
Rapid Systematic Review of International Evidence on Integrated Models of Care for People with Long-term Neurological Conditions

Technical Report

Project 08/1610/124

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1. Introduction and methods

1.1 Background

This paper is the technical report of a 'rapid' review of evidence on integrated models of care for people with long-term neurological conditions (LTNCs). The review was part of a larger project to support the development of a benchmarking tool that could be used to evaluate progress in local health and social care communities in developing integrated care for LTNCs. The final report of the project as a whole summarises the findings of the review (Bernard *et al.*, 2010). This report, by contrast, provides full technical details about how the review was conducted and about its detailed findings.

There is an extensive literature on what people with long-term conditions (LTCs) need from health and social care services, although only a relatively small part of this is about neurological conditions, and the messages from this are clear. Much of this material was used in developing the Quality Requirements (QRs) for the National Service Framework (NSF) for Long-Term Neurological Conditions (DH, 2005a).

Similarly, there is a large literature on joint working and multi-disciplinary/professional approaches to work with people with LTCs. The NSF itself recommended 'neuroscience networks' as a way of helping to achieve implementation of the NSF and suggested some 'key features' of such a network. However, this element of the NSF document seemed less based in research evidence than are the QRs. This is, perhaps, not surprising because it is less clear what the literature tells us about what helps or hinders service integration across boundaries, or what contributes to the experience of continuity of care.

The NSF Good Practice guide (DH, 2005b) included examples of 'evaluated' models of good practice in relation to all the QRs. However, these were described only briefly and the models were not compared in a way that suggests any common indicators or benchmarks of good practice. The Good Practice Guide also suggested ten questions that organisations could use to assess their preparedness for implementing the NSF, drawing on the Modernisation Agency's *Managing Long Term Conditions Self-Assessment Tool*. Some of the self-assessment questions give examples of ways in which elements of the NSF Quality Requirements could be met (for example, integrated health and social care working via the use of pooled budgets). Others, however, were more generic and gave few guidelines about how change might be achieved for organisations developing from a low base of integration.

To the best of our knowledge, before our project no review - systematic or otherwise - had attempted to extract from the literature or from existing services a set of indicators or benchmarks of best practice that might ensure the delivery of good quality integrated

services. Neither had any review attempted to assess the contribution of integrated services to different types of continuity of care.

The overall aim of the larger project was to carry out such a review and to integrate its findings with the views of people affected by LTNCs (including informal carers), their organisations, and health, social care and other relevant professionals. From this, benchmarks for good models of integrated services would be developed and tested.

1.2 What kind of review?

Systematic reviews involve systematic and recorded searching of electronic and paper-based research sources, clear criteria for inclusion of identified studies in the review, and systematic and auditable extraction of data from these studies. They have become the method of choice when reviewing discrete issues of clinical effectiveness of, say, single drugs or interventions and have been highly influential in developing clinical guidelines. Their usefulness in reviewing the evidence on more complex interventions or models of service delivery has been debated, however (Mays *et al.*, 2001), and more flexible approaches to reviewing knowledge have been developed in different settings. The Social Care Institute for Excellence, for example, has developed the 'systematic knowledge review' that, while relying on systematic identification of information, casts its net much more widely than research literature (Coren and Fisher, 2006). However, whether confined to research papers or including evidence from a wider range of stakeholders, it remains the case that the principles of systematically searching for, selecting and extracting evidence about an issue give a weight to the outcomes of a review that more traditional approaches cannot match (Mays *et al.*, 2001).

Full systematic reviews in complex areas usually take a long time to carry out and new approaches to the rapid assessment of evidence are being developed (Davies, 2003). We proposed using such an approach for this project, broadly following Centre for Reviews and Dissemination Guidelines (CRD, 2001) for identifying and appraising evidence.

A rapid review, in theory, searches systematically, but not necessarily exhaustively, for available evidence, critically appraises studies and sifts out those that are of poor quality. This material is then used to collate descriptive outlines of the evidence and provide an overview of that evidence and what it is telling us (Davies, 2003). There are several reasons why such an approach might be used rather than a full systematic review (www.gsr.gov.uk/professional_guidance/rea_toolkit). The rationale that was most relevant to our research was the uncertainty about the effectiveness of models of integrated care and the existence of some recent research. It has been argued that in such situations a rapid evidence assessment 'can provide a quick synthesis of the available evidence by shortening the traditional systematic review process' (*ibid*).

1.3 Objective of the review

The objective was to carry out a rapid review of evidence on best models of integrated service provision for LTNCs, how to achieve these models, and their impact on different types of continuity of care. The original intention had been to carry out a single review, concentrating on material that referred to best practice in integrated services, best models for service configuration, and their impact on continuity of care, particularly focusing on diversity of need and the factors that help or hinder the development of integrated services. However, as we began to collect material from the searches (see below), it became clear that we were identifying two distinct sources of evidence. On the one hand, we found a tranche of evaluative research that, mostly, concentrated on the outcomes of integrated models of care. On the other hand, there was a seam of descriptive studies that more often described how models of care were established and run and that, where outcomes had been considered at all, included more qualitative assessment of impact. If we had concentrated only on the first type of evidence, we felt we would find very little to help us understand what constituted good models of integrated care. If we concentrated only on the latter type of evidence, we would miss all the research that had attempted to evaluate the outcomes of integrated care models, as against other ways of delivering care.

However, because these two types of evidence were so very different, it was difficult to see how they could be incorporated into a single review process. After discussion within the team, we decided to adopt two strategies. First, we would deal with the evaluative literature, explore the outcomes it was reporting, and synthesise the messages from this research. Secondly, we would deal with the descriptive literature, plus such descriptions as there were of the models included in the evaluative literature, and synthesise the information contained in these papers about how the models of care operated, who worked in them, what elements of provision they included, and what types of continuity of care they seemed to provide. Throughout the rest of this technical report, these two different approaches are called the 'evaluative review' and the 'descriptive review'.

1.4 Review methods

1.4.1 Main search strategy

In our research proposal, we said that we would develop specific search strategies for electronic and other sources that would identify relevant published and 'grey' literature in health, social care and other fields (including housing, employment, social security). While preparing the proposal, simple initial searches had suggested that we would find relatively little information about models of integrated care for people with LTNCs and

we therefore suggested that we might need to extend the searches to integrated care for other types of long-term conditions.

We also proposed hand searching key journals, internet searches and contacts with key organisations and researchers as ways of identifying relevant material, alongside material referred to in the NSF document itself. The searches were to be confined to material published since 1985 and in English.

The main aim of our strategy was, therefore, to develop approaches that would provide systematic but not necessarily comprehensive retrieval of relevant studies, as appropriate for a 'rapid' review.

1.4.2 Databases used

Fifteen bibliographic and other electronic databases were searched, providing coverage of health and social sciences literature, grey literature and current research.

The following databases were used:

MEDLINE, CINAHL, EMBASE, HMIC, DARE, HTA, NHSEED, SIGLE, Social Policy and Practice, Social Science Citation Index, ASSIA, Social Services Abstracts, Sociological Abstracts, NRR, SOSIG and The Cochrane Database of Systematic Reviews.

1.4.3 Keyword strategy

The electronic search strategies were developed in two phases. The information specialist (KL) worked with the team to construct keyword strategies using freetext and thesaurus terms to search the selected databases for publications related both to integrated models of care and to long-term neurological conditions.

The first stage of searching (see Appendix 1) used thesaurus terms (where available) and freetext to identify models of integrated care. Specific terms for Motor Neurone Disease and related conditions, Parkinson's Disease and related conditions, and Multiple Sclerosis and related conditions, plus generic terms for long-term neurological conditions were also used. These strategies were run to identify material from 1985 onwards.

In an attempt to increase the relevant literature related specifically to integrated care, a second phase of searching included extra terms for multidisciplinary working, identified from the results of the first phase of searching. We also at this stage included specific terms for epilepsy and cerebral palsy (see Appendix 2). These

strategies were run to identify any material from the new terms using the original date restrictions. However, as there had been a nine months gap since the first phase of searches, a top up search was also run on the original terms. All results were de-duplicated against the material retrieved from the first phase of searches.

1.4.4 Search restrictions

We did not include methodological filters to restrict search results to specific study designs, nor were language restrictions used. Inclusion criteria date limits restricted the publication dates of retrieved studies to 1985 onwards.

The second phase and top-up searches were run in December 2006.

1.4.5 Additional strategies

The main electronic searches outlined above identified more possibly relevant material than had been anticipated when the proposal was written. As a result, given the more limited approach to identifying material that is involved in a rapid evidence assessment, we did not subsequently carry out Web searching, contact experts, or carry out any hand-searching of relevant journals. Neither did we extend the searching to other long-term conditions. However, we did carry out limited identification of relevant material from the reference lists of studies that we included in the review. After a study had been included for data extraction (see below) we checked its reference list for any apparently relevant studies. If a study thus identified was a randomised controlled trial (RCT) we obtained the full paper and submitted it to the selection methods described below. We also identified and obtained any systematic reviews identified.

1.4.6 Inclusion and exclusion criteria for selection of studies

Decisions about the inclusion and exclusion of papers were taken in two stages. The first stage was to identify from the results of the electronic searches all material that was actually about models of integrated care for people with LTNCs (i.e. selection for relevance). The point of this stage was not simply to identify papers that would eventually be reviewed, but also to allow us to determine the range of models of integrated care being described in the literature.

