey literature. Literature was reviewed by two panels of reviewers. A quantitative-literature panel reviewed 153 papers and a non-quantitative-literature panel reviewed 118 papers.

Findings from the literature review

The review of the quantitative literature showed that stroke services had been most thoroughly researched in terms of effectiveness. Randomised controlled trials (RCTs) and systematic reviews had demonstrated the benefit of organised inpatient stroke unit care in a stroke unit over ordinary care (by implication not organised or specialised) on general medical wards. RCTs and systematic reviews of rehabilitation interventions in the post-discharge phase up to 1 year also showed consistent benefits (for example by an occupational therapist) but there was no clear preference for any particular service model in terms of efficacy. Even though stroke was the most heavily researched, and even though the stroke unit studies were used to justify the NHS setting targets for the development of stroke units in the English NHS in the NSF for Older People, there are no good cost-effectiveness studies in this area.

Few studies have been undertaken for people with traumatic brain injury and no evidence compares different models of inpatient care for this condition. A small number of studies indicate that patients with post-traumatic amnesia of 1 hour or more benefit from routine follow-up contact, giving information and advice, and that there is a subgroup of patients with moderate to severe injury who benefit from a higher level of intervention, and who may not present themselves unless routine follow-up is provided. The cost-effectiveness of doing so is not known. There is no evidence of benefit for the routine use of case management. No RCTs or robust studies have evaluated acute or sub-acute care for people with spinal cord injuries. The studies for Parkinson's disease have mainly assessed nurse specialists compared with

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ordinary non-specialist care and conclude that there may be benefits in terms of satisfaction but not in terms of other health outcomes, and that there was also little difference in terms of costs between having such specialists and leaving care to ordinary medical care alone. For multiple sclerosis, a number of small studies of brief periods of inpatient rehabilitation showed a mixed picture when compared with community alternatives, and there are no useful economic studies. Very few longer-term studies were found. Specialist epilepsy nurses have been evaluated, but it is not clear whether they improve outcomes compared to ordinary medical care, and nor are the economic consequences known. The studies examined that were not condition-specific found that more intense rehabilitation therapy in a mixed inpatient rehabilitation unit reduced length of stay, but the economic consequences of this were not known.

The literature review provides little firm assistance to commissioners of services for those with long-term neurological conditions wishing to deliver the NSF for Long-Term Neurological Conditions in terms of illustrating clearly dominant models of health service delivery, or providing evidence of comparative outcome or cost data concerning most forms of inpatient or outpatient services.

Despite the lack of information about any particular service model, the literature *is* consistent with a beneficial effect of rehabilitation and re-states the view (based upon user experience and specialist opinion) that services should be accessible, patient-centred, long-term, joined up and participation-orientated. However, no evidence of how these outcomes could be achieved or the economic consequences of so doing were identified. The main message is therefore to confirm that there is a deficiency of evidence.

Implications for research

There are many barriers to conducting research in rehabilitation. They include the lack of dedicated research and development (R&D) funding into models of specialist rehabilitation for long-term neurological conditions, and a lack of R&D capacity in rehabilitation (including health economics) social services and the non-statutory sector. The lack of a clear terminology to describe rehabilitation interventions or to describe or classify services and the lack of measures of outcome in the participation domain, in addition to the difficulties of small numbers of patients in some specialist services in single centres and the perceived benefit of intervention, making randomisation to 'no treatment' unethical, make RCT designs difficult. As a result it may only be possible to run trials comparing active treatments, which are then more likely to be inconclusive.

One way forward is to encourage the development of national networks of providers of services for long-term neurological conditions; examples include networks of all Young Disabled Units and community traumatic-brain-injury teams. At first these networks could compare and contrast their services, aiming to undertake clinical benchmarking studies and the like. Having done so, systematic cohort studies could be undertaken to compare costs and outcomes against the natural variability of provision, when controlled for confounding variables. Work of this sort could be valuable in itself if done

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systematically, but it could also eventually lead to the formulation of RCTs. For example, if most Young Disabled Units have a waiting list, then a multi-centre cross-over RCT would be possible. Research networks already exist in other areas (most notably cancer).

Another way forward is to attempt to ensure that new services and developments are evaluated before they reach a point of acceptability and ordinariness that randomisation to them is impossible or unacceptable. An example would be the development of new vocational rehabilitation services, or new home-based alternatives to hospital care. The difficulty here is that the pressures upon commissioners is to meet, as best they can, the terms of the policy documents that drive them rather than to provide the evidence base for doing so. To prevent this requires widespread recognition of the absence of an evidence base, the rapid availability of research funding and accessible research expertise, and some sort of policy pressure towards evaluation of effectiveness. At present the drive to evaluate is limited to the evaluation of the degree to which a service has been implemented rather than its effectiveness.

Key conclusions

Specialist rehabilitation services for long-term neurological conditions are poorly described. They tend to focus on the acute aspects of management, usually in major cities. This leaves deficiencies in rural areas and in the community and longer-term service delivery. The charitable sector has tended to meet the shortfall in statutory provision to the extent that it is a major provider of services. The private sector, presumably funded mainly through insurance claims from traumatic brain injuries, is also a major provider of longer-term care, especially residential services. However, the evidence base to guide commissioners in the provision of services is inadequate. Only stroke units have a robust body of evidence to support them, but for most long-term neurological conditions the evidence base is essentially absent (rather than negative). Much investment into evaluating these services is required. We propose that a network of rehabilitation services is established with the objective of developing the capacity to undertake the necessary research.

The Report

Section 1 Introduction

The National Service Framework (NSF) for Long-Term Neurological Conditions (Department of Health, 2005a) defines a long-term neurological condition as one that results from disease of, injury to 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. This definition includes sudden-onset conditions such as stroke, intermittent conditions such as epilepsy, progressive conditions such as Parkinson's disease, and stable neurological conditions, but with changing needs due to development or ageing. It is estimated that around 350,000 people in the UK need help for activities of daily living due to a long-term neurological condition.

The rationale for the UK developing a national framework for service delivery for this group of people and their carers is that this group is large in number, that the needs of these people are often complex and severe, that the needs of these people are not being met adequately at present, and that without the organisational focus that a NSF brings, services for these people will not be prioritised.

The NSF for Long-Term Neurological Conditions put forward a number of quality requirements for services for this group of patients and carers, for example that services be person-centred, that diagnoses are made rapidly and that patient outcomes consider participation and not solely activity. The NSF did not specify the models of care to be used to meet these quality requirements. This is unsurprising given that there is no clear understanding of what services actually exist for this group of patients, who have not hitherto been managed clinically as a coherent group. Furthermore, there is no consensus about the research evidence base regarding service delivery and organisation in this area.

For the wider aims and the quality requirements of the NSF to be met, commissioners and providers of services for those with long-term neurological conditions will need to ensure that the services they commission and deliver represent the best value for money and so will require information about effectiveness and cost-effectiveness. This is not simple, because of the range of conditions covered by the NSF, its long-term scope and the diversity of services.

For these reasons, we had two aims. The first was to identify and describe existing service models provided to people with long-term neurological conditions. The second was to examine the evidence base for their effectiveness and cost-effectiveness. The first aim was met by undertaking a 'mapping study' in which a taxonomy of service models was developed and tested. The second aim was met through a systematic review of the literature. This study was supported by a grant from the NHS Service Delivery and Organisation (SDO) R&D Programme.

Section 2 Methods

2.1 Concepts and terminology

There are several possible ways in which services could reduce the impact of long-term neurological conditions upon health and well-being. One way would be to prevent them. Another would be to cure them. Research into the genetic and cellular mechanisms underlying neurological degeneration offers the hope that these approaches might be possible in the future. But for now, with exception of those caused by vascular disease, these conditions can be neither prevented nor cured, and so health and social services are called upon to optimise the health and well-being of those affected by them. Doing so entails a number of steps which include making the diagnosis, identifying the problems experienced by the patient and then providing interventions that ameliorate them. Interventions include pharmaceutical, physical and psychological therapies, provision of aids, appliances or adaptations, information provision and personal care. Optimising the health of people with these conditions may involve attempts to promote recovery – the restorative rehabilitation approach – or attempts to optimise health even in the face of increasing neurological impairments – the adaptive rehabilitation approach. Rehabilitation was defined for this project (after Wade and de Jong, 2000) as an active educational and problem-solving process that focuses primarily on the patient with a diagnosis of a long-term neurological condition with accompanying activity limitations, and which aims to minimise the somatic and emotional distress of both the patient and their associates (family and others).

Specialist services have developed for people with neurological conditions because they have complex problems that often require multiple interventions from many different experienced professionals. The term specialist rehabilitation services in this report was used to refer to when this overall process was undertaken by a team whose members have special expertise in the condition of interest. Evidence of the existence of a team included regular meetings of its members. Evidence of special expertise included the possession of specialist qualifications.

The definition of a specialist service was not a simple one. The Royal College of Physicians' Multiple Sclerosis guidelines used the following: 'A specialist service is a group of specialists who work together regularly managing people with a particular group of problems, and who between them have all the necessary knowledge and skills to assess and resolve over 90% of the problems faced' (National Clinical Guidelines, 2004). It defines specialists as health care professionals 'with the necessary knowledge and skills in managing people with the problem concerned, usually evident by having a relevant further qualification, and keeping up to date through [continuing professional development]'. The guidelines describe specialist services as those which:

- undertake assessment,
- undertake specific pharmacological or other therapies,
- provide an integrated programme of rehabilitation when the person has complex problems,

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- monitor change (impairment severity, activity limitations),
- give advice to other services,
- include specialist doctors, nurses, physiotherapists, occupational therapists, speech and language therapists, clinical psychologists and social workers,
- have ready access to other relevant specialist services, e.g. dietetics, liaison psychiatry, continence-advisory/-management services, chiropody and podiatry, and ophthalmology.

An important problem of this definition is that it excludes specialist but non-comprehensive services such as specialist driving centres and vocational rehabilitation services.

For this project, a service was defined as a group of (therapeutic) interventions delivered by one or more people or organisation(s), which may incorporate one or more programmes, methods, techniques or approaches.

To be defined as specialist rehabilitation service, services had to be:

- other than generic primary, intermediate or secondary health and social services (although much of the care received by people with these conditions are provided by such generic services), and
- provided by more than one professional grouping (even though certain interventions by individual professionals are effective, for instance drug therapy for Parkinson's disease).

Non-comprehensive services were included, for example those which solely promoted return to work.

2.2 Methodology: mapping

To organise mapping and description of services, a typology of services was necessary. The research team was unable to locate a pre-existing suitable typology, and therefore the methodology for this project needed to generate a typology. Also, no single register of services existed, and so a method was needed that could use multiple sources of information.

The method chosen was to look for several 'key informants'. Key informants were chosen from user, provider and commissioner groups. They were selected on the basis that they were likely to have knowledge of existing services in their area, including within the non-statutory sector. The process of identifying and engaging these informants would necessarily evoke descriptive, qualitative data from these informants as well as numerical data. It was intended to use the responses to generate a working typology or classification of services. Having such a typology, it would be possible to create geographical maps to illustrate provision, and potentially to examine process and outcome information regarding such services. This process is what is meant by mapping in this report.

2.3 Method: mapping

The neurological conditions included stroke, traumatic brain injury, spinal cord injury, epilepsy, multiple sclerosis, Parkinson's disease and other hereditary or degenerative diseases (excluding the primary dementias). The choice of this

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method required considerable effort in any given area to seek out and engage informants in sufficient depth. It was initially planned to survey the whole of England in this way, but it soon became clear that this was not feasible given the level of detail that was required for each area of the country, and so mapping was undertaken in selected areas only (four English strategic health authorities, SHAs). The four selected SHAs studied were the South Central, East Midlands, North East and North West SHAs, serving a total population of 17.5 million people.

For each selected SHA, three groups of key informants were identified within each neurological condition:

- users of the services (patients and their carers),
- service providers,
- service commissioners.

By adopting this strategy data elicited from each group of informants were intended to be cross-referenced to maximise the likelihood of a comprehensive map of existing rehabilitation services.

Multiple means were used to identify key informants:

- contacting the responsible service manager in each SHA; the NSF for Long-Term Neurological Conditions called for local networks of providers to be established, so it was possible that those responsible for local services might already have been identified;
- identifying personnel through national user groups and charities;
- identifying informants through specialist professional societies: the British Society of Rehabilitation Medicine (for specialist neurological rehabilitation units) and occupational therapists via the College of Occupational Therapists Specialist Section – Neurological Practice;
- a snowball strategy: asking identified informants to propose others;
- identification of contacts known personally by the study team.

Those key informants who were service users were approached initially by telephone contact, wherever possible with prior provision of an information sheet. Written consent was obtained before proceeding with data gathering.

Data gathering was by interview and in many cases a pre-interview questionnaire was sent and used.

Interview guides and questionnaires were generated by a project advisory mapping panel. This comprised a service user, two occupational therapists experienced in neurological rehabilitation delivery, a senior nurse, two consultants in rehabilitation medicine, a public health physician employed by the SHA and a service commissioner from the local primary care trust (PCT). Separate versions of the interview guides were created as appropriate for interviewing the different groups of key informants. Interview guides included questions designed to elicit numerical, categorical and qualitative data.

In interviews, those commissioning services were asked open questions dependent on the type of commissioner interviewed, such as:

- what neurological rehabilitation services, support and facilities are available for people with a long-term neurological conditions in your area?

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- which of these are specialist services?
- tell me about the services you own, commission or manage for people with long-term neurological conditions in your area.

Those who were able to identify services were then asked in more detail about them and data were collected about these services using the service provider questionnaire. However, in most cases commissioners, particularly in the statutory sector, knew little in detail about the services they commissioned and directed us to service managers or providers involved. Therefore, commissioner interviews were often unstructured and required detailed note taking.

The statutory service provider interview schedule comprised 40 questions. Most of these were closed questions to allow simple numerical categorisation of responses. There were six specific open questions. These were:

- which geographical areas and PCT areas do you accept referrals from?
- how is the service funded?
- would you describe yourself as a specialist? If so, why? If not, why not?
- are there any groups of patients or carers who you think are not being served?
- where else might patients receive such services from (e.g. private/other voluntary organisations)?
- which (if any) national or professional guidelines or documents, or other influences have been particularly helpful or formative in the development or organisation of your service in recent years?

Additional open response questions asked for detail where simple response categories were insufficient. The questionnaires also attempted to capture the extent to which services matched the more specific criteria for specialist services identified in the Royal College of Physicians' guidelines for Multiple Sclerosis (National Clinical Guidelines, 2004).

The voluntary service provider interview schedule was similar to the statutory provider questionnaire, with fewer questions, again mostly closed but with scope for additional clarification using open items.

The service user interview schedule was oriented towards finding out about individuals, services or organisations that specialise in helping people with long-term neurological conditions. Service users were asked about:

- the type of help they had received and where it came from,
- their experiences of using services in their area,
- their knowledge of the existence of other services locally,
- how these were accessed and what they did,
- their own unmet need and suggestions for how this might be overcome.

Interviews were carried out by one of six research assistants. Three were therapists (two occupational therapists, one speech and language therapist) experienced in multi-disciplinary work with people with neurological conditions, two were psychology assistants (one of whom was also a service user with a spinal cord injury), and one was a service user. All of the research assistants interviewed people from each key informant group except for the

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service user who only interviewed service users. In most cases interviews were conducted by telephone. Often, more than one call was required to set up a convenient time for interview and to allow informants to find and check information. In many cases participants asked that the interview schedule be sent in advance to allow necessary information to be gathered.

The overall framework used to select questions for the interviews and to interpret the findings was drawn from systems methodology (Checkland and Scholes, 1999). Systems theory considers health services to be complex human activity systems, which are defined by the interactions between those who use the services (in the terminology, 'customers'), provide the service ('actors'), the changes the service brings about ('transformations'), the value system ('world view') in which this activity is deemed desirable, the 'owners' or stakeholders of the services and the 'environment' in which the service is set, which enables or limits the service.

For telephone interviews, qualitative data were extracted by the researcher conducting the interview. Additional qualitative data from returned questionnaires were extracted by one of the six research assistants. Working independently, the researchers read and analysed the data extracted from interviews and questionnaires. The framework approach (Ritchie and Spencer, 2002) was used to identify themes which were then organised into tables, at this stage by the researchers working as a team. A further researcher then independently analysed all of the qualitative data from the service providers and service users for consistency, indexing and coding it into meaningful categories and retrieving common themes for analysis, and these findings were then critically discussed between all researchers.

2.4 Methodology: literature review

The aim was to review the effectiveness of specialist rehabilitation services for people with long-term neurological conditions. This was required to be done in parallel with the mapping study. A typical, firmly defined, quantitative literature review was thought not to be useful here, given that a typology of services did not exist and hence that such a typology could not be used to guide the search, and it was expected that the research literature would be poorly indexed.

Rehabilitation has, and still does, suffer from a problem with terminology and even the words to describe health states themselves are still undergoing revision. For example, the International Classification of Impairments, Disabilities and Handicaps (ICIDH) launched by the World Health Organization in 1980 (World Health Organization, 1980) was replaced by the International Classification of Functioning and Health (ICF) in 2001 (World Health Organization, 2001). In this report, the terminology of the ICF is used throughout for consistency. In this climate of uncertainty of terminology during the latter two decades of the twentieth century, debate raged about the 'medical' and 'social' models of rehabilitation (Oliver, 1990). It is hardly surprising that there will be confusion regarding the evidence base for rehabilitation if the fundamental concepts underpinning it are poorly understood and lacking in consensus.

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Apart from problems with terminology, rehabilitation research has lagged behind research in other fields because of problems with measurement (what can't be defined can't be measured), methodological problems of how to deal with complexity (rehabilitation is often described as 'the black box') and the lack of adequate and sustained funding (rehabilitation has hitherto had few industrial sponsors, or few short-lived dedicated NHS R&D funding streams). Rehabilitation research of relevance to the UK is therefore likely to be of relatively poor quality and to be poorly described and in non-indexed journals, when compared with more research-mature medical areas such as diabetes, heart disease or cancer.

The NSF for Long-Term Neurological Conditions acknowledged the difficulty in examining the relevant evidence base, arguing that the usual hierarchies of research evidence (normally used simply to seek reliable evidence of effectiveness) gave inadequate acknowledgement of the importance of qualitative and clinical effectiveness studies for the purposes of service delivery and organisation.

This literature review therefore required a search strategy that would identify qualitative and quantitative reports. This would require not only a careful choice of the searching strategy but also a careful selection process to avoid being overwhelmed by material of no or marginal importance to the key topic. It would also require a review process that was capable of handling both qualitative and quantitative research reports.

A systematic approach was chosen using broad keywords, capturing a large number of article titles, which were then screened for relevance. Abstracts were sought for those titles selected, and these too were screened for relevance before the full journal article was acquired. Articles were classified into two groups: primarily quantitative and evaluative studies, such as might be found in a standard systematic review, and those with qualitative or non-standard designs. Where there was doubt, articles were put into both groups. Each group of articles was reviewed by a separate review panel.

2.5 Methods: literature review

2.5.1 Searching and identification

The aim was to identify all relevant English language journal articles, peer-reviewed articles, policy documents, service descriptions, book chapters and informal reports from the UK and other countries, provided that they described a specialist neurological rehabilitation service for a long-term neurological condition that produces activity limitation or evaluated the acceptability, effectiveness and cost-effectiveness of a specialist neurological rehabilitation service.

The following databases were searched for the period 1985 to April 2005:

- Cochrane Central Register of Controlled Trials,
- Medline,
- EMBASE,
- Allied and Complementary Medicine Database,
- CINAHL,

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- Physiotherapy Evidence Database,
- British Nursing Index,
- Database of Abstracts of Reviews of Effectiveness,
- NHS Economic Evaluation Database,
- Health Management Information Consortium Database,
- National Research Register,
- Medical Research Council Register of clinical trials,
- PsychLit,
- OT Seeker.

The specialised registers of the following Cochrane Review Groups were searched:

- Effective Practice and Organisation of Care Group,
- Dementia and Cognitive Improvement Group,
- Stroke Group,
- Neuromuscular Disease,
- Movement Disorders,
- Consumers and Communication.

Citation lists from the following condition-specific guidelines were searched:

- Royal College of Physicians,
- Scottish Intercollegiate Guidelines Network (SIGN),
- National Institute for Health and Clinical Excellence (NICE).

Reports such as book chapters and policy documents were identified from:

- The Kings Fund,
- interviews with key informants in the mapping exercise,
- contact with established rehabilitation networks such as the College of Occupational Therapists Specialist Section – Neurological Practice (COT SSNP) and British Society of Rehabilitation Medicine (BSRM),
- websites of the Cochrane Collaboration , Department of Health, Health Technology Assessment, COT SSNP, NICE, SDO R&D Programme, SIGN, Bandolier, Neurological Alliance and ACPIN,
- e-mails to health economists with interest in neurology from the Register of Health Economists,
- requests for information made to librarians and information officers of the Cochrane Collaboration, Department of Health, Health Technology Assessment, COT SSNP, NICE, SDO, SIGN, Royal College of Physicians, British Psychological Society, Chartered Society of Physiotherapists, Royal College of Speech and Language Therapists, British Association of Social Workers, Royal College of Nursing, British Association of Prosthetists and Orthotists, British Society for Rehabilitation Medicine, British Dietetic Association, Royal College of Medicine, Huntington’s Disease Association, Society for Progressive Supranuclear Palsy, Brain Injury Association, National Spinal Cord Injury Association, College of Occupational Therapists, Royal College of General Practitioners, Multiple Sclerosis Trust, Multiple Sclerosis Society, Parkinson’s Disease Society, Stroke

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Association, Motor Neurone Disease Association, Progressive Supranuclear Palsy Association, Headway, Epilepsy Action, National Society for Epilepsy and the Muscular Dystrophy Campaign.

The keywords used for searching the electronic databases were selected after discussion by members of the research team, and revised in the light of exploratory preliminary searches (see search strategies, Appendix 1). They were:

- service delivery,
- service organisation/organisation,
- neurological rehabilitation,
- neurological approach,
- specialist rehabilitation,
- service model.

Searching was undertaken by two researchers (occupational therapists experienced in delivering and evaluating neurological rehabilitation services) with assistance from a university librarian.

2.5.2 Selection for review

The same two researchers who undertook the searching undertook the selection process. The titles of articles were read by both reviewers to check for potential relevance to the review question. Titles were excluded if they were unlikely to refer to papers meeting the following four criteria, that the article referred to would:

- concern one of the specified neurological conditions,
- be about rehabilitation,
- refer to a service, and
- be about a specialist (non-generic) service.

Abstracts on articles not excluded were acquired.

Each acquired abstract was considered independently by the two researchers for fit with the four criteria. When uncertainty existed, a third reviewer was consulted. A service was 'a group of (therapeutic) interventions delivered by one or more people or organisation(s) and may incorporate one or more programs, methods, techniques or approaches' and rehabilitation was 'an active educational and problem solving process that primarily focuses on the patient with a diagnosis of a long-term neurological condition with accompanying activity limitations, and which aims to minimise the somatic and emotional distress of both the patient and their family'. Articles were excluded if they had a primary focus on single component interventions, or focused on services specifically for children.

Selected articles were classified by the two researchers as either qualitative or quantitative, recorded on one of two Microsoft Access databases, and referred to the quantitative and qualitative panels for review. Articles containing material appearing to be both quantitative and qualitative were referred to both panels.

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2.5.3 Examination of selected articles

Qualitative

Unlike the review of quantitative literature, there is much debate about the overall appropriateness of the activity of appraising qualitative research, and there are no widely accepted criteria regarding the best method to perform such reviewing (Dixon Woods *et al.*, 2004, 2006; Petticrew and Roberts, 2006) in qualitative research. Even experienced qualitative researchers and reviewers are likely to disagree with one another about quality and relevance of qualitative papers in the context of systematic reviewing, and the use of structured reviewing tools does not improve this agreement (Dixon Woods *et al.*, 2006). However, structured reviewing tools assist in making explicit the reasoning underlying judgements about quality, and experts in the field recommend use of short sets of prompts to help cue systematic appraisal and reflection on qualitative research papers (Dixon Woods *et al.*, 2004).

The qualitative panel developed a review process and data extraction process based on that suggested by McKeivitt *et al.* (2004). The relevant Critical Appraisal Skills Programme (CASP) reviewing tools for primary qualitative research articles and reviews were applied. There was no appropriate and available appraisal tool for the other forms of report that came under the remit of this panel. Therefore for expert commentaries and editorials, descriptive accounts and surveys of practice and service delivery, and for the policy documents, individual reviewer's comments on quality were recorded on a bespoke data-extraction form (Appendix 2) covering the following areas:

- type of publication,
- methodology,
- type(s) of data collection used,
- participants/subjects,
- type of service/setting(s) involved,
- type of intervention provided to participants,
- stated research question,
- stated summary of findings,
- any stated implications for service delivery or organisation of specialist rehabilitation for long-term neurological conditions,
- reviewer's comments on implications for service delivery or organisation of specialist rehabilitation for long-term neurological conditions,
- any other comments.

Studies identifying models of rehabilitation were evaluated according to the extent to which they were explicit (whether they defined their terms), supported by research evidence and comprehensive (not just addressing one component of a disease, such as spasticity).

For literature included from countries other than the UK special attention was paid to relevant differences in the contexts in which specialist rehabilitation services were delivered.

In view of the volume of literature identified, each article was reviewed by one member of the panel, and an experienced member of the School of

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Sociology and Social Policy was employed to review selected policy documents.

The qualitative panel met to discuss summaries of the reviewed papers, until the most important key themes had been clarified.

Quantitative

The quantitative review panel adopted SIGN's appraisal tools and checklists (Scottish Intercollegiate Guidelines Network, 2004) for case control studies, cohort studies, RCTs, systematic reviews and meta-analyses and economic evaluations.

The selected articles were grouped according to the diagnosis considered in each article and reviewed by two panel members who prepared a short report summarising the papers reviewed. Any articles that were found to be economic evaluations or contain information relevant to economic aspects of care were reviewed by a health economist (as well as the disease specific reviewer).

Section 3 Results

3.1 Results: mapping

3.1.1 Informants

The mapping exercise took place between September 2006 and February 2007. In total 205 informants were interviewed. The breakdown of these by region and key informant type is shown in Table 1.

Table 1 Source of key informants

SHA area	Number of informants	Provider	Commissioner	User
South Central	34	17 (11 statutory, 6 non-statutory)	9 (7 statutory, 2 non-statutory)	8
North West	26	15 (13 statutory, 2 non-statutory)	3 (1 statutory, 2 non-statutory)	8
North East	20	18 (16 statutory, 2 non-statutory)	2 (2 statutory)	0
East Midlands	53	37 (35 statutory, 2 non-statutory)	7 (4 statutory, 3 non-statutory)	9
National	72	52 (43 statutory, 9 non-statutory)	2 (2 non-statutory)	18
Total	205	139	23	43

Many informants gave information about more than one long-term neurological condition. For example in the North East region one informant could describe services for Parkinson's disease, multiple sclerosis, Huntingdon's disease, motor neurone disease, muscular dystrophy and stroke. Similarly, more than one informant was able to comment on any given long-term neurological condition. Again using the North East region as an example, nine different informants gave information about stroke.

3.1.2 Development of typology

The interviews yielded a number of factors that defined or discriminated between services. These were whether the service:

- dealt with patients during an acute phase of illness, a sub-acute phase, or the chronic phase;
- was hospital-based (inpatient, outpatient or outreach) or community-based;
- was condition-specific or not;
- was a team or an individual (individuals could be uni-disciplinary or the case manager of a virtual team);
- was run by the statutory (health or social services), private or voluntary sector;

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- was solely for carers, provided carer support, or did not specifically involve carers;
- focused on activity or participation;
- was national, regional or local;
- was innovative and not easily classified.

Although potentially services could have been observed with any combination of each of the factors listed above, a finite number of service patterns (25) were observed and these are shown in Table 2. These 25 service models were sufficient to populate regional and national maps of services and to accommodate all the services that were identified.

Table 2 Taxonomy of service models

Code	Service model	Stage of rehabilitation
1		Specialist inpatient acute unit
2		Non-specialist acute unit
3		Surgical acute unit
4		Specialist inpatient rehabilitation unit
5		Specialist inpatient combined (acute and rehabilitation) unit
6		Inpatient services
7		Condition-specific specialist nurse
8		Condition-specific specialist therapist
9		Case management
10		Third-sector condition-specific nurse
11		Third-sector condition-specific therapist
12		Outreach rehabilitation (NHS/PCT) team
13		Outpatient services, statutory sector
14		Specialist community rehabilitation (NHS/PCT) team
15		Specialist community rehabilitation, private sector
16		New innovative models
17		Regional specialist centre (driving, communication, assistive devices)
18		Statutory residential facility for respite or long-term care
19		Private- or third-sector residential rehabilitation facilities, respite or long-term care
20		Multi-disciplinary clinic

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21		Outpatient services, private sector
22		Specialist outpatient services, statutory sector
23		Specialist outpatient services, private sector
24		Third-sector rehabilitation
25		Third-sector social, patient and carer support

Coloured markers are used in accompanying regional maps.

Inpatient acute units (codes 1–3) included acute stroke units and neurosurgical and neurology wards where patients were admitted when medically unstable for critical care or neurosurgery. These units had high nursing levels and dealt with the acute phase, usually the initial few days or weeks. Rehabilitation focused on nursing care and therapy to reduce the consequences of immobility, confusion, and swallowing and breathing difficulties, and the assessment and identification of rehabilitation goals. These units were in acute hospitals.

Non-acute inpatient services (codes 4–6) only or mainly accepted patients with neurologically disabling disorders. These units saw people for rehabilitation typically following a period of acute care, for review or for respite. For many patients the clinical concern was the transition between hospital and community and emphasis was on the personal and instrumental activities of daily living (ADL). Specialist inpatient combined units included units where acute and sub-acute rehabilitation took place. These were usually in acute hospitals. Rehabilitation was provided generally for a period of several weeks.

The next group consisted of services run by individuals as opposed to teams (codes 7–11). In specialist nursing services, the patients were often referred soon after diagnosis and contact continued indefinitely. The specialist nurses provided support and education as well as co-ordinating other services. In this sense they were case managers, although they did not use the term. They focused on people in their own homes, rather than those in institutions. They often provided a service alongside other community rehabilitation services. They were felt to help patients negotiate service boundaries. Another role was education of other staff. Specialist therapists also provided services, many working in ways similar to specialist nurses, but others gave profession-specific therapy.

Case managers (code 9) did not deliver rehabilitation interventions themselves but co-ordinated the delivery of such services by others.