The second stage was to identify material that, because of its design, allowed us to say something about the comparative merits of models of integrated care against some alternative way of providing services.

1.4.7 Developing the inclusion and exclusion criteria

There are no universally recognised definitions of integrated care, and the definition of continuity of care on which we based our proposal (Freeman *et al.*, 2001) has not yet become a recognised way of describing the outcomes of care models or services. Further, much of the literature that is about models of integrated care has a purely clinical focus; for example, research about multi-disciplinary rehabilitation teams is often solely about their impact on clinical or functional outcomes and does not consider the impact they might have on patients' experiences of continuity of care. In order to filter the material we had identified, therefore, we developed inclusion and exclusion criteria in two stages.

The research team first examined the titles and, where available, abstracts of the material identified by the electronic searches. We then developed a first set of inclusion and exclusion criteria to guide the selection for *relevance*. As is common in reviews of research on service delivery and organisation (Parker *et al.*, 2000; Mays *et al.*, 2001; CRD, 2001) these criteria developed as the range and nature of the material identified through searching became clear. The overall focus was on material that referred to best practice in integrated services, best models for service configuration, and impact on continuity of care, particularly focusing on diversity of need and the factors that help or hinder the development of integrated services.

The final inclusion and exclusion criteria for this stage are outlined in Table 1.1. The inclusion criteria operated as an algorithm to guide decision-making; the exclusion criteria were applied individually.

Table 1.1 Inclusion and exclusion criteria for relevance

<i>Inclusion criteria</i>	<i>Exclusion criteria</i>
Adults AND	Mental health only
Neurological condition AND	Learning disability only
Any aspect of integrated service delivery and organisation OR	Any other, non-neurological condition
Transition to adult services OR	Children and adolescents, unless about transition to adult services
Team working of any sort OR	Epidemiological studies
Patients'/families' views of service delivery OR	Clinical description or management of condition
Anything else that might throw light onto how to design and deliver integrated services	Studies about developing measures e.g. quality of life, disability measures
	Studies about health care financing outside of UK
	Single case reports/studies
	Foreign language

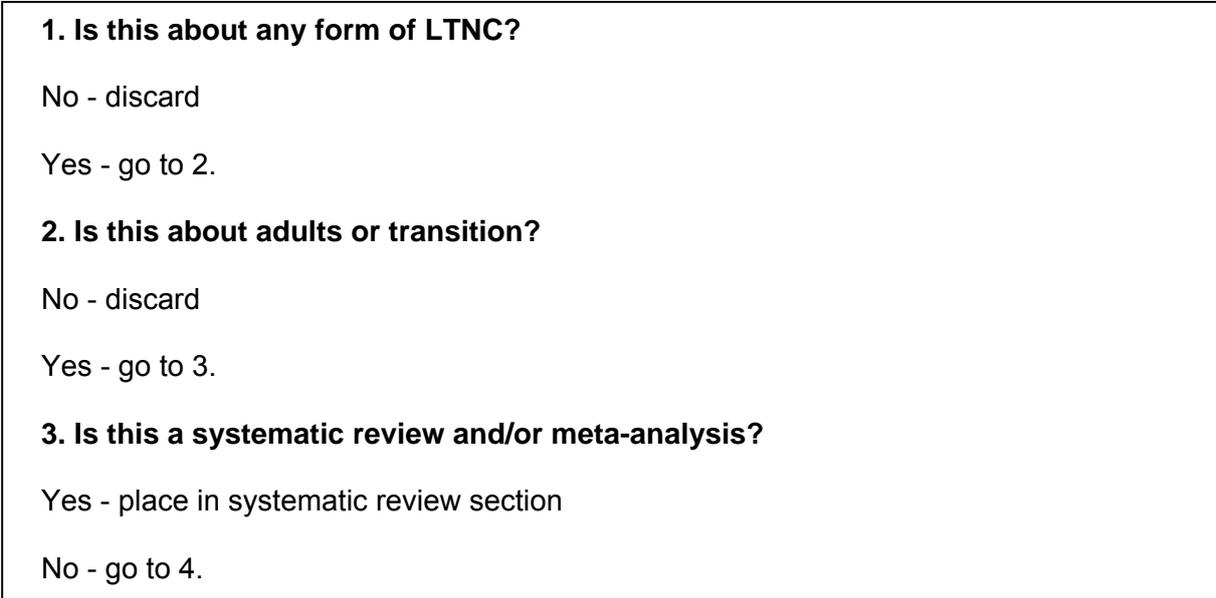
The second stage of selection was to identify studies to be included for review in either the evaluation element or the description element.

The criteria for stage two are outlined in Table 1.2 and the algorithm derived from these and used to guide decision-making is at Figure 1.1. The definitions of continuity of care, evaluation, description and systematic review or meta-analysis that we used in the algorithm are at Appendix 3.

Table 1.2 Inclusion and exclusion criteria for selection for review

<i>Inclusion criteria</i>	<i>Exclusion criteria</i>
About a long-term neurological condition	Single case studies
About adults or about transition to adulthood	Foreign language
Describes a method of ensuring or improving continuity of care	
Evaluates a method of ensuring or improving continuity of care	
Systematic review and/or meta-analysis about ways of ensuring or improving continuity of care	

Figure 1.1 Algorithm used to guide selection for review



1.4.8 Selection of material

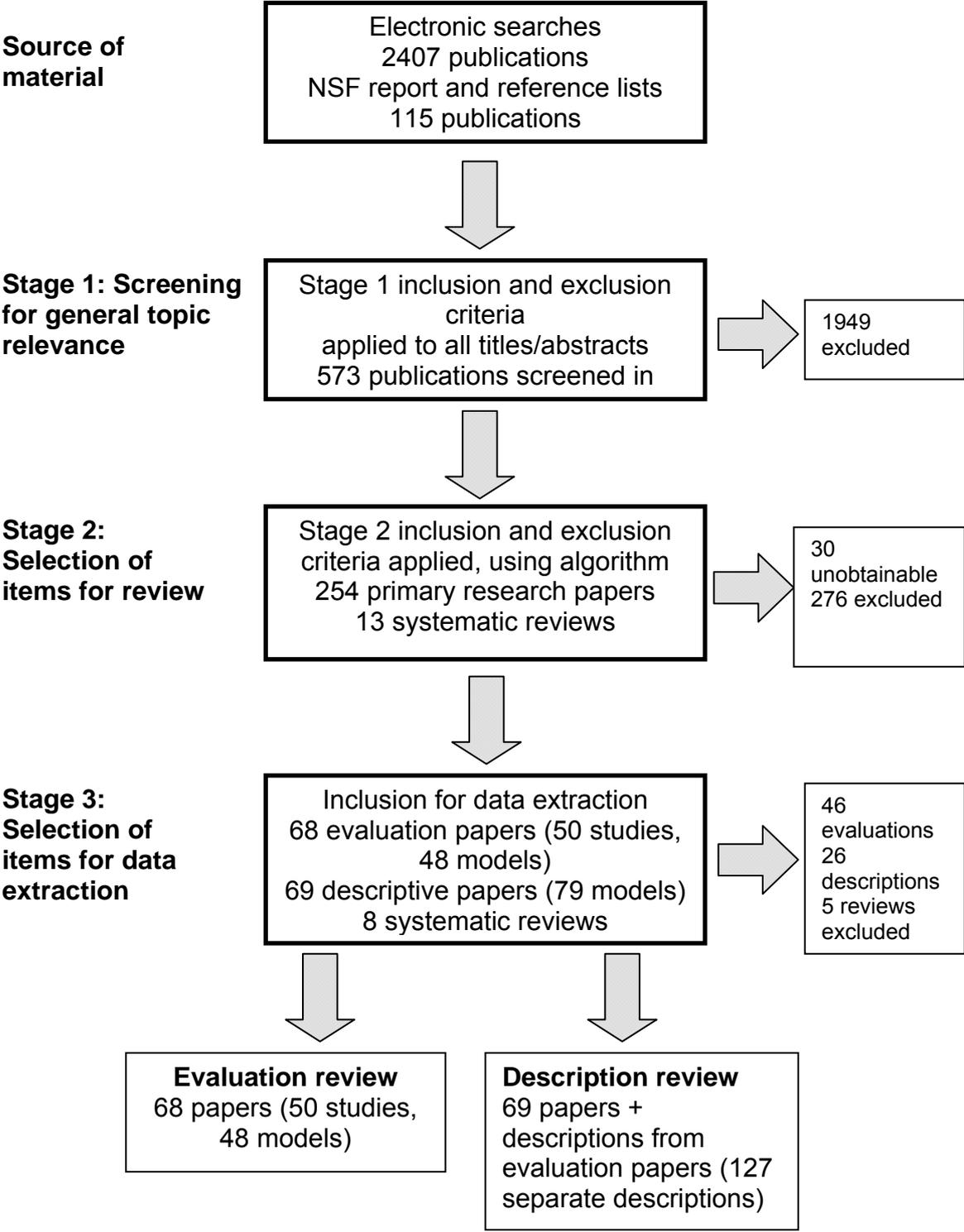
For the first stage, members of the team worked separately and then in pairs to select material for relevance. They used the titles and, where available, abstracts of the publications identified in the searches and applied the criteria listed in Table 1.1. In all cases, the pairs of reviewers worked to agreement – discussing and resolving any disagreements after each had independently reviewed titles and abstracts. If a disagreement could not be resolved, a third member of the team looked at the material and took a ‘casting vote’.

All material identified as of potential relevance was then obtained in hard copy form and entered the next stage of selection. This was done as in stage one – in pairs to agreement – but this time based on a full reading of the material. The criteria listed in Table 1.2, and the algorithm at Figure 1.1, were used to classify material into one of the following categories: ‘out’, ‘in for evaluation’, ‘in for description’, or ‘in as a review’. Further selection of material took place as data extraction started, often because it became clear when attempting to extract the data that the model being evaluated or described was not, in fact, delivering continuity of care. Examples of such papers included studies of rehabilitation teams described as multi-disciplinary but which, on closer inspection, did not act to facilitate continuity of care beyond a limited clinical setting.

Papers that were included in the evaluation section of the review were also reviewed for the descriptive section.

The results of the selection process are summarised in Figure 1.2.

Figure 1.2 Results of the staged selection process



1.4.9 Data extraction

The main questions for the review of the evaluative studies was whether models of care designed in some way to enhance continuity of care had any effect on a range of clinical, social and economic outcomes. Data extraction for the evaluative part of the review covered:

- Publication and study details
- Details of the model of care
- Study quality
- Mortality
- Length of hospital stay
- Clinical outcomes
- Physical function/impairment
- Mental function
- Coping
- Service use
- Health and social care costs
- Costs to the patient and/or family
- Quality of life
- Patients views of the model of care
- Family impact
- Expressed need
- Social outcome (e.g. employment, finances)
- Knowledge of condition
- Staff views of the model of care
- Communication with the patient and/or family
- Other outcomes relevant to continuity of care.

By contrast, the focus of the descriptive review was on the contents of service models that might deliver continuity of care. The data extraction form for this part of the review was developed by reading a randomly selected proportion of the publications and analysing qualitatively the material that they contained. The form was then piloted, using the themes that this analysis had generated, and then amended slightly in the light of the piloting. The final version of the form covered the following broad areas:

- What is the model of care?
- Where is it delivered?
- What conditions does it cover?
- Who delivers the model?
- What service elements are included in this model?
- Aspects of service delivery and organisation
- What types of continuity of care does it deliver?

A detailed listing of the information extracted is at Appendix 4.

Both data extraction forms were created using Microsoft Excel and information was entered directly onto the spreadsheets. All researchers in the team extracted data from the papers. A different member of the team then checked the accuracy of data entry prior to analysis.

1.4.10 Quality of studies

The Jadad quality of trials algorithm and the Cochrane Effective Practice and Organisation of Care (EPOC) Group's quality criteria for randomised controlled trials (RCTs) were used for any randomised or quasi-randomised studies included in the evaluation section of the review (Jadad, 1998; EPOC, 2002). We had planned to use the EPOC quality criteria for controlled before and after studies or interrupted time series studies. However, none of the remaining studies fell clearly into these categories.

As is necessary in reviews of this sort, we excluded the Jadad criterion of double-blinded assessment of outcomes, as this is almost impossible to achieve in research where a model of care is being evaluated.

1.4.11 Analysis of evaluative data

The wide variation among models of care, combined with the different conditions covered, made analysis of the results challenging. We could simply have analysed all the studies together, on the basis that all the models were intended to improve the experience of care for people with LTNCs. Alternatively, we could have attempted some grouping, based on the underlying philosophy of care (e.g. multi-disciplinarity), the professionals involved (e.g. nurse specialists) or the condition. Further, we had a mix of research designs and could have used these to order the material. Each approach has its attractions and limitations. The one that seemed to offer most opportunity both for synthesis of common messages and exploration of the diversity that comes with different conditions, was to group studies both by model of care and by condition. We also gave more emphasis to RCTs and to before-and-after studies that had both intervention and control groups than to other research designs.

In Chapter 2, we look first at the models of care evaluated and then at condition sub-groupings. Where possible, we then analyse the findings by sub-group, although the sub-group chosen varies from outcome to outcome, depending on the number of studies available for analysis.

We present a narrative synthesis (Mays *et al.*, 2005) of the material. The intention, when we wrote the proposal for the work was to analyse the material so that we could identify key indicators of best practice or the best models of integration, what they achieved and for whom. For reasons explored in the results chapters, we do not believe that current evidence based on published research allows us to do this with confidence.

1.4.12 Analysis of descriptive data

Although the descriptive material was extracted as text statements, these were converted for analysis into two categories – ‘clearly present in the description’ and ‘not clearly present in the description’. These data were then subject to simple frequency analysis and cross-tabulation by the three main commonly reported models of care in the descriptive part of the review. These were multi-disciplinary teams or clinics (41 in total), clinical nurse specialists (30 in total) and assessment and disease management initiatives (29 in total). For the analysis, we explored these three models and their characteristics separately, comparing them in each case with all other models of care.

We were able to address six of the descriptive questions outlined above:

- What is the model of care?
- Where is it delivered?
- What conditions does it cover?
- Who delivers the model?
- What service elements are included in this model?
- What types of continuity of care does it deliver?

Conclusive statements about the other question - aspects of service delivery and organisation, such as funding sources, modes of access to the service, inclusion and exclusion criteria for the service - were relatively uncommon; in most cases, at least half of the papers reported nothing about such aspects of the model of care. Given this, we did not carry out any further analysis of this part of the descriptive material.

Interpretation of the descriptive data is, of course, circumscribed by the level of detail provided in the papers we reviewed. For example, some provided detailed and exhaustive information on the staff involved in delivering care; others did not. So, if one paper about a multi-disciplinary team listed all types of professionals involved, but another detailed only the medical staff involved and referred to ‘the rest of the multi-disciplinary team’ we have no way of knowing if the two teams were similar or different in their composition. As a result, our descriptive analysis in this example represents the *least* that can be said about team composition across the papers

reviewed. Other aspects of description will be similarly limited. However, our main aim in the descriptive analysis was to see how each model of integrated care compared with the others. There was no indication that descriptions of specific models were more or less likely than others to include detailed information so bias in comparing different models is unlikely.

1.4.13 Reporting of studies

To make the text in the following chapters easier to read, we refer to studies by their first author and date only. Appendix 5 gives full bibliographical details of all included studies.

2. Findings of evaluation studies

2.1 Details of included studies

2.1.1 Numbers of studies included

Two thousand four hundred and seven papers were identified in the electronic searches, plus 115 from reference lists, hand searching and author searching. Of these, 573 were identified as being potentially relevant for the review, based on their title and, where available, abstract. Of these, 114 were initially classed as evaluations and therefore entered the next stage of this part of the review. The selected papers were obtained and read in full. After further selection, 49 separate studies, reported in 68 papers, were included in the evaluation element of the review (see Figure 1.2, Chapter 1).

The 49 studies covered 47 separate models of care provision (Table 2.1). Two of the models had been evaluated in separately reported studies but the data from these are included only once in what follows.

Table 2.1 Details of model of care evaluated

<i>First author and year</i>	<i>Model of care</i>	<i>Compared with</i>	<i>Condition</i>	<i>Country</i>	<i>Settings for model of care being evaluated</i>
Carne 205	Multi-disciplinary assessment and management	Nothing	PD	USA	VA Medical Centre
Craig 2003	Multi-disciplinary team management of relapse, combined with IV steroid treatment	Usual care	MS	UK	In- and out-patient hospital setting
Edmonds 2005 and 2006	Palliative care service	Usual care	MS	UK	In place of patient's choice
Trend 2002 and associated papers	Multi-disciplinary rehabilitation with group educational support	Usual care	MS	UK	Day hospital
Makepeace 2001	Multi-disciplinary community team	Nothing	MS	UK	Community (?home)
Sitzia 1998	Multi-disciplinary rehab with post-discharge follow-up	Nothing	PD and MS	UK	In-patient hospital setting and home

<i>First author and year</i>	<i>Model of care</i>	<i>Compared with</i>	<i>Condition</i>	<i>Country</i>	<i>Settings for model of care being evaluated</i>
Bhatt 2005	Onward referral from accident and emergency departments	Nothing	Epilepsy	UK	Acute hospital A&E
Chataway 2006	Home-based IV steroid administration	Out-patient administration	MS	UK	Home
Freeman 1994	Personal list system in general practice	Seeing a different GP on different visits	Epilepsy	UK	Primary care
Goodwin 2002	Multi-disciplinary review in primary care	Nothing	Epilepsy	UK	Primary care
Hosking 2002	Nurse specialist in tertiary referral centre	Nothing	Epilepsy	UK	In-patient and out-patient hospital setting and home
Gunter 2004	Disease management programme	Usual care	Epilepsy	USA	Primary care
Goldstein 1997	Out-patient clinic in tertiary referral centre	Nothing	Epilepsy	UK	Out-patient
Jansen 2006	Trans-mural care model	Usual care	MS	Netherlands	Hospitals, rehabilitation setting and primary care
Leach 2005	Review and follow-up of patients previously 'unknown' to specialist services	Nothing	Epilepsy	UK	Primary care and out-patient
Lambert 2001	GP care with access to nurse specialist	Usual GP care	Epilepsy	UK	Primary care
Rasmusson 2005	Telemedicine clinic	Ambulatory (out-patient) clinic	Epilepsy	USA	Home
Redhead 1996	Evidence-based care standards	Care before standards were introduced	Epilepsy	UK	Primary care
Schull 1992	Nurse specialist as case-manager	No case manager	Epilepsy	USA	In and out-patient
Ridsdale 1996 and associated	Nurse specialist and nurse-led clinic	Usual care	Epilepsy	UK	Primary care and outpatient