Specialist community teams (codes 12–15) included outreach rehabilitation teams such as hospital at home and early discharge services, and also specialist community rehabilitation teams in health and social services, including both condition-specific teams (traumatic-brain-injury services or stroke) and those offering services to people with all neurological conditions. Typically these teams offered interdisciplinary management aimed at promoting activity, participation and well-being.

For patients in the community, specialist outpatient services (codes 13 and 22, for sub-acute and chronic phases respectively) included multi-disciplinary

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clinics such as neurology clinics or problem-focused clinics (e.g. spasticity) and specialist outpatient therapy services in the statutory and non-statutory sectors. Patients referred were medically stable, living in the community and attending a rehabilitation department or unit for specific programme of rehabilitation. Rehabilitation here was interdisciplinary or uni-disciplinary management to improve or maintain mobility, increase independence or promote activity, participation and well-being. Rehabilitation might include assistance in return to work or education, or leisure activities and independent community life. Some services linked with services in other sectors such as Job Centre Plus, Headway and support groups.

Innovative services (code 16) included a social enterprise scheme in the North East, called Neural Pathways, which operated like an agency to supply specialist therapists from all over the UK to infill identified gaps in service provision for people with long-term neurological conditions. Also in the North East, a one-stop nurse-led brain-injury outpatient clinic was found, to which patients experiencing problems as a result of a brain injury could refer themselves. There was also a collaborative venture between two NHS consultants in rehabilitation medicine, one based in Whitehaven (North West) and another in Newcastle (North East), who worked collaboratively to provide an outreach service to people with motor neurone disease in rural areas.

Regional Specialist Centres (code 17) included Regional Mobility Centres (Driving Assessment), Regional Communication Aids Centres and Regional Assistive Devices Centres. Regional Mobility Centres were those registered with the Forum of Regional Mobility Centres who offered professional advice and assessment to individuals with a medical condition or those recovering from an accident or injury affecting their ability to drive, or get in and out of a motor vehicle. Regional Communication Aids Centres offered people with speech impairments comprehensive assessment, education, training and loan of both low- and high-technology communication equipment and support. Regional Assistive Devices Centres offered assessment, referral and follow-up support for environmental controls equipment, matching people's abilities and environment with technology.

Specialist third-sector rehabilitation services (code 24) included those that involved structured daytime activity, family support and advocacy (such as Headway) or rehabilitation to improve or maintain mobility, increase independence and or promote activity, participation and well-being.

Specialist inpatient neurological rehabilitation units in the chronic phase (codes 18 and 19) included services for people with long-term rehabilitation and residential care needs. We found few statutory facilities and a growing number of services in the private sector, which offered cross-cutting services for patients who were minimally responsive and those with continuing rehabilitation needs but high nursing dependency. Patients in this service category were medically stable but often unable to return home, yet did not require intensive rehabilitation. Some were minimally responsive to commands, but others had complex physical, behavioural and or cognitive deficits and or nursing dependency needs. Rehabilitation areas included mobility and activities for social inclusion.

The services primarily for carer and family support (code 25) were often provided in the third sector by condition-specific charities or service-user

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representative groups. Services included support groups, self-help groups, outreach and respite services and advice and telephone information services. Carers, patients and family members received support from these services. This help sometimes included advocacy and or benefits help. These services were distinguished from rehabilitation services offered by some of the same providers.

3.1.3 Service provision

England

Although the mapping study primarily examined services in the four SHAs of study, the methods included gathering information from national sources, such as national charities. This enabled an England-wide view of certain facilities, services and organisations. Map 1 (see separate Maps document) illustrates the distribution of the statutory services that were known for all of England, as enumerated below:

- 50 neurorehabilitation units (Young Disabled Unit),
- 9 spinal injury centres,
- 45 brain-injury services (NHS),
- 98 brain-injury services (non-NHS),
- 196 stroke units,
- 12 Regional Mobility Centres (Driving Assessment),
- 17 Regional Communication Aids Centres,
- 3 Regional Assistive Devices Centres.

Map 2 (see separate Maps document) illustrates the distribution of non-statutory organisations in England, as enumerated below:

- 83 Headway branches,
- 3 Rehabilitation UK centres,
- 7 BIRT specialist rehabilitation units,
- 6 BIRT continuing rehabilitation units,
- 23 BIRT supported housing,
- 86 Stroke Association dysphasia support,
- 62 Stroke Association family support,
- 19 Huntington's Disease Association (HDA) regional care advisors (areas),
- 71 Multiple Sclerosis Society specialist posts,
- 4 Multiple Sclerosis Society physiotherapy projects,
- 1 Multiple Sclerosis Society community rehabilitation team,
- 3 Multiple Sclerosis Society respite centres,

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- 35 Multiple Sclerosis therapy centres,
- 12 Motor Neurone Disease Association (MNDA) regional care centres,
- 19 MNDA care advisors (areas),
- 9 Muscular Dystrophy Campaign (MDC) care advisors,
- 1 MDC neuromuscular clinic.

South Central

Maps 3–6 (see separate Maps document) illustrate the findings from more detailed enquiry in the South Central region for traumatic brain injury (Map 3), spinal cord injury (Map 4), stroke (Map 5) and progressive neurological conditions (Map 6). Appendix 3 lists the services that populate these maps.

Most specialist neurological rehabilitation services for people with traumatic brain injury (Map 3) were centralised around the major towns and cities of Oxford, Southampton, Aylesbury, Milton Keynes and Newport, with few services in rural areas. No acute-only inpatient rehabilitation units were identified. Specialist inpatient rehabilitation took place in eight specialist inpatient units. Four of these offered post-acute rehabilitation only and four offered combined acute care and rehabilitation. Five specialist community rehabilitation teams were identified for people with traumatic brain injury in the statutory sector. Statutory outpatient services also existed in Milton Keynes, Oxford, Reading, Portsmouth and the Isle of Wight. A number of services for people with traumatic brain injury were also identified in the independent sector including four community rehabilitation services (three in Southampton) and one specialist outpatient service in Oxford. St Mary's Rehabilitation Medicine on the Isle of Wight was one of the only services offering residential rehabilitation services in the statutory sector. There were a number of non-statutory sector residential rehabilitation services, offering long-term care or respite for people with traumatic brain injury. Non-statutory-sector rehabilitation included nine branches of Headway. No specialist worker posts were identified.

For people with a spinal cord injury (Map 4), most of the specialist neurological rehabilitation services were centralised around the major urban centres of Oxford, Southampton, Aylesbury and Milton Keynes, with few services in rural areas. Six services offering specialist inpatient rehabilitation were identified. Four of these also provided rehabilitation in the acute phase, immediately following trauma, whereas two delivered post-acute rehabilitation. Two of the services also offered outpatient rehabilitation. Other specialist services for people with a spinal injury included specialist community rehabilitation teams and Regional Specialist Centres (driving, communication and assistive devices). One private sector service, Rehab Without Walls, based in Milton Keynes, also offered specialist services to people with a spinal injury.

In the South Central region, services for stroke (Map 5) were good for the acute and post-acute phases following injury by specialist neurological rehabilitation services centralised around the larger towns and cities of Oxford, Southampton, Aylesbury, Milton Keynes, Portsmouth, Reading,

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Basingstoke and Newport. But few services were identified in rural areas. Twelve specialist inpatient combined (acute and rehabilitation) units, one specialist inpatient acute unit and eight inpatient rehabilitation (post-acute) units were identified for people with stroke.

Many of the same teams offering specialist community rehabilitation to people with traumatic brain injury also offered services to people with stroke. Four statutory-sector specialist community rehabilitation teams were identified in Milton Keynes, Aylesbury (two) and Southampton. There were few stroke specialist community rehabilitation teams. Four specialist outpatient services in the statutory sector were identified. These were linked to inpatient rehabilitation services in three cases (Bletchley Therapy Unit, Milton Keynes and the Oxford Centre for Enablement) and the Neuro Rehabilitation Unit, Royal Berkshire, Reading. There were no residential facilities for respite or long-term care identified in the statutory sector for people with stroke and only one long-term care facility offering residential rehabilitation and respite care was identified in the private sector. One non-statutory-sector service also offered respite care. People with stroke had access to the four regional specialist centres offering specialist assessment of driving, communication and assistive devices. Stroke-specific specialist nurses or therapists existed within teams in inpatient and community services rather than independently or in case management. Non-statutory sector rehabilitation services were predominantly delivered by the Stroke Association and included dysphasia support and family support services. These were geographically dispersed.

Services for people with progressive diseases (Map 6) were centralised around the major urban centres of Oxford, Southampton, Aylesbury, Milton Keynes, Portsmouth and Newport, with few services in rural areas. People with progressive disease had access to specialist inpatient rehabilitation services in Portsmouth, Southampton, Aylesbury (two), Gosport, Oxford and Reading. Five specialist community rehabilitation teams (Milton Keynes, Aylesbury, Newbury and Southampton) and four outpatient services (Milton Keynes, Reading, Portsmouth and Isle of Wight) offering services to people with progressive conditions, and one outreach team for people with multiple sclerosis (Amersham), were identified in the statutory sector. These were largely based alongside inpatient services in the established rehabilitation centres and larger cities. In spite of the respite and long-term care needs of many people with progressive conditions, only one statutory service provider for residential rehabilitation, respite or long-term care was identified (Isle of Wight), and another existed in the independent sector. People with progressive conditions also had access to regional specialist assessment centres for driving, communication and assistive devices based in Berkshire, Oxford and Southampton. For people with multiple sclerosis many services were delivered by or supported by the charitable sector. Multiple sclerosis therapist posts funded by the Multiple Sclerosis Society existed throughout the region (Amersham, Aylesbury, Newbury, Oxford, Reading, Southampton and Milton Keynes) and Multiple Sclerosis Therapy Centres offered rehabilitation services in Aylesbury, Portsmouth, Oxford and Reading. Other non-statutory-sector rehabilitation services for people with progressive conditions included Regional Care Advisors for the Muscular Dystrophy Campaign and the Motor Neurone Disease Association in Oxford, South Bucks Hospice, High Wycombe, and a partnership funding for a Specialist Rare

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Neurological Conditions Nurse in Reading. Little private-sector rehabilitation provision for people with progressive diseases was identified.

East Midlands

Maps 7–10 (see separate Maps document) illustrate the findings from more detailed enquiry in the East Midlands region for traumatic brain injury (Map 7), spinal cord injury (Map 8), stroke (Map 9) and progressive neurological conditions (Map 10). Appendix 4 lists the services that populate these maps.

In the East Midlands several examples of specialist inpatient rehabilitation units were found but very few specialist condition-specific outpatient services for people with progressive neurological conditions, acquired brain injury other than stroke and spinal cord injury. For people who have suffered a stroke services were better organised, particularly around academic centres.

A growing number of community services offering rehabilitation to people with long-term neurological conditions were found but, apart from specialist stroke services, most were generic.

Most specialist services for people with a traumatic brain injury (Map 7) in neurological rehabilitation services were centralised around major cities (Nottingham, Derby, Leicester, Lincoln and Northampton) with few services in rural areas. Five outreach teams offering services to people with traumatic brain injury were found, three of which were dedicated to this condition (Nottingham, Derby, Leicester). No services for long-term, residential or respite care were found in the statutory sector, but nine were found in the non-statutory sector, three of which offered services for people with behavioural problems. There was a regional specialist surgical acute unit for those requiring surgery for head injury but no dedicated inpatient acute unit for people in the acute phase following traumatic brain injury. Seven units offered specialist inpatient rehabilitation for people in the early weeks and months following traumatic brain injury. These were geographically dispersed (Nottingham, Mansfield, Derby, Northampton, Lincoln, Mansfield, Leicester). People receiving neurosurgical intervention at the Regional Specialist Centre in Nottingham were referred back to their local area for rehabilitation and follow-up. Informants stated that because referral pathways were unclear, some patients would be likely to be missed by these arrangements. In many rural areas specialist brain-injury rehabilitation services did not exist. The majority of services for people with traumatic brain injury were delivered by neurology or generic outpatient (18 identified) or community-based (15) services in the statutory sector. Few specialist therapists or nurses for people with a traumatic brain injury were identified in the East Midlands, although some may exist within the services we identified. Two case-management services for traumatic brain injury were identified, one in the independent sector. Voluntary-sector rehabilitation was sometimes provided by one of the seven branches of Headway.

Services for people with spinal cord injuries (Map 8) were similar to those for traumatic brain injury: most services were centred on the main cities (Nottingham, Derby, Leicester and Lincoln) with few services in rural areas. Routine outpatient services with neurology expertise and generic community rehabilitation teams, including local authority physical disability services, provided most of the service. These were the same services as those

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identified for people with traumatic brain injury. There were very few dedicated services for people with a spinal cord injury. Five specialist workers (nurses and therapists) were identified. The same specialist inpatient units that catered for people with other acquired brain injuries and those with progressive disease also saw people with spinal cord injuries, as there was no specialist spinal injuries unit in the region. However, some people with spinal injuries were seen in the regional surgical acute unit in Nottingham.

Specialist inpatient rehabilitation services (Map 9) were more prevalent for people with stroke. Fifteen combined (acute and rehabilitation) stroke units, one acute stroke unit and eight rehabilitation units were identified. Dedicated stroke teams existed in some areas in the community. In fact, there were two community stroke teams in Nottingham, plus specialist outpatient and outreach services. As with the other conditions rehabilitation provision reduced markedly in rural areas. A few independent services for people with stroke were identified. These were predominantly focused on overcoming physical limitations and improving mobility, for example physiotherapy services. Voluntary-sector services included Stroke Association dysphasia support groups and family support.

Even more so than with other conditions, specialist services for people with progressive neurological diseases (Map 10) were focused around the cities of Nottingham, Leicester and Lincoln, and to a lesser extent Derby. Specialists from Leicester offered outreach services to surrounding community hospitals, producing a hub-and-spoke model. There were few specialist services in rural areas.

North East

Maps 11–14 (see separate Maps document) illustrate the findings from the more detailed enquiry in the North East region for traumatic brain injury (Map 11), spinal cord injury (Map 12), stroke (Map 13) and progressive neurological conditions (Map 14). Appendix 5 lists the services that populate these maps.

Five regional specialist centres provided services for driving, communication and assistive devices and all were based in Newcastle.

Most specialist neurological rehabilitation services for people with traumatic brain injury (map 11) were centralised around Newcastle, the major city in the region, with few services in rural areas, although some services also provided outreach services where therapists travelled to rural areas to avoid patients needing to travel long distances (e.g. Northumberland Head Injury Service, based in Morpeth). There was a predominance of specialist inpatient rehabilitation units (three in Newcastle, two in Sunderland, one each in Middlesbrough, Hartlepool, Prudhoe and North Tyneside) and there were two private residential rehabilitation facilities, providing respite or long-term care (Newcastle and Peterlee). Specialist community rehabilitation was provided by five NHS/PCT teams (Newcastle, Morpeth, Chester le Street, Gateshead and Wallsend) and five private rehabilitation teams (all based in Newcastle). A further four rehabilitation services were delivered by third-sector providers, branches of Headway and the Brain Injury Rehabilitation Trust Supported Housing. These were located in Northumberland, Teesside, Gateshead and Sunderland.

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Most specialist neurological rehabilitation services for people with spinal cord injuries (map 12) were centralised around Newcastle, with few services in rural areas. Specialist inpatient rehabilitation units predominated (two in Sunderland, one each in Newcastle, North Tyneside and Middlesbrough) and there was a specialist Spinal Injuries Unit in Middlesbrough. Specialist community rehabilitation was provided by three NHS/PCT teams (Newcastle, Chester le Street and Wallsend) and one private team in Newcastle.

Once again, for people with stroke, most specialist neurological rehabilitation services (map 13) were centralised around the major city of Newcastle, with few services in rural areas. The majority were combined (acute and rehabilitation) inpatient units offering rehabilitation in the acute and sub-acute phases. They were based in North Shields, Newcastle, Wansbeck, Hexham, Middlesbrough, Gateshead, South Shields, Bishop Auckland, Sunderland and Durham. The rest were rehabilitation-only inpatient units located in Sunderland (two), Middlesbrough, Newcastle, Hartlepool, Peterlee, Darlington and North Tyneside. These services were supported by third-sector provision from the Stroke Association; that is, communication aids, family and dysphasia support services located in Newcastle, Sunderland, Blyth Valley, Gateshead, Easington, Guisborough and Middlesborough. Like people with traumatic brain injury and spinal cord injury, people with stroke living in larger cities were well served by statutory specialist outpatient and community rehabilitation services. These were located in Newcastle and Gateshead (outpatient services) and specialist community rehabilitation was provided by five NHS/PCT teams (Newcastle, Chester le Street, Gateshead, Easington and Wallsend) and one NHS/PCT outreach team in Newcastle.

For people with other long-term neurological conditions and people with progressive diseases, most specialist neurological rehabilitation services (map 14) were centralised around Newcastle, with few services in rural areas. The aforementioned specialist inpatient rehabilitation units in Sunderland, Middlesbrough, Newcastle and North Tyneside also offered services to people with progressive conditions. Specialist community rehabilitation was delivered by four NHS/PCT teams (two in Newcastle and one each in Chester le Street and Wallsend). Third-sector rehabilitation services were provided by a Multiple Sclerosis therapy centre, Motor Neurone Disease Association care centre and care advisors, Muscular Dystrophy Association care advisor and Huntington's Disease Association regional care advisory service (four in Newcastle and one each in Middlesbrough and Durham). Services were also provided by NHS/PCT specialist nurses for multiple sclerosis and Parkinson's disease (Newcastle and Middlesbrough) and third-sector condition-specific therapists from the Multiple Sclerosis Society (Stockton on Tees, Durham and Sunderland).

Two statutory specialist outpatient services, one each in Newcastle and Gateshead, provided for all long-term neurological conditions (traumatic brain injury, spinal injury, stroke and progressive conditions) and there was one service offering a statutory specialist outpatient service in Newcastle, specifically for traumatic-brain-injury and Huntington's disease patients with neurobehavioural problems.

In addition to statutory inpatient and outpatient services in the North East, new innovative models of organising and delivering services to people with long-term neurological conditions were also identified. Services in the North

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East had evolved around an academic centre of expertise, creating a 'hub' of excellence but lesser or absent provision in more remote areas. Poor communication between centres sometimes meant patients 'fell through gaps' in the system. Following a 2005 review of services in the North East by local and regional commissioners, which involved numerous stakeholders, including service users, it was recognised that efforts were needed to improve service provision and so promote equitable and timely access to services for people with long-term neurological conditions in the North East. The chosen model was to establish a 'managed clinical neurosciences network', to provide links between services based on referral, shared pathways, training, development and clinical governance and thus overcome structural barriers imposed by individual institutions and traditional boundaries between primary, secondary and tertiary care.

As a result a number of initiatives were set up to bridge gaps identified in existing service provision. These included:

- a improved services in the Durham Dales by creating Multiple Sclerosis Specialist Nurses who link with the regional services at Hunters Moor and a clinic exchange where a consultant from Hunters Moor goes to Teeside to run a dystonia clinic with multiple sclerosis nurses and multiple sclerosis nurses travel to Hunters Moor;
- b a one-stop nurse-led head-injury clinic at Newcastle General Hospital;
- c a new specialist central hub of expertise in the form of Walkergate Park, a service designed to house inpatient and outpatient services, provide education, training and research for neurorehabilitation, and where behavioural, psychological and psychiatric problems could be addressed; that is, problems which are currently addressed outside of the area at great cost;
- d improved use of the independent sector. For example, one independent-sector limited company offered community multi-disciplinary rehabilitation for patients with traumatic brain injury or stroke, by filling gaps in NHS services. For instance, if a patient receiving a community rehabilitation service required speech and language therapy but the service didn't currently have a speech and language therapist and was unable recruit, this new service would provide such a therapist.

Similarly, new innovative ways of working were identified in the third sector. For example, the Motor Neurone Disease Association exchange staff between their Care Centres in Newcastle and those in Carlisle and Whitehaven.

North West

Maps 15–18 (see separate Maps document) illustrate the findings from more detailed enquiry in the North West region for traumatic brain injury (Map 15), spinal cord injury (Map 16), stroke (Map 17) and progressive neurological conditions (Map 18). Appendix 6 lists the services that populate these maps.

Services for people with traumatic brain injuries in the North West (Map 15) followed similar patterns to those seen in other areas. Inpatient services were well-developed (specialist inpatient combined (acute and rehabilitation) units). Outpatient and community follow-up services were poorer, and these were supported by services from the non-statutory sector. Most specialist

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neurological rehabilitation services were centralised around the cities of Liverpool, Manchester and Carlisle, with few services in rural areas. Acute inpatient rehabilitation services were provided in Ormskirk, and specialist inpatient combined units offered specialist brain-injury rehabilitation in Stockport, Burnley, Rochdale, Leigh, Wirral, Preston, Carlisle, Whitehaven and Liverpool. Community teams existed in Chorley, Liverpool, Warrington, Southport and Chester. There were also several community rehabilitation services in the private sector (largely physiotherapy) in Bury, Oldham and Manchester (two) providing specialist rehabilitation for people with traumatic brain injury. Fifteen non-statutory-sector specialist services were identified. The only residential rehabilitation services identified were non-statutory-sector services in Bury, Burnley and Warrington.

Most specialist neurological rehabilitation services for spinal cord injury (Map 16) were centralised around the cities of Liverpool and Manchester, with few services in rural areas. People with spinal cord injuries had access to seven specialist inpatient combined (acute and rehabilitation) units offering specialist neurological rehabilitation. Other statutory service providers included the community neurorehabilitation team in Southport and outpatient services allied to the Walton Centre in Liverpool and Taylor Rehabilitation in Leigh. There were no identified statutory services for respite or long-term care but two were found in the non-statutory sector. Non-statutory-sector provision included the Brain and Spinal Injuries Centre in Salford. Regional specialist centres included the Driving Assessment Centre, Wigan and the ACE Centre-North in Saddleworth (communication).

Inpatient services for stroke were well developed (Map 17). Two acute units, four rehabilitation-only units and 35 specialist inpatient combined (acute and rehabilitation) units were identified for people with stroke. However, outpatient and community provision was poor and linked to only a few specialist centres centralised around the cities of Liverpool, Manchester and Carlisle, with few services in rural areas. Non-statutory-sector provision was through the Stroke Association: 41 Stroke Association dysphasia support services and Stroke Association family support services were identified.

Statutory service provision for people with progressive neurological conditions (Map 18) was limited and widely dispersed. Specialist services included inpatient rehabilitation services in Ormskirk, Stockport, Burnley, Rochdale, Leigh, Wirral, Preston, Carlisle, Whitehaven and Liverpool. Specialist Parkinson's disease and multiple sclerosis nurses in the statutory sector and specialist community rehabilitation teams were found in Liverpool and Southport. A multi-disciplinary clinic Movement Disorder Service was identified in St Helens and specialist outpatient services in Liverpool and Leigh. There was access to two Regional Specialist Assessment Centres (driving, and communication aids). A community multiple sclerosis team provided services for people in Liverpool and a specialist community neurological rehabilitation team operated in Southport. An innovative motor neurone disease hub-and-spoke service operated between Carlisle and Newcastle. This collaborative venture between two NHS Consultants in Rehabilitation Medicine, one based in Whitehaven (North West) and another in Newcastle (North East), ensured provision of an outreach service to people with motor neurone disease in rural areas.

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Two private-sector community teams offered specialist services to people with progressive conditions in Bury and Manchester. Identified residential rehabilitation facilities were all non-statutory-sector provision (Bury, Warrington and Alderley Edge). As in other areas, statutory services provision was supplemented by charitable-sector services including four Multiple Sclerosis Society-funded specialist therapists posts and two physiotherapy services in the Isle of Man, Liverpool, Stockport, Carlisle, West Cumbria and Liverpool; three Motor Neurone Disease Association Care Centres, in Liverpool, Preston and Manchester; three Regional Motor Neurone Disease Care advisors for Cheshire Lancashire and Cumbria; and the Neuromuscular Centre in Winsford.

Summary of findings across regions

In discussion with informants, it was clear that not all relevant rehabilitation expertise was to be found in specialist services and that generic services could also deliver high-quality rehabilitation. It follows that it should not be assumed that specialist services are necessarily better than non-specialist services without evidence to show that this is true (such as for stroke units).

Statutory specialist services were centred on cities, with apparently poor provision in rural areas, although provision was generally better for stroke which is a common condition. In fact there might be a risk of duplication of services or failure to obtain scale economies, as shown by two separate community stroke services in Nottingham (explained by the split between services for the city of Nottingham and the county of Nottinghamshire that surrounds it). The hub-and-spoke model through community hospitals (for progressive neurological conditions) appeared one potential solution for rarer conditions.

This survey provided only a snapshot, but while assembling the information it was clear that community services were developing rapidly. They were subject to changes associated with re-organisation of PCTs and the presence of the NSF for Long-Term Neurological Conditions. Skilled staff were appearing to be attracted to these services, and this might prove a challenge to hospital-based services if the supply of expertise is limited or not enlarged. This process may also reflect re-provision of services that were previously in hospital settings in the community and this may explain reports of recent cuts in services. For example, in West Berkshire, Caversham Ward recently reduced from 23 to 16 beds and Henley Younger Disabled Unit reduced from 12 beds to eight. In Lincolnshire in specialist inpatient rehabilitation beds reduced from 20 to 12 in 2001. In Nottingham, the recent closure of the Cedars Rehabilitation Unit resulted in the loss of a large, purpose-built hydrotherapy pool which had been bought by service users and a purpose-built heavy workshop used for vocational rehabilitation.

Examples of cross working were seen such as a primary-care-funded specialist nurse who operated stroke-prevention transient ischaemic attack clinics in secondary care and delivered education to secondary care staff, but many such arrangements relied upon goodwill rather than joint commissioning.

The large number of non-statutory services identified was remarkable. The key informants pointed out that the charities 'filled in the gaps' that statutory

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services did not meet. The presence of a large non-statutory sector could therefore be seen as evidence of a historical failure of statutory services to meet clinical needs, and it was noticeable that common conditions with a longer history of health-service interest, such as stroke, relied upon the non-statutory sector much less than other, perhaps more neglected, conditions such as traumatic brain injury. However, it should be noted that it is now more common simply to acknowledge this state of affairs and for the non-statutory sector to be the providers of services under contracts with the NHS rather than funded entirely by charitable donations or insurance claims. The non-statutory sector was also a source of useful diversity and innovation, being perhaps driven by unmet needs. Examples included advocacy services and unique services such as 'Partners for inclusion' in Sheffield, a not-for-profit partnership between disabled people and service providers which promoted independent living for disabled people.

Innovative models of service provision were also identified within the statutory services. These included service networks and social enterprise schemes. One network in Nottingham was involved in establishing clinical pathways for people with long-term conditions and neurological diseases, which cross service boundaries between health, PCTs and social services, to ensure that rehabilitation needs and NSF requirements were met. By establishing a web-based information resource it aimed to promote continuity of care and better access to services.

Most of the long-term rehabilitation and care and respite in the community took place in purpose-built non-statutory sector facilities and this sector was growing. Organisations involved included the Neurological Alliance, Multiple Sclerosis Trust and Multiple Sclerosis Society. There seemed to be growing expertise in this sector, in spite of limited finance for some services. There were a growing number of private providers of vocational rehabilitation case-management services.

3.1.4 Views of users, providers and commissioners

Results of mapping: users' views

Fifty service users and service-user representatives were identified and 43 were interviewed. Seventeen user organisations were represented:

- Headway, Lincolnshire,
- Headway UK,
- Neurological Alliance, Buckinghamshire,
- Neurological Alliance, Berkshire,
- Neurological Alliance, Lincolnshire,
- Nottingham University Hospital Stroke Partnership Action Group,
- At a Stroke, Nottingham,
- Myasthenia Gravis Association, Derby,
- Motor Neurone Disease Association,
- Muscular Dystrophy Campaign,
- Parkinson's Disease Society (East Midlands),
- Headway, Derby,

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- Huntington's Disease Association,
- National Society for Epilepsy,
- Multiple Sclerosis Society, Coventry local branch,
- Berkshire multiple sclerosis therapy centre,
- Lincolnshire Post Polio Network.

Service users were all living in the community in their own homes at the time of interview. Their age ranged from 31 to 82 years (mean 55 years). They represented people with a range of neurological conditions including spinal injuries (two), multiple sclerosis (four), motor neurone disease (three), stroke (six), other acquired brain injury (three), traumatic brain injury (one), Parkinson's disease (one), muscular dystrophy (two) and four other progressive conditions. Their level of physical dependency varied and of those ($n=23$) who completed a Barthel scored between 0 and 20 (mean 14.6). Service users were generally policy-aware: nine documents were cited by them.

An overwhelming common issue identified was a deficiency in longer-term support. The emotional tone was sometimes strong, with aftercare being described as 'a very bad joke'. Acute care services were spoken of highly.

Concerns included the following:

- a lack of information or poor information. One service user gave an almost paranoid explanation: 'It's not about accessing them, it's about knowing they exist, information is awful and information is power. I don't think people want to share power. People use jargon as a method of excluding others'. Many people purchased private therapy or equipment when NHS services for these existed, but also where services did not exist;
- a deficiency with longer-term support was access barriers such as distance from the specialist services in rural areas;
- not meeting the criteria for entry: a person with multiple sclerosis was refused therapy because the criteria for the service required her to be able to get better, thereby denying an adaptive rehabilitation stance;
- unclear responsibilities of various services: service users were unclear which occupational therapy services (health or social services) paid for and dealt with different equipment or alterations;
- some specialist services did not properly meet the perceived need. The wife of a man with a progressive disease felt that 6-monthly reviews meant the service provider did not 'get a representative picture' and that they weren't able to monitor change. She felt 'this should be done locally by the physios [non-specialist] who see him more regularly'. Some specialist services that they could not get or got little of were deemed 'worse than useless'. Local (non-specialist) services were often preferred over specialist ones because of their availability. Respite care was also mentioned as a need that was not well met;
- assessment for equipment was often poorly tailored to individual need: examples included wheelchairs;
- specialist speech and language therapy was mentioned as deficient.

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Continuity and expertise was valued if available. Some were prepared to put themselves out and to travel to ensure continuity of contact with certain people. One lady with multiple sclerosis who used to go to local hospital (3 miles away), followed her lady consultant when she moved to a hospital 17 miles away, 'because the service from her had been so good'. Another man referred himself 'to the other end of country to the best person to see, for a clinical trial', who then referred him to a centre in London. He said 'the trip there every 6 months for a check up is worth it to get expert advice on a wasting disease'. This gave him confidence when 'locally there is a high turnover of staff, therefore lack of expert input and continuity'. Accolades for specific neurologists with specific expertise, general practitioners (GPs), occupational therapists or social workers were noted, and factors such as responsiveness, being able to talk (particularly about highly specific or sensitive issues), practical help and trust in their advice were given as reasons for this approval.