<i>First author and year</i>	<i>Model of care</i>	<i>Compared with</i>	<i>Condition</i>	<i>Country</i>	<i>Settings for model of care being evaluated</i>
papers					setting
Simons 2006	Patient education	Care before programme was introduced	PD	UK	Day hospital
Macht 2006	As above	As above	As above	Spain, Finland, Italy, Netherlands, UK, Estonia, Germany	As above
Upton 1996	Tertiary assessment centre	Nothing	Epilepsy	UK	Hospital
Montgomery 1994	Patient education and health promotion programme	Usual care	PD	USA	Community (?home)
Ward 2004	Individualised patient education	Usual printed information	PD, MS and other progressive neurological disorders	UK	Home
Reynolds 2000	Nurse specialist 'follow-up' care	Usual consultant-led follow-up care	PD	UK	Out-patient
Jahanshahi 1994	Nurse practitioner	Usual care	PD and dystonia	UK	Home
Ridsdale 2000	Nurse specialist	Usual care	Epilepsy	UK	Local hospital
O'Hara 2002	Consumer-focused, professional advice about self-care	Usual care	MS	UK	Patient's home and local therapy centres
Davis 2004	Two methods of supported implementation of national care guideline	Postal dissemination of guideline	Epilepsy	UK	Primary care
Hobson nd	Nurse specialist	Out-patient clinic	PD	Uk	Patient's home and 'community'
Holloway 2006 and associated papers	User-led care pathway	Nothing	PD	UK	Out-patient and home
D'Arcy 2006; Balaratnam nd	Multi-disciplinary community clinic	Nothing	MS	UK	Out-patient and home
MacLean	Computer-based	Nothing	MS	UK	Out-patient

<i>First author and year</i>	<i>Model of care</i>	<i>Compared with</i>	<i>Condition</i>	<i>Country</i>	<i>Settings for model of care being evaluated</i>
2005	patient information				and home
Oeseburg 2004	Transmural care	Nothing	MS	Netherlands	Out-patient, community and home
Hoogervorst 2003	Screening instrument to facilitate appropriate referral to multi-disciplinary teams	Use of Expanded Disability Status Scale and Guy's Neurological Disability Scale	MS	Netherlands	Out-patient
Pozzilli 2002	Multi-disciplinary home care	Usual care in MS centre (hospital)	MS	Italy	Home
Freeman 1999	Multi-disciplinary in-patient rehabilitation with recommendations for post-discharge services	Nothing	MS	UK	In-patient
Rossiter 1998 and 1995	Integrated care pathway	Nothing	MS	UK	Specialist rehabilitation unit
Barnes 1996	Multi-disciplinary out-patient clinic	Nothing	General neurological	UK	Mainly out-patient. Some in-patient for people at a distance
Castleton 2005	Integrated care across health and social care services	Nothing	PD	UK	Out-patient and community
Roy 1991	Integrated care across hospital and community services	Nothing	General neurological	New Zealand	Community and in-patient
Verza 2006	Inter-disciplinary assessment protocol for assistive technology	Care before protocol was introduced	MS	Italy	Rehabilitation centre and home
Van den Berg 2005	Multi-disciplinary clinics for symptomatic and palliative care	Usual care	ALS	Netherlands	Out-patient?
Traynor 2003 and other paper	Multi-disciplinary clinic	Usual care	ALS	Ireland	Community and out-patient clinics
Haig 1994	Multi-disciplinary team assessment	Nothing	'Wide variety of	USA	Out-patient

<i>First author and year</i>	<i>Model of care</i>	<i>Compared with</i>	<i>Condition</i>	<i>Country</i>	<i>Settings for model of care being evaluated</i>
			disabilities'		
Hicks 1993	Respite care	Nothing	MND	UK	Hospice
Hurwitz 2004 and associated papers	Nurse specialist	Usual primary care	PD	UK	Primary care and home

2.1.2 Type of studies

Table 2.2 gives brief details of the studies included in the evaluative review.

Table 2.2 Details of evaluation studies

<i>First author and year</i>	<i>Design</i>	<i>Inclusion criteria</i>	<i>Exclusion criteria</i>	<i>Size of patient population</i>	<i>Total number of patients studied</i>	<i>% of patient population studied</i>
Carne 2005	Retrospective record review	Individuals with neurologist confirmed PD who had been or were being treated with levodopa or dopamine antagonists at initial assessment and who had a follow-up evaluation between 8m and 16m after initial assessment.	Individuals who had undergone surgical interventions to treat their PD.	Not given	43	n/a
Craig 2003	Randomised controlled trial	Confirmed diagnosis of MS and a relapse requiring admission as either day case or inpatient, for treatment with a three-day course of IVMP 1 g/day.	None stated	53 patients 'approached', 50 said to be eligible. Nine refused.	41 randomised	82%
Edmonds 2005 and 2006	Randomised controlled trial. Waiting list control group received service after 3 months.	Not stated	17 people excluded from study were: clinically urgent (5), refused (5), unable to consent (4), withdrawn following protocol violation (1), lived outside study area (1), did not have MS (1).	69	52 randomised	75%
Trend 2002; Wade 2003; Gage 2006	Randomised, single blind controlled crossover trial. Waiting list control group received intervention 6 m after entry to trial.	PD diagnosed clinically by a consultant neurologist, consent, able to attend day hospital using own or provided transport.	Score <7 on Hodkinson's Mini-Mental State Test.	Not given	144 (seven patients dropped out and were later 're-registered' and re-randomised).	not known

<i>First author and year</i>	<i>Design</i>	<i>Inclusion criteria</i>	<i>Exclusion criteria</i>	<i>Size of patient population</i>	<i>Total number of patients studied</i>	<i>% of patient population studied</i>
Makepeace 2001	1. Questionnaire survey of 116 users. 2. Before and after outcome study of 38 new referrals.	1. Those known to team initially and those referred in first year. 2. individuals referred to service in first 6 m.	None stated	116 people known and referred to team in first 12m of operation.	116	100%
Sitzia 1998	Before and after study of convenience sample of service users between April 1994 and November 1996.	Diagnosis of PD or MS	None stated	102	102	100%
Bhatt 2005	Retrospective record review to audit care for suspected first seizures against practice recommendations	Diagnosis recorded in case notes as seizure, fit, epilepsy or epileptic fit.	Report of a similar previous event	158 presented, 38 of whom were classified as 'first fit' category	38	100%
Chataway 2006	Randomised controlled trial	Older than 18 yrs. Clinically definite MS. Definite relapse of more than 24 hours but less than 4 weeks.	Minor relapse not requiring steroids. Relapse severe enough to require hospitalisation. Evidence of intercurrent infection. History of adverse side effects after previous steroid use. Had previously participated in this trial.	285 screened	149 eligible. 11 declined. 138 randomised	48% of total population. 93% of eligible population.

<i>First author and year</i>	<i>Design</i>	<i>Inclusion criteria</i>	<i>Exclusion criteria</i>	<i>Size of patient population</i>	<i>Total number of patients studied</i>	<i>% of patient population studied</i>
Freeman 1994	Comparative, 'semi-structured' interview survey of patients with epilepsy in four different primary care practices.	Active epilepsy (seizure in past two years or current antiepileptic medication). Aged 15-64 inclusive. Fit to be interviewed in own right. Registered with practice for at least 2 years. Had at least 3 recorded consultations with a GP.	Severely ill with other unrelated condition. Primarily alcoholic with secondary epilepsy. Mental handicap or personality disorder noted in records.	Not reported. 112 were eligible	99	88% of eligible
Goodwin 2002	Survey of primary care epilepsy patients and recording of outcomes of two-stage review.	Primary care patients with epilepsy identified via database searches using diagnostic codes and prescribing data.	Under 16 years. Already under specialist review.	506 patients on anti-epileptic drugs identified in 9 practices. 303 after application of exclusion criteria.	303 offered appointments, 116 attended for review by practice nurse.	38% of eligible.
Hosking 2002	Survey of users of ENS service in tertiary referral centre	Newly diagnosed patients Women considering pregnancy. Patients with refractory epilepsy and treatment or compliance issues. Pre- and post-surgical patients. Survey of all patients who had one inpatient or outpatient consultation or more than one telephone contact with ENS in previous 6 months.	None stated	Hospital receives average 1100 new referrals of patients with seizure disorders a year and provides follow-up care for 7000 patients through outpatient clinics. 300 patients referred TO ENS by epilepsy consultants in first 6 months.	193 users of ENS service sent a questionnaire - no details about how selected.	Not clear