Specialist care was contrasted with non-specialist care, for example when the latter was thought to be causally related to development of a pressure sore.

The lack of provision meant service users turned to non-statutory providers, such as private and voluntary organisations. Service users told us that third-sector services were 'picking up the pieces' and filling in the gaps. A typical example was Headway, about which it was stated that it provided the only form of late rehabilitation and ongoing support for people with traumatic brain injury. Another example was Back Up Trust, a national charity that provide opportunities for people with spinal cord injury: 'This was the best form of rehabilitation by far for me' said one man.

Certain charities were especially helpful in sorting out benefits and contributing to the cost of housing adaptations. Financial difficulties were common, and there were problems not only in affording grants, but also the perverse effect of employment reducing entitlement to certain benefits. Others expressed great satisfaction with direct payments and alluded to the improvement they had made to their quality of life. 'Direct payments has meant that they can employ own carer, hours to suit and can build up relationship. Much better than care via agency'.

Two people highlighted the benefits of web-based support services. A man with a spinal cord injury explained that online forums are good for peer support, or for family and friends who want to research the condition in a discreet manner.

Informants made specifications or suggestions for improvements.

- Overwhelmingly people spoke of the need for better-co-ordinated care with continuity, across the statutory sectors and the voluntary sector.
- Another theme was person-centredness: 'a joint health and social service that was people-driven, rather than budget-driven' said one well-informed person. An example of person-centredness was for services to be fit for those with cognitive impairment.
- Another suggestion was to address emotional health, participation and adaptation as opposed solely to use physical and restorative approaches.
- Other suggestions were for financial help, or assistance to negotiate the barriers for such help; more respite care; more specialist speech and

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language therapists; and information and support on sexuality and sexual health for people with spinal cord injuries.

Despite efforts to secure greater numbers of service providers, the sample was relatively small and the recruitment methods relied on volunteers. Most of the interviewees came via membership organisations such as the Multiple Sclerosis Society, Headway and the Motor Neurone Disease Association and support groups for people with spinal cord injury. Campaigning organisations such as these will hold a viewpoint that may not be universally representative of all service users. It is also possible that some of the people who chose to participate were seeking an opportunity to air negative views and experiences. Nevertheless these are their personal views and experiences and in that sense remain valid.

Results of mapping: service providers' views

The breakdown of providers by region and profession are shown in Table 3. Although the majority of service-provider key informants were occupational therapists, each interviewee reported on the specialist service as a whole, delivered in most cases by a multi-disciplinary team. This high representation of occupational therapist interviewees resulted from a presentation given by one of the researchers (JE) at the national meeting of the Occupational Therapists Specialist Section – Neurological Practice (formerly NANOT) followed up with information calling for participants in a NANOT newsletter.

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Table 3 Service providers by profession and region

Professional identity	East Midlands	South Central	North West	North East	Other regions	Total
Occupational therapist	11	2	2	6	40	61
Physiotherapist	5	0	2	2	4	13
Nurse	5	4	1	4	1	15
Modern matron	0	1	0	0	0	1
Service manager	0	4	2	5	1	12
Traumatic brain-injury case managers	2	0	0	0	0	2
Therapy team leader/co-ordinator	1	1	1	0	1	4
Therapist/condition specific specialist	0	4	0	0	0	4
Orthoptist	1	0	0	0	0	1
Consultant in rehabilitation medicine	5	3	4	0	1	13
Psychologist	1	1	0	0	0	2
Speech and language therapist	1	0	0	0	0	1
Other	2	5	3	0	0	10
Total	34	25	15	17	48	139

Staff identified many problems, in hospital and the community:

- staff deficits (clinical psychology, counsellors, family therapists and social workers in particular, and all therapists in general);
- bed shortages in hospital-based units, to the extent that in some cases the early and sub-acute phase was missed by specialist services and delivered by non-specialist services;
- inadequate budgets for aids and appliances, especially those with high costs;
- lack of resources in one sector led to inefficiencies in others, long stays in hospital were partly due to a lack of community provision;
- lack of resources led to certain groups such as those in care homes being excluded from services;
- deficiencies in the provision of ongoing support: resoundingly, this concern applied to people with mild to moderate traumatic brain injury;
- poorly joined-up services, such as the failure to identify those with mainly cognitive problems after traumatic brain injury, who often re-presented late. Also noted was the tendency to pass responsibility for some patients from one service to another (such as the non-statutory sector) and then take an 'out-of-sight, out-of-mind' approach, as opposed to attempting partnership working;

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- the private sector provides some units for severely affected people, but these were expensive and often funded from insurance claims. Funding for those without such support was patchy. Other funding concerns included the use of acute hospital tariffs for some conditions, which were seen to be too small for the lengths of stay that were required;
- a need for services that helped patients to adjust to loss, to cope with changes in family relationships, to deal with fatigue and to reduce anxiety;
- regional centres which were unable to meet the needs of those living any distance away.

A few views were expressed about preferred ways of providing services. Teams or services for people with progressive conditions where there was specialist nurse or therapy involvement were thought good at providing continuity and responding to maintenance needs. However, where specialist nurses were working in isolation with no team back up, rehabilitation was a problem.

Providers commented on the meaning of a specialist in this field. Answers included years of experience for some, specialist qualifications and accreditation for others (such as doctors), or completion of postgraduate courses (such as for specific therapies or equipment). The ability to deal with complexity was another self-cited attribute.

Results of mapping: commissioners' views

Twenty-three informants were service commissioners, of both statutory and non-statutory services, as listed below:

- five commissioning managers from the PCT,
- one district manager in health,
- two SHA service leads for long-term neurological conditions,
- one PCT 'lead officer' for neurological conditions,
- one manager of the Lincolnshire Neurological Alliance and member of the SHA Health Board,
- four clinical directors (three doctors and one clinical neuropsychologist),
- one director of a private hospital,
- one National Neurological Alliance commissioner,
- one director of the National Muscular Dystrophy Campaign,
- one director of nursing (health),
- one executive director of the Neuromuscular Centre (a non-statutory service),
- one Parkinson's Disease Society regional service manager,
- one manager for the National Society for Epilepsy,
- one Multiple Sclerosis Society Service development officer,
- one SHA strategic service development manager.

There were difficulties in identifying and arranging to interview informed service commissioners in the statutory sector because some claimed to be too busy to participate or others knew too little. Even still, some knew about

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services at a strategic level whereas as others knew more at an operational level. In general, those working at a local level know more about the services they 'owned', including their strengths and limitations and gaps in provision.

Some statutory service commissioners recognised limitations in service provision in their area. Gaps identified included:

- a dearth of community rehabilitation provision which was seen as compromising the ability to move patients across services appropriately, such as from hospital to community;
- a paucity of psychological services and liaison psychiatry to address adjustment needs and cognitive and behavioural problems and care for older adults, who at present are generally cared for by community teams and networks.

Service commissioners also acknowledged the conflict between centralised specialist rehabilitation, which is better able to meet clinical need, and locally provided services, which are better able to address social needs (reduced travelling distance) and a need to monitor transport costs. 'One cannot use too much of our budget for transport services for non-medical needs'.

One told us that geography is a real problem for carers. There needs to be many more community-based services: at the moment there is too much 'hub'.

As with service providers, several commissioners identified variability in access to specialist services, resulting from inadequate pathways, such as from an emergency department to a specialist service for traumatic brain injury. One told us, 'Even when there are clear guidelines, they are not always followed'. Another said, 'There can be problems with referrals to a service as pathways often depend on an individual person, so for example, if a specialist nurse is off sick people may not be referred'. Unique contracting arrangements with certain services resulted in inequality of access: people can be seen quicker if they come from different routes, for example the Job Centre Plus contract demands a specific time scale for referral and assessment.

The fact that not all of the needs of people with long-term neurological conditions could be met within a PCT often meant commissioning specialist services out of area. Problems ensued when, for example, those with challenging behaviour following a traumatic brain injury needed to move from specialist residential or slow-stream rehabilitation back into the community.

Commissioners recognised the tension between the need for life-long services offering re-assessment and review, and the need for appointments for new patients.

Some private-sector service commissioners had seen an increase in resources as PCTs had increased their willingness to purchase private-sector services where statutory services did not exist: 'Over the past 3 years, resources available to the service have increased, the NHS Trust are more supportive'. But the cost of these services has not gone unnoticed: one PCT commissioner was conscious of this expense: 'There is a huge expense involved in placing patients in the private sector, it can lead to "out of sight, out of mind"

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attitude. Also, there is little incentive for the private-service provider to move patients on as they generate a lot of income for them.'

Commissioners in the non-statutory sector were familiar with financial decision-making and aware of the need to justify the need for specialist services. Several examples of partnership working to jointly commission and pilot posts between the voluntary and statutory sector were given. One from the West Berkshire Neurological Alliance was involved in establishing the need for, jointly commissioning and evaluating the roles of specialist workers including a 'rare neurological conditions nurse specialist', and a specialist occupational therapist for multiple sclerosis. This was justified by an 'impact study', which reported a three to one return on investment for the multiple sclerosis specialist worker on the (unproven) presumption of saved hospital bed days (Quinn, 2006).

At the Neuromuscular Centre in Cheshire, services were under review to explore greater 'efficiency'. A support worker had been appointed to fulfil the role of occupational therapist and counsellor, and to provide help with funding applications. In contrast, some local commissioners in statutory services commented on their inability to plan strategically for neurological rehabilitation services. Funding for them was problematic. Local commissioners seemed financially frustrated and disempowered from making strategic decisions about service developments. Not only were they unable to plan services to address recognised need but they were also unable to ensure continuity of care. One commissioner relied on short-term research and development (R&D) funding for service developments which did not receive ongoing funding.

Several of the commissioners were frustrated by financial decision-making beyond their control, particularly in relation to complex specialised services such as specialist neurological rehabilitation inpatient units (Young Disabled Units) which do not have cost-effectiveness data to support them and require service-level agreements to be negotiated regionally. During the 12 months of this study reports were obtained of several units which had been closed or lost beds. Competing policy pressures were mooted as possible reasons for this, such as 'renegotiation of appropriate contracts was neglected by a Trust pursuing Foundation status'. Another case was funded by the PCT through the Acute Medicine Tariff (Payment by Results), which was considered to be insufficient.

The NSF for Long-Term Neurological Conditions was seen as helpful in acknowledging the need and setting standards for service provision. But there was also scepticism: 'National guidelines are generally used to stop people closing down services rather than for development or growth'. In one case the NSF was considered to be 'particularly unhelpful' as it was used by the PCT to justify the closure of a community-based neurological rehabilitation unit and transfer services elsewhere.

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3.2 Results: literature review

3.2.1 Searching and identification

The electronic database search strategy identified 4728 references for consideration from electronic databases and peer-reviewed sources, and hand-searching of policy documents, grey literature and reference lists provided by requests for relevant information from libraries of charitable and professional organisations identified a further 376 references, giving rise to a total of 5104 references. The abstracts of 4661 of these were not acquired because their titles did not meet the criteria or they were duplicates, leaving 443 abstracts to be assessed. Of these, the papers of 212 did not meet the criteria, leaving 231 articles selected for review. Seventy-nine of these were deemed to be solely qualitative, 139 were solely quantitative and 14 were considered to have content relevant to review by both panels: from the electronic search the quantitative panel reviewed 153 papers and the qualitative panel reviewed 93.

The search of other literature generated the names of 60 articles, reports, book chapters and publications from charitable and service-user organisations and professional bodies which were considered for inclusion. Thirty of these were excluded for failure to meet inclusion criteria and there were five duplications. A total of 25 were felt to be relevant and were included in the review.

As a result of the two search and selection strategies, the qualitative panel reviewed 118 papers and the quantitative panel reviewed 153 papers.

3.2.2 Examination of selected articles

Qualitative

In total 118 studies were reviewed by the qualitative panel. These studies varied in terms of how well they addressed the research question, study design and strength of evidence. Ninety-three papers were identified from the electronic and hand-searching strategies described, and a further 25 papers, reports and policy documents were identified.

During the review, 30 papers were excluded when two or more panel members agreed that they did not address the criteria for this study: 24 did not meet the definition of specialist neurological rehabilitation, four papers were out of date, one was solely about children and one was referred to the quantitative panel. Therefore this section of the report is based on the 63 papers that were reviewed.

Studies were grouped into six categories:

- primary qualitative ($n=13$),
- expert opinion based on high-level, sound-basis guidance ($n=13$),
- expert opinion (clinical and academic) ($n=16$),
- surveys of service provision ($n=4$),
- audits/evaluations of service provision or innovation ($n=7$),
- descriptions of services and service innovations ($n=10$).

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Primary qualitative papers

Thirteen primary qualitative research papers were reviewed, as summarised in Table 4 (further details are given in Appendix 7).

Table 4 Summary of primary qualitative research papers

Study	Main aims of study	Method of data collection	Type of service/setting(s) involved
Larsson Lund and Tamm (2001)	To describe how a group of mainly elderly disabled persons experienced their rehabilitation over a period of time, focusing on their interactions with professionals, relatives and the community.	In-depth interviews	Hospital, at home and in other community settings
Finlayson (2004)	To describe health-related concerns and service needs in older people with multiple sclerosis.	In-depth interviews	N/A
Scheer <i>et al.</i> (2003)	To examine access barriers to primary, specialist and rehabilitative care and their consequences for individuals' health, functioning and well-being and health services utilisation.	Semi-structured interviews	Primary, specialist and rehabilitative care
Neri and Kroll (2003)	To explore the <ol style="list-style-type: none"> 1. scope and nature of consequences that adults with disabilities perceive as a result of inappropriate access to health care services; 2. variability of consequences by demographic attributes; 3. inter-relatedness and multidimensionality of these consequences. 	Semi-structured interviews	
Brown <i>et al.</i> (2006)	To investigate whether health and social care services met the needs of patients with motor neurone disease and their carers. To explore preferences for service delivery and to compare with services provided locally	Structured interview with patients and carers; questionnaire to commissioners	NHS and social services for people with motor neurone disease
Corben and Rosen (2005)	To explore patients' perceptions of self-management; the experience of living with a long-term condition	Interview Literature review	Self-management

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Lewinter and Mikkelsen (1995)	Not specified clearly. Patients interviewed concerning their experience of rehabilitation in an experimental stroke unit.	Semi-structured interviews	Stroke unit
Pound <i>et al.</i> (1999)	To identify differences in the process of care between three care settings. To determine whether these differences could be explained by differences in the type of patients admitted to each setting.	Non-participant observation of 12 patients in three settings: stroke unit, elderly care unit and general medical ward	Stroke unit; elderly care unit; general medical ward
Low <i>et al.</i> (2004)	To explore the impact of two methods of post-hospital stroke rehabilitation (domiciliary or day hospital) on carers' perceptions of health services and their quality of life.	Semi-structured interviews in parallel with an RCT comparing domiciliary and day hospital care	Day hospital or domiciliary rehabilitation after a hospital admission for stroke
von Koch <i>et al.</i> (2000b)	To describe the content of a programme involving early hospital discharge and continued rehabilitation at home after stroke.	Observation, field notes, therapy notes review	Early discharge services for stroke
von Koch and Widen Holmqvist (2001)	To explore differences between rehabilitation in the home environment and the hospital, and to study the implementation of the programme from the service deliverer's perspective.	Observation, field notes, semi-structured interviews, medical records review	Hospital or home rehabilitation after stroke
Dowswell <i>et al.</i> (2000)	To capture details about support provided by stroke specialist nurses. To gain insight into the process of care and to understand problems facing stroke patients and carers in the first year following stroke'	Review of diaries of specialist nurses	Specialist community stroke nurses
Warner <i>et al.</i> (2005)	To determine whether the quality of service can be improved to people experiencing a relapse of multiple sclerosis.	Action research, before and after study, structured interviews with service users	Specialist multiple sclerosis nurse telephone helpline and clinic in district general hospital

Larsson *et al.* (2001) studied 15 people with long-term conditions (nine with stroke, three with a spinal cord injury and three with other diseases), age range 30–84 years. From their description, the authors posited that the rehabilitation process could be seen as in three 'chains', each one consisting of a number of phases, as follows.

- A medical rehabilitation chain that starts at the onset of disability. This chain was relatively short and reflected the informants' interactions with the professionals.

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- A psychological rehabilitation chain that represented the informants' internal struggle towards a new meaningful life.
- A social rehabilitation chain, which became visible later in the rehabilitation process and reflected the informants' interactions with their relatives and their experiences of a stigmatising society.

This study and others suggested that the first of these phases is the one that services are most engaged with, but that the latter two were the most troublesome over time.

The importance of the long-term focus was noted in other studies. The interviews of patients with multiple sclerosis reported by Finlayson (2004) did not directly describe rehabilitation services but, by indicating what unmet needs were found, revealed the importance of long-term follow-up and the goals of services. These patients feared further losses of mobility and independence, becoming a burden on others, and requiring nursing-home care.

One issue causing problems in the delivery of services for people with long-term conditions was access to services. Scheer *et al.* (2003) and Neri and Kroll (2003) explored access barriers to care in 30 working-age people with spinal cord injury, cerebral palsy or multiple sclerosis in the USA. The main barriers were:

- environmental, such as transport,
- poor disability literacy among health care providers,
- financial, related to health insurance coverage.

As our survey of UK key informants showed, the latter barrier is also present in the UK, due to the contribution of insurance claims to expensive services for injured patients.

Other than characterise the problems faced by people with long-term neurological conditions, some papers asked users for suggestions. Brown *et al.* (2006) interviewed 11 people with motor neurone disease and nine family carers as well as 17 commissioners from PCTs and social care agencies in the NHS and social services to explore their preferences for service delivery compared with local service provision. The three most important ways of improving services identified were:

- introducing knowledgeable, specialist neurological teams in primary care,
- through inter-professional and multi-agency co-operation,
- by involving patients and family carers in the development of services.

Promoting self-management was deemed to be important in this study, as it was in Corben and Rosen's (2005) interview study of nine people with a range of different long-term conditions (2–40 years since diagnosis).

Several service settings were examined. One was the hospital stroke unit, and these findings must be considered in the light of the well-known fact that RCTs of stroke units has shown them to be better than ordinary medical wards in terms of survival, activity and residential status. Lewinter and Mikkelsen (1995) examined a stroke unit in Copenhagen, finding both positive and negative views. A positive aspect was that, being in a unit and hence being with others, self-help and mutual and family support was possible. The

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negative comments were related to deficiencies in rehabilitation, particularly after discharge. Some important non-physical areas not dealt with were psychological, sexual and counselling needs and social problems. Pound *et al.* (1999) compared care on a stroke unit, an elderly care unit and a general medical ward. On the stroke unit patients had more opportunities for independence and mobility, and spent more time with visitors than patients on the medical ward. More attempts at interaction (with drowsy speech or cognitively impaired patients) were also made on the stroke unit than on medical wards. The elderly care unit also encompassed these aspects of care. Negative aspects of stroke unit care included less eye contact, being ignored and being treated in a dehumanising way more often than patients in other settings. Stroke unit patients also had more negative interactions and activities than in other settings. Clearly, qualitative studies of stroke units reveal different aspects of them compared to RCTs.

Home- and hospital-based rehabilitation, when examined as different ways of providing hospital after care, were considered in several studies. Low *et al.* (2004) explored the impact of domiciliary and day hospital delivery of stroke rehabilitation on informal carers in a study carried out in parallel with an RCT. The domiciliary stroke team were perceived to be more convenient and comfortable for stroke survivors and their carers and gave carers more opportunities to learn. They also allowed the rehabilitation process to focus on problems that related to the home environment. Day hospital care had greater social benefits (particularly rated by carers of patients with severe cognitive difficulties) and gave carers more time for themselves. The day hospital was also perceived to have better co-ordinated medical and therapy care with access to equipment and space. The authors proposed a mixed model incorporating domiciliary and day hospital care that incorporates the benefits of education, convenience and respite. The authors drew attention to carers' quality of life, especially psychosocial issues such as the disruption that caring has on the carers' lives. von Koch *et al.* (2000b) and von Koch and Widen Holmqvist (2001) sought to explore possible differences between rehabilitation sessions in the home and those in the hospital environment and concluded that the home setting itself promoted active patient participation.

Dowswell *et al.* (2000) examined specialist nurse diaries to 'unpack the black box of a nurse led support service'. Specialist nurse support involved information and advice, support and monitoring and was a flexible, individualised approach. Services were found to be flexible and varied. It was not time-limited and capable of dealing with complex problems.

Warner and co-workers (2005) used action research and demonstrated that a specialist nurse telephone helpline and review clinic for multiple sclerosis speeded up access to treatment. Being a demonstration project, it may not be easily replicated, and by virtue of its design it did not provide information about cost or effectiveness.

In summary, the contribution of the primary qualitative literature to this project was to illustrate the deficiency of accessible, long-term services that met psychological and social needs. Research studies of services found the same limitations, focusing upon stroke units and hospital after care rather than longer-term services.

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Expert opinion, based on high-level guidance

The 13 expert opinion papers based on high-level guidance are summarised in Table 5. Further details are given in Appendix 8.

Table 5 Summary of expert opinion papers based on high-level guidance

Study	Main aims of document	Type(s) of data collection used
NICE (2006) Clinical Guideline 35: <i>Parkinson's Disease - Diagnosis and management in primary and secondary care</i>	Guidelines for diagnosis and management in primary and secondary care	Policy documents, NICE clinical guideline
NICE (2003) Clinical Guideline 8: <i>Multiple Sclerosis: Management of multiple sclerosis in primary and secondary care</i>	Guidelines for management of multiple sclerosis in primary and secondary care	Policy documents, NICE clinical guideline
Multiple Sclerosis Trust (2006) <i>Therapists in Multiple Sclerosis: delivering the long-term solutions</i>		Examples of evidence based on good practice; case studies
Prime Minister's Strategy Unit (2005) <i>Improving the Life Chances of Disabled People - Final Report</i>		Professional/expert opinion: Prime Minister's Strategy Group, other government agencies, Early Years Expert Group, Independent Living Expert Group
National Collaborating Centre for Chronic Conditions (2004) <i>Multiple Sclerosis: National clinical guidelines for diagnosis and management in primary and secondary care</i>		Systematic literature review, professional/expert opinion, user views
Motor Neurone Disease Association (2003) <i>No Time to Lose: Motor neurone disease and the National Service Framework on long- term conditions</i>	Recommendations for motor neurone disease based on the NSF for Long-term Conditions	Summary of evidence from relevant literature, unsystematic literature review and recommendations
Turner-Stokes (2003) <i>Rehabilitation Following Acquired Brain Injury</i>	Guidelines for rehabilitation following acquired brain injury based on evidence 'so far as resources allow'	Included evidence from systematic review, Cochrane review, reviews for national stroke and multiple sclerosis

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		guidelines Professional/expert opinion Users' views
Department for Work and Pensions (2006) <i>A New Deal for Welfare: Empowering people to work</i>	Increase the number of people who remain in work when they fall sick or become disabled Increase the number leaving benefits and finding employment Better address the needs of all those who need extra help and support	Policy documents, welfare reform
Inter-agency Advisory Group on Vocational Rehabilitation after Brain Injury (2004) <i>Vocational Assessment and Rehabilitation after Acquired Brain Injury</i>		Inter-agency guidelines
Department of Health (2005a) <i>The National Service Framework for Long-Term Conditions</i>	Quality requirements for NSF, with 'evidence-based markers of good practice'	Policy document, NSF
Department of Health (2006a) <i>Supporting People with Long-Term Conditions to Self Care - A guide to developing local strategies and good practice</i>	Document: 'Explains how health and social care services can support self care through an integrated package consisting of a range of elements at a local level' Includes self-care information, self-monitoring devices, self-care skills education and training and self-care support networks	Policy document
Department of Health (2005b) <i>Independence, Well-being and Choice: Our vision for the future of social care for adults in England</i>	Proposals for reducing dependency where possible; empowering service users, involving in assessment and increasing choice; improving access to services; shift focus of delivery to more proactive and preventative model; supporting carers; social care workforce training and standards	Policy document
Department of Health (2002a) <i>Specialised Services National Definition set: 7 Complex specialised rehabilitation for brain injury and complex disability (adult)</i>		Definition set

The need for specialised, knowledgeable, well-trained staff was strongly and consistently expressed across reports in this category. An example of where

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such skill and expertise is evident is in predicting and managing the rapid decline as seen in motor neurone disease, but expertise was also recognised as important in the management of other diagnoses including multiple sclerosis and Parkinson's disease, and needs such as a vocational rehabilitation.

These papers were largely policy documents, and repeated the findings noted in this study's examination of key informants, and the primary qualitative research. They recommended developing models of care that improved access to expertise, and provided individualised and long-term plans for care.

Most documents recommended that service users should help with service development to improve choice, and to avoid the apparent mis-match between service provision and perceived need.

Co-ordination of services, across sectors, was recommended to facilitate information flow but also to enable rational planning to avoid gaps or duplicate provision. Typical of this was the NSF for Long-Term Neurological Conditions itself, which stated 11 quality requirements, for implementation by 2015. It presumed that there would be a small number of specialist tertiary centres for some conditions, requiring a larger number of specialist units in local hospitals (staff in the latter trained by those in the former), with seamless transitions to community services including vocational ones.

The NICE Clinical Guideline 8 for Multiple Sclerosis (NICE, 2003) indicated that everyone with the condition should have access to seamless and responsive services and the ability to self-refer after discharge. *Supporting People with Long-Term Conditions to Self Care - A guide to developing local strategies and good practice* (Department of Health, 2006a) promoted self-management. Being position or policy papers, these papers were largely aspirational, and the recommendations were not financially underpinned, nor strongly supported by robust cost-effectiveness studies. Instead, a consumer-focused approach was taken, on the presumption that the primary aim was to meet stated perceived patient and carer need.

Expert opinion, clinical and academic

The 16 papers that fell into the category expert opinion (clinical and academic) are shown in Table 6 and further details of them are given in Appendix 9. Generally they were considered to be weaker than the 13 expert-opinion papers based on high-level sound-basis guidance, because the former were based on personal or unsystematic reviews of the literature whereas the latter had more extensive and multiple sources of information.

Table 6 Expert-opinion papers, clinical and academic

Study	Main aims of study	Type of data collection	Type of service/setting(s)
Watson and Quinn (1998)	Stroke rehabilitation	Professional/expert opinion	Stroke rehabilitation
Das Gupta and Turner-Stokes (2002)	To outline the principles of severe traumatic-brain-injury management from a clinical perspective	Unsystematic review and professional(s) expert opinion, educational article	Acute, post-acute and long-term rehabilitation and support for traumatic brain injury

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	To review evidence for effectiveness of rehabilitation in severe traumatic brain injury		
Hale (2004)	To review 'current literature on stroke rehabilitation in the community and debate the issue as to whether it is truly community-based or just merely an extension of institutionalised care'	Unsystematic review and descriptive overview of research including trials, qualitative and grey literature on different forms of stroke rehabilitation delivery outside of hospitals	Community-based rehabilitation for stroke
Cadilhac <i>et al.</i> (2006)	To develop a model of practice using literature evidence, expert opinion and collection of data from stroke units To collect perceptions of facilitators and barriers to an integrated stroke model	Professional/expert opinion	Integrated stroke model covering a geographically spread client base
Mackay <i>et al.</i> (1995)	To review literature and report on local innovations (1995) in south London and propose alternative models of care for evaluation	Unsystematic 'personal' review	Stroke units, stroke community rehabilitation
Stuart and Zafonte (2004)	To describe planning, funding, organisation and information management in a traumatic-brain-injury program in Florida	Description, observation and field notes	State-wide programme in Florida for individuals with traumatic brain injury
Ward <i>et al.</i> (2003)	N/A	Professional/expert opinion	Multi-disciplinary services
Wade (2003)	N/A	Professional/expert opinion, supported by evidence from published literature	Community rehabilitation
Holmes (2005)	To illustrate how the 11 quality requirements from the NSF apply to the support and	Professional/expert opinion, use of hypothetical cases to demonstrate typical problems (e.g. dysphagia)	Rehabilitation services for motor neurone disease

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	practical care of people with motor neurone disease		
Shue (1993)	To describe the collaborative model of service delivery, which 'facilitates the return of brain-injured individuals from US rehabilitation facilities to their home communities in Ontario'	Comment by professional(s) Description of a pilot including 10 selected brain-injured people	A collaborative model of service delivery, incorporating inpatient rehabilitation, long-term community-based care in the USA
Bakheit (1995)	To describe and highlight the need for an integrated hospital-community model	Unsystematic 'personal' review Descriptive/synthesis	An integrated hospital/community model
Burke (1995)	To describe a range of models of specialised brain-injury rehabilitation and to discuss their relationship with each other	Unsystematic 'personal' review Descriptive/synthesis	Several models are described and compared, including: <ul style="list-style-type: none"> • the comprehensive centre • cognitive rehabilitation • behaviour rehabilitation • slow-stream rehabilitation • coma arousal programme • acute rehabilitation • outpatient rehabilitation • transitional rehabilitation • vocational rehabilitation • children's services
Inman (1999)	To tease apart the aspects of different care models that are most effective To review and discuss the evidence for interventions for symptom control	Unsystematic literature review	Spinal Cord Injury Units
Barnes and Radermacher (2001)	To summarize some models of community rehabilitation and the evidence for their effectiveness	Comment by professional(s), unsystematic 'personal' review	Community rehabilitation

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Department of Health (2003) <i>NHS Changing Workforce Programme</i> , 2nd edn	To 'illustrate how new roles can meet patients' needs more effectively, while at the same time giving staff more opportunities to develop their skills and experience' (p.2)	Review of services for service users with stroke and their carers under the NHS Changing Workforce Programme; examples of education and work across health care disciplines and in different contexts (e.g. hospital, community), sharing expertise	Specialist stroke services; community follow-up and rehabilitation across all health care settings
Johnson and Thompson (1996)	None stated	Results from an earlier audit of 135 admissions to a neurorehabilitation unit (Freeman <i>et al.</i> , 1997) Comment by professional(s)	Multi-disciplinary Neurorehabilitation unit, UK

These papers re-enforced points made in other papers. For example, Das Gupta and Turner-Stokes' (2002) review of the evidence for the effectiveness of rehabilitation following severe traumatic brain injury called for long-term, participation-orientated, co-ordinated services. One paper proposed another model of illness, the 'Stages of stroke', aiming by such a model to illustrate the deficiencies in service provision in the long term (Watson and Quinn, 1998).

Patients spend less time in hospital, for example after stroke, each year. This provides one of the pressures towards community rehabilitation. But Hale (2004) criticised community stroke rehabilitation services on the basis that they tend to be extensions of hospital care, rather than models of participation-oriented long-term care and support, citing the World Health Organization definition of community-based rehabilitation, which suggests that community rehabilitation involves community development and social integration for people with disabilities, and should be delivered through combined efforts of users, carers and services in health, education, vocation and social services.

Cadilhac *et al.* (2006) proposed and described a model of delivering organised accessible community stroke care to a geographically spread client base in Australia. Stroke care experts, state and federal government and consumer representatives and staff ($n=12$) from four demonstration hospitals which already had stroke units and two sites in Victoria and two in Queensland were consulted about their perceptions of the proposed integrated stroke model. Not surprisingly 'Factors for enhancing the delivery of optimal stroke services included a multi-disciplinary team, clinician leaders, dedicated positions, standardised approaches to care, adequate funding to support initiatives, administrative support, commitment to in service training, and professional development and good communication amongst health care providers.' Many of the barriers were related to health-system-wide problems such as high attrition rates and limited health professionals in rural areas.

Barnes and Radermacher (2001) reviewed models of community rehabilitation and summarized evidence for their effectiveness. They included early discharge schemes, hospital at home, care management, the individual therapist in the community, nursing and other interventions (including a referrals facilitator working between primary care and voluntary sector and

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specialist care attendants on discharge providing care for 2 weeks). They found no evidence that a particular form of community rehabilitation is preferable to any other, sparse evidence for case management and no difference between standard service, medical outpatients and specialist nurse input. However, the authors suggested that case management in the community makes sense as the means to co-ordinate care. They also drew attention to the fact that in several studies reporting positive outcomes of early discharge services, effectiveness is reported to be enhanced by better co-ordination and communication between team members. Barnes and Radermacher (2001) claim that most studies reviewed show 'that community rehabilitation in whatever form is at least as effective as the traditional alternative of hospital care,' but that there are considerable gaps in knowledge and that 'many studies, not surprisingly, also find that patients and their carers prefer delivery of care within the home setting.'

Stuart and Zafonte (2004) described a state-wide program in Florida for individuals with traumatic brain injury, the essentials of which were a surveillance scheme, a dedicated revenue source and integration of medical and social services.

Shue (1993) described a collaborative model of service delivery, which incorporated inpatient rehabilitation and long-term community-based care for people with brain injury. It included innovative models of community care including shared accommodation, shared care homes and fostering.

The focus of many papers was as much to demonstrate the effectiveness of rehabilitation, as opposed to discussing models to deliver effective interventions. Inman (1999) considered the effectiveness of spinal cord injury rehabilitation in a review and discussion of evidence for different care models and the usefulness of specific interventions for symptom control such as spasticity and pain. He included books and journal articles, published over a 30-year period between 1965 and 1997, together with surveys and hospital statistics in connection with the incidence of spinal cord injury, impact of early admission on pressure sores, contractures, impairment, disability, impact of age on outcome, discharge venue, outcome in the community, transport, vocational outcome, social relationships, ambulatory devices, neural stimulators, spasticity and pain management (intrathecal phenol, medication, electrical stimulation). He concluded that to achieve the best functional outcome and prevent medical complications, prolonging rehabilitation and early transfer of patients to a specialist centre appeared to be essential. He called for prospective controlled studies to demonstrate the effectiveness of different interventions using measures of participation. Burke (1995) synthesised evidence about cognitive and behaviour rehabilitation, slow-stream rehabilitation, coma arousal programmes, acute rehabilitation, outpatient rehabilitation, transitional rehabilitation and vocational rehabilitation for people with brain injuries. He also emphasised the importance of an integrated network of specialized brain-injury rehabilitation services, wherein patients can move from one part of the system to another as the need requires, regardless of their financial ability to pay for these services. Like Shue (1993), he also raised the important issue of alternative forms of accommodation and other essential aspects of community support (such as attendant care, day activity, maintenance therapy, home nursing

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services, respite care, counselling and case management services) required by people in the community.

The recurring themes of the importance of long-term co-ordinated participation orientated services were therefore stressed again in this section. The reasoning in general might be termed common sense: once the nature of long-term conditions is appreciated, short term services are obviously inadequate, the omission of participation-focused services is inadequate, fragmented services run by different agencies that do not work together is obviously inadequate, and so on.

Surveys of service provision

Surveys of service provision included the four papers in Table 7 (Appendix 10).

Table 7 Surveys of service provision

Study	Main aims of study	Type(s) of data collection used
Deane <i>et al.</i> (2003)	To discover information pertaining to standard occupational therapy for Parkinson's disease	Content analysis and descriptive statistics of a postal survey of occupational therapists.
Scheer <i>et al.</i> (2003)	To examine access barriers to primary, specialist and rehabilitative care and their consequences for individuals' health, functioning and well-being and health services' utilisation	Semi-structured interviews as part of national (US) survey of 537 working adults Thematic coding using NVivo
Barnes (1997a)	To produce a report on the state of neurological rehabilitation in Europe To recommend standards for provision of neurological services for disabled people	Questionnaire survey of each European member country
O'Connor and Delargy (2003)	To describe a Young Disabled Unit	Observation and field notes of all patients in one Young Disabled Unit, Co. Dublin, Republic of Ireland Review of health records, collection of biographical and demographic details

Few new points emerged from these papers. However, the review of a Young Disabled Unit by O'Connor and Delargy (2003) described the complex case mix dealt with by this service, the long waiting lists and inadequate care in other settings, and the long lengths of stay on the unit, in part attributed to inadequate community provision. This case study highlighted the huge needs of many people with severe brain injury and how costly they are to health and social services. No evidence of the cost-effectiveness of such units was provided by this report, or referred to.

Descriptive evaluations, audits and surveys

Seven papers were descriptive evaluations, audits and surveys (Table 8, Appendix 11). They were not of high generalisability due to their design.

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Table 8 Descriptive evaluations, audits and surveys

Study	Aim	Methodology; type(s) of data collection used
Sheriff and Chenoweth (2003)	To describe a Parkinson's disease research project	Pre- and post-comparison
Holloway (2006)	To develop and implement the tools for a care pathway framework for people with Parkinson's disease	Semi-structured interviews, and sample characteristic data collections
Rossiter and Thompson (1995)	To trial the use of integrated care pathways in a non-acute setting in 13 patients with multiple sclerosis	Retrospective document review for 13 integrated care pathways
Barnes and Skeil (1996)	To discuss the experience of working within a multi-disciplinary neurological clinic in a regional rehabilitation centre	Retrospective survey of aspects of a service and questionnaire to patients on their views and preferences
Commission for Healthcare (2006)	To find out what patients who have had a stroke thought about the care they received after leaving hospital	Questionnaire/survey
Barker (2006)	N/A	Policy document: professional/expert opinion, user views Included experiences of 30 stroke survivors and experiences of callers to helpline
Keaton <i>et al.</i> (2004)		E-mail questions from care-givers; responses from nurse specialist and E-rehabilitation team

One paper, a *Survey of Patients: Caring for people after they have had a stroke* (Commission for Healthcare, 2006), was large and sought to determine what patients who have had a stroke thought about the care they received after leaving hospital. The findings complement and replicate much of what is said in the more strongly based expert-opinion findings of our review: community provision is poor, people also feel uninvolved in decisions and some people do not feel they get enough emotional support.

Care pathways were the subject of studies by Rossiter and Thompson (1995) and Holloway (2006) on multiple sclerosis and Parkinson's disease respectively. Few hard data supported their use in either paper, but in both cases the care pathway was introduced as a means of co-ordinating long-term services. These papers therefore do not describe models of services, but means of working in a co-ordinated service.

Barker (2006) in a report on 'Getting back to work after stroke' published by the Stroke Association and Different Strokes, uses the experiences of 30 working-age stroke survivors and callers to a helpline to understand the problems faced by people wanting to return to work after a stroke. Recommendations for helping people return to work proposed included greater provision of services, and for employers to be encouraged to offer flexible and accessible retraining and work opportunities for stroke survivors.

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Descriptions of services and service innovations

Ten descriptions of services and service innovations were reviewed (Table 9, Appendix 12).

Table 9 Descriptions of services and service innovations

Study	Method of data collection	Aim	Type of service/setting(s) involved
Moskowitz <i>et al.</i> (2001)	Unsystematic 'personal' review	To review clinical characteristics and to discuss therapeutic approaches that are effective in the middle and late stages of Huntington's disease	Nursing home care in late-stage Huntington's disease
Burke <i>et al.</i> (2000)	Descriptive case study, retrospective notes review	To encourage specialist brain-injury services to offer extended rehabilitation programmes to patients, with very severe injuries' To report case study of 'a patient who has undergone a long, intensive, expensive rehabilitation after suffering a severe traumatic brain injury' To illustrate the outcome of such a rehabilitation programme	Interdisciplinary team in a specialist private long-term rehabilitation unit in Australia
Hintgen <i>et al.</i> (2000)	Descriptive	To describe the role and use of head-injured volunteers in an inpatient and outpatient neuroscience and trauma programme	Inpatient and outpatient neuroscience and trauma programme
Keaton <i>et al.</i> (2004)	E-mail questions from care-givers; Responses from nurse specialist and E-rehabilitation team		Web-based resource for stroke care-givers
Kendall <i>et al.</i> (2003)	Description of a model Literature review		Transitional rehabilitation
Steiner and Pierce (2002)	Descriptive, survey element, online feedback		Web-based information and support for care-givers of people with stroke
La Marche <i>et al.</i> (1995)	N/A		Interactive Community-based Model (ICBM) of vocational rehabilitation

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Kirshblum (2002)	Descriptive?	To describe the Model Spinal Cord Injury System (MSCIS) in the USA	A 'centres of excellence' model for spinal cord injury
Wahiquist (1984)	Mixed methods: Self-report survey of the clinic population Uricult dipslides distributed to a sample of nine people Data about hospitalisations gathered, nature of the disability	Not clear – description of symptoms 'During the first year, the objective was to define the scope of health problems for a given population' 'In the second year, interventions directed toward a reduction in the principle cause of morbidity were evaluated'	Nurse-managed multiple sclerosis clinic
Wood and Langton-Hewer (1996)	Review of medical records		Stroke and neurological rehabilitation ward

A variety of points of relevance to this report emerged in these papers. In general, ideas for services of interventions were described or proposed, without any evaluative element.

The case study by Burke *et al.* (2000) described a patient with severe traumatic brain injury who appeared to benefit from rehabilitation, funded by a compensation claim, over a 2-year period. The case illustrates how long and hence how expensive rehabilitation can be, and yet that benefits were observed during this intervention in keeping with clinical effectiveness. The obvious question is the cost-effectiveness of such interventions.

In an innovative proposed model of service, Hintgen *et al.* (2000) described the use of volunteers in an inpatient and outpatient neuroscience and trauma programme. Volunteers drawn from survivors of traumatic brain injury were given training in communication and mentored by experienced staff. Their role was to facilitate communication and shared activities (patient and volunteer). Volunteers were found to 'foster affective connections, reduce language barriers, and develop relationships with patients'. There is a potential role for trained volunteers in other service provision such as stroke rehabilitation, and potential for stroke survivors to volunteer to support other patients.

Moskowitz *et al.* (2001) reviewed the literature on the middle and late stages of Huntington's disease. The authors proposed a model of care based on geographically dispersed centres of excellence providing a framework to develop diagnostic, treatment, educational and research efforts to address the spectrum of health-care needs encountered by families with Huntington's disease.

Kendall *et al.* (2003) described the development of transitional rehabilitation for people with spinal cord injuries in Australia, a time-limited, community-based service that assists individuals in their home or home-like settings by utilising a flexible and client-focused model of service delivery designed to facilitate early discharge from hospital. Being time-limited, it is unlikely to

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deal with the long-term problems faced by this population, and again considers community rehabilitation as a means of providing some hospital acute care in another setting as opposed to delivering participation-focused community care.

Steiner and Pierce (2002) described the development of a web-based support system for stroke carers and the results of a pilot evaluation. The development of the service was prompted by a need to provide remote support for carers in remote geographical locations in the USA. The service involved being able to e-mail questions to a nurse, to chat to other carers and receive educational information. During a 3-month pilot study, five stroke carers completed a weekly online survey about their problems and successes in caring for a person with stroke, as well as their use of and problems with the web pages. The authors concluded that participants were satisfied with the service but two dropped out before end of the 3-month period and one person was not able to use it consistently because of poor telephone connection. No information was given about the time required to deliver the service and respond to e-mails, nor any indication of whether other methods of delivery would have been simpler or more acceptable to service users. The study hints at the potential to use new technologies to provide information, and support to people with long-term conditions in community settings.

La Marche *et al.* (1995), described 'the interactive community-based model of vocational rehabilitation (ICBM)':

- Phase 1 home-based evaluation and treatment,
- Phase 2 community and work activities,
- Phase 3 work-related activities,
- Phase 4 work placement,
- Phase 5 maximal vocational performance.

No data on the effectiveness or cost-effectiveness of this model were presented.

A nurse-managed clinic in multiple sclerosis was described by Wahiquist, (1984). The main intervention was to improve bladder care and reduce urinary infections which appeared to be a major cause of ongoing morbidity. No evidence of effectiveness was presented.

Kirshblum (2002) described the Model Spinal Cord Injury System (MSCIS) in the USA in which a systems approach to spinal cord injury is used and where services are joined up from acute centres to community and vocational services. Although it sounds ideal, no comparative data were presented.

Wood and Langton Hewer (1996) describe the development of a stroke and neurological rehabilitation unit in a district general hospital aiming to move away from a biomedical model of care towards a biopsychosocial model of care. Whether such a change to the focus of acute care makes any longer-term benefit was not answered by this study.

Summary of qualitative studies

The qualitative studies reviewed largely called for services to be long term, to focus on participation as well as activity, to be co-ordinated and to be accessible. Descriptions of models of rehabilitation-, hospital- and community-based services, including specialist individuals, were given, as well as

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innovations such as the use of fostering for people with head injury, or the internet to support people with stroke.

Quantitative

One hundred and fifty three papers were reviewed by this panel, of which 25 were excluded, leaving 128 included for inclusion in this report. Table 10 illustrates the conditions covered by these studies and the research designs used.

Table 10 Summary of study designs of papers reviewed by quantitative panel

Condition	RCT	Non-RCT	Total
Stroke	50	34	84
Brain injury	3	14	17
Mixed neurological conditions	1	5	6
Parkinson's disease	2	2	4
Multiple sclerosis	2	2	4
Epilepsy	0	3	3
Spinal cord injury	0	4	4
Economic evaluations	27 (21 of these also included in condition-specific sections)		

Stroke

The search identified 84 stroke articles: 14 systematic reviews and meta-analyses, 43 RCTs (most included in previous systematic reviews and meta-analyses) and 27 further publications of multiple methodologies (Table 11). These are summarised in Appendix 13.

The most comprehensive systematic review of the stroke literature was conducted by the Royal College of Physicians Inter Collegiate Working Party for Stroke in their production of the National Clinical Guidelines for Stroke (latest edition 2004; National Clinical Guidelines, 2004).

Systematic reviews of RCTs (of adequate methodological rigour) of inpatient services show that organised inpatient care (as opposed to care on general medical wards) is associated with reductions in death, death or disability and death or institutionalisation (Stroke Unit Trialists Collaboration, 1997; updated in the *Cochrane Database of Systematic Reviews*, Stroke Unit Trialists' Collaboration, 2007). Mobile stroke teams within a hospital setting are not recommended because the health outcomes are similar to those achieved by general medical wards and inferior to those achieved by stroke units (Langhorne and Duncan, 2001). The interventions provided by organised stroke care fall within the remit of rehabilitation as used in this report.

The evidence suggests that all patients with stroke benefit from being managed in specialised stroke units in hospital and that those managed at home do less well. No RCTs have shown that the availability of home care services for patients with acute stroke can improve patient outcomes or reduce costs. The small number of trials and the number of participants make it difficult to determine any harms of treatment at home (Langhorne *et al.*, 2006). The desire to evaluate stroke services that prevent admission to

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hospital has waned now that acute treatments have been developed, and indeed this has driven developments to expedite hospital assessment rather than prevent it.

Instead of avoiding hospital admission, but still in the context of the worldview in which health care should only be provided in hospital if it cannot be provided in a community setting, there has been interest in early discharge services. An individual patient data meta-analysis of 12 early supported discharge services (many of which were from the UK) demonstrated that this model of care can accelerate early discharge from hospital without compromising functional outcome. This sort of service is applicable for approximately 40% of stroke patients and can shorten length of stay by a mean of 8 days. Better outcomes were seen for patients who had mild to moderate stroke who were receiving early supported discharge. Better outcomes were also seen when early discharge services were co-ordinated and provided by a multi-disciplinary team (Langhorne *et al.*, 2005b) as opposed to less co-ordinated services without a defined multi-disciplinary team.

A systematic review of day hospital care for stroke patients showed no advantage of day hospital care over other alternatives (conventional care, outpatient physiotherapy and occupational therapy, home-based physiotherapy), although the findings were confounded by poor methodology of some trials, poor descriptions of services in others and problems arising from the variety of measurement instruments applied (Dekker *et al.*, 1998). A systematic review of outpatient therapy-based rehabilitation services (14 trials, $n=1617$) specialising in stroke rehabilitation, when compared with routine care up to 1 year after stroke demonstrated significantly better outcomes in both personal and instrumental ADL (Outpatient Service Trialists, 2003; Legg and Langhorne, 2004).

Despite being one of the most common causes of prevalent activity limitation in the community, and hence a valid target for adaptive rehabilitation services, evidence for therapy-based stroke services for patients beyond 1 year after stroke are limited. This area is the subject of an ongoing Cochrane Database systematic review led by one of the authors of this report (Noor Aziz, 2006) in which five studies were identified (two late mobility studies delivered by physiotherapists, one intensive outpatient rehabilitation (occupational therapist and physiotherapist), one occupational therapy study delivered in a nursing home and one aftercare programme in a rehabilitation centre).

Evidence for community occupational therapy is strong in terms of outcome in personal and extended activities of daily living and in leisure engagement after stroke (Walker *et al.*, 2004). On the other hand, evidence for family stroke liaison workers (another individual who attempts to provide specialist intervention to improve well-being after stroke) showed equivocal findings. Sixteen RCTs ($n=4916$) were identified in a systematic review of stroke liaison workers (Ellis *et al.*, 2005). Typically these interventions provided a multi-faceted service including more than one of education and information provision, social support and liaison with other services. Overall, no benefits were found on the primary outcomes of subjective health status or extended activities of daily living although a pre-planned subgroup analysis found that

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patients with mild to moderate impairment in activities of daily living had significant reduction in levels of dependence.

The review of the literature pertaining to stroke also picked up audit studies. The National Sentinel Audit for Stroke (Rudd *et al.*, 1999, 2001a, 2001b; Intercollegiate Working Party for Stroke, 2006) has been conducted bi-annually in England, Wales and Northern Ireland since 1998 to measure the compliance of sites to national standards of stroke care. These were retrospective audits of the organisation of services and process of care using case notes. The first round of the audit identified that only 18% patients spent more than 50% of their time on a stroke unit, and these had the best compliance with the standards for the processes of care. This audit concluded that an urgent review of stroke service organisation was required. A comparison between regions demonstrated widespread variations in the provision of specialist stroke services with differences in case mix, mortality, length of stay and institutionalisation rates for hospitalised patients that could not be explained. By 2006, after the NSF for Older People had set targets for the provision of stroke units in all acute hospitals in England, 91% of the 238 participating sites had a stroke unit, 50% had an acute stroke unit, 26% had a combined unit, 29% had a mobile stroke team, 22% had an early supported discharge service and 32% had a specialist community stroke team. There were few services which included psychologists or orthotists and the level of service provision still varied between England, Wales and Northern Ireland.

In summary the evidence base related to stroke shows that:

- 1 hospital care should be provided on a unit that provides organised care rather than non-specialised general medical wards;
- 2 early discharge services, also providing organised after care, should be available for the proportion of patients who can use them;
- 3 some sort of community rehabilitation for some patients in the first year after stroke can be effective, but it is not clear what service model should be used, nor who should use them;
- 4 we identified no/few specialist rehabilitation models for the longer-term optimisation of health after stroke;
- 5 the delivery of stroke care has been observed to improve in the UK in line with published evidence, although it should be noted that the evidence base is strong (based on meta-analyses) and there has been strong policy pressure in the UK for change to occur.

Table 11 Summary of quantitative studies on stroke

Author(s)	Design	Subjects	Intervention	Results
Burton and Gibbon (2005)	RCT	176	Specialist nurse vs standard care	12 month, NHP 42.6, $P=0.012$; special care 1.5 $P=0.045$
Grasel and Biehler (2005)	Quasi-randomised RCT	62	Intense training for discharge transition vs standard care	No difference between groups
Dey <i>et al.</i> (2005)	RCT	308	Inpatient mobile stroke team vs normal care	No differences seen
Baskett <i>et al.</i> (1999)	RCT	100	Home-based therapy vs outpatient therapy	No significant differences seen except contact time longer
Bautz-Holter <i>et al.</i> (2002)	RCT	82	Early discharge	Shorter length of stay, health outcomes similar
Anderson, H.E. <i>et al.</i> (2000)	RCT	155	Physician or physiotherapist	Reduced re-admission rate
Anderson, C. <i>et al.</i> (2000a)	RCT	86	Early discharge	No significant difference except poorer mental health care in early-discharge group
Ma <i>et al.</i> (2004)	RCT	392	Stroke unit: medical care, rehabilitation therapies, speech and language therapist, neuropsychology, education components	Greater improvements in Barthel index (BI), National Institutes of Health Stroke Scale (NIHSS) and Oxford Handicap Scale (OHS) were observed. Also fewer complications
Lincoln <i>et al.</i> (2004)	RCT	421	Community team	No difference except aspects of patient and carer satisfaction better with community team
Ricauda <i>et al.</i> (2004)	RCT	120	Home treatment vs hospital treatment	Mortality was not significantly different in the two groups but

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				depressive scores and admission rates to nursing homes were lower in the home-treated elderly patients.
Rudd <i>et al.</i> (1997)	RCT	331	Early discharge vs conventional policy	Early discharge feasible: no significant differences in clinical outcomes but increased satisfaction with hospital care was found in the community therapy group and the community therapy group also had significantly shorter length of stay (LOS) despite having more impairments.
Sulch <i>et al.</i> (2002)	RCT	154	Integrated care pathway (ICP) vs conventional multi-disciplinary (MDT) care	Higher frequency of stroke-specific assessments (ICP 84%, MDT 60%), nutritional assessment (ICP 74%, MDT 22%), documentation of provision of information (ICP 89%, MDT 45%) and early discharge notification to GP (ICP 80%, MDT 45%)
von Koch <i>et al.</i> (2000a)	RCT		Early discharge	Shorter LOS with early discharge
Drummond <i>et al.</i> (2005)	RCT	72	Stroke unit	Stroke unit patients tended to have better outcome for death, death or disability, death or institutional care
Anderson <i>et al.</i> (2000b)	RCT	86	Early supported discharge plus community care	Early supported discharge and home-based rehabilitation less costly than conventional care, but not statistically significant

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Evans <i>et al.</i> (2002)	RCT	267	Stroke unit care vs stroke team care	Sun analysis showed better outcomes in subset of patients with large-vessel disease
Donnelly <i>et al.</i> (2004)	RCT	113	Early discharge and community stroke team vs usual care	No significant difference between two models, except carers more satisfied and community stroke team option cost less
Indredavik <i>et al.</i> (1997)	RCT		Stroke unit vs general wards	Stroke unit improved survival, increased chances of being at home and produced better functional outcome at 5 years
Indredavik <i>et al.</i> (1999)	RCT		Stroke unit vs general wards	Stroke unit produced better survival, proportion at home and proportion with BI >60 at 10 years
Indredavik <i>et al.</i> (1998)	RCT		Stroke unit vs general wards	Stroke unit produced better functional outcome (Frenchay Activities Index, FAI) and quality of life (NHP and Visual Analogue Scale).
Indredavik <i>et al.</i> (2000)	RCT		Early supported discharge with mobile team vs standard service	Early discharge patients were more independent in ADL, more were at home at 6 weeks and they spent less time in hospital. No differences in proportion at home at 26 weeks or survival.
Holmqvist <i>et al.</i> (2000)	RCT		Early supported discharge and rehabilitation at home	50% reduction in hospitalisation in early-discharge group

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Holmqvist <i>et al.</i> (1998)	RCT		Early supported discharge and rehabilitation at home	No differences in outcome; 50% reduction in hospital stay in early discharge group (15 vs 30 days)
Hui <i>et al.</i> (1995)	RCT		Day hospital vs conventional medical management	Significant difference in BI at 3 months in favour of day hospital group; fewer outpatient visits at 6 months; no significant difference in costs
Juby <i>et al.</i> (1996)	RCT		Stroke unit vs general medical and rehabilitation wards	Stroke unit patients were more independent in ADL and showed better mood and adjustment
Roderick <i>et al.</i> (2001)	RCT	140	Domiciliary rehabilitation programme vs geriatric day hospital	No differences seen between the two services
Ronning and Guldvog (1998a)	Quasi-randomised RCT	550	Stroke unit vs general ward	Trend for stroke unit to have better outcomes
Teng <i>et al.</i> (2003)	RCT	114	Home rehabilitation vs usual care	Short Form 36-item survey (SF-36) higher scores in intervention group; costs higher in usual care (because of readmissions); better scores for carers in intervention group re: stress
Thorsen <i>et al.</i> (2005)	5-year RCT follow-up	54	Home rehabilitation or routine care	Better EADL results at 5 years in home care group
Rodgers <i>et al.</i> (1997)	RCT	92	Early supported discharge vs usual hospital care	No differences
Rodgers <i>et al.</i> (1999)	RCT	204	Day hospital vs routine plus information control	Day hospital improved patient and carer knowledge but not perceived health status

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Ronning and Guldvog (1998b)	Quasi-randomised RCT	802	Stroke unit or general medical wards	Improved survival in stroke unit patients at both 12 months and 18 months
Ronning and Guldvog (1998c)	RCT	251	Hospital-based rehabilitation unit or to rehabilitation in community	Better overall outcome in hospital rehabilitation group for dependency or death ($P=0.01$, OR 0.49 (0.28–0.86))
Kalra (1994)	RCT	146	Stroke unit vs general wards	Functional recovery greater and more rapid in stroke unit
Mayo <i>et al.</i> (2000)	RCT	114	Home rehabilitation vs usual care	Home intervention was better
von Koch <i>et al.</i> (2001)	RCT	83	Early discharge and home rehabilitation vs usual care	No difference on univariate, except for resource use
Walker <i>et al.</i> (1999)	RCT	185	Occupational therapy vs no intervention	Occupational therapy better
Wolfe <i>et al.</i> (2000)	RCT	43	Rehabilitation team at home vs usual care	No overall differences
Young and Forster (1992)	RCT	124	Day hospital vs home treatment	Home more effective
Young and Forster (1993)	RCT	124	Day hospital vs home treatment	Home more cost-effective
Corr and Bayer (1995)	RCT		Occupational therapy vs no intervention	No difference seen
Fagerberg <i>et al.</i> (2000)	RCT		Integrated stroke service: stroke unit and community vs usual care	No difference seen
Lincoln <i>et al.</i>	RCT	139	Stroke unit	Mortality rates lower in stroke unit

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(2000)				
Logan <i>et al.</i> (1997)	RCT	111	Intense occupational therapy vs less intense	Higher EADL scores with intense occupational therapy
Dennis <i>et al.</i> (1997)	RCT	417	Stroke family care worker vs usual care	No differences on physical outcomes; satisfaction high for patients and carers for family support worker groups
Kalra <i>et al.</i> (2000)	RCT	457,	Stroke unit vs community care	Mortality, institutionalisation and dependence lower in stroke unit
Forster and Young (1996)	RCT	240	Specialist nurse support	No significant differences
Gilbertson <i>et al.</i> (2000)	RCT	138	Domiciliary occupational therapy or routine follow-up	No significant differences
Gladman and Lincoln (1994)	RCT	327	Home- vs hospital-based rehabilitation	No difference overall, but a subgroup of younger patients benefited from home rehabilitation, and a subgroup of frail older people benefit from hospital-based rehabilitation in a day hospital.
von Koch <i>et al.</i> (2000b)	Cohort		Early supported discharge and rehabilitation at home	Average duration programme 14 weeks, mean no visits 12, total time 23h 20 min, face-to-face contact 54%
Dennis and Langhorne (1994)	Meta-analysis	Not stated	Specialised stroke unit care	Stroke services need: neurovascular clinics, acute stroke area, stroke rehabilitation unit, outpatient, day hosp or domiciliary care for those not admitted, continuing care and support, close links with primary care

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Pound <i>et al.</i> (1999)	Non-participant observation		Stroke unit, elderly care unit, general medical ward	Many stroke unit patients spent more time out of bed and had more opportunities to be independent than patients in other settings
Early Supported Discharge Trialists (2005)	Systematic review and meta-analysis	14 RCTs	Interventions to accelerate discharge	Reduced LOS, institutionalisation and long-term dependency
Langhorne <i>et al.</i> (2005b)	Meta-analysis		Early supported discharge service vs ordinary hospital care	Early supported discharge reduced death or dependency absolute reduction 6%; 8 days shorter LOS, greater satisfaction
Langhorne <i>et al.</i> (2000)	Meta-analysis		Hospital avoidance service	No difference except trend towards higher hospital use in intervention; may be more expensive
Kramer <i>et al.</i> (2000)	Cohort		Health-maintenance organisations vs fee for service: the latter more likely to have specialised rehabilitation, whereas the former tended to be in nursing homes with an implication of a less intense or no real rehabilitation	ADL similar at 12 months but fee-for-service patients more likely to be at home (OR 1.8) and health-maintenance organisation patients more likely to be in NHs (OR 2.4)
Jorgensen <i>et al.</i> (1999)	Cohort		Stroke unit vs general ward	OR 0.6 for death in stroke unit cohort
Greenberg <i>et al.</i> (2004)	Retrospective cohort		Hospital outpatient department	A variety of complaints were identified
Murray <i>et al.</i> (2004)	Survey	50	District nursing teams in three Bradford PCTs	Uncertainty of post-discharge stroke care. Identified types of long-term problems people after stroke experience. Highlighted a lack of training/awareness. Need a stroke care co-ordinator role developed.