<i>First author and year</i>	<i>Design</i>	<i>Inclusion criteria</i>	<i>Exclusion criteria</i>	<i>Size of patient population</i>	<i>Total number of patients studied</i>	<i>% of patient population studied</i>
Gunter 2004	Before and after study of epilepsy patients in 9 primary care centres that did and 3 that did not implement the disease management programme.	Confirmed diagnosis of epilepsy, via electronic algorithm applied to drug, diagnosis and procedure codes in practice utilization data, followed by physician verification or medical record confirmation of presence of epilepsy. Continuous enrolment with the health care plan from May 1995 to June 1996.	None stated	Pre-intervention 630 met all three criteria for a seizure disorder, were continuously enrolled and had diagnosis confirmed by primary care provider or by chart review. Post-intervention 596 met all three criteria, enrolled and had disorder confirmed by provider.	Not entirely clear but probably all identified patients at both time points: 630 and 596.	385 (61%) pre-intervention and 362 (61%) post-intervention identified patients responded to questionnaire. Of these only 225 (36% and 38% respectively) completed both and were included in the study results. 193 were from intervention sites, 32 from comparison sites.
Goldstein 1997	Survey of patients	Attending clinic between 31st January 1996 and 22 May 1996	Learning disability or visual impairment	94	94	100%
Jansen 2006	Surveys ten months apart of patients in areas with and without the TCMMS model. Not clear whether 'baseline' was before implementation of the TCMMS.	Diagnosis of MS only, but people volunteered for the study via Dutch MS Society website. Patients were then 'accepted to participate in the study group if the neurologist or nurse specialists believed that they could benefit from the health care provided by the TCMMS'. (p.385). No further details given about	None stated	Not given	220	not known

<i>First author and year</i>	<i>Design</i>	<i>Inclusion criteria</i>	<i>Exclusion criteria</i>	<i>Size of patient population</i>	<i>Total number of patients studied</i>	<i>% of patient population studied</i>
		this.				
Leach 2005	Data collection during review and subsequent analysis. Data obtained from patients, carers, relatives and correspondence.	All patients in 26 general practices in DGH catchment area with diagnosis of epilepsy and on anti-epileptic drugs. Identified from practice records.	Children under 16. Adults already attending local epilepsy clinic. Patients aged 80 or over.	1156 adults (>16) with epilepsy, 1033 < 80 >16	676 >16 < 80 and never attended epilepsy clinic. Only 275 attended for review.	65% of total eligible had never attended clinic. 41% attended.
Lambert 2001	Questionnaire survey of GPs in Bristol area.	Working in Bristol area (not otherwise defined).	None stated	460 GPs	312 replied	68% of GPs
Rasmusson 2005	Retrospective chart review of patients in telemedicine and traditional clinic treated by the same health care professional.	None mentioned	People treated by different health care professional	72 for traditional clinic and 83 for teleclinic between 21/4 and 12/7 2004.	155	100% of those with same health care professional
Redhead 1996	Two audit cycles, 22m apart, in two primary care practices, using three agreed care standards. Audit based on clinical records	Patient with epilepsy currently taking AEDs.	Patient taking AEDS for reasons other than epilepsy	150 across two practices at first audit, 163 at second.	150 and 163	100%
Schull 1992	Random assignment of patients to case-management or not, although	Adults with epilepsy admitted to hospital with 'epilepsy-related diagnosis' which could include new onset, drug toxicity,	Those undergoing surgical procedures for evaluation of treatment of uncontrolled seizures	Not clear	42	n/k

<i>First author and year</i>	<i>Design</i>	<i>Inclusion criteria</i>	<i>Exclusion criteria</i>	<i>Size of patient population</i>	<i>Total number of patients studied</i>	<i>% of patient population studied</i>
	nowhere described as an RCT	uncontrolled seizures, medication overdose, seizures related to intercranial lesions.				
Ridsdale 1996 and other papers	RCT, apparently with waiting list control.	Patients over 15 with active epilepsy, defined as currently taking prescribed AED for seizures or not taking AED but reported seizure in past two years.	Other severe illness. Severe psychological illness. Intellectual impairment.	326 with epilepsy in six general practices (37 GPs)	283 who met inclusion criteria.	87%
Simons 2006;	Before and after design, alongside programme evaluation	Self-selected from local branches of PD Society and responses to articles in local press.	Possible cognitive decline, indicated by scores of 21 or lower on Mini Mental State Examination (MMSE)	Not known	22 people with PD, 14 carers.	n/a
Macht 2006	As above	Recruited from self-help groups and outpatient clinics in seven participating countries. No further details given.	No reference here to exclusion on basis of cognitive status, Only results reported are those for people with PD, not carers	Not known	22 people with PD in UK. 151 across all 7 countries. 52 'relatives' of person with PD	n/a
Upton 1996	Descriptive survey of assessment unit patients before discharge (interview with structured questionnaire) and 6 months later (postal questionnaire). Carers also	Patients discharged from assessment unit over nine month period (not specified when).	Admitted for short term (less than 3 weeks) drug changes. 'Incapable' (not otherwise defined) of 'completing the necessary information'. Discharged at short notice so no time to arrange interview.	99 considered suitable for inclusion	76 interviewed, also 76 carers	77% of patients. Not known for carers

<i>First author and year</i>	<i>Design</i>	<i>Inclusion criteria</i>	<i>Exclusion criteria</i>	<i>Size of patient population</i>	<i>Total number of patients studied</i>	<i>% of patient population studied</i>
	surveyed (postal questionnaire) soon after discharge					
Montgomery 1994	RCT, with waiting list control group.	Patient with self-reported Parkinson's Disease with diagnosis independently confirmed by their physician. Programme is available to patients with PD receiving any medications free for 9 months 'with a continuing program being provided free for patients receiving ' various drugs from Sandoz Pharmaceuticals or Somerset Pharmaceuticals.	None mentioned	Not clear. Mentions 10,000 PD patients receiving the programme 'free' in the USA.	322	Not clear
Ward 2004	RCT with standard intervention for control group	Aged over 15. Recorded diagnosis of: multiple sclerosis, Parkinson's disease and other causes of progressive parkinsonism, motor neurone disease, Huntington's disease and other degenerative disorders affecting CNS, muscles or peripheral nerves. Patients of GPs within City of Nottingham boundaries.	Dementing disorders such as Alzheimer's disease. Participants whose clinical features seemed incompatible with recorded diagnosis. Those with neurological complications of primarily non-neurological condition.	438 patients identified from 53% of eligible practices that actually participated. 342 said to be eligible.	114	26% of those identified, 34% of those said to be eligible.

<i>First author and year</i>	<i>Design</i>	<i>Inclusion criteria</i>	<i>Exclusion criteria</i>	<i>Size of patient population</i>	<i>Total number of patients studied</i>	<i>% of patient population studied</i>
Reynolds 2000	RCT	Seen by consultant at least once for medical assessment and confirmation of diagnosis of idiopathic Parkinson's disease. Not previously seen by PD nurse specialist. Able to understand requirements of study and give informed consent. No clinical evidence of dementia. New referral to clinic	None mentioned	Not given	185	n/k
Jahanshahi 1994	RCT	Diagnosis of idiopathic PD. Current treatment with dopaminergic medication. Hoehn and Yahr stage of illness II or above. Age <70. No clinical evidence of dementia. Dystonia patients: primary or secondary generalised or segmented dystonia, aged 16 or more.	Lived more than 50 miles from hospital	Not given	64	n/k
Ridsdale 2000	RCT	Aged over 17. Newly diagnosed epilepsy involving 2 or more attacks at initial treatment with AEDs	Learning or language difficulty that would make completion of questionnaire difficult. Severe medical or psychological disease.	159 referred, 128 met criteria	102 randomised	64%

<i>First author and year</i>	<i>Design</i>	<i>Inclusion criteria</i>	<i>Exclusion criteria</i>	<i>Size of patient population</i>	<i>Total number of patients studied</i>	<i>% of patient population studied</i>
O'Hara 2002	RCT	MS diagnosis confirmed by GP. Community-based and living in West London or counties 'contiguous with Greater London'. Recruited via voluntary organisation	None.	278 invited to take part	183 randomised	66%
Davis 2004	RCT (cluster randomised)	All general practices in Tayside. Patients who were receiving medication for epilepsy and were older than 16.	Four practices that had participated in pilot study	71 eligible practices, 3 declined. 53 locations randomised. 3284 patients identified as receiving AEDs. 1259 receiving AEDs for conditions other than epilepsy. Total eligible 2025	1133	56%
Hobson nd	Simple costing study	n/a	n/a	n/a	n/a	n/a
Holloway 2006; Lloyd 2001	Descriptive survey-based. Recruitment interview with follow-up semi-structured interview 12	People with PD attending neurology outpatient clinic. Living in single LA borough		73 patients were initially identified	24 pts were recruited (note that paper 664 says 26)	33%

<i>First author and year</i>	<i>Design</i>	<i>Inclusion criteria</i>	<i>Exclusion criteria</i>	<i>Size of patient population</i>	<i>Total number of patients studied</i>	<i>% of patient population studied</i>
	months later. Interviews with neurologist and PD nurse specialist interview.					
D'Arcy 2005	Self-completion questionnaires sent to all patients within a week of their appointments.	All patients attending the clinic	None mentioned	Estimated to be 150 - 170 people within PCT. 120 identified.	27	22.5%
Balaratnam nd	Audit to establish impact on A & E attendances or hospital stays. 6 year study period: 3 years prior to the clinic starting and 3 years during the clinic's operation. Data from hospitals and patient satisfaction questionnaires.	All patients initially included	Excluded patients without diagnosis of MS by 10/09/00	71 patients seen between 10/09/03 and 20/12/06	Not given	Not given
MacLean 2005	Feedback from users (no details about how collected)	Not stated	Not stated	Not given	31	Not given