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Outpatient Service Trialists (2003)	Systematic review	14 RCTs including 1617 patients	Therapy-based rehabilitation	Therapy-based rehabilitation services reduced odds of a poor outcome (OR 0.72) and increased personal ADL scores (mean difference 0.14, $P=0.02$)
Rodgers <i>et al.</i> (2003)	National postal survey	91 consultant members of the British Association of Stroke Physicians		The NSF target for hospital-based stroke service is not currently being met in most units.
Rudd <i>et al.</i> (2001b)	Retrospective audit	6894 patients from 12 trusts covering 210 trust sites		Proportion of stroke patients spending more than 50% of their time in a stroke unit varied from 10 to 27%. 30-day mortality varied between 21 and 33%. Institutionalisation rates varied between 6 and 19% similar to discharge disability and LOS variations.
Salter <i>et al.</i> (2006)	Retrospective chart review	435		Those admitted early (within 30 days of admission for first-ever stroke) to stroke rehabilitation had greater functional gains and shorter lengths of stay than those having delayed admission.
Diez-Tejedor and Fuentes (2001)	Cohort	1491	Stroke unit vs stroke team	Stroke unit outcomes better
Stroke Unit Trialists' Collaboration (1997)	Systematic review	19 trials with 3249 patients	Organised inpatient care vs conventional treatment	Stroke unit care reduced odds of death (0.83); death or dependency (0.69); death or institutionalisation (0.75)
Ronning <i>et al.</i> (2001)	Quasi-randomised RCT	135	Stroke unit v general medical ward	Better survival at 30 days and one year for stroke unit patient but no

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				differences in destination
Rudd <i>et al.</i> (2001a)	National audit; repeated within 18 months	5589	None	Between first and second audit, proportion of patients on stroke units increased from 19 to 26%. Other standards e.g. assessment, rehabilitation and discharge planning improved but other standards remained poor, e.g. carers needs, cognitive assessment
Rudd <i>et al.</i> (1999)	National audit	6894	None	18% patient on stroke unit, for 50% of hospital stay. Only 64% of trusts had stroke physician; only 50% had stroke team. 41% of patients contacted by GP within 3 days of discharge
Jorgensen <i>et al.</i> (2000)	Geographically controlled trial	1241	General wards vs stroke unit	Stroke unit generally favourable
Jorgensen <i>et al.</i> (1995)	Geographically controlled trial		General wards vs stroke unit	Stroke unit did better
Langhorne <i>et al.</i> (2005a)	Systematic review	Six clinical trials	Mobile stroke teams	Stroke teams better than conventional care, equivalent to stroke units
Langhorne and Duncan (2001)	Systematic review	Nine clinical trials	Organised care vs an alternative	Substantial benefit for organised care
Stegmayr <i>et al.</i> (1999)	Non-randomised controlled trial	14,308	General ward vs stroke unit	Stroke units showed benefit, but less than in trials
Stroke Unit Trialists' Collaboration (2007)	Systematic review	23 clinical trials	Organised inpatient care vs general care	Organised care is better

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Walker <i>et al.</i> (2004)	Systematic review	8 clinical trials	Community occupational therapist vs no routine therapy	Higher ADL and leisure scores
Dekker <i>et al.</i> (1998)	Systematic review		Day hospital vs various alternatives	Neutral result
Kalra <i>et al.</i> (1993)	Controlled study	245	Stroke unit, general medical wards	Stroke unit improved outcome and reduced hospital stay without increasing therapy time.
Kwakkel <i>et al.</i> (1997)	Meta-analysis	9 studies, 1051 patients	Intensity of therapeutic intervention	Small but statistically significant intensity effect
Fjaertoft <i>et al.</i> (2003)	Long-term follow-up of an RCT	320	Extended stroke unit service (mobile stroke team providing comprehensive follow-up) vs ordinary stroke service unit service	56.3% in extended vs 45.0% in ordinary service were independent (modified Rankin Scale ≤ 2). No significant difference in BI or final residence. Patients with moderate to severe stroke benefited from extended service.
Geddes and Chamberlain (2001)	Cohort	1076 patients in 6 community rehabilitation teams	Community teams	Mean age 71, median time between stroke and intervention by service 6 weeks. BI 15 at start and 18 at end. Median duration of intervention 12 weeks
Glader <i>et al.</i> (2001)	Cohort	8194	Stroke units vs general wards	Better ADL in stroke unit patients who had been independent prior to stroke, and lower case fatality if living at home prior to stroke.
Gladman <i>et al.</i> (1995)	Analysis of two trials	451	Home vs hospital rehabilitation post discharge from hospital	Marginal benefit found in the home group
Claesson <i>et al.</i> (2000)	RCT		Integrated service stroke unit and community	No difference in costs between those in this service and control

BI, Barthel index; EADL, Extended Activities of Daily Living index; LOS, length of stay; NHP, Nottingham Health Profile; OR, odds ratio.

Traumatic brain injury

Seventeen brain-injury studies were identified: one was excluded during the review process because on closer inspection it did not describe or evaluate a service (Table 12, Appendix 14).

Ricker *et al.* (2002) conducted a survey of 400 members of the Brain Injury Association about their use of and access to technology including computers, but was not a controlled study. Buffington and Malec (1997) reported a cohort of people who had a vocational rehabilitation service. Ponsford *et al.* (2003) performed a cohort study of long-term family and emotional adjustment in close relatives of individuals with traumatic brain injury. As none of these had control groups, no comment on the effectiveness of services can be made.

In a Cochrane systematic review, Turner-Stokes *et al.* (2005) considered the available RCT evidence for multi-disciplinary services for acquired brain injury in adults of working age. Most of their information came from patients with stroke, which was included under the heading 'acquired brain injury'. From the 'best evidence' synthesis of these studies, they concluded that there is 'strong evidence' to suggest that:

- the majority of patients with mild traumatic brain injury make a good recovery,
- patients with post-traumatic amnesia of less than 1 hour, usually not admitted to hospital, do not need any specific intervention,
- patients with post-traumatic amnesia of 1 hour or more do benefit from routine follow-up contact giving information and advice,
- there is a subgroup of patients with moderate to severe injury who benefit from a higher level of intervention, and who may not present themselves unless routine follow-up is provided.

The studies examined to make these conclusions are reviewed later in this section.

There were two non-systematic reviews of the evidence for traumatic-brain-injury rehabilitation (Cope, 1995; Rice-Oxley and Turner-Stokes, 1999). Both suggested that there is evidence, albeit it not from RCTs, which is robust enough to support the efficacy of rehabilitation for traumatic brain injury. The main argument is that people receiving interventions tend to get better during periods of intervention, and that when the totality of evidence about the nature of the problems and the nature of the interventions are reviewed in detail it is hard not to assume that some of the observed improvements in outcomes are due to the interventions and would not have taken place otherwise. Both Rice-Oxley and Turner-Stokes (1999) and Cope (1995) were concerned to address the therapeutically nihilistic question of whether anything should be done for people with traumatic brain injury, rather than identifying the question of this review, which is to consider the best way of delivering specialist services for these people.

There were no RCTs of inpatient services. Non-randomised studies comparing cohorts of people in receipt of specialist services to cohorts without such care have been undertaken for acute brain-injury units (Aronow, 1987; Morgan *et al.*, 1988; Mackay *et al.*, 1992; Semlyen, 1998) but these are open to selection and outcome-ascertainment biases. These studies all reported better

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outcomes for specialist care. Other studies (Eames *et al.*, 1996; Edwards *et al.*, 2003) report cohorts treated in such units, but little can be inferred about the effectiveness of such units from such surveys.

Three RCTs of community services were found. Powell *et al.* (2002) compared the efficacy of community-based rehabilitation to an information control intervention after severe traumatic brain injury (sustained between 3 months and 20 years previously) in a single blind RCT involving 112 people aged between 16 and 65. Fifty-four were randomised to the outreach team service and 56 to an information-only control group. Outreach sessions took place in community settings such as participants' homes, work places or day centres and averaged two per week for a mean of 6 months. Forty-eight outreach and 46 control patients were followed up between 18 and 40 months after allocation and compared on measures of activity and participation (Barthel index, the Brain Injury Community Rehabilitation (BICRO-39) scales, FIM+FAM) and a subgroup on the Hospital Anxiety and Depression scales (HADS). Outreach patients had significantly better scores on the Barthel index and BICRO-39 total score and self-organisation and psychological well-being subscales but not on indices of socialising, productive employment or anxiety or depression. The magnitude of the benefits was unrelated to time since injury. The authors concluded that structured multi-disciplinary rehabilitation delivered in community-based settings for severe traumatic brain injury can improve social functioning and yield benefits in terms of functional ability, independence in a range of ADL activities and aspects of psychological functioning even years after the injury.

Wade *et al.* (1997) examined the role of routine outpatient follow-up after a head injury in a RCT involving 1156 consecutive head-injury (any severity) patients presenting to emergency departments over a 13-month period. Participants, aged between 16 and 65 and living in Oxfordshire, were prospectively randomised to early (within 7–10 days) outpatient follow-up by the Oxford head-injury service (a specialist team) or standard treatment and followed-up 6 months after injury by independent clinicians blind to the intervention group. Some 59% of patients were lost to follow-up by 6 months, at which point there was no significant difference between the two groups in post-concussion symptoms (Rivermead Post-concussion Symptoms questionnaire) or changes in work, leisure, social and domestic activities (Rivermead Head Injury follow-up questionnaire). However, subgroup analysis revealed that patients with moderate or severe injuries (post-traumatic amnesia ≥ 1 hour or admitted to hospital) had significantly fewer difficulties in everyday activities if seen within 7–10 days after injury by the specialist service. The paper concluded that routine follow-up is most likely to benefit those with moderate and severe head injuries.

Wade *et al.* (1998) examined whether patients admitted to hospital with a head injury benefited from a routinely offered early intervention service, as opposed simply to a routine follow-up. A total of 314 patients aged 16–65 admitted to hospital with a head injury of any severity were prospectively randomised using a block randomisation procedure to either specialist-team intervention or standard treatment and followed-up 6 months after injury. Outcomes included the Rivermead Head Injury follow-up questionnaire and the Rivermead Post-concussion Symptoms questionnaire. Participants were contacted 7–10 days after injury and offered assessments and intervention as

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needed. This involved information, support and advice and 46% also had further outpatient intervention or support by phone. One hundred and eighty-six people were randomized to the intervention and 130 to the routine practice groups and 132 and 86 were followed up at 6 months, respectively. The trial group had significantly better participation as determined by the Rivermead Head Injury follow-up questionnaire (Crawford *et al.*, 1996) and significantly fewer severe post-concussion symptoms at 6 months than controls. On the basis of these findings the authors recommended specialist early intervention for all people with head injury if they were admitted to hospital or post-traumatic amnesia of more than 1 hour, and those reporting post-concussive symptoms to a GP.

In a non-randomised retrospective study, Ponsford *et al.* (2006) compared a group of 77 patients with traumatic brain injury (with moderate to severe traumatic brain injury) receiving a community-based programme with a comparison group ($n=77$) who were treated as outpatients at a rehabilitation centre. At 2 years post-injury there were no significant differences in ADL performance or employment rates but patients receiving the community-based service were less likely to be independent in shopping or financial management and had more communication problems and more inappropriate behaviour. The authors attributed the findings to those in receipt of community services getting less face-to-face occupational therapy, social work and speech and language therapy than the outpatient group, due to time and resource constraints. However, the findings could be explained by biases arising from the study design rather than demonstrating that a community team is an inferior model to an outpatient service.

There were no RCTs of services for carers. In a small non-randomised controlled study, Smith *et al.* (2006) compared 17 carers of people with acquired brain injury in the UK who had received a community rehabilitation service with 24 carers who had received a conventional outpatient service in an adjacent geographical area. Carers were compared on levels of met family need (Family Needs Questionnaire), and measures of family dysfunction (Family Assessment Device), carer psychopathology (General Health Questionnaire 28) and carer emotional acceptance (Acceptance and Action Questionnaire). The carers of the community-service sample fared better on all measures except carer psychopathology. Being non-random, retrospective, using non-blind assessment of outcome and having small numbers, the reliability of these findings regarding the merits of an organised team service compared with a less organised service are questionable. The study does not report on the health of the people with the brain injury themselves.

Greenwood *et al.* (1994) examined the effects of case management after severe head injury in a study in which 126 people admitted to six hospitals were recruited, and where three hospitals had been randomised to deliver case management and three had not. Outcomes in terms of motor and cognitive impairment and activity limitation were compared at 12 and 24 months post-injury. There were no significant differences in outcome between the groups. Case management increased contact with but not time spent in treatment from formal rehabilitation. In view of the fact that only six hospitals were randomised, the benefits of randomisation were unlikely to have been seen, so this was similar to a well-controlled trial.

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In terms of getting people back to work, Buffington and Malec (1997) described a specialised brain-injury vocational service (a case-management system) for people with brain injury in Minnesota, USA, and examined its effects on vocational outcome at 1 year, in a series of cases referred to the service in its first 2 years. Of the 158 people referred for vocational rehabilitation, 80 met entry criteria for the service and were included. At one year 68/80 were in work, 28 (41%) were in unsupported, competitive employment, 22 were in supported or transitional employment services and fewer than 10% were in sheltered employment. Thirty-seven percent were back with a previous employer (two-thirds of these placements were within 3 months of injury). The job-retention rate after 3 months was 100%. Other potential factors that may contribute to successfully getting people back to work were identified in the review by Cope (1995). Graded work re-entry programmes were reported to be more effective at returning people to work than day hospital or inpatient rehabilitation programmes (Haffey and Abrams, 1991). 'Supported employment' was advocated by Ben-Yishay *et al.* (1987) in two case reports, and Prigatano *et al.* (1984) reported on cognitive rehabilitation as part of a neuropsychological rehabilitation programme in a cohort of service recipients in Minnesota. However, many of these studies report on single cohorts in receipt of a service or individual cases. Malec *et al.* (1993) reported the outcomes for a cohort of 29 people with brain injuries who received a group-oriented comprehensive-integrated approach to post-acute brain-injury rehabilitation in the USA. The proportion in transitional or competitive work placements increased from 7 to 59% from the beginning to the end of the programme. A year later, of the 21 graduates, 48% were in competitive work, one was in transitional work and 29% were unemployed.

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Table 12 Quantitative studies on traumatic brain injury

Author(s)	Design	Subjects	Setting	Intervention	Results
Semlyen <i>et al.</i> (1998)	Non-randomised controlled study	51 severe traumatic brain injury	Community, UK	Co-ordinated multi-disciplinary rehabilitation in specialist regional rehabilitation unit vs single discipline approach at local hospitals	Better function with usual care but results confounded by baseline differences
Smith <i>et al.</i> (2006)	Non-randomised controlled study	Carers of people with acquired brain injury	Community, UK	Community rehabilitation team vs. conventional outpatient service	Better outcomes with community rehabilitation service, but not a RCT
Turner-Stokes <i>et al.</i> (2005)	Systematic review	Acquired brain injury in adults of working age			In mild 'acquired brain injury' strong evidence suggests most patients recover well with appropriate information, without additional specific intervention. In moderate to severe acquired brain injury strong evidence of benefit from formal intervention.
Buffington and Malec (1997)	Cohort	80 adults with traumatic or other acquired brain injury	Regional trauma centre, USA	Vocational rehabilitation	Service described
Ponsford <i>et al.</i> (2006)	Non-randomised controlled trial	77 traumatic-brain-injury patients with moderate to severe traumatic brain injury matched to 77	Community, Australia	Community-based rehab team vs. outpatient treatment	No differences in ADL performance or employment outcomes; community group had more communication problems and more

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		controls (retrospective traumatic-brain-injury outpatients)			inappropriate behaviour; design issues make interpretation difficult
Ponsford <i>et al.</i> (2003)	Cohort	143 people with traumatic brain injury	Community, Australia	Outpatient follow-up clinic	
Rice-Oxley and Turner-Stokes (1999)	Non systematic literature review/expert opinion	Acquired brain injury, traumatic brain injury and stroke			
Wade <i>et al.</i> (1997)	RCT	1156 consecutive head-injury patients	Community, UK	Specialist traumatic-brain-injury team Follow-up appointment vs not	No overall difference but possible benefit for people with moderate or severe brain injury
Wade <i>et al.</i> (1998)	RCT	314 patients with head injury	Community, UK	Early intervention by a specialist service vs treatment as usual	Less social disability and fewer severe symptoms in intervention group
Cope (1995)	Non-systematic review	Traumatic brain injury	Hospital and community, UK and overseas	Many trials reviewed, divided into acute hospital, sub-acute community and residential, and specialist vocational	Generally concludes that the totality of evidence is favourable
Eames <i>et al.</i> (1996)	Cohort	Mixed brain injury	Residential, UK	Residential rehabilitation	Reduction in need from 87 to 55%, with a mean of 11 months LOS observed
Mackay <i>et al.</i> (1992)	Non-randomised controlled study	38 severe head injury	Residential, USA	Specialised unit vs no formalised programmes	Formalized programmes had shorter LOS, cognitively higher levels and more discharges to home
Powell <i>et al.</i> (2002)	RCT	112	Community, UK	Community-based rehabilitation vs.	Outreach patients were significantly more likely to show gains on the BI

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				information on alternative resources	and BICRO-39 total score and self-organisation and psychological well-being subscales; magnitude of gains unrelated to time since injury
Ricker <i>et al.</i> (2002)	Survey	71 members of a brain-injury association	Community, USA	Tele-rehabilitation	Strong interest in the possibility of accessing a tele-rehabilitation service
Greenwood <i>et al.</i> (1994)	Geographically controlled trial	Closed head-injury patients	Acute care and community, UK	Case management vs no case management	No difference
de Guise <i>et al.</i> (2005)	Cohort	348 consecutive admissions	Hospital, Canada	Inpatient unit Canada	Majority frontal and temporal lesions, mean age 40
Edwards <i>et al.</i> (2003)	Cohort study, analysis of database	290 patients discharged from hospital over 5 years	Hospital, UK	Hospital rehabilitation unit	Stable case mix over 5 years, improvement in disability and dependency in majority of patients; ethnic diversity didn't affect functional outcome

LOS, length of stay.

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Spinal cord injury

Unlike stroke and to a lesser extent traumatic brain injury, the articles found relating to spinal cord injury were limited in number (only four were found) and design, and systematic reviews have not been conducted (Table 13, Appendix 15).

Smith (2002) reported a retrospective patient survey of self-reported outcome after spinal cord injury of 800 spinal injury unit survivors and 99 controls who reported not being in a specialist unit during their hospital stay. Respondents were recruited in the UK via an advert in a specialist newsletter. It was not possible to adjust for the confounding effects of the major differences between the two groups: for example, not even age or co-morbidity were reported. No useful interpretation was possible.

Another attempt to examine the effect of rehabilitation, but without using a reliable study design, aimed to compare patients given early and subsequent specialist care to those not given the early specialist care. DeVivo *et al.* (1990) reported a retrospective cohort study using routinely collected data comparing a cohort that had early admission to a spinal cord injury unit specialising in early care ($n=315$) followed by rehabilitation, with a cohort that had later admission directly to the rehabilitation unit ($n=401$). The study took place in Alabama, USA, between 1973 and 1985. Outcomes included length of stay, complications and costs. Significant benefits in cost, length of stay and pressure-sore incidence favoured the early group, but these are questionable as significant bias may have arisen because those entering rehabilitation late may have been specially selected because of their complications and failure to recover well.

The third article reviewed was purely descriptive. Ronen *et al.* (2004) conducted a retrospective cohort study of 1411 participants, 1117 with non-traumatic spinal cord lesions and 250 with traumatic spinal cord lesions. The setting was a rehabilitation hospital in Israel and data were derived from admissions between 1962 and 2002. The main outcome measures were length of stay and the Spinal Cord Independence Measure (SCIM II); comparators were traumatic versus non-traumatic, aetiology and severity of the cord lesion, and decade of admission. The mean length of stay for traumatic spinal cord lesions was 239 days and 106 days for non-traumatic spinal cord lesions. Lesion aetiology, severity and decade of admission were associated with length of stay ($P<0.001$). Reports of this sort do not justify any particular service model, but give an indication of the very long hospital stays associated with this spinal cord injury, especially the traumatic variety. This longitudinal study also indicates that length of stay is falling over time, without an increase in dependency at the point of discharge. The reasons for this cannot be ascertained.

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Table 13 Quantitative studies on spinal cord injury

Author(s)	Design	Subjects	Setting	Intervention	Results
Kirshblum (2002)	Discussion paper	Spinal cord injury		Network rather than individual elements in isolation	None, but two papers are cited as providing evidence for benefits of elements of the system
DeVivo <i>et al.</i> (1990)	Cohort	800 spinal cord patients and 99 controls	Hospital unit, USA	Early vs late referral to spinal cord injury rehabilitation unit	LOS lower in the early referral group, costs about the same (unit cost in early unit higher than alternative)
Ronen <i>et al.</i> (2004)	Retrospective cohort study	1411; 1117 with non-traumatic spinal cord lesions and 250 with traumatic spinal cord lesions	Rehabilitation hospital, Israel.	Rehabilitation hospital	LOS is within the range of other European countries; aetiology and severity of spinal cord lesions were associated with different LOS.
Smith (2002)	Retrospective cohort comparison	Spinal cord injury patients on national database of Spinal Injury Association, UK	Community, UK	Specialist spinal cord injury rehabilitation	Specialist unit had lower incidence pressure sores, required less assistance in ADL, better social activities, but no significant difference in life satisfaction

LOS, length of stay.

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Parkinson's disease

The literature search identified four Parkinson's disease studies (Table 14, Appendix 16). Service models for specialist rehabilitation identified from the studies identified in this review included geriatric day hospitals and community specialist nurses.

Trend *et al.* (2002) describes a before/after evaluation of a cohort of 137 Parkinson's disease patients undergoing multi-disciplinary rehabilitation in day hospital in South-East England over 3 years. Participants attended day hospital once a week for 6 weeks with their carer. Health-related quality of life measures were administered at the start and at the final visit (6 weeks) by an assessor who was not masked to the intervention. The intervention was well tolerated (97 completed; 81%) and the measures – EuroQol, HADS, Emerson and Enderby measures of voice and articulation and timed 10-m walk – were appropriate and demonstrated positive change in the group. The same team described a cost-consequences analysis of the programme described by Trend *et al.* in 2002 (Gage *et al.*, 2006). Data from 118 participants were used to establish the unsurprising finding that that the main costs arose from direct and overhead costs of treatment. The same team reported a cross-over, waiting-list control RCT (Wade *et al.*, 2003) of multi-disciplinary rehabilitation for 144 people with Parkinson's disease. The intervention was attendance at day hospital in South-East England, once a week for 6 weeks and participants received group education and individual attention as appropriate from a specialist nurse, occupational therapist, physiotherapist and/or a speech and language therapist. Assessments were conducted independently at entry, 24 weeks and 48 weeks and included the Parkinson's disease disability questionnaire, the Parkinson's disease questionnaire (PDQ39), the Short Form 36-item health survey (SF-36), the Euroqol EQ-5D, the stand-walk-sit test, the nine-hole peg test of manual dexterity, the HADS, and selected items concerning speech from the unified Parkinson's disease rating scale (UPDRS). Carers were assessed using the carer strain index and the Euroqol EQ-5D. Difficulties with transport and recurrent illness resulted in only 71 patients having all three assessments. The results did not indicate that the intervention had a significant effect using pre-specified measures. There was a positive effect on sit-to-stand times for the early intervention group with a 1.4-second mean difference at baseline increasing to a 3.4-second mean difference at 24 weeks. However, this was not statistically significant. There was overall decline in other measures in both groups.

Jarman *et al.* (2002) conducted a RCT comparing community nurses specialising in Parkinson's disease as advisors to GPs with management by a GP without the service. In 438 GP practices in nine randomly chosen health authority areas of England, the study examined health outcomes and health care costs of 1859 patients, 1041 of whom were managed by a nurse specialist and 818 by their GP only. Details of the intervention were sparse, but each patient received on average eight assessments (a proportion of which were conducted by phone). Outcomes included survival, a test of chair rising function (Columbian rating scale), a test of visuomotor co-ordination (dot in square test), bone fracture, health-related quality of life questionnaires (the Parkinson's disease questionnaire PDQ39, Euroqol EQ-5D) and health care costs. No significant differences were seen in health outcome between the groups. Significant differences in the scores on a global health question

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were in favour of the community nurses. There was no increase inpatient health care costs. Methodologically, there was limited information on allocation concealment and masking of assessment. However, with 1859 participants the study was large enough to have shown significant between-group differences on motor or quality-of-life scores if they existed.

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Table 14 Quantitative studies on Parkinson's disease

Author(s)	Design	Subjects	Setting	Intervention	Results
Jarman <i>et al.</i> (2002)	RCT	1859 Parkinson's disease patients on GP register	Community, UK	Specialist Parkinson's disease nurse vs routine GP care	No significant difference in health outcome; significant difference in scores on global health question in favour of nurses; no increase in patient health care costs
Wade <i>et al.</i> (2003)	RCT	94 patients with Parkinson's disease	Community, UK	Programme of multi-disciplinary day hospital rehabilitation and group support vs routine care	May improve mobility; overall decline in both groups
Trend <i>et al.</i> (2002)	Before-and-after comparison	Parkinson's disease and no cognitive impairment	Community, UK	Multi-disciplinary rehabilitation in day hospital 1 day a week for 6 weeks with carers	Significant improvement in patients over time, no significant improvement in carers
Gage <i>et al.</i> (2006)	Cost-consequences analysis	118 Parkinson's disease patients attending day hospital	Community, UK	Programme of weekly multi-disciplinary rehabilitation in day hospital	Main costs were day hospital overheads and hospital transport; improved immediate functional outcome but this was lost over 4 months, high satisfaction; no carer benefits noted

Four papers relating to multiple sclerosis were reviewed (Table 15, Appendix 17).

A review paper (Thompson 2000) identified studies of packages of comprehensive care that were mainly concerned with demonstrating the effectiveness of inpatient rehabilitation. They were single-group pre- and post-intervention designs and mainly retrospective. The review identified a randomised trial (which the electronic search had missed) by Freeman *et al.* (1997) who randomly allocated 66 patients with multiple sclerosis to receive elective, sub-acute inpatient rehabilitation or a waiting-list control group, and showed a significant benefit on a measure of independence in activities of daily living (FIM) and handicap. It also identified the study by Solari *et al.* (1999) (which the search had also missed), who conducted a randomised single blind trial comparing an inpatient rehabilitation programme with home exercises in 50 ambulatory patients with multiple sclerosis. This trial also showed significant benefits in ability as assessed on the FIM, and on the mental health component of the SF-36, but not on physical health measures. Both trials had blind assessment of outcome but allocation concealment was not reported.

Francabandera *et al.* (1988) compared inpatient and outpatient rehabilitation in a prospective randomised trial with 84 patients with multiple sclerosis. No significant differences were found. A RCT (Pozzilli *et al.*, 2002) evaluated home-based management compared with hospital care. The method of randomisation was described, but it is not clear how outcome assessment was masked to allocation. The sample size was moderate ($n=201$). Outcomes were assessed on data from those who completed the follow-up assessments and not on an intention-to-treat basis. No significant differences were found between home-based and hospital-based care in terms of functional status. Percentage changes in SF-36 scores were compared between groups and showed some significant differences in favour of home-based intervention. Reding *et al.* (1987) compared inpatient rehabilitation with acute hospital care but the study was retrospective and used case-matched groups and so is unhelpful.

Only one trial was identified evaluating outpatient rehabilitation (Di Fabio *et al.*, 1998) in 46 patients with multiple sclerosis, showing reductions in fatigue and multiple sclerosis-related symptoms with rehabilitation.

The RCT by La Rocca *et al.* (1996) evaluated a medical community job-retention model as compared with standard medical care. The job-retention programme comprised interviews with a psychologist and an employment specialist. These considered overall functioning, multiple sclerosis symptoms, interpersonal issues, review of employment history and information about work-related matters. This was followed up with a telephone call 10–12 weeks later to provide any additional information requested and to offer further advice if needed. The method of randomisation was not described, nor is it clear how outcome assessment was masked to allocation. The sample size was small ($n=43$). Outcomes were assessed on data from those who completed the follow-up assessments and not on an intention-to-treat basis. There was no significant difference between the groups in job retention at

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1 year after random allocation. The programme was feasible but few people made use of the services offered.

The cohort study (Vickrey *et al.*, 2000) compared three models of service delivery in the USA: fee for service, a group model health-maintenance organisation and an independent practice association managed care plan. There was no random allocation to services and the groups differed on most socio-demographic and clinical characteristics. There were few differences in symptom management or access to disease-modifying agents, although there was a trend to more referrals and treatment in the fee for service group.

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Table 15 Quantitative studies on multiple sclerosis

Author(s)	Design	Subjects	Setting	Intervention	Results
Pozzilli <i>et al.</i> (2002)	RCT	201	Home and hospital, Italy	Home (community) rehabilitation vs hospital care	No significant differences in outcomes; trends to improved quality of life in home group
La Rocca <i>et al.</i> (1996)	RCT	43 multiple sclerosis patients at risk of losing their jobs	Community, USA	Job-retention programme vs normal medical care	No difference (more about feasibility than effectiveness)
Thompson (2000)	Review	People with multiple sclerosis		Neurological rehabilitation	
Vickrey <i>et al.</i> (2000)	Non-randomised controlled study	People with multiple sclerosis	Community, USA	Managed care plan (IPA) vs fee-for-service (FFS) vs health-maintenance organisation	Few differences in symptom management, trend to more referrals and treatment in FFS group; no difference in access to disease modifying agents; general health and symptoms more often assessed in FFS and IPA systems

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Epilepsy

This review identified three studies on epilepsy services (Table 16, Appendix 18): a review, a survey and a cohort study. The review concerned evidence for specialist epilepsy nurses (Bradley and Lindsay, 2001b). The survey described neuropsychological services (Reynders and Baker 2002) but provided no evidence of efficacy. The cohort study described a vocational services programme and also gave no information on efficacy (Fraser *et al.*, 1983).

The review of specialist epilepsy nurses comprised a Cochrane review of specialist epilepsy outpatient clinics and nurse-based liaison services. Three RCTs were identified (Ridsdale *et al.*, 1997, 2000; Warren, 1998). The reviewers considered that all three trials had used appropriate methods of randomisation and allocation concealment but none included blinded assessment of outcome. Two trials (Ridsdale *et al.*, 1997, 2000) conducted an intention-to-treat analysis. The reviewers concluded that specialist epilepsy nurses improved outcomes for people with epilepsy, in that people who had not had an epileptic seizure in the previous 6 months were at lower risk of depression (Ridsdale *et al.*, 1999) but not in those who had had a seizure, and that newly diagnosed patients whose knowledge about epilepsy was poor improved in knowledge scores following nurse intervention (Warren, 1998). These positive findings came from individual studies and the authors did not pool the results from the different studies due to clinical heterogeneity. Important outcomes, such as seizure frequency, social or psychological functioning, knowledge about epilepsy, costs of care and adverse effects showed no significant differences between intervention and control groups. This led to the conclusion that there was insufficient evidence to support the provision of specialist epilepsy nurses.