<i>First author and year</i>	<i>Design</i>	<i>Inclusion criteria</i>	<i>Exclusion criteria</i>	<i>Size of patient population</i>	<i>Total number of patients studied</i>	<i>% of patient population studied</i>
Oeseburg 2004	Open case study design. Follow up assessments at 5, 10 and 15 months after care plan implemented. Interviews with nurse specialists coordinating the intervention.	MS patients known to the University Medical Centre Groningen August 1999 - Dec 2000 who lived in a specific geographic area.	None mentioned	40	40	100%
Hoogervorst 2003	Comparison of INTERMED, neurologists' assessment (Expanded Disability Status Scale: EDSS), patient self report (Guy's Neurological Disability Scale: GNDS) and healthcare needs as defined by a professional MDT. programme.	Newly referred out-patient clinic patients fulfilling MS diagnostic criteria.	None mentioned	100 consecutive referrals	100	100%
Pozzilli 2002	Randomised controlled trial.	Clinically definite MS. Living in Rome service area.	None mentioned	297 patients screened	201 (96 declined to participate)	68%

<i>First author and year</i>	<i>Design</i>	<i>Inclusion criteria</i>	<i>Exclusion criteria</i>	<i>Size of patient population</i>	<i>Total number of patients studied</i>	<i>% of patient population studied</i>
Freeman 1999	Single-group, prospective, descriptive, longitudinal study.	Clinical or laboratory-supported diagnosis of MS In progressive phase of the disease. Considered suitable for inpatient rehabilitation.	Within 1 month of relapse or receiving steroids Other diseases that may interfere with outcome Cognitively impaired such that they were unable to give informed consent.	186	50	27%
Rossiter 1998 (and 1995)	Audit of rehabilitation programme using integrated care pathway. Three cohorts of patients.	Clinically definite MS. Considered at assessment to have potential for functional gains or to require an appropriate care package.	None stated	125	125	100%
Barnes 1996	Questionnaire survey of patients' views of clinic.	New referrals to disability clinic at a regional rehabilitation centre during 12m period.	None stated	77	77	100%
Castleton 2005	Descriptive before and after study of patients, carers and staff.	Diagnosed as suffering with PD in one of 3 participating practices.	None stated	66 pts with PD identified.	37	56%

<i>First author and year</i>	<i>Design</i>	<i>Inclusion criteria</i>	<i>Exclusion criteria</i>	<i>Size of patient population</i>	<i>Total number of patients studied</i>	<i>% of patient population studied</i>
Roy 1991	Retrospective record review. 1987 - Sept 1989. Also case co-ordinator surveyed about perceived outcomes.	Patients referred to the service.	None stated	296	242	82%
Verza 2006	Before and after record review and interview survey of impact of interdisciplinary approach on equipment use.	Not stated	Not stated	54	54	100%
Van den Berg 2005	Descriptive impact study using face to face structured interviews with patients and care givers	Met the El Escorial diagnostic criteria for probable or definite ALS.	Insufficient knowledge of Dutch language. Cognitive disorder. Other diseases that could effect the muscular-skeletal system	216	208	96%
Traynor 2003	Comparison of Irish ALS Register data for those receiving specialist and non-specialist care.	Reviewed on more than two occasions at ALS clinic. First visit occurred within one year of the time of diagnosis.	ALS mimic syndrome	345 Irish residents diagnosed as having suspected, possible, probable or definite ALS between 1st Jan 1996 and 31st Dec 2000	344	99.7%

<i>First author and year</i>	<i>Design</i>	<i>Inclusion criteria</i>	<i>Exclusion criteria</i>	<i>Size of patient population</i>	<i>Total number of patients studied</i>	<i>% of patient population studied</i>
Haig 1994	Descriptive follow-up survey using telephone standardized questionnaire one year after initial evaluation	Not stated	Information from referral or initial interview suggests assessment by multiple professionals not needed	41	41	100%
Hicks 1993	Retrospective record review.	Original referral requested inpatient respite.	Referred for symptom control or terminal care	22	22	100%
Hurwitz 2004, Jarman 2002, Hurwitz 1999	Randomised controlled trial.	Taking one or more anti-parkinsonism medication A hospital or GP diagnosis of PD.	Aged 17 or younger Severe mental illness or cognitive impairment sufficient (in the view of their GP) to preclude valid informed consent	3392	1836 (1859 randomised but 23 died before intervention began)	54%

Fourteen randomised controlled trials (RCTs), so described, were included, along with a fifteenth study that was not described as an RCT but which said that patients had been randomly assigned to one of two study groups. We have defined this last study as a pseudo-randomised design.

We defined 14 other studies as having used a comparative design of some type. These were studies that had measured outcome variables before the introduction of a new service or model of care and again at some point afterwards, or which had compared groups that did and did not use a particular model of care. Some before and after studies included groups that had and had not received the service or model of care; others included only groups that had received the service or model of care with no comparison group.

Four studies were based on surveys, and we defined another nine as based on audit or retrospective record review. In some of the latter, people receiving the service or model of care being evaluated were compared with those who were not.

Finally, five 'other' designs were included. These were: a comparison of different methods of assessing service need, a mixture of record review and survey, a case study design with follow-up assessments (which, where appropriate, we have analysed alongside the 'before and after' studies), a study that said it was based on 'feedback' from users but with no details about how this was achieved, and a simple costing study.

2.1.3 Numbers of people studied

At least 4,848 people were included in the 15 randomised or quasi-randomised studies. Not all papers reported the numbers randomised but only those who entered or completed the study. The individual trials ranged in size from 41 people randomised to 1,859 randomised.

The 14 before-and-after studies (which included the study that reported UK and international results in two papers) ranged in size from 24 participants to 1,226, and the four survey-based studies ranged between 54 and 312. Nine retrospective record review or audit studies included between 22 and 344 people and the five 'other' studies included between 31 and 100 people.

2.1.4 Where the studies were based

The majority of studies (33) had been carried out in the UK, and 12 of these were RCTs. One of the UK studies was part of an international project (Spain, Finland, Italy, Netherlands, UK, Estonia and Germany). Six studies (2 RCTs) were in the USA,

four in the Netherlands, two (1 RCT) in Italy, and one each in Ireland and New Zealand.

2.1.5 Conditions covered and models of care evaluated

Tables 2.3 and 2.4 summarise the conditions covered, the design of the studies, and the model of care that was evaluated.

Table 2.3 Type of study, condition, number of patients studied, and quality assessment

<i>First author and year</i>	<i>Design</i>	<i>Condition</i>	<i>Total number of patients studied</i>	<i>Quality score for RCTs (Jadad – max 3)</i>	<i>Quality score for RCTs (EPOC – max 6)</i>
RCTs					
Chataway 2006	RCT	MS	138 randomised	3	5.5
Craig 2003	RCT	MS	41 randomised	1	3
Davis 2004	RCT, cluster randomised	Epilepsy	1133	2	6
Edmonds 2005 and 2006	RCT. Waiting list control group received service after 3 months.	MS	52 randomised	2	3
Hurwitz 2004, Jarman 2002, Hurwitz 1999	RCT	PD	1836 (1859 randomised but 23 died before intervention began)	2	5
Jahanshahi 1994	RCT	PD	64 randomised	1	3
Montgomery 1994	RCT, with waiting list control group.	PD	322	1	4
O'Hara 2002	RCT	MS	189	3	5.5
Pozzilli 2002	RCT	MS	201	2	4
Reynolds 2000	RCT	PD	185 randomised	1	1
Ridsdale 1996 and other papers	RCT, apparently with waiting list control.	Epilepsy	283	2	2

<i>First author and year</i>	<i>Design</i>	<i>Condition</i>	<i>Total number of patients studied</i>	<i>Quality score for RCTs (Jadad – max 3)</i>	<i>Quality score for RCTs (EPOC – max 6)</i>
Ridsdale 2000	RCT	Epilepsy	102	2	2.5
Trend 2002; Wade 2003; Gage 2006	Randomised, single blind controlled crossover trial. Waiting list control group received intervention 6 m after entry to trial.	PD	144	2	5
Ward 2004	RCT with standard intervention for control group	MS. PD and other	116	3	3
Pseudo-randomised trial					
Schull 1992	Random assignment of patients to case-management or not, although nowhere described as an RCT	Epilepsy	42	1	2
Before and after studies					
Barnes 1996	Questionnaire survey of patients' views of clinic.	General neurological	77	-	-
Castleton 2005	Descriptive before and after study of patients, carers and staff.	PD	37	-	-
Freeman 1994	Comparative, 'semi-structured' interview survey of patients with epilepsy in four different primary care practices.	Epilepsy	99	-	-
Freeman 1999	Single-group, prospective, descriptive, longitudinal study.	MS	50	-	-
Goodwin 2002	Survey of primary care epilepsy patients and recording of outcomes of two-stage review.	Epilepsy	303 offered appointments, 116 attended for review by practice nurse.	-	-
Gunter 2004	Before and after study of epilepsy patients in 9 primary care	Epilepsy	Not entirely clear but probably all identified patients at both	-	-

<i>First author and year</i>	<i>Design</i>	<i>Condition</i>	<i>Total number of patients studied</i>	<i>Quality score for RCTs (Jadad – max 3)</i>	<i>Quality score for RCTs (EPOC – max 6)</i>
	centres that did and 3 that did not implement the disease management programme.		time points: 630 and 596.		
Haig 1994	Descriptive follow-up survey using telephone standardized questionnaire one year after initial evaluation	General neurological	41	-	-
Holloway 2006; Lloyd 2001	Descriptive survey-based. Recruitment interview with follow-up semi-structured interview 12 months later. Interviews with neurologist and PD nurse specialist .	PD	24 (paper 664 says 26)	-	-
Hosking 2002	Survey of users of ENS service in tertiary referral centre	Epilepsy	193	-	-
Jansen 2006	Surveys ten months apart of patients in areas with and without the TCMMS model. Not clear whether 'baseline' was before implementation of the TCMMS.	MS	220	-	-
Makepeace 2001	1. Questionnaire survey of 116 users. 2. Before and after outcome study of 38 new referrals.	MS	116	-	-
1. Simons 2006 2. Macht 2006	Before and after design, alongside programme evaluation	PD	1. 22 people with PD, 14 carers in UK. 2. 151 across all 7 countries. 52 relatives of people with PD	-	-
Sitzia 1998	Before and after study of convenience	PD or MS	102	-	-

<i>First author and year</i>	<i>Design</i>	<i>Condition</i>	<i>Total number of patients studied</i>	<i>Quality score for RCTs (Jadad – max 3)</i>	<i>Quality score for RCTs (EPOC – max 6)</i>
	sample of service users between April 1994 and November 1996.				
Verza 2006	Before and after record review and interview survey of impact of interdisciplinary approach on equipment use.	MS	54	-	-
Survey-based					
Goldstein 1997	Survey of patients	MS	94	-	-
Lambert 2001	Questionnaire survey of GPs in Bristol area.	Epilepsy	312 GPs	-	-
Upton 1996	Descriptive survey of assessment unit patients before discharge (interview with structured questionnaire) and 6 months later (postal questionnaire). Carers also surveyed (postal questionnaire) soon after discharge	Epilepsy	76 and 76 carers	-	-
Van den Berg 2005	Descriptive impact study using face to face structured interviews with patients and care givers	ALS	208	-	-
Retrospective record review or audit					
1. Balaratnam nd. 2. D'Arcy 2005	1. Audit to establish impact on A & E attendances or hospital stays. 6 year study period: 3 years prior to the clinic starting and 3 years during the clinic's operation. Data from hospitals and patient satisfaction questionnaires.	MS	1. Not given 2. 27	-	-

<i>First author and year</i>	<i>Design</i>	<i>Condition</i>	<i>Total number of patients studied</i>	<i>Quality score for RCTs (Jadad – max 3)</i>	<i>Quality score for RCTs (EPOC – max 6)</i>
	2. Self-completion questionnaires sent to all patients within a week of their appointments				
Bhatt 2005	Retrospective record review to audit care for suspected first seizures against practice recommendations	Epilepsy	38	-	-
Carne 2005	Retrospective record review	PD	43	-	-
Hicks 1993	Retrospective record review.	MND	22	-	-
Rasmusson 2005	Retrospective chart review of patients in telemedicine and traditional clinic treated by the same health care professional.	Epilepsy	155	-	-
Redhead 1996	Two audit cycles, 22m apart, in two primary care practices, using three agreed care standards. Audit based on clinical records	Epilepsy	150 and 163	-	-
Rossiter 1998 (and 1995)	Audit of rehabilitation programme using integrated care pathway. Three cohorts of patients.	MS	125	-	-
Roy 1991	Retrospective record review. 1987 - Sept 1989. Also case co-ordinator surveyed about perceived outcomes.	General neurological	242	-	-
Traynor 2003	Comparison of Irish ALS Register data for those receiving specialist and non-specialist care.	ALS	344	-	-

<i>First author and year</i>	<i>Design</i>	<i>Condition</i>	<i>Total number of patients studied</i>	<i>Quality score for RCTs (Jadad – max 3)</i>	<i>Quality score for RCTs (EPOC – max 6)</i>
Other					
Hobson nd	Simple service costing study	PD	n/a	-	-
Hoogervorst 2003	Comparison of INTERMED, neurologists' assessment (Expanded Disability Status Scale: EDSS), patient self report (Guy's Neurological Disability Scale: GNDS) and healthcare needs as defined by a professional MDT.	MS	100	-	-
Leach 2005	Data collection during review and subsequent analysis. Data obtained from patients, carers, relatives and correspondence.	Epilepsy	275	-	-
MacLean 2005	Feedback from users (no details about how collected)	MS	31	-	-
Oeseburg 2004	Open case study design. Follow up assessments at 5, 10 and 15 months after care plan implemented. Interviews with nurse specialists coordinating the intervention.	MS	40	-	-

Table 2.4 Condition and model of care evaluated

<i>First author and year</i>	<i>Model of care</i>
ALS/MND	
Traynor 2003	Multi-disciplinary clinic
Van den Berg 2005	Multi-disciplinary clinics for symptomatic and palliative care
Hicks 1993	Respite care
Epilepsy	
Schull 1992	Nurse specialist as case-manager
Ridsdale 1996 and associated papers	Nurse specialist and nurse-led clinic
Ridsdale 2000	Two appointment with nurse specialist
Lambert 2001	GP care with access to nurse specialist
Hosking 2002	Nurse specialist in tertiary referral centre
Goodwin 2002	Multi-disciplinary review in primary care
Leach 2005	Review and follow-up of patients previously 'unknown' to specialist services
Freeman 1994	Personal list system in general practice
Upton 1996	Tertiary assessment centre
Goldstein 1997	Out-patient clinic in tertiary referral centre
Rasmusson 2005	Telemedicine clinic
Gunter 2004	Disease management programme
Redhead 1996	Evidence-based care standards
Davis 2004	Supported implementation of national care guidelines
Bhatt 2005	Onward referral from accident and emergency departments
Multiple sclerosis	
Hoogervorst 2003	Screening instrument to facilitate appropriate referral to multi-disciplinary teams
Verza 2006	Inter-disciplinary assessment protocol for assistive technology

<i>First author and year</i>	<i>Model of care</i>
Rossiter 1998 and 1995	Integrated care pathway
Freeman 1999	Multi-disciplinary in-patient rehabilitation with recommendations for post-discharge services
Makepeace 2001	Multi-disciplinary community team
D'Arcy 2006; Balaratnam nd	Multi-disciplinary community clinic
Craig 2003	Multi-disciplinary team management of relapse, combined with IV steroid treatment
Pozzilli 2002	Multi-disciplinary home care
Chataway 2006	Home-based IV steroid administration
Oeseburg 2004	Transmural care (same as Jansen?)
Jansen 2006	Trans-mural care model
O'Hara 2002	Consumer focused, professional advice about self-care
MacLean 2005	Computer-based patient information
Edmonds 2005 and 2006	Palliative care service
Parkinson's disease	
Trend 2002 and associated papers	Multi-disciplinary rehabilitation with group educational support
Carne 2005	Multi-disciplinary assessment and management
Castleton 2005	Integrated care across health and social care services
Simons 2006	Patient education
Macht 2006	As above
Montgomery 1994	Patient education and health promotion programme
Holloway 2006 and associated papers	User-led care pathway
Jahanshahi 1994	Nurse practitioner
Hobson nd	Nurse specialist
Reynolds 2000	Nurse specialist
Hurwitz 2004 and associated papers	Nurse specialist

<i>First author and year</i>	<i>Model of care</i>
Mixed neurological	
Haig 1994	Multi-disciplinary team assessment
Barnes 1996	Multi-disciplinary out-patient clinic
Sitzia 1998	Multi-disciplinary rehab with post-discharge follow-up
Roy 1991	Integrated care across hospital and community services
Ward 2004	Individualised patient education

Because of the way we constructed the electronic searches for material, we did not expect to get an even representation of LTNCs among the studies. As a result, we had 15 studies about models of integrated care for epilepsy, 14 for multiple sclerosis (MS), 11 for Parkinson's disease (PD), three for motor neurone disease (MND) or amyotrophic lateral sclerosis (ALS), and five for more than one LTNC.

Six of the RCTs were solely about or included MS, six were solely about or included PD, and three RCTs and the pseudo-randomised trial were about epilepsy. Despite having a search strategy specifically for cerebral palsy, no evaluative studies about this condition were suitable for inclusion.

There was relatively little homogeneity among the models of care being evaluated. The biggest single grouping was of nurse specialists or practitioners (nine studies), followed by patient information or education (five studies) and multi-disciplinary clinics (four studies). However, overall, 14 of the studies referred specifically to some form of multi-disciplinary approach to service provision – whether via rehabilitation care (3), clinics (4), teams (3), review and assessment (3), or home care (1). Six studies in total evaluated some form of standards, protocols or pathways, whether for screening, assessment or care provision, and four evaluated 'integrated' or 'transmural' care', so described.

2.1.6 Quality of studies selected

Table 2.3 summarises the quality scores achieved by the randomised and quasi-randomised studies included in the evaluative review. Five of fourteen such studies scored two or more on the Jadad criteria and five or more on the EPOC criteria. Another three scored two or more on the Jadad criteria but did not achieve five or more on the EPOC criteria.