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Table 16 Quantitative studies on epilepsy

Author(s)	Design	Subjects	Setting	Intervention	Results
Reynders and Baker (2002)	Survey	16 centres	UK	N/A	Progress is being made towards meeting the 1991 ILAE recommendations; areas for development include nationally recognised training for neuropsychologists, developing centres of excellence, assessment of psychological health and quality-of-life assessment
Bradley and Lindsay (2001b)	Systematic review	647 participants with epilepsy	Mixed	Specialist epilepsy nurse vs normal care	No significant difference
Fraser <i>et al.</i> (1983)	Cohort	106 patients attending regional epilepsy centre		Vocational rehabilitation in epilepsy centre	Number of months employed in last 2 years predicts continued employment; subjects more satisfied with one-to-one contact than group activities

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Non-diagnosis specific services

Six studies examined non-diagnosis specific services (Table 17, Appendix 19).

One RCT of a mixed inpatient neurorehabilitation unit compared greater and lesser intensities of physiotherapy and occupational therapy (Slade *et al.*, 2002). Of the 141 patients recruited to the trial, 100 had had a stroke, 26 had traumatic brain injury and 35 had other neurological disorders, including multiple sclerosis. Overall 75 patients were randomly allocated to the experimental group to receive more therapy and 66 to the control group. All patients were under 65. The study was methodologically robust and the randomisation was sound. The main outcome was that length of stay was reduced significantly by 14 days with 67% more therapy in the intervention group. No significant differences were found in Barthel ADL scores. Thus the patients who received more therapy were discharged more quickly but were not functionally better than those who received the control intervention.

Thorn (2000) aimed to identify relevant research in rehabilitation nursing over a 10-year period (1988–1998) to both highlight existing knowledge and identify gaps in the literature. The search strategy employed was broad and the method of selecting papers for the review was not described. The inclusion criteria were papers examining rehabilitation nursing and papers concerned primarily with neurological inpatients. The resulting 43 identified papers covered diverse areas: the role of neurological rehabilitation nurses; specific neurological nursing problems and evaluations of nursing interventions. The studies were largely of poor-quality design, and no concrete conclusions could be drawn in any of the areas listed. The author underlined the need for both focus and rigour in future research in the field in her conclusions.

Four cohort studies were conducted: McMillan and Ledder (2001) described community rehabilitation teams for brain injury; Wilson *et al.* (2002) looked at the prevalence of the persistent vegetative state; Beatty *et al.* (2003) reported on a convenience sample of people with long-term neurological conditions in the USA; and O'Connor and Delargy (2003) described a Young Disabled Unit. None of these provide evidence about effectiveness of services for these conditions.

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Table 17 Quantitative papers on non-diagnosis specific services

Author(s)	Design	Subjects	Setting	Intervention	Results
Slade <i>et al.</i> (2002)	RCT	Patients admitted to inpatient rehabilitation unit	Inpatient, UK	Intensity of therapy	Significant reduction in length of stay (14 days) with more intensive (67% more therapy) rehabilitation (physiotherapy and occupational therapy); no significant difference in Barthel score
O'Connor and Delargy (2003)	Survey	42 inpatients of Young Disabled Unit	Young Disabled Unit, Ireland	Young Disabled Unit for selected severely affected cases	Patients were admitted a mean of 627 days after onset of disability, and stayed for a mean of 621 days
Thorn (2000)	Literature review	13 original papers reviewed (sample sizes of papers ranged from five to 80)	Neurological rehabilitation nursing in USA, UK and five other countries (unspecified) up to 1998	N/A	Research in this area lacks depth and direction such that a sound evidence base cannot be developed at present; this speciality generates little research and what is produced lacks quality
McMillan and Ledder (2001)	Survey	40 Community rehabilitation teams	25 Health Authorities, UK	Community neurorehabilitation teams, self defined	40 teams in 15.6 million people, 35 teams surveyed: incomplete coverage, and low rate per head of brain injury when covered
Wilson <i>et al.</i> (2002)	Survey	35 vegetative or minimally responsive	Hospitals, Northern Ireland	Assessment protocol	35 patients identified, reported unsatisfactory services, 7/12 in one unit changed, 5/12 remained unaltered on RLA scale, seven improved on WHIM 5 with little progress
Beatty <i>et al.</i> (2003)	National survey	800 adults with cerebral palsy, multiple sclerosis, spinal cord injury or arthritis	Community, USA	None	Only half population received the rehabilitation services they needed; respondents with poorest health and lowest incomes were least likely to receive health services

Twenty-seven papers identified related to economic evaluations. The majority of the empirical economic studies were undertaken in the UK (11 studies, one of which undertook a comparative study with Denmark). Two studies were undertaken in each of Australia, Sweden and USA, and a single study was reported from each of Canada, Hong Kong, Ireland and Northern Ireland, Italy and Spain. Therefore, the majority of economic work on neurological conditions found for this review stems from developed countries and is largely relevant to the UK setting. The studies were published between 1990 and 2006, with 20 being published in 2000 or more recently. The publication date did not necessarily correspond with the quality of the study.

In terms of the spread of economic studies across neurological conditions, the majority of studies pertained to stroke care (18 studies). In contrast there were few studies for other neurological conditions examining the economic issues of providing care to these patient groups. Just two studies were found for traumatic brain injury, one of which was a systematic review and the other a non-randomised controlled study. Three studies were found to evaluate services for patients with Parkinson's disease, one study for multiple sclerosis, spinal cord injury and epilepsy. For studies that looked across neurological conditions two were found reporting survey results of only indirect relevance to resource-allocation decision-making.

Eighteen studies were found to contain economic information or to have undertaken full economic evaluations related to stroke (64% of all studies identified to contain information of relevance to economic aspects) (Table 18). There have been three reviews which report results on economic aspects of stroke care (Dekker *et al.*, 1998; Evers *et al.*, 2000; Brady *et al.*, 2005). These reviews suggest that there are few full economic evaluations of stroke care and the quality of the studies was generally poor. As to whether services were cost-effective or not the evidence was mixed with no clear messages about what services were cost-effective. Brady *et al.* (2005) concluded that there was 'some' evidence that stroke units had lower mean patient costs than other wards in acute care, and that early supported discharge services had 'moderate' evidence of lower costs than usual care, whereas community-based rehabilitation had 'insufficient' evidence. The underlying study design of studies in stroke was the RCT except one (Diez-Tejedor and Fuentes, 2001). The empirical studies found covered inpatient care (comparing stroke units or teams with each other or with conventional ward care), and rehabilitation (comparing day hospital rehabilitation with routine hospital rehabilitation or community rehabilitation or home physiotherapy, also comparing early supported discharge with routine discharge and management). Regarding inpatient stroke care, one study combined incremental costs and outcomes to form an incremental cost-effectiveness ratio (Grieve *et al.*, 2000). Grieve *et al.* found that care in Copenhagen, which is characterised by stroke patients being admitted earlier onto specialist stroke units, was more expensive but more effective such that a value judgement would have to be made by a resource-allocation decision-maker as to whether \$21,579 to \$37,444 (US dollars, 1995) per life year gained represents good value for money.

Interpretation of the other studies examining inpatient stroke care (Claesson *et al.*, 2000; Diez-Tejedor and Fuentes, 2001; Evans *et al.*, 2002; Dey *et al.*,

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2005) is ambiguous because costs and outcomes were not combined. The study by Evans *et al.* did not monetarise resource use and Dey *et al.* did not capture resource use or costs. A similar observation can be made with respect to the studies of other rehabilitation services. Just one study (Byford *et al.*, 1995) combined costs and outcomes to form a mean cost per unit increase in Barthel index score, which the authors used to suggest that early discharge compared with usual care was likely to be cost-effective. The evidence of cost-effectiveness for day hospital rehabilitation compared with conventional hospital rehabilitation (Hui *et al.*, 1995; Roderick *et al.*, 2001) was inconclusive in that neither study found a significant difference in costs or outcomes between services, although Hui *et al.* (1995) concluded they had demonstrated a functional improvement on the Barthel ADL index at 3 months. Young and Forster (1993) found that total costs were significantly lower for a group treated with a home physiotherapy service when compared with a day hospital rehabilitation service and outcomes were not significantly different between groups, although the study follow-up period was short at just 8 weeks so may not measure the true longer-term difference in costs or benefits for these services. A range of studies were undertaken to assess the cost-effectiveness of home rehabilitation, comparing early discharge services with in-hospital rehabilitation (Byford *et al.*, 1995; Beech *et al.*, 1999; Anderson *et al.*, 2000a; von Koch *et al.*, 2001; Teng *et al.*, 2003; Donnelly *et al.*, 2004) and home to hospital rehabilitation after routine discharge (Gladman *et al.*, 1994). The evidence from these studies is mixed; for instance, whereas Gladman *et al.* found that total costs were lower for the routine hospital rehabilitation group, Teng *et al.*, Donnelly *et al.*, von Koch *et al.* and Anderson *et al.* found costs to be lower for the home-based rehabilitation group (but only in Teng *et al.*'s study was it clear that this difference was statistically significant). On the benefits side, most studies failed to find a significant difference in outcomes between comparator groups except Teng *et al.*, who found the one aspect of the SF-36 to be significantly better in the group receiving home-based care. Despite the number of stroke studies including economic components, it is still hard to draw any firm conclusions about how best to provide stroke care and rehabilitation on the grounds of cost-effectiveness data.

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Table 18 Economics studies on stroke

Author, country	Study design/ time period of study, type of economic evaluation	Perspective/cost categories	Intervention vs comparator	Outcomes	Sample size/ power calculation/ sensitivity analysis?	Incremental Cost Effectiveness Ratio	Methodological limitations
Evers <i>et al.</i> (2000), most studies USA or UK	Systematic review Most CMA or CEA based on cohort studies	Only to studies report perspective (both societal)	Diagnosis, therapy, rehabilitation, teams, protocol and location of care	Not clearly reported	23 studies found/ NR	Only a few full economic evaluations undertaken of cerebrovascular disease and the quality of studies was generally poor	
Claesson <i>et al.</i> (2000), Sweden	RCT/12 months CMA	Not explicit/ hospitalisation, institutionalised living, outpatient care, support and informal care	Non-intensive stroke unit with a care continuum vs conventional care	Survival, BI, ADL or NHP (as reported in a previous paper)	249; 166 stroke unit group and 83 general medical ward or conventional care/ NR/NR	NR Total cost per patient per year did not significantly differ between groups. There was high variability, in part related to disease severity. Outcomes did not differ significantly SEK 1996 prices	The high variability in costs, as the authors suggest, requires a larger sample studied over a longer time period to determine the cost-effectiveness or not of this intervention.
Diez-Tejedor and	Cohort/not explicit but	Not explicit/ hospital costs (no	Stroke units vs stroke teams	Systematic and neurological	1491 consecutive	NR A reduction in cost	The costs component of

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Fuentes (2001), Spain	appears as if acute phase only NR; cost analysis	detailed breakdown provided)		complications, and destination at discharge	patients (not clear how many received stroke unit or team)/NR/NR	per patient for stroke units and improved function and reduced discharge rates to nursing homes (all significant)	the study is poorly described and the results poorly presented; cost and outcomes were not combined to assess the cost-effectiveness
Evans <i>et al.</i> (2002), UK	RCT/ 3 months for resource use data N/A; considers resource use (not costed) and outcomes separately	Not explicit/ hospital stay and therapy duration	Stroke unit care vs stroke team care	Mortality, institutionalisation, orgozo scale, Barthel index, Frenchay, mRankin, Euroqol EQ-5D	Intervention=80 large-vessel infarct and 49 small vessel; control=84 large-vessel infarct and 54 small vessel/ power calculation used	NR Mortality, institutionalisation, MRankin, Frenchay and Barthel index were significantly better for the stroke unit patients with large-vessel disease but there was no significant difference for small-vessel disease. Length of stay was comparable for stroke units and stroke teams for both large-vessel and small-vessel disease. However, duration of therapies was	Not a full economic evaluation. Resource-use data were not valued by applying unit cost data; therefore, costs and benefits are not combined

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						longer for both patient groups in stroke units as compared to stroke teams.	
Grieve <i>et al.</i> (2000), UK and Denmark	Observational cohort data/ 12 months CEA	Hospital and community health services	London Stroke care vs Copenhagen stroke care (more went directly into stroke units as opposed to general medical care wards)	Life years gained	625; 297 in Copenhagen and 328 in London/ NR/ one-way sensitivity analysis	Incremental Cost Effectiveness Ratio for Copenhagen compared to London care model=\$21,579 to \$37,444 per life year saved for patients with cerebral infarctions in US\$ 1995 prices	Potential limitations include the comparability of the two groups and the generalisability of results
Dey <i>et al.</i> (2005), UK	RCT/12 months Not an economic evaluation nor a cost study	Not collected	Inpatient mobile stroke team vs non	Mortality, Barthel index, NEADL, Frenchay Aphasia, Simple Qs, EuroQol, HADS	308; 157 intervention and 151 control	Not feasible No significant difference in the Euroqol EQ-5D scores were found at 12 months Further research is needed to estimate the incremental cost of this intervention	No cost data collected but given no difference in Euroqol EQ-5D score suggest a CMA study may be sufficient to choose the cheapest service
Brady <i>et al.</i> (2005), international	Systematic review N/A; all studies	Most were health only or health and social care; five studies captured costs to patients	(i) Stroke unit vs other ward; (ii) early supported discharge vs usual	Not clearly reported for each individual study but Barthel index, ADL, mortality,	Sample sizes varied between 78 and 2770; nine studies had sample sizes of	None reported (i) Stroke unit care had slightly lower costs than	No formal assessment of methodological quality

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	review cost-consequences or cost analyses	or informal carers	care; (iii) rehabilitation in the community vs usual care	dependence, return home; seven studies found no significant difference in outcomes	140 or less/NR/ more than half conducted sensitivity analyses	rehabilitation on other hospital wards; outcomes mixed (3 studies) (ii) The better studies indicated costs were moderately lower for early supported discharge (iii) Community rehabilitation had conflicting evidence	conducted
Dekker <i>et al.</i> (1998), international	Literature review N/A; four studies report economic data	Insufficient detail given	Day hospital rehabilitation vs routine hospital rehabilitation or conventional management or home physiotherapy/rehab	Varied according to trial, mainly ADL, mood	Ranged from 96 patients to 327 patients/NR/NR	None reported States one study found no difference, whilst two showed day hospital 'less resource-efficient'; a further study showed day hospital rehabilitation as more 'cost-efficient'	Economic results are not clearly reported or discussed
Hui <i>et al.</i> (1995), Hong Kong	RCT/ 6 months NR; cost consequences	Not explicit but secondary care perspective – inpatient stay, outpatient clinic	Day hospital vs conventional medical management	Barthel index, Self rated well-being scale, Geriatric Depression Scale, Satisfaction with	120; 59 geriatric day hospital and 61 conventional care	NR No significant difference in costs at 6 months between groups	Numerous study details were not reported, for instance details of the sample

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		attendances and hospital readmissions.		services	/NR/NR	Well-being and satisfaction did not significantly differ at 6 months, although the authors conclude that they demonstrated functional improvement on the BI at 3 months	size calculation, blinding, how resource use was measured. The perspective of the cost study was narrow.
Roderick <i>et al.</i> (2001), UK	RCT/ 6 months CEA reported but costs and outcomes not combined	Health and social service perspective; rehabilitation services, GP, district nurse and hospital outpatient visits, hospital readmission and social service costs (occupational therapist, day centres, home care, meals on wheels)	New domiciliary rehabilitation programme vs geriatric day hospital care	Primary: Barthel index; secondary: RMI, FAI, SF-36, Philadelphia Morale Scale	140 stroke patients 55+ randomised; 66 to domiciliary and 74 day hospital/ power calculation used/ sensitivity analysis undertaken but NR	NR Neither costs nor outcomes were significantly different between the two services UK£ 1996–1997 prices	
Anderson <i>et al.</i> (2000a), Australia	RCT/ 6 months CMA	Health care system and patients and their families; hospital costs, home based rehabilitation costs, community	Early hospital discharge and home-based rehabilitation vs conventional care in the rehabilitation of stroke patients	NR; shown to be equally effective in a previous paper	86 patients 42 home based care, 44 conventional care/ sample size calculation done but NR/	Not appropriate Total costs were lower in the home-based scheme but not significantly different, although they remained	Like the majority of studies in this review, the sample-size calculation was undertaken

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		services (e.g. GP and nursing visits, meals on wheels, etc.) and caregiver costs			sensitivity analysis undertaken	lower in all sensitivity analyses \$Aust 1997–1998 prices	based on the clinical rather than economic outcomes.
Young and Forster (1993), UK	RCT/ 8 weeks CMA	Not explicit: Direct costs to the service; day hospital costs, home physiotherapy costs, health authority costs, district nursing costs, home care services and other local authority services	Day hospital vs home physiotherapy for stroke rehabilitation	NHP, FAI	95; 43 day hospital and 52 home physiotherapy /NR/NR	Not appropriate Total costs were significantly lower for the home physiotherapy group No significant difference in NHP or FAI between groups UK£ 1988–1989 price year	Short study time frame may not be adequate to reflect longer-term costs or outcomes
von Koch <i>et al.</i> (2001), Sweden	RCT/ 12 months NR; cost consequences	Health and social care plus informal care	Early discharge and home rehabilitation vs usual care	Mortality, ADL, FAI, Sickness Impact Profile, Social Occupational Classification, BI	83; 42 intervention and 41 usual care/ power calculation reported based on difference in costs /NR	NR It is not clear whether the lower cost estimated for early discharge patients compared to those receiving usual care is significantly different or not. Certain elements of cost were statistically different (including the costs to the	Unclear whether total costs were significantly lower for the intervention; some important methodological details missing

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						neurology department and to the county-based day hospital). No significant differences were found for any outcome measure. SEK price year unclear	
Donnelly <i>et al.</i> (2004), Northern Ireland	RCT/12 months NR; cost consequences	Not explicit; health and social services; cost categories not explicitly detailed	Early discharge and community-based multi-disciplinary stroke team (CST) vs usual care (hospital rehabilitation)	Barthel, NEADL, SF-36, QoL, Patient and carer satisfaction	113; 59 early discharge and CST vs 54 usual care (cost data collected for a subsample of 38 patients)/ sample size calculation reported/ NR	NR The mean cost of the CST group was less than the usual care group but this difference was not significantly different. No outcomes (except for patient satisfaction, which was higher for community rehabilitation) differed significantly between groups at baseline or 12 months. UK£ price year unclear.	Very small sample of patients used for the cost analysis and no sensitivity analysis performed
Teng <i>et al.</i> (2003),	RCT/3	Health care	4 week tailored home care of	SF-36 (presented in a previous	114; 58 home intervention and	NR, new intervention	Short follow-up period and

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Canada	months Not explicit; cost analysis and CEA	system	rehabilitation and nursing care vs usual care	paper); Burden Index (carer stress)	56 usual care/ NR/ multiway sensitivity analysis	dominates The total costs per person were lower (by CAN\$3281) in the home-based group compared to the hospital group, this was statistically significant The PCS component of the SF-36 was 5 points higher and significant. Carers in the home-based group had significantly lower burden scores than usual care. CAN\$ price year 1997–1998	narrow perspective.
Beech <i>et al.</i> (1999), UK	RCT/12 months Not explicit; cost analysis and CMA	Not explicit; health and social care services	Early discharge compared to usual care	Previous paper reported outcomes on motoricity index, mini- mental, FAI, BI, HADS, NHI, caregiver strain and pound questionnaires	331; 167 early discharge and 164 to conventional care/ NR/ limited sensitivity analysis conducted	Not applicable Average costs were 8% lower for the early discharge group (£6800 vs £7432 per patient) but it is not clear if this difference was statistically significant.	Not clear whether the difference in costs between groups was statistically different or not

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						A previous paper reported that none of the outcomes were statistically different except patient satisfaction, which was higher for early discharge patients. UK£1997 price year	
Gladman <i>et al.</i> (1994), UK	RCT/14 months Not explicitly stated – CMA	Health service costs	Home versus hospital rehabilitaton after discharge from hospital	NR, but state there was no difference in outcomes (reported in a previous paper)	327: 162 domiciliary group and 165 routine hospital-based group/ NR/NR	Not appropriate Total costs were lower for the routine hospital-based group (although for the health care for the elderly stratum the reverse was found) but it is not clear if this difference was significant or not. UK£1989/1990 price year	As the authors report, the perspective taken is narrow, excluding social services costs and patient/informal care costs
Byford <i>et al.</i> (1995), UK	Prospective and retrospective observational cohort data/12	Not explicit; hospital and community services	Early discharge compared to usual care	BI (reported in a previous study)	Group x (prospective outcome data): 10 placed and 61 unplaced patients	Mean cost per unit increase in BI £5859.48 unplaced and £586.85 placed.; tentatively looks	As the authors report, this study lacked comprehensive data and faced methodological

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months CEA	Group y (retrospective cost data): 8 placed and 41 unplaced/ NR/NR	as though placement scheme cost-effective	problems (e.g. using data on outcomes and costs from different samples and collected in different ways)
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BI, Bartel index; CEA, cost-effectiveness analysis; CMA, cost-minimisation analysis; FAI, Frenchay Activity Index; NHP, Nottingham Health Profile; NR, not reported.

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Two studies were found to contain economic information relating to traumatic brain injury (Table 19). Neither were full economic evaluations; instead, one was undertaken as a non-randomised controlled study and the other reviewed studies of traumatic brain injury. Ponsford *et al.* (2006) stated an aim as 'to assess its [community-based therapy] cost-effectiveness relative to the previous centre-based outpatient therapy intervention model'. However, this study did not do this; at best it can be called a cost-consequences study since the differences in cost and the multiple outcomes were not combined to inform resource-allocation decision-making. The methods employed in the economic component of the study were brief and therefore it was impossible to determine whether they captured all the appropriate cost categories and to determine how they valued resources, for instance. Since neither costs, nor most outcomes, were significantly different between the community-based model and the centre-based outpatient therapy model this study was unlikely to be informative to resource allocation decision makers but may be useful in designing future full economic evaluations of the topic.

Cope (1995) reviewed a number of papers, principally to determine the effectiveness of traumatic-brain-injury rehabilitation, but also reported changes to costs. The overall assertion of the review was that rehabilitation for people with traumatic brain injury improves return to work and that this produces cost savings. This assertion was made even when papers were broken down into categories by setting (intensive care unit/acute neurosurgical setting, acute inpatient hospital rehabilitation, post-acute rehabilitation, residential, specialised rehabilitation, and neurobehavioural interventions). Not enough detail was given surrounding the economic components of the studies, for instance about the perspective or range of costs included. It does not appear as though any of the studies included in the review combine the change in costs with the change in outcomes. Such evidence has limited use in informing resource-allocation decision-making.

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Table 19 Economic studies on traumatic brain injury

Author	Study design/ time period of study	Reported type of economic evaluation	Perspective/ cost categories	Intervention vs comparator	Outcomes	Sample Size/power calculation/ sensitivity analysis?	Incremental Cost Effectiveness Ratio	Methodological limitations
Ponsford <i>et al.</i> (2006), Australia	Experimental case control design/ 2 years	Cost- effectiveness analysis	Not explicit; number of therapy sessions (no monetary value attached), cost of travel and attendant care	Community- based therapy vs centre-based outpatient programme	A range of outcomes used from return to employment, independence in activities of daily living, through to mobility and communication	154; 77 community- based and 77 centre- based/ NR/NR	Not reported Costs were not significantly different between groups; most outcomes not significantly different between groups Price year not stated but presumably AUS\$	Poor-quality economic study, limited methods given, unclear all appropriate costs included, costs and outcomes never combined and the conclusion of lower costs in the community group is inappropriate given the differences were insignificant between groups
Cope (1995), USA	Review of traumatic- brain-injury rehabilitation studies	Not applicable; but no full economic evaluations reviewed	Not explicitly reported; most only looked at length of stay and change in productivity	Intensive care unit/acute neurosurgical setting, acute inpatient hospital rehabilitation, post-acute rehabilitation,	Mixed but included independence, living placement, and function	22 studies/ NR/NR	Traumatic- brain-injury care and rehabilitation improves return to work and produces cost savings	None of the studies included appear to undertake full economic evaluations where an incremental

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residential and specialised rehabilitation, and neurobehavioural interventions	for the health care system	cost-effectiveness ratio is reported, that is they do not combine costs and benefits to inform resource-allocation decision-making; narrow perspectives taken
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In the USA, a single study by DeVivo *et al.* (1990) examined whether there were any benefits to early admission to an organised multi-disciplinary spinal cord injury care system compared with patients who received acute care elsewhere and joined the specialist service only for rehabilitation. The study concluded that early admission resulted in reduced mortality, reduced incidence of pressure ulcers and a marginal increase in chance of neurological recovery. At the same time the authors reported reduced lengths of stay which resulted in lower hospital charges for those admitted early. The study is quite dated and only captures charges (which may not be representative of the true opportunity costs of care) for the period of acute care. The early and late groups were likely to have been considerably different in terms of case mix, and so this may account for the finding that outcomes and costs differed.

Two studies evaluated the use of community-based Parkinson's disease nurse specialists (Table 20). Both studies, Jarman *et al.* (2002) and Hurwitz *et al.* (2005), are by the same group of authors and appear to report the same study data (1859 patients with Parkinson's disease across nine randomly selected health authorities) presenting the same finding that nurse specialists had little impact on patient outcomes and that nor did the intervention change patient health care costs significantly. The authors estimate costs in the year preceding the study and in the year following randomisation from a health care perspective. A third study (Gage *et al.*, 2006) reported a cost-consequences study of a multi-disciplinary rehabilitation programme for people with Parkinson's disease without major cognitive loss. The study captured the health care costs of the intervention and those incurred by the patient through travel to appointments but did not present an incremental analysis of how these costs compared with usual care or the patients' care costs preceding the multi-disciplinary programme. Outcomes were presented as incremental changes between baseline scores and immediately post-treatment and at 4-months after treatment. Although mobility improved at 4 months ($P=0.09$) this and other outcomes were not significantly different at that time. The authors reported that they could not conclude whether the programme was worth funding or not because it was for funders to decide how much value they place on mobility gains. However, in actual fact the results cannot inform resource-allocation decision-making because in part the comparator is not wholly appropriate and as a consequence of this costs are presented for the intervention rather than as incremental costs. It is important to compare the costs of a new intervention with standard care because the intervention may have consequences on the patients' use of wider health and social care resources.

In multiple sclerosis, Pozzilli *et al.* (2002) undertook a cost-minimisation study in the expectation that home-based care ($n=133$) 'would improve patient health outcomes without increasing health care costs' (p. 250) compared with usual hospital care ($n=68$). However, cost minimisation is about minimising cost given equivalent outcomes and requires prior evidence or evidence gained within the study to demonstrate the equivalence of outcomes. Cost minimisation was not an appropriate technique to employ given their original hypothesis. The RCT study results found no significant difference in functional status between the intervention and control group, although there were significant differences on four of the SF-36 health dimensions. Health care costs were also found to be a little lower in the home-based care group by

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€822 per patient per year (1999 prices), although it is not clear to what extent this difference was statistically significant.

A systematic review of specialist epilepsy nurses for treating epilepsy by Bradley and Lindsay (2001b) found one study evaluating the costs of treatment. This study by Warren (1998) found that specialist epilepsy nurse care was cheaper than usual care for the health service at 6 months. However, it only considered the costs of a specialist centre and did not combine change in costs with change in outcomes to inform resource-allocation decision-making.

Two studies were found to contain information about resource use or need but neither study used this information to inform an economic evaluation or undertake a cost analysis for mixed neurological conditions. O'Connor and Delargy (2003) undertook a descriptive study of patients admitted to a Young Disabled Unit in Ireland. The average length of stay in the Young Disabled Unit was 621 bed days with a range from 29 to 1949 bed days. These data were not presented separately by condition or by patient characteristic, nor was a monetary value attached to resource use. Beatty *et al.* (2003) reported patient self-reported need and actualisation of services in order to assess the level of access that patients with cerebral palsy, multiple sclerosis, spinal cord injury or arthritis have to the services they need in the USA. The results showed significant differences in use of services and primary care physicians by condition. Those with spinal cord injury were least likely to use services, followed by multiple sclerosis patients and then cerebral palsy patients. Those needing support with arthritis received the greatest level of access to services. Data on the percentages of respondents who perceived a need for a service and who actually received one provide important information but mainly as a measure of equity of access rather than to inform the efficiency questions which economic evaluation aims to address.

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Table 20 Economic studies on progressive neurological conditions

Author, country	Study design/ time period of study	Type of economic evaluation	Perspective/ cost categories	Intervention vs comparator	Outcomes	Sample size/ power calculation/ sensitivity analysis?	ICER	Methodological limitations
Jarman <i>et al.</i> (2002), UK	RCT/ 2 years	Not stated but cost-analysis/ CCA	Not explicit: health and local authority Institutional, respite, hospital, day care, medication, community, GP care, social security benefits, home aids and adaptations and specialist nurses	Community-based nurses specialising in Parkinson's disease compared to control (routine GP care)	Survival, stand-up test, dot in square test, bone fracture, global health question, PDQ39, Euroqol EQ-5D	1859 patients with Parkinson's; 1028 intervention and 808 control/ sample size calculation included/ bootstrapped costs	Not reported No significant difference in costs nor outcomes found except on the global health question where patients in intervention group did better UK£ 1996 price year	
Hurwitz <i>et al.</i> (2005), UK	RCT/2 years	Not stated but cost-analysis/ CCA	Not explicit: health and local authority Institutional, respite, hospital, day care,	Community-based nurses specialising in Parkinson's disease compared to control (routine GP	Survival, stand up test, dot test, bone fracture, PDQ39, global health question,	1859 patients with Parkinson's; 1028 intervention and 808 control/	Not reported No significant difference in costs nor outcomes found except on the global	This paper appears to report the same study results as Jarmen <i>et al.</i> (2002)

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			medication, community, GP care, social security benefits, home aids and adaptations and specialist nurses	care)	Euroqol EQ-5D	sample size calculation included/ bootstrapped costs	health question where patients in intervention group did better UK£ 1996 price year	
Gage <i>et al.</i> (2006), UK	Mixture, pre/post study and RCT	CCA	Health service and participants; treatment costs and transport costs only	Programme of multi-disciplinary rehabilitation	Mixture; patient outcomes (mobility, speech and language, anxiety, depression, HRQL (disease specific and generic)) Carer outcomes (anxiety, depression, generic HRQL and carer strain). Social services (unmet need and carer danger) Receipt of home care and perceptions of	118 Parkinson's patients attending day hospital/ NR/NR	Not appropriate The authors conclude that it is not possible to say whether the service should be funded. This is because a judgement is required about the value of mobility (not significant at 4 months), which along with speech and language, depression and generic HRQL improved immediately post-treatment.	The costs of the intervention are presented but it is not clear that these are incremental; that is, compared with usual care or another appropriate comparator, which is at odds with the approach taken, with consequences. The perspective is very narrow and does not include knock-on costs to the wider health service, for instance. No decision can be made about the value of the

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					programme	UK£ 1999– 2000 price year	service.	
Pozzilli <i>et al.</i> (2002), Italy	RCT/12 months	Cost- minimisation analysis	National health service, inpatient care, outpatient and home care costs	Home care vs control (hospital care)	EDSS, MMSEFIM, mood measure (STAXI, STAI), CDQ-clinical depression questionnaire, SF-36	201 multiple sclerosis patients; 133 to intervention and 68 to control/ sample size calculation reported/ multivariate sensitivity analysis reported	Not appropriate Home-based care showed a saving of €822 per patient per year; it is not clear if this is significant but all resource use was significantly different between groups. The authors conclude there were no differences in functional status although home-based care was significantly better on four of the SF-36 dimensions. Euros 1999 price year	A detailed paper although lacking in detail on the degree of significance of the costs difference; also a fairly narrow perspective was taken.

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DeVivo <i>et al.</i> (1990), USA	Cohort study/not explicit but appears as if acute phase only	Not reported; considers costs and outcome separately	Not stated/hospital charges	Early admission to multi-disciplinary spinal cord injury care compared to acute care elsewhere and referral to specialist care for rehabilitation only	Mortality and some complications	661 Spinal cord injury patients; 284 early admission group and 377 delayed admissions group/ NR/NR	Not reported Mean hospital charges were only significantly different for quadriplegia, and not paraplegia, patients. Five (1.6%) of early admission patients died in rehabilitation compared to six (1.5%) elsewhere US\$ 1990 price year	Perspective limited and charges used rather than costs; the comparison group is probably an inadequate control; data were retrospective, of uncertain quality, and did not include important outcomes
Bradley and Lindsay (2001b), mixed	Systematic literature review	Not applicable; not an economic evaluation or a cost analysis	One study that reports costs does so from a health service perspective (Warren, 1998)	Specialist epilepsy nurse	Euroqol EQ-5D (Warren, 1998)	268 epilepsy patients and 20 people with learning or language disabilities (Warren, 1998)/ NR/NR	Not reported The Warren (1998) study suggests specialist epilepsy nurse care is cheaper than standard care. Health status as measured by Euroqol EQ-	The review does not report the actual cost savings of the Warren (1998) study.

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5D was not significantly different between groups.

CCA, cost-consequences analysis; HRQL, health-related quality of life.

Section 4 Discussion

4.1 Main findings of the study

This study undertook a mapping exercise to establish the taxonomy of services for people with long-term neurological conditions and hence to describe the range of services that exist for them in England. In doing this, it consulted users, providers and commissioners of such services, and from these informants it obtained an impression of services in England in 2006. The study also undertook a systematic literature review to establish the evidence base for different models of services, examining qualitative and policy documents as well as reports of evaluative research designs.

The main findings of the mapping study were that many different types of service exist, and that they differed according to whether the service

- dealt with patients during an acute phase of illness, a sub-acute phase or the chronic phase,
- was hospital-based (inpatient, outpatient or outreach) or community-based,
- was condition-specific or not,
- was a team or an individual (individuals could be uni-disciplinary or the case manager of a virtual team),
- was run by the statutory (health or social services), private or voluntary sector,
- was solely for carers, provided carer support or did not specifically involve carers,
- focused on activity or participation,
- was national, regional or local.

Some services were innovative and not easily classified.

The opinions of service users and service providers were quite similar to those obtained from the review of the qualitative and policy documents. The main views were that

- clinician expertise and person-centredness were noticed and valued by users,
- access to services was considered to be poor,
- services were not considered to be joined up,
- the orientation of services was poor, being focused primarily on hospital or acute provision, and not towards the long term, and not being focused on psychological function or participation outcomes.

Statutory services were best developed for stroke but were patchy for other conditions, most notably traumatic brain injury. Services tend to be based around major cities, and, with only a few exceptions, coverage of rural areas seemed poor. Hub-and-spoke models to disseminate centrally held expertise were described and might be successful, but they might be of no greater use than non-specialist services if they are so diffuse that they lack expertise or

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the ability to be patient-centred. Novel, web-based support services remain highly experimental.

Non-statutory services were extensive and seem to have developed because of a failure for statutory services to meet needs. Recent policies now encourage non-statutory services to be commissioned by health and social services, as opposed to relying entirely on charitable or insurance claims.

The review of the quantitative literature showed that stroke services had been most thoroughly researched in terms of effectiveness. RCTs and systematic reviews had demonstrated the benefit of organised inpatient stroke care in a stroke unit over ordinary care (by implication not organised or specialised) on general medical wards. RCTs and systematic reviews of rehabilitation interventions in the post-discharge phase up to 1 year also showed consistent benefits (for example by an occupational therapist) but there was no clear preference for any particular service model in terms of efficacy. Even though stroke was the most heavily researched, and even though the stroke unit studies were used to justify the NHS setting targets for the development of stroke units in the English NHS in the NSF for Older People, there are no good cost-effectiveness studies in this area.

Few studies have been undertaken for people with traumatic brain injury and no evidence compares different models of inpatient care for this condition. A small number of studies indicate that patients with post-traumatic amnesia of 1 hour or more benefit from routine follow-up contact giving information and advice and that there is a subgroup of patients with moderate to severe injury who benefit from a higher level of intervention, and who may not present themselves unless routine follow-up is provided. The cost-effectiveness of doing so is not known. There is no evidence of benefit for the routine use of case management.

No RCTs or robust studies have evaluated acute or sub-acute care for people with spinal cord injuries.

The studies for Parkinson's disease have mainly assessed nurse specialists compared with ordinary non-specialist care and conclude that there may be benefits in terms of satisfaction but not in terms of other health outcomes, and that there was also little difference in terms of costs between having such specialists and leaving care to ordinary medical care alone.

In multiple sclerosis, a number of small studies of brief periods of inpatient rehabilitation showed a mixed picture when compared to community alternatives, and there are no useful economic studies. Very few longer-term studies were found.

Specialist epilepsy nurses have been evaluated, but it is not clear whether they improve outcomes compared to ordinary medical care; nor are the economic consequences known.

The studies examined that were not condition-specific found that more intense rehabilitation therapy in a mixed inpatient rehabilitation unit reduce length of stay, but the economic consequences of this were not known.

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4.2 Limitations of the study

The typology of services described in this report was derived from the reports of services given by the informants, and using them it was possible to allocate services to categories such that true geographic maps could be created. However, this typology was limited to the range of services found in England in 2006, and may not be adequate for future services. For example, we found novel services difficult to classify. This may be because, as yet, they are too ill defined to do so, or that the typology is inadequate for all types of service.

The concordance between the views of key informants consulted in the mapping exercise and the findings of the qualitative and policy literature review is mutually re-enforcing, despite the drawbacks that the key informants may have been biased and the literature search will inevitably have been somewhat selective.

The literature search process was clearly not perfect. Examples of this include the observation that review papers were identified which cited research papers that were not, but should have been, found by the search strategy. This may be because trials in the rehabilitation field are poorly described and indexed. The extent of the bias introduced by deficiencies in the search and selection strategy is difficult to establish. However, the authors (including within them international experts in research in this field) themselves did not identify any major studies to have been omitted.

4.3 Key research gaps

Future research should

- include well-designed RCTs and economic evaluations of neurological rehabilitation services for people with long-term neurological conditions other than stroke;
- identify the incidence and prevalence of neurological conditions;
- examine the extent to which the long-term rehabilitation needs of people with long-term neurological conditions are identified, reviewed and addressed;
- explore ways (e.g. networks) of ensuring that rehabilitation continuity can be maintained in transitions between services, service providers and rehabilitation phases; for example, acute and sub-acute, hospital and community, so that service gaps can be reduced;
- evaluate long-term co-ordinated participation-orientated services;
- evaluate novel methods of providing and supporting rehabilitation services; for example, tele-rehabilitation or the use of trained volunteers;
- evaluate new services such as vocational rehabilitation services;
- evaluate new home-based alternatives to hospital care;
- include robust economic evaluations of specialist neurological rehabilitation service models, for example 'younger disabled units'.

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4.3.1 For stroke

Research should include good cost-effectiveness studies comparing models of community-based stroke rehabilitation and those aimed at the longer-term optimisation of health after stroke.

4.3.2 For traumatic brain injury

Research should evaluate models of community rehabilitation, with particular emphasis on measuring participation; for example, work, leisure and social activity and longer-term outcomes. Other work should include

- developing measures of participation,
- comparing different models of inpatient care,
- determining the effectiveness and cost-effectiveness of case management.

Studies examining the cost-effectiveness and cost benefits of specialist neurological rehabilitation for people with traumatic brain injury should do so from a societal and personal as well as a health services perspective because traumatic brain injury is typically an affliction of younger adults (mean age 29 years) and the effects are long-lasting.

4.3.3 For Parkinson's disease

Future efforts should include high-quality RCTs and cohort studies to determine the best methods of delivering rehabilitation (1) to all people with Parkinson's disease and (2) to younger people with the disease.

The effects of early rehabilitation and therapeutic interventions delivered in the community should be determined. The deterioration in health over time and high mortality rates should be taken into account in study design, particularly if a long-term follow-up is required.

4.3.4 For spinal cord injuries

Research should evaluate acute or sub-acute care for people with spinal cord injuries using RCTs or robust study designs.

4.3.5 For epilepsy

Specialist epilepsy nurses have been evaluated, but it is not clear whether they improve outcomes compared with ordinary medical care, and nor are the economic consequences known. Future research should address this.

4.3.6 For multiple sclerosis

Well-designed RCTs are needed to determine the best way of organising and delivering services for people with multiple sclerosis. Economic studies and those addressing longer-term needs would seem important.

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4.3.7 Qualitative research

In order to ensure that future services are designed to meet service users' needs and priorities and that future service evaluations capture the extent to which service users' needs are met, more primary qualitative research is needed.

This should

- *describe the rehabilitation process* and the context of rehabilitation service provision to advance understanding about which components of services that contribute most to effects and thus develop propositions for quantitative testing;
- *explore recipients' and providers' views of rehabilitation services*;
- *explore and evaluate methods of involving service users* in the design, uptake, provision and evaluation of specialist neurological rehabilitation services;
- *investigate the impact of home-based compared with specialist centre-based rehabilitation service provision* with respect to acceptability and impact on both carers and patients, and examine how the advantages of home delivery can be maximised while ameliorating the disadvantages;
- *investigate the impact of specialist neurological rehabilitation compared with generic rehabilitation services* in terms of acceptability and impact on both carers and patients.

4.4 Implications of the study

Unfortunately, this review of the evidence provides little firm assistance to commissioners of services for those with long-term neurological conditions and wishing to deliver the NSF for Long-Term Neurological Conditions in terms of illustrating clearly dominant models of health service delivery, or even in providing much in the way of comparative outcome or cost data concerning most forms of inpatient or outpatient services. Although not the subject of this review of service models, the literature is generally consistent with a beneficial effect of rehabilitation in general, despite the lack of information about any particular service model. The review re-states the view based upon user experience and specialist opinion that services should be accessible, patient-centred, long-term, joined up and participation-orientated, yet it was unable to provide evidence of how these outcomes can be achieved or the economic consequences of attempting to do so. The main message is therefore to confirm that there is an evidence deficiency.

There are many implications for the research community. Many research barriers exist, including:

- a lack of dedicated R&D funding towards models of specialist rehabilitation for long-term neurological conditions;
- a lack of R&D capacity in rehabilitation, including health economics;
- a lack of R&D capacity in social services and the non-statutory sector;
- a lack of a clear terminology to describe rehabilitation interventions;
- a lack of a clear terminology to describe or classify services;
- a lack of outcome measures in the participation domain;

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- a perceived benefit of intervention, making randomisation to 'no treatment' unethical, with the result that only trials comparing active treatments are possible, which are then more likely to be inconclusive;
- small numbers in some specialist services in single centres.

One way forward is to encourage the development of national networks of providers of services for long-term neurological conditions; for example, networks of all Young Disabled Units, community traumatic-brain-injury teams, etc. At first these networks could compare and contrast their services, aiming to undertake clinical benchmarking studies and the like. Having done so, systematic cohort studies could be undertaken to compare costs and outcomes against the natural variability of provision, when controlled for confounding variables. Work of this sort could be valuable in itself if done systematically, but it could also eventually lead to the formulation of RCTs. For example, if most Young Disabled Units have a waiting list, then a multi-centre cross-over RCT would be possible. Research networks already exist in other areas (most notably cancer).

Another way forward is to attempt to ensure that new services and developments are evaluated before they reach a point of acceptability and ordinariness that randomisation to them is impossible or unacceptable. An example would be the development of new vocational rehabilitation services, or new home-based alternative to hospital care. The difficulty here is that the pressures upon commissioners is to meet, as best they can, the terms of the policy documents that drive them rather than to provide the evidence base for doing so. To prevent this requires widespread recognition of the absence of an evidence base, the rapid availability of research funding and accessible research expertise, and some sort of policy pressure towards evaluation of effectiveness. At present the drive to evaluate is limited to the evaluation of the degree to which a service has been implemented rather than its effectiveness.

4.5 Key conclusions

Specialist rehabilitation services for long-term neurological conditions are poorly described. They tend to focus on the acute aspects of management, usually in major cities. This leaves deficiencies in rural areas and in community and longer-term service delivery. The charitable sector has tended to meet the shortfall in statutory provision to the extent that it is a major provider of services. The private sector, presumably funded mainly through insurance claims from traumatic brain injuries, is also a major provider of longer-term care, especially residential services. However, the evidence base to guide commissioners in the provision of services is inadequate. Only stroke units have a robust body of evidence to support them, but for most long-term neurological conditions the evidence base is basically absent (rather than negative). Much investment into evaluating these services is required. We propose that a network of rehabilitation services is established with the objective of developing the capacity to undertake the necessary research.

References

- Andersen, H.E., Schultz, L.K., Kreiner, S., Forchhammer, B.H., Eriksen, K. and Brown, A. 2000. Can readmission after stroke be prevented? Results of a randomized clinical study: a postdischarge follow-up service for stroke survivors. *Stroke* 31: 1038–45
- Anderson, C., Rubenach, S., Mhurchu, C.N., Clark, M., Spencer, C. and Winsor, A. 2000a. Home or hospital for stroke rehabilitation? Results of a randomised controlled trial. Health outcomes at 6 months. *Stroke* 31: 1024–31
- Anderson, C., Mhurchu, C.N., Rubenach, S., Clark, M., Spencer, C. and Winsor, A. 2000b. Home or hospital for stroke rehabilitation? Results of a randomised controlled trial. *Stroke* 31: 1032–7
- Aronow, H.U. 1987. Rehabilitation effectiveness with severe brain injury: translating research into policy. *Journal of Head Trauma Rehabilitation* 2: 24–36
- Bakheit, A. 1995. Delivery of rehabilitation services - an integrated hospital-community model. *Clinical Rehabilitation* 9: 142–9
- Barker, G. 2006. *Getting Back to Work After Stroke*. London: The Stroke Association and Different Strokes
- Barnes, M. 1997a. Minimum standards in neurological rehabilitation. *European Journal of Neurology* 4: 325–31
- Barnes, M.F. 1997b. Standards in neurological rehabilitation, June 1997. European Federation of Neurological Societies Task Force. *Behavioural Neurology* 10: S1–7
- Barnes, M.P. and Skeil, D.A. 1996. Outpatients in neurological rehabilitation. *International Journal of Rehabilitation Research* 19(1): 39–45
- Barnes, M.P. and Radermacher, H. 2001. Neurological rehabilitation in the community. *Journal of Rehabilitation Medicine* 33(6): 244–8
- Baskett, J.J., Broad, J.B., Reekie, G., Hocking, C. and Green, G. 1999. Shared responsibility for ongoing rehabilitation: a new approach to home-based therapy after stroke. *Clinical Rehabilitation* 13: 23–33
- Bautz-Holter, E., Sveen, U., Rygh, J., Rodgers, H. and Bruun, W.T. 2002. Early supported discharge of patients with acute stroke: a randomized controlled trial. *Disability and Rehabilitation* 24(7): 348–55
- Beatty, P.W., Hagglund, K.J., Neri, M.T., Dhont, K.R., Clark, M.J. and Hilton, S.A. 2003. Access to health care services among people with chronic or disabling conditions: patterns and predictors. *Archives of Physical Medicine & Rehabilitation* 84(10): 1417–25
- Beech, R., Rudd, A.G., Tilling, K. and Wolfe, C.A. 1999. Economic consequences of early inpatient discharge to community-based rehabilitation for stroke in an Inner-London teaching hospital. *Stroke* 30: 729–35
- Ben-Yishay, Y., Silver, S.M. and Piassetzky, E. 1987. Relationship between employability and vocational outcome after intensive holistic cognitive rehabilitation. *Journal of Head Trauma Rehabilitation* 2: 35–48

Specialist rehabilitation for neurological conditions

- Botterell, E.H., Jousse, A.T., Kraus, A.S., Thompson, M.G., WynneJones, M. and Geisler, W.O. 1975. A model for the future care of acute spinal cord injuries. *Canadian Journal of Neurological Sciences* 2(4): 361–80
- Bradley, P. and Lindsay, B. 2001a. Epilepsy clinics versus general neurology or medical clinics. *Cochrane Database of Systematic Reviews* 1: CD001910
- Bradley, P. and Lindsay, B. 2001b. Specialist epilepsy nurses for treating epilepsy. *Cochrane Database of Systematic Reviews* 4: CD001907
- Brady, B.K., McGahan, L. and Skidmore B. 2005. Systematic review of economic evidence on stroke rehabilitation services. *International Journal of Technology Assessment in Health Care* 21(1): 15–21
- Brown, J.B., Lattimer, V. and Tudball, T. 2006. An investigation of patients and providers' views of services for motor neurone disease. *British Journal of Neuroscience Nursing* 1(5): 249–52
- Buffington, A.L.H. and Malec, J.F. 1997. The vocational rehabilitation continuum: maximizing outcomes through bridging the gap from hospital to community-based services. *Journal of Head Trauma Rehabilitation* 12(5): 1–13
- Burke, D., Alexander, K., Baxter, M., Baker, F., Connell, K., Diggles, S. *et al.* 2000. Rehabilitation of a person with severe traumatic brain injury. *Brain Injury* 14(5): 463–71
- Burke, D.C. 1995. Models of brain injury rehabilitation. *Brain Injury* 9(7): 735–43
- Burton, C. and Gibbon, B. 2005. Expanding the role of the stroke nurse: a pragmatic clinical trial. *Journal of Advanced Nursing* 52(6): 640–50
- Byford, S., Geddes, J. and Bonsall, M. 1995. *Stroke Rehabilitation: a Cost-Effectiveness Analysis of a Placement Scheme*. Working Paper 140. York: Centre for Health Economics, University of York
- Cadilhac, D.A., Moodie, M.L., Lalor, E.E., Bilney, L.E. and Donnan, G.A. National Stroke Foundation. 2006. Improving access to evidence-based acute stroke services: development and evaluation of a health systems model to address equity of access issues. *Australian Health Review* 30(1): 109–18
- Checkland, P. and Scholes, J. 1999. *Soft Systems Methodology in Action*. Chichester: John Wiley
- Claesson, L., Gosman-Hedstrom, G., Johannesson, M., Fagerberg, B. and Blomstrand C. 2000. Resource utilization and costs of stroke unit care integrated in a care continuum: a 1-year controlled, prospective, randomized study in elderly patients. *Stroke* 31: 2569–77
- Commission for Healthcare. 2006. *Survey of Patients: Caring for people after they have had a stroke (a follow up survey of patients)*. London: Commission for Healthcare
- Cope, D.N. 1995. The effectiveness of traumatic brain injury rehabilitation: a review. *Brain Injury* 9(7): 649–70
- Corben, S. and Rosen, R. 2005. *Self-management for Long-term Conditions. Patients' Perspectives on the Way Ahead*. Kings Fund working paper. London: Kings Fund

Specialist rehabilitation for neurological conditions

- Corr, S. and Bayer, A. 1995. Occupational therapy for stroke patients after hospital discharge: a randomized controlled trial. *Clinical Rehabilitation* 9: 291–6
- Crawford, S., Wenden, F. and Wade, D.T. 1996. The Rivermead Head Injury Follow up Questionnaire: a study of a new rating scale and other measures to evaluate outcomes after head injury. *Journal of Neurology, Neurosurgery, and Psychiatry* 60: 510–14
- Das Gupta, R. and Turner-Stokes, L. 2002. Traumatic brain injury. *Disability & Rehabilitation* 24(13): 654–65
- Deane, K.H., Ellis-Hill, C., Dekker, K., Davies, P. and Clarke, C.E. 2003. A survey of current occupational therapy practice for Parkinson's disease in the United Kingdom. *British Journal of Occupational Therapy* 66(5): 193–200
- de Guise, E., Feyz, M., LeBlanc, J., Richard, S.L. and Lamoureux, J. 2005. Overview of traumatic brain injury patients at a tertiary trauma centre. *Canadian Journal of Neurological Sciences* 32(2): 186–93
- Dekker, R., Drost, E. and Groothof, J. 1998. Effects of day-hospital rehabilitation in stroke patients: a review of randomised clinical trials. *Scandinavian Journal of Rehabilitation Medicine* 30: 87–94
- Dennis, M. and Langhorne, P. 1994. So stroke units save lives: where do we go from here? *British Medical Journal* 309: 1273–7
- Dennis, M., O'Rourke, S., Slattery, J., Staniforth, T. and Warlow, C. 1997. Evaluation of a stroke family care worker: results of a randomised controlled trial. *British Medical Journal* 314: 1071–7
- Department of Health. 2000. *The NHS Plan: The Governments' response to the royal commission on long term care*. London: HMSO
- Department of Health. 2002a. *Specialised Services National Definition set: 7 Complex specialised rehabilitation for brain injury and complex disability (adult)*. London: Department of Health
- Department of Health. 2003. *NHS Changing Workforce Programme (2nd Edition) New ways of working in stroke care - Examples of new or extended roles for those involved with the care of stroke victims and their carers*. London: Department of Health
- Department of Health. 2005a. *The National Service Framework for Long-Term Conditions*. London: Department of Health
- Department of Health. 2005b. *Independence, Well-being and Choice: our vision for the future of social care for adults in England*. London: Department of Health
- Department of Health. 2006a. *Supporting People with Long-Term Conditions to Self Care - a guide to developing local strategies and good practice*. London: Department of Health
- Department for Work and Pensions. 2006. *A New Deal for Welfare: empowering people to work*. London: HMSO
- DeVivo, M.J., Stover, S.L., Fine, P.R. and Kartus, P.L. 1990. Benefits of early admission to an organised spinal cord injury care system. *Paraplegia* 28: 545–55

Specialist rehabilitation for neurological conditions

- Dey, P., Woodman, M., Gibbs, A., Steele, R., Stocks, S.J., Wagstaff, S. *et al.* 2005. Early assessment by a mobile stroke team: a randomised controlled trial. *Age & Ageing* 34(4): 331–8
- Diez-Tejedor, E. and Fuentes, B. 2001. Acute care in stroke: do stroke units make the difference? *Cerebrovascular Diseases* 11(suppl 1): 31–9
- Di Fabio, R.P., Soderberg, J., Choi, T., Hansen, C.R. and Schapiro, R.T. 1998. Extended outpatient rehabilitation: its influence on symptom frequency, fatigue, and functional status for persons with progressive multiple sclerosis. *Archives of Physical Medicine and Rehabilitation* 79(2): 141–6
- Dixon Woods, M., Shaw, R.L., Agarwal, S. and Smith, J.A., 2004. The problems of appraising. *Qualitative Research* 13: 223–5
- Dixon Woods, M., Bonas, S., Booth, A., Jones, D.R., Miller, T., Sutton, A.J. *et al.* 2006. How can systematic reviews incorporate qualitative research? A critical perspective. *Qualitative Research* 6(1): 27–44
- Donnelly, M., Power, M., Russell, M. and Fullerton, K. 2004. Randomised controlled trial of an early discharge rehabilitation service. The Belfast Community Stroke Trial. *Stroke* 35: 127–33
- Dowswell, G., Lawler, J. and Young, J. 2000. Unpacking the 'black box' of a nurse-led stroke support service. *Clinical Rehabilitation* 14 (2): 160–71
- Drummond, A.E.R., Pearson, B., Lincoln, N.B. and Berman, P. 2005. Ten year follow-up of a randomised controlled trial of care in a stroke rehabilitation unit. *British Medical Journal* 331: 491–2
- Eames, P., Cotterill, G., Kneale, T.A., Storrar, A.L. and Yeomans, P. 1996. Outcome of intensive rehabilitation after severe brain injury: a long term follow up study. *Brain Injury* 10(9): 631–50
- Early Supported Discharge Trialists. 2005. Services for reducing duration of hospital care for acute stroke patients. *Cochrane Database of Systematic Reviews* 1: CD000443
- Edwards, M.J., McNeil, J.E. and Greenwood, R.J. 2003. Process and outcome during early inpatient rehabilitation after brain injury. *Disability & Rehabilitation* 25(8): 405–10
- Ellis, G., Mant, J., Langhorne, P., Dennis, M. and Winner, S. 2005. Stroke liaison workers for stroke patients and carers. *Cochrane Database of Systematic Reviews* 1: CD005066
- Evans, A., Perez, I., Harraf, F., Melbourn, A., Steadman, J., Donaldson, N. and Kalra, L. 2001. Can differences in management processes explain different outcomes between stroke unit and stroke-team care? *Lancet* 358: 1586–92
- Evans, A., Harraf, F., Donaldson, N. and Kalra, L. 2002. Randomized controlled study of stroke unit care versus stroke team care in different stroke subtypes. *Stroke* 33(2): 449–55
- Evers, S.M., Ament, A.J. and Blaauw, G. 2000. Economic evaluation in stroke research: a systematic review. *Stroke* 31: 1046–53
- Fagerberg, B., Claesson, L., Gosman-Hedstrom, G. and Blomstrand, C. 2000. Effect of acute stroke unit care integrated with care continuum versus conventional treatment: a randomized 1-year study of elderly patients: the Goteborg 70+ Stroke Study. *Stroke* 31: 2578–84

Specialist rehabilitation for neurological conditions

- Finlayson, M. 2004. Concerns about the future among older adults with multiple sclerosis. *American Journal of Occupational Therapy* 58(1): 54–63
- Fjaertoft, H., Indredavik, B. and Lydersen, S. 2003. Stroke unit care combined with early supported discharge: long-term follow-up of a randomized controlled trial. *Stroke* 34: 2687–91
- Forster, A. and Young J. 1996. Specialist nurse support for patients with stroke in the community: a randomized controlled trial. *British Medical Journal* 312: 1642–6
- Fraser, R.T., Clemmons, D., Trejo, W. and Temkin, N.R. 1983. Program evaluation in epilepsy rehabilitation. *Epilepsia* 24(6): 734–46
- Freeman, J.A., Langdon, D.W., Hobart, J.C. and Thompson, A.J. 1997. The impact of inpatient rehabilitation on progressive multiple sclerosis. *Annals of Neurology* 42: 236–44
- Francabandera, F.L., Holland, N.J., Wiesel-Levison, P. and Scheinberg, L.C. 1988. Multiple sclerosis rehabilitation: inpatient vs. outpatient. *Rehabilitation Nursing* 13(5): 251–3
- Gage, H., Kaye, J., Owen, C., Trend, P. and Wade, D. 2006. Evaluating rehabilitation using cost-consequences analysis: an example in Parkinson's disease. *Clinical Rehabilitation* 20(3): 232–8
- Geddes, J.M.L. and Chamberlain, M.A. 2001. Home-based rehabilitation for people with stroke: a comparative study of six community services providing co-ordinated, multidisciplinary treatment. *Clinical Rehabilitation* 15: 589–99
- Gilbertson, L., Langhorne, P., Walker, A. and Murray, G. 2000. Domiciliary occupational therapy for patients with stroke discharged from hospital: randomised controlled trial. *British Medical Journal* 320: 603–6
- Glader, E.L., Stegmayr, B., Johansson, L., Hulter, A. and Wester, P. 2001. Differences in long-term outcome between patients treated in stroke units and in general wards: a 2-year follow-up of stroke patients in Sweden. *Stroke* 32: 2124–30
- Gladman, J. and Lincoln, N. 1994. Follow-up of a controlled trial of domiciliary stroke rehabilitation (Domino Study). *Age & Ageing* 23: 9–13
- Gladman, J.R., Lincoln, N.B. and Barer, D.H. 1993. A randomised controlled trial of domiciliary and hospital-based rehabilitation for stroke patients after discharge from hospital. *Journal of Neurology, Neurosurgery, and Psychiatry* 56: 960–6
- Gladman, J., Whynes, D. and Lincoln, N. 1994. Cost comparison of domiciliary and hospital-based stroke rehabilitation. *Age & Ageing* 23: 241–245
- Gladman, J., Forster, A. and Young, J. 1995. Hospital and home-based rehabilitation after discharge from hospital for stroke patients: analysis of two trials. *Age & Ageing* 24: 49–53
- Grasel, E., Biehler, J., Schmidt, R. and Schupp, W. 2005. Intensification of the transition between inpatient neurological rehabilitation and home care of stroke patients. Controlled clinical trial with follow-up assessment six months after discharge. *Clinical Rehabilitation* 19(7): 725–36

Specialist rehabilitation for neurological conditions

- Greenberg, E., Treger, J. and Ring, H. 2004. Post-stroke follow-up in a rehabilitation center outpatient clinic. *Journal of Israel Medical Association Journal* 6(10): 603–6
- Greenwood, R.J., McMillan, T.M., Brooks, D.N., Dunn, G., Brock, D., Dinsdale, S. *et al.* 1994. Effects of case management after severe head injury. *British Medical Journal* 308: 1199–1205
- Grieve, R., Porsdal, V., Hutton, J. and Wolfe, C. 2000. A comparison of the cost-effectiveness of stroke care provided in London and Copenhagen. *International Journal of Technology Assessment in Health Care* 16(2): 684–95
- Haffey, W.J. and Abrams, D.L. 1991. Employment outcomes for participants in a brain injury work reentry program: preliminary findings. *Journal of Head Trauma Rehabilitation* 6: 24–34
- Hale, L.A. 2004. Community-based or home-based stroke rehabilitation: confusion or common sense? *New Zealand Journal of Physiotherapy* 32(3): 131–9
- Hintgen, T.L., Radichel, T.J., Clark, M.B., Sather, T.W. and Johnson, K.L. 2000. Volunteers, communication, and relationships: synergistic possibilities. *Topics in Stroke Rehabilitation* 7(2): 1–9
- Holloway, M. 2006. Traversing the network: a user-led Care Pathway approach to the management of Parkinson's disease in the community. *Health and Social Care in the Community* 14(1): 63–73
- Holmes, T. 2005. Clinical update. Motor Neurone Disease and the NSF for long-term neurological conditions. *Primary Health Care* 15(9): 27–31
- Holmqvist, L., von Koch, L., Kostulas, V., Holm, M., Widsell, G., Tegler, H. *et al.* 1998. A randomised controlled trial of rehabilitation at home after stroke in southwest Stockholm. *Stroke* 29: 591–7
- Holmqvist, L., von Koch, L. and de Pedro-Cuesta, J. 2000. Use of healthcare, impact on family caregivers and patient satisfaction of rehabilitation at home after stroke in southwest Stockholm. *Scandinavian Journal of Rehabilitation Medicine* 32: 173–9
- Hui, E., Lum, C., Woo, J. and Kay, R.L.C. 1995. Outcomes of elderly stroke patients: day hospital versus conventional medical management. *Stroke* 26: 1616–19
- Hurwitz, B., Jarman, B., Cook, A. and Bajekal, M. 2005. Scientific evaluation of community-based Parkinson's disease nurse specialists on patient outcomes and health care costs. *Journal of Evaluation in Clinical Practice* 11(2): 97–110
- Indredavik, B., Slordahl, S. and Bakke, F. 1997. Stroke unit treatment. Long-term effects. *Stroke* 28: 1861–6
- Indredavik, B., Bakke, F. and Slordahl, S. 1998. Stroke unit treatment improves long-term quality of life: a randomised controlled trial. *Stroke* 29: 895–9
- Indredavik, B., Bakke, F., Slordahl, S., Rokseth, R. and Haheim, L. 1999. Stroke unit treatment. 10-year followup. *Stroke* 30: 1524–7
- Indredavik, B., Fjaertoft, H., Ekeberg, G., Loge, A. and Morch, B. 2000. Benefit of an extended stroke unit service with early supported discharge: a randomized, controlled trial. *Stroke* 31: 2989–94

Specialist rehabilitation for neurological conditions

- Inman, C. 1999. Effectiveness of spinal cord injury rehabilitation. *Clinical Rehabilitation* 13(suppl 1): 25–31
- Inter-agency Advisory Group on Vocational Rehabilitation after Brain Injury. 2004. *Vocational Assessment and Rehabilitation after Acquired Brain Injury*. Inter-agency guidelines. London: British Society for Rehabilitation Medicine/ Royal College of Physicians
- Intercollegiate Working Party for Stroke. 2006. *National Sentinel Audit for Stroke*. London: Royal College of Physicians
www.rcplondon.ac.uk/pubs/brochure.aspx?e=215
- Jarman, B., Hurwitz, B., Cook, A., Bajekal, M. and Lee, A. 2002. Effects of community based nurses specialising in Parkinson's disease on health outcome and cost: randomised controlled trial. *British Medical Journal* 324: 1072–5
- Johnson, J. and Thompson, A. 1996. Rehabilitation in a neuroscience centre: the role of expert assessment and selection. *British Journal of Therapy and Rehabilitation* 3(6): 303–8
- Jorgensen, H.S., Nakayama, H., Raaschou, H.O., Larsen, K., Hubbe, P. and Olsen, T.S. 1995. The effect of a stroke unit: reductions in mortality, discharge rate to nursing home, length of hospital stay, and cost. A community-based study. *Stroke* 26(7): 1178–82
- Jorgensen, H.S., Kammersgaard, L.P., Nakayama, H., Raaschou, H.O., Larsen, K., Hubbe, P. and Olsen, T.S. 1999. Treatment and rehabilitation on a stroke unit improves 5-year survival. A community-based study. *Stroke* 30(5): 930–3
- Jorgensen, H.S., Kammersgaard, L.P., Houth, J., Nakayama, H., Raaschou, H.O., Larsen, K. *et al.* 2000. Who benefits from treatment and rehabilitation in a stroke unit? A community-based study. *Stroke* 31(2): 434–9
- Juby, L.C., Lincoln, N.B. and Berman, P. 1996. The effect of a stroke rehabilitation unit on functional and psychological outcome: a randomised controlled trial. *Cerebrovascular Diseases* 6: 106–10
- Kalra, L. 1994. The influence of stroke unit rehabilitation on functional recovery from stroke. *Stroke* 25(4): 821–5
- Kalra, L., Dale, P. and Crome, P. 1993. Improving stroke rehabilitation a controlled study. *Stroke* 24: 1462–7
- Kalra, L., Evans, A., Perez, I., Knapp, M., Donaldson, N. and Swift, C.G. 2000. Alternative strategies for stroke care: a prospective randomised controlled trial. *Lancet* 356: 894–9
- Keaton, L., Steiner, V., Masterson, M., Smith, J.L., Pierce, L.L., Lance, K. and Rice, M.S. 2004. An E-rehabilitation team helps caregivers deal with stroke. *Internet Journal of Allied Health Sciences & Practice* 2(4): 17p.
- Kendall, M.B., Ungerer, G. and Dorsett, P. 2003. Bridging the gap: transitional rehabilitation services for people with spinal cord injury. *Disability & Rehabilitation* 25(17): 1008–15
- Kirshblum, S.C. 2002. Clinical activities of the model spinal cord injury system. *Journal of Spinal Cord Medicine* 25(4): 339–44
- Kramer, A.M., Kowalsky, J.C., Lin, M., Grigsby, J., Hughes, R. and Steiner, J.F. 2000. Outcome and utilization differences for older persons with

Specialist rehabilitation for neurological conditions

stroke in HMO and fee-for-service systems. *Journal of the American Geriatrics Society* 48(7): 726–34

- Kwakkel, G., Wagenaar, R.C., Koelman, T.W., Lankhorst, G.J. and Koetsier, J.C. 1997. Effects of intensity of rehabilitation after stroke. A research synthesis. *Stroke* 28: 1550–6
- La Marche, J.A., Reed, L.K., Rich, M.A., Cash, A.W., Lucas, L.H. and Boll, T.J. 1995. The interactive community-based model of vocational rehabilitation. *Journal of Head Trauma Rehabilitation* 10(4): 81–9
- Langhorne, P. and Duncan, P. 2001. Does the organization of postacute stroke care really matter? *Stroke* 32: 268–74
- Langhorne, P., Dennis, M.S., Kalra, L., Shepperd, S., Wade, D.T. and Wolfe, C.D. 2000. Services for helping acute stroke patients avoid hospital admission. *Cochrane Database of Systematic Reviews* 2: CD000444
- Langhorne, P., Dey, P., Woodman, M., Kalra, L., Wood-Dauphinee, S., Pate, N. and Hamrin, E. 2005a. Is stroke unit care portable? A systematic review of the clinical trials. *Age & Ageing* 34: 324–30
- Langhorne, P., Taylor, G., Murray, G., Dennis, M., Anderson, C., Bautz-Holter, E. *et al.* 2005b. Early supported discharge services for stroke patients: a meta-analysis of individual patients' data. *Lancet* 365: 501–6
- La Rocca, N.G., Kalb, R.C. and Gregg, K. 1996. A program to facilitate retention of employment among persons with multiple sclerosis. *WORK: A Journal of Prevention, Assessment & Rehabilitation* 7(1): 37–46
- Larsson Lund, M. and Tamm, M. 2001. How a group of disabled persons experience rehabilitation over a period of time. *Scandinavian Journal of Occupational Therapy* 8(2): 96–104
- Legg, L. and Langhorne, P. 2004. Rehabilitation therapy services for stroke patients living at home: systematic review of randomised trials. *Lancet* 363: 352–6
- Lewinter, M. and Mikkelsen, S. 1995. Patients' experience of rehabilitation after stroke. *Disability and Rehabilitation* 17(1): 3–9
- Lincoln, N.B., Husbands, S., Trescoli, C., Drummond, A.E.R., Gladman, J.R.F. and Berman, P. 2000. Five year follow up of a randomised controlled trial of a stroke rehabilitation unit. *British Medical Journal* 320: 549–50
- Lincoln, N.B., Walker, M.F., Dixon, A. and Knights, P. 2004. Evaluation of a multiprofessional community stroke team: a randomized controlled trial. *Clinical Rehabilitation* 18(1): 40–7
- Logan, P., Ahern, J., Gladman, J. and Lincoln, N. 1997. A randomised controlled trial of enhanced social services occupational therapy for stroke patients. *Clinical Rehabilitation* 11: 107–13
- Low, J.T., Roderick, P. and Payne, S. 2004. An exploration looking at the impact of domiciliary and day hospital delivery of stroke rehabilitation on informal carers. *Clinical Rehabilitation* 18(7): 776–84
- Ma, R.H., Wang, Y.J., Qu, H. and Yang, Z.H. 2004. Assessment of the early effectiveness of a stroke unit in comparison to the general ward. *Chinese Medical Journal* 117(6): 852–5
- Mackay, L.E., Bernstein, B.A., Chapman, P.E., Morgan, A.S. and Milazzo, L.S. 1992. Early intervention in severe head injury: long-term benefits of a

Specialist rehabilitation for neurological conditions

formalized program. *Archives of Physical Medicine and Rehabilitation* 73(7): 635–41

Mackay, S., Traill, P., Watson, C., Beech, R., Wolfe, C.D. and Rudd, A.G. 1995. Stroke rehabilitation: service delivery options and innovations. *British Journal of Therapy and Rehabilitation* 2(9): 502–4

Malec, J.F., Smigielski, J.S., DePmelo, R.W. and Thompson, J.M. 1993. Outcome evaluation and prediction in a comprehensive-integrated post acute outpatient brain injury rehabilitation programme. *Brain Injury* 7: 15–29

Mayo, N.E., Wood-Dauphinee, S., Cote, R., Gayton, D., Carlton, J., Buttery, J. and Tamblyn, R. 2000. There's no place like home: an evaluation of early supported discharge for stroke. *Stroke* 31(5): 1016–23

McKevitt, C., Redfern, J., Mold, F. and Wolfe, C. 2004. Qualitative studies of stroke a systematic review. *Stroke* 35: 1499–1505

McMillan, T.M. and Ledder, H. 2001. A survey of services provided by community neurorehabilitation teams in South East England. *Clinical Rehabilitation* 15(6): 582–8

Morgan, A.S., Chapman, P. and Takarski, L. 1988. Improved care of the traumatically brain injured. Paper presented at the Eastern Association for Surgery of Trauma- First Annual Conference, Longboat Key, FL

Moskowitz, C.B. and Marder, K. 2001. Palliative care for people with late-stage Huntington's disease. *Neurologic Clinics* 19(4): 849–65

Motor Neurone Disease Association. 2003. *No Time to Lose: MND and the National Service framework on long - term conditions*. Northampton: MND Association

Multiple Sclerosis Trust. 2006. *Therapists in MS: delivering the long term solutions*. Letchworth: MS Trust

Murray, J., Young, J., Forster, A. and Ashworth, R. 2004. A survey to investigate the role of the district nurse in stroke care. *British Journal of Community Nursing* 9(8): 318–24

National Clinical Guidelines (2004) *Multiple Sclerosis: National clinical guidelines for diagnosis and management in primary and secondary care*. London: Clinical Effectiveness and Evaluation Unit, Royal College of Physicians. www.rcplondon.ac.uk/pubs/books/MS/index.asp

National Collaborating Centre for Chronic Conditions. 2004. *Multiple Sclerosis: National Clinical Guidelines for diagnosis and management in primary and secondary care*. London: Clinical Effectiveness and Evaluation Unit, Royal College of Physicians

Neri, M.T. and Kroll, T. 2003. Understanding the consequences of access barriers to health care: experiences of adults with disabilities. *Disability & Rehabilitation* 25(2): 85–96

NICE. 2003. *Clinical Guideline 8. Multiple Sclerosis: Management of Multiple Sclerosis in primary and secondary care*. London: National Institute for Health and Clinical Excellence

NICE. 2006. *Clinical Guideline 35. Parkinson's Disease - Diagnosis and management in primary and secondary care*. London: National Institute for Health and Clinical Excellence

Specialist rehabilitation for neurological conditions

- O'Connor, R.J. and Delargy, M.A. 2003. Acute hospital discharges of patients with major disability: a review of patients admitted to a young disabled unit. *Irish Medical Journal* 96(7): 209–11
- Oliver, M. 1990. *The Politics of Disablement*. Basingstoke: Macmillan
- Outpatient Service Trialists. 2003. Therapy-based rehabilitation services for stroke patients at home. *Cochrane Database of Systematic Reviews* 1: CD002925
- Petticrew, M. and Roberts, H. 2006. *Systematic Reviews in the Social Sciences: a Practical Guide*. Malden, MA: Blackwell Publishing
- Ponsford, J., Olver, J., Ponsford, M. and Nelms, R. 2003. Longterm adjustment of families following traumatic brain injury where comprehensive rehabilitation has been provided. *Brain Injury* 17: 453–68
- Ponsford, J., Harrington, H., Olver, J. and Roper, M. 2006. Evaluation of a community-based model of rehabilitation following brain injury. *Neuropsychological Rehabilitation* 16(3): 315–28
- Pound, P., Sabin, C. and Ebrahim, S. 1999. Observing the process of care: a stroke unit, elderly care unit and general medical ward compared. *Age & Ageing* 28: 433–40
- Powell, J., Heslin, J. and Greenwood, R. 2002. Community based rehabilitation after severe traumatic brain injury: a randomised controlled trial. *Journal of Neurology, Neurosurgery, and Psychiatry* 72(2): 193–202
- Pozzilli, C., Brunetti, M., Amicosante, A.M., Gasperini, C., Ristori, G., Palmisano, L. and Battaglia, M. 2002. Home based management in multiple sclerosis: results of a randomised controlled trial. *Journal of Neurology, Neurosurgery, and Psychiatry* 73(3): 250–5
- Prigatano, G.P., Fordyce, D.J., Zeiner, H.K., Roueche, J.R., Pepping, M. and Wood, B.C. 1984. Neuropsychological rehabilitation after closed head injury in young adults. *Journal of Neurology, Neurosurgery, and Psychiatry* 47: 505–13
- Prime Minister's Strategy Unit. 2005. *Improving the Life Chances of Disabled People. Final Report*. London: Prime Minister's Strategy Unit
- Quinn, A. 2006. *Evaluation of MS Specialist Worker Post in West Berkshire*. Reading: School of Health and Social Care, University of Reading
- Reding, M.J., La Rocca, N.G. and Madonna, M. 1987. Acute-hospital care versus rehabilitation hospitalisation for management of nonemergent complications in multiple sclerosis. *Journal of Neurologic Rehabilitation* 1: 13–17
- Reynders, H.J. and Baker, G.A. 2002. A review of neuropsychological services in the United Kingdom for patients being considered for epilepsy surgery. *Seizure: European Journal of Epilepsy* 11: 217–23
- Ricauda, N.A., Bo, M., Molaschi, M., Massaia, M., Salerno, D., Amati, D. et al. 2004. Home hospitalization service for acute uncomplicated first ischemic stroke in elderly patients: a randomized trial. *Journal of the American Geriatrics Society* 52(2): 278–83
- Rice-Oxley, M. and Turner-Stokes, L. 1999. Effectiveness of brain injury rehabilitation. *Clinical Rehabilitation* 13 (suppl 1): 7–24

Specialist rehabilitation for neurological conditions

- Ricker, J.H., Rosenthal, M., Garay, E., DeLuca, J., Germain, A., Abraham-Fuchs, K. and Schmidt, K.U. 2002. Telerehabilitation needs: a survey of persons with acquired brain injury. *Journal of Head Trauma Rehabilitation* 17(3): 242–50
- Ridsdale, L., Robins, D., Cryer, C. and Williams, H. 1997. Feasibility and effects of nurse run clinics for patients with epilepsy in general practice: randomised controlled trial. Epilepsy Care Evaluation Group. *British Medical Journal* 314: 120–2
- Ridsdale, L., Kwan, I. and Cryer, C. Group T.E.E.C. 1999. The effect of a special nurse on patients' knowledge of epilepsy and their emotional state. *British Journal of General Practice* 49: 285–9
- Ridsdale, L., Kwan, C., Cryer, C. and the Epilepsy Care Evaluation Group. 2000. Newly diagnosed epilepsy: can nurse specialists help? A randomized controlled trial. *Epilepsia* 41(8): 1014–19
- Ritchie, J. and Spencer, L. 2002. Qualitative data analysis for applied policy research. In Huberman, A.M. and Miles, M.B. (eds), *The Qualitative Researcher's Companion*. London: Sage Publications
- Roderick, P., Low, J., Day, R., Peasgood, T., Mullee, M.A., Turnbull, J.C. *et al.* 2001. Stroke rehabilitation after hospital discharge: a randomized trial comparing domiciliary and day-hospital care. *Age & Ageing* 30(4): 303–10
- Rodgers, H., Soutter, J., Kaiser, W., Pearson, P., Dobson, R., Skilbeck, C. and Bond, J. 1997. Early supported discharge following acute stroke: pilot study results. *Clinical Rehabilitation* 11: 280–7
- Rodgers, H., Atkinson, C., Bond, S., Suddes, M., Dobson, R. and Curless, R. 1999. Randomized controlled trial of a comprehensive stroke education program for patients and caregivers. *Stroke* 30: 2585–91
- Rodgers, H., Dennis, M., Cohen, D. and Rudd, A. 2003. British Association of Stroke Physicians. British Association of Stroke Physicians: benchmarking survey of stroke services. *Age & Ageing* 32(2): 211–17
- Ronen, J., Itzkovich, M., Bluvshstein, V., Thaleisnik, M., Goldin, D., Gelernter, I. *et al.* 2004. Length of stay in hospital following spinal cord lesions in Israel. *Spinal Cord* 42(6): 353–8
- Ronning, O. and Guldvog, B. 1998a. Stroke units versus general medical wards, I: twelve- and eighteen month survival: a randomized, controlled trial. *Stroke* 29: 58–62
- Ronning, O.M. and Guldvog, B. 1998b. Stroke unit versus general medical wards, II: Neurological deficits and activities of daily living A quasi-randomised controlled trial. *Stroke* 29: 586–90
- Ronning, O. and Guldvog, B. 1998c. Outcome of sub acute stroke rehabilitation: a randomized controlled trial. *Stroke* 29: 779–84
- Ronning, O., Guldvog, B. and Stavem, K. 2001. The benefit of an acute stroke unit in patients with intracranial haemorrhage: a controlled trial. *Journal of Neurology, Neurosurgery, and Psychiatry* 70: 631–4
- Rossiter, D. and Thompson, A.J. 1995. Introduction of integrated care pathways for patients with multiple sclerosis in an inpatient neurorehabilitation setting. *Disability & Rehabilitation* 17(8): 443–8

Specialist rehabilitation for neurological conditions

- Rudd, A.G., Wolfe, C.D., Tilling, K. and Beech, R. 1997. Randomised controlled trial to evaluate early discharge scheme for patients with stroke. *British Medical Journal* 315: 1039–44
- Rudd, A.G., Irwin, P. and Rutledge, Z. 1999. The national sentinel audit of stroke: a tool for raising standards of care. *Journal of the Royal College of Physicians London* 33: 460–4
- Rudd, A., Lowe, D., Irwin, P., Rutledge, Z. and Pearson, M. 2001a. National stroke audit: a tool for change? *Quality in Health Care* 10: 141–51
- Rudd, A.G., Irwin, P., Rutledge, Z., Lowe, D., Wade, D.T. and Pearson, M. 2001b. Regional variations in stroke care in England, Wales and Northern Ireland: results from the National Sentinel Audit of Stroke. Royal College of Physicians Intercollegiate Stroke Working Party. *Clinical Rehabilitation* 15(5): 562–72
- Salter, K., Jutai, J., Hartley, M., Foley, N., Bhogal, S., Bayona, N. and Teasell, R. 2006. Impact of early vs delayed admission to rehabilitation on functional outcomes in persons with stroke. *Journal of Rehabilitation Medicine* 38(2): 113–17
- Scheer, J., Kroll, T., Neri, M.T. and Beatty, P. 2003. Access barriers for persons with disabilities: the consumer's perspective. *Journal of Disability Policy Studies* 13(4): 221–30
- Scottish Intercollegiate Guidelines Network. 2006. *Critical Appraisal: Notes And Checklists, 2001–2006*. www.sign.ac.uk/methodology/checklists.html (accessed 26 June 2007)
- Semlyen, J.K., Summers, S.J. and Barnes, M.P. 1998. Traumatic brain injury: efficacy of multidisciplinary rehabilitation. *Archives of Physical Medicine & Rehabilitation* 79(6): 678–83
- Sheriff, J.N. and Chenoweth, L. 2003. Challenges in conducting research to improve the health of people with Parkinson's disease and the well-being of their family carers. *International Journal of Rehabilitation Research* 26(3): 201–5
- Shue, K.L. 1993. Repatriation Community Programs, Part I: A collaborative model of service delivery. *Brain Injury* 7(4): 367–76
- Slade, A., Tennant, A. and Chamberlain, M.A. 2002. A randomised controlled trial to determine the effect of intensity of therapy upon length of stay in a neurological rehabilitation setting. *Journal of Rehabilitation Medicine* 34(6): 260–6
- Smith, M. 2002. Efficacy of specialist versus non-specialist management of spinal cord injury within the UK. *Spinal Cord* 40(1): 10–16
- Smith, M.J., Vaughan, F.L., Cox, L.J., McConville, H., Roberts, M., Stoddart, S. and Lew, A.R. 2006. The impact of community rehabilitation for acquired brain injury on carer burden: an exploratory study. *Journal of Head Trauma Rehabilitation* 21(1): 76–81
- Solari, A., Filippini, G., Gasco, P., Colla, L., Salmaggi, A., La Mantia, L. *et al.* 1999. Physical rehabilitation has a positive effect on disability in multiple sclerosis patients. *Neurology* 52: 57
- Stegmayr, B., Asplund, K., Hulter-Asberg, K., Norrving, B., Peltonen, M., Terént, A. and Wester, P.O. for the Riks-Stroke Collaboration. 1999. Stroke units in their natural habitat: can results of randomized trials be

Specialist rehabilitation for neurological conditions

- reproduced in routine clinical practice? Riks-Stroke Collaboration. *Stroke* 30: 709–14
- Steiner, V. and Pierce, L.L. 2002. Innovations in practice. Building a Web of support for caregivers of persons with stroke. *Topics in Stroke Rehabilitation* 9(3): 102–11
- Stroke Unit Trialists' Collaboration. 1997. Collaborative systematic review of the randomised controlled trials of organised inpatient (stroke unit) care after stroke. *British Medical Journal* 314: 1151
- Stroke Unit Trialists' Collaboration. 2007. Organised inpatient (stroke unit) care for stroke. *Cochrane Database of Systematic Reviews* 4: CD000197
- Stuart, M. and Zafonte, R. 2004. Fighting the silent epidemic: the Florida Brain and Spinal Cord Injury Program. *Journal of Head Trauma Rehabilitation* 19(4): 329–40
- Sulch, D., Evans, A., Melbourn, A. and Kalra, L. 2002. Does an integrated care pathway improve processes of care in stroke rehabilitation? A randomized controlled trial. *Age & Ageing* 31(3): 175–9
- Teng, J., Mayo, N.E., Latimer, E., Hanley, J., Wood-Dauphinee, S., Cote, R. and Scott, S. 2003. Costs and caregiver consequences of early supported discharge for stroke patients. *Stroke* 34(2): 528–36
- Thompson, A.J. 2000. The effectiveness of neurological rehabilitation in multiple sclerosis. *Journal of Rehabilitation Research & Development* 37(4): 455–61
- Thorn, S. 2000. Neurological rehabilitation nursing: a review of the research. *Journal of Advanced Nursing* 31(5): 1029–38
- Thorsen, A.M., Holmqvist, L.W., de Pedro-Cuesta, J. and von Koch, L. 2005. A randomised controlled trial of early supported discharge and continued rehabilitation at home after stroke. Five year follow-up of patient outcome. *Stroke* 36: 297–302
- Trend, P., Kaye, J., Gage, H., Owen, C. and Wade, D. 2002. Short-term effectiveness of intensive multidisciplinary rehabilitation for people with Parkinson's disease and their carers. *Clinical Rehabilitation* 16(7): 717–25
- Turner-Stokes, L. (ed.) 2003. *Rehabilitation Following Acquired Brain Injury. National Clinical Guidelines*. London: Royal College of Physicians & British Society of Rehabilitation Medicine
- Turner-Stokes, L., Disler, P.B., Nair, A. and Wade, D.T. 2005. Multi-disciplinary rehabilitation for acquired brain injury in adults of working age. *Cochrane Database of Systematic Reviews* 3: CD004170
- Vaughn, S.L. and King, A. 2001. A survey of state programs to finance rehabilitation and community services for individuals with brain injury. *Journal of Head Trauma Rehabilitation* 16(1): 20–33
- Vickrey, B.G., Shatin, D., Wolf, S.M., Myers, L.W., Belin, T.R., Hanson, R.A. *et al.* 2000. Management of multiple sclerosis across managed care and fee-for-service systems. *Neurology* 55(9): 1341–9
- von Koch, L. and Widen Holmqvist, L. 2001. Early supported discharge and continued rehabilitation at home after stroke. *Physical Therapy Reviews* 6(2): 119–40

Specialist rehabilitation for neurological conditions

- von Koch, L., Widen Holmqvist, L., Kostulas, V., Almazan, J. and de Pedro-Cuesta, J. 2000a. A randomized controlled trial of rehabilitation at home after stroke in Southwest Stockholm: outcome at six months. *Scandinavian Journal of Rehabilitation Medicine* 32(2): 80–6
- von Koch, L., Holmqvist, L.W., Wottrich, A.W., Tham, K. and de Pedro-Cuesta, J. 2000b. Rehabilitation at home after stroke: a descriptive study of an individualized intervention. Randomized Controlled Trial. *Clinical Rehabilitation* 14(6): 574–83
- von Koch, L., de Pedro-Cuesta, J., Kostulas, V., Almazan, J. and Widen-Holmqvist, L. 2001. Randomized controlled trial of rehabilitation at home after stroke: one-year follow-up of patient outcome, resource use and cost. *Cerebrovascular Diseases* 12: 131–8
- Wade, D.T. 2003. Community rehabilitation, or rehabilitation in the community? *Disability & Rehabilitation* 25(15): 875–81
- Wade, D.T. and de Jong, B.A. 2000. Recent advances in rehabilitation. *British Medical Journal* 320: 1385–8
- Wade, D.T., Crawford, S., Wenden, F.J., King, N.S. and Moss, N.E. 1997. Does routine follow-up after head injury help? A randomised controlled trial. *Journal of Neurology, Neurosurgery, and Psychiatry* 62(5): 478–84
- Wade, D.T., King, N.S., Wenden, F.J., Crawford, S. and Caldwell, F.E. 1998. Routine follow-up after head injury: a second randomised controlled trial. *Journal of Neurology, Neurosurgery, and Psychiatry* 65(2): 177–83
- Wade, D.T., Gage, H., Owen, C., Trend, P., Grossmith, C. and Kaye, J. 2003. Multidisciplinary rehabilitation for people with Parkinson's disease: a randomised controlled study. *Journal of Neurology, Neurosurgery, and Psychiatry* 74: 158–62
- Wahlquist, G.I. 1984. Impact of a nurse managed clinic in multiple sclerosis. *Journal of Neurosurgical Nursing* 16(4): 193–6
- Walker, M.F., Gladman, J.R.F., Lincoln, N.B., Siemonsma, P. and Whiteley, T. 1999. Occupational therapy for stroke patients not admitted to hospital: a randomised controlled trial. *Lancet* 354: 278–80
- Walker, M.F., Leonardi-Bee, J., Bath, P., Langhorne, P., Dewey, M., Corr, S. *et al.* 2004. Individual patient data meta-analysis of randomized controlled trials of community occupational therapy. *Stroke* 35: 2226–32
- Ward, C.D., Phillips, M., Smith, A. and Moran, M. 2003. Multidisciplinary approaches in progressive neurological disease: can we do better? *Journal of Neurology, Neurosurgery, and Psychiatry* 74 (suppl 4): iv8–12
- Warner, R., Thomas, D. and Martin, R. 2005. Multiple sclerosis. Improving service delivery for relapse management in multiple sclerosis. *British Journal of Nursing* 14(14): 746–50, 752–3
- Warren, E. 1998. An evaluation of nurse specialist/case manager interventions in the management of epilepsy. Report. North Western Regional Health Authority R&D Directorate
- Watson, L.D. and Quinn, D.A. 1998. Stages of stroke: a model for stroke rehabilitation. *British Journal of Nursing* 7(12): suppl
- Wilson, F.C., Harpur, J., Watson, T. and Morrow, J.I. 2002. Vegetative state and minimally responsive patients--regional survey, long-term case outcomes and service recommendations. *Neurorehabilitation* 17(3):231–6

Specialist rehabilitation for neurological conditions

- Wolfe, C., Tilling, K. and Rudd, A. 2000. The effectiveness of community-based rehabilitation for stroke patients who remain at home: a pilot randomized trial. *Clinical Rehabilitation* 14: 563–9
- Wood, V. and Langton Hewer, R. 1996. Development of a stroke and neurological rehabilitation unit in a district general hospital. *Journal of the Royal College of Physicians of London* 30(6): 533–7
- World Health Organization. 1980. *International Classification of Impairments, Disabilities and Handicaps*. Geneva: World Health Organization
- World Health Organization. 2001. *International Classification of Functioning, Disability and Health [ICF-2]*. Geneva: World Health Organization; www3.who.int/icf/intros/ICF-Eng-Intro.pdf (accessed 15 May 2008)
- Young, J. and Forster, A. 1992. The Bradford Community Stroke Trial: results at six months. *British Medical Journal* 304: 1085–9
- Young, J. and Forster, A. 1993. Day hospital and home physiotherapy for stroke patients: a comparative cost-effectiveness study. *Journal of the Royal College of Physicians of London* 27: 252–8

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Addendum

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