These eight studies scoring relatively highly varied in their disease focus (Table 2.4). Four were exclusively about MS, two exclusively about PD, one about epilepsy and one about MS, PD and other neurological conditions. They varied even more in the model of care they were evaluating; there were eight distinct approaches to integrated care in the eight studies.

2.1.7 Outcomes reported

As one would hope from a review that attempted to find studies about integrated care, the outcome most often reported was access to or use of services (21 studies), though this means that it was not reported at all in over half. The next most commonly reported outcome was patients' views of the model of care being evaluated (18 studies), followed by disability and impairment (16 studies), quality of life (15 studies), and clinical outcomes (15 studies). Given the emphasis on the ability of integrated care to reduce hospital admission and/or shorten hospital stay, relatively few studies (6) reported this outcome. Similarly, there were few studies (8) that reported costs to the health service of the models of care being evaluated, and none reported costs to social care services. Table 2.5 summarises the full range of outcomes reported in the evaluation studies reviewed.

Table 2.5 Outcomes reported in reviewed studies

<i>Outcome</i>	<i>Number of studies reporting</i>
Use of or contact with services	21
Patient's view of model of care	18
Disability/impairment	17
Clinical outcomes	15
Quality of life	15
Mental health	11
Impact on family and/or carers	8
Costs to health services	8
Other outcomes	7
Hospital admission	6
Communication in team or with patient	5
Patient or carer expressed need	4
Knowledge of condition	4
Social outcome e.g. education, employment	3
Staff views of model of care	3
Mortality	3
Costs to patients or families	2
Coping or stress	1
Costs to social care services	0

2.2 Synthesis of findings

As described in Chapter 1, the wide variation among models of care, combined with the different conditions covered, made analysis of the results challenging. In what follows, we look first at all the models of care evaluated and then at sub-groupings. In doing this we have given more emphasis to the RCTs and any before-and-after studies that had both intervention and control groups. Where possible, we have then analysed the findings by sub-group, although the sub-group chosen varies from outcome to outcome, depending on the number of studies available for analysis.

2.3 Access to and use of services

One of the key criticisms of provision for people with long-term conditions is that they experience difficulties accessing services. This seems particularly so when needed services are not 'in the gift' of the service providers with which the people with long-term conditions have their main or only contact. Integrated care, by definition, aims to bridge the gaps that cause these difficulties, so one might expect to see improvement in access to and use of certain sorts of services. On the other hand, there is also an assumption in much current policy that more integrated provision, as 'close' to the service user as possible, should reduce the demand for more expensive acute and/or hospital-based services. In analysing the data from this section of the review, then, we have looked at both increases and decreases in access to and use of services.

Twenty-one studies reported contact with or use of services (see Table 2.6).

Table 2.6 Use of or contact with services

<i>First author and year</i>	<i>Model of care</i>	<i>Type of service</i>	<i>Measure used</i>	<i>When measured</i>	<i>Results for controls/ before</i>	<i>Results for subjects/ after</i>	<i>Statistical significance</i>
ALS/MND							
Van den Berg 2005	Multi-disciplinary clinics for symptomatic and palliative care	Professional care giver	Reported n of visits	12m period		Results not reported, said to be similar for both groups	-
Hicks 1993	Respite care	Community support services	N referred for additional support	Not clear	-	9/15 patients received additional support	Not tested
		Medical specialities	As above	As above	-	None referred	-
		Voluntary sector	As above	As above	-	'Some' were referred. No other details.	-
Epilepsy							
Schull 1992	Nurse specialist as case-manager	Emergency department visits	No of seizure-related visits	90 days after original admission	5	4	Not reported
		Ambulatory care clinic	% of appointments kept	As above	69	82	Not reported
Lambert 2001	Nurse specialist and general practitioner	Consultant follow-up	N and % offered and taking up follow-up	Not clear	-	177/275 (64%) offered follow-up; 108/275 (39%) accepted; 87.275 (32%) continued follow-up	-
Hosking 2002	Nurse specialist in tertiary referral centre	GP	% reporting change in frequency of contact	Not reported	-	32% less 51% no difference 6% more 11% nk	-

<i>First author and year</i>	<i>Model of care</i>	<i>Type of service</i>	<i>Measure used</i>	<i>When measured</i>	<i>Results for controls/ before</i>	<i>Results for subjects/ after</i>	<i>Statistical significance</i>
		Consultant	As above	As above	-	34% less 52% no difference 4% more 10% 'invalid'	-
		Contact with nurse specialist for urgent advice	% of patients	As above	-	32% nil 28% once 28% 2-5 times 4% 5 or more times 8% nk/ invalid	-
		Any contact with nurse specialist	% of patients	As above	-	13% nil 17% once 43% 2-4 times 15% 5-9 times 6% 10 or more times 7% invalid	-
Redhead 1996	Evidence-based care standards	GP	N (%) of epilepsy patients seen	In past 12m	First audit: 125/150 (83)	Second audit: 155/163 (95)	Not tested
Davis 2004	Supported implementation of national care guidelines	Review consultations with GP	Mean n of recorded consultations	Before and after intervention period	Reported as graphs only	Reported as graphs only	Not reported. Said to be no sig diffs between the groups
		Consultations with GP that involved counselling about epilepsy	As above	As above	As above	As above	As above
		% of patients whose reviews conformed to guidelines	% recorded in record	As above	Not reported	Not reported	As above

<i>First author and year</i>	<i>Model of care</i>	<i>Type of service</i>	<i>Measure used</i>	<i>When measured</i>	<i>Results for controls/ before</i>	<i>Results for subjects/ after</i>	<i>Statistical significance</i>
Bhatt 2005	Onward referral from accident and emergency departments	Neurology clinic	N referred directly	Not clear	-	8/12	-
			Median and mean (range) weeks from seizure to clinic attendance	As above	-	16, 15 (5-20) n=10	-
		MRI and EEG	N booked	As above	-	10/12	-
			Median, mean (range) weeks from referral to MRI	As above	-	12, 12 (5-22), n=10	-
			Median, mean (range) weeks from referral to EEG	As above	-	16, 15 (5-20), n=10	-
Multiple sclerosis							
Freeman 1999	Multi-disciplinary in-patient rehabilitation with recommendations for post-discharge services	Wheelchair services clinic	N of patients recommended for and receiving initial contact from services by specified time	At assessment and follow-up at 3 and 9m**	-	27/50 recommended 21/27 by 3m 27/27 by 9m	-
		Community OT	As above	As above	-	21/50 recommended 19/21 by 3m 21/21 by 9m	-
		District nurse			-	14/50 recommended 13/14 by 3m 14/14 by 9m	-
		Out-patient physiotherapy			-	12/50 recommended 8/12 by 3m 12/12 by 9m	-

<i>First author and year</i>	<i>Model of care</i>	<i>Type of service</i>	<i>Measure used</i>	<i>When measured</i>	<i>Results for controls/ before</i>	<i>Results for subjects/ after</i>	<i>Statistical significance</i>
		Out-patient physiotherapy review			-	8/50 recommended 7/8 by 3m 8/8 by 9m	-
		Community physiotherapy			-	8/50 recommended 5/8 by 3m 8/8 by 9m	-
		Other			-	10/50 recommended 5/10 by 3m 9/10 by 9m	-
		Psychology/ counselling			-	8/50 recommended 8/8 by 9m	-
		Social worker			-	7/50 recommended 6/7 by 3m 6/7 by 9m	-
		Home help			-	6/50 recommended 6/6 by 3m	-
		Care manager			-	6/50 recommended 3/6 by 3m 6/6 by 9m	-
		Day care			-	4/50 recommended 1/4 by 3m 3/4by 9m	-
		Re-housing			-	3/50 recommended 0/3 by 3m 1/3 by 9m	-
		Housing adaptations			-	30/50 recommended 20/30 by 3m 26/30 by 9m	-

<i>First author and year</i>	<i>Model of care</i>	<i>Type of service</i>	<i>Measure used</i>	<i>When measured</i>	<i>Results for controls/ before</i>	<i>Results for subjects/ after</i>	<i>Statistical significance</i>
		Respite care			-	2/50 recommended 1/2 by 3m 2/2 by 9m	-
Makepeace 2001	Multi-disciplinary community team	District nurse	Mean n of contacts in 6m*	Before / after referral to team	0.84	5.45	None reported
		Physiotherapy			3.53	10.24	
		Psychology			0.05	0.66	
		Psychiatry			0.03	0.34	
		Out-patient			0.79	1.34	
		Family counsellor			0	0.71	
		OT			0.55	1.05	
		Social worker			0.24	1.21	
		GP			2.45	2.16	
		Consultant			0.97	0.79	
Craig 2003	Multi-disciplinary team management of relapse, combined with IV steroid treatment	Physiotherapy	Mean hours(range) of treatment time	Not clear	0.26 (0 to 1.3)	2.62 (1.25 to 5.0)	Not reported but difference claimed to be significant
		OT	As above	As above	0.075 (0 to 0.75)	1.49 (0.25 to 4.0)	As above
		Speech therapy	N (%) of people seen	As above	0 (0)	3 (15)	Not reported but

<i>First author and year</i>	<i>Model of care</i>	<i>Type of service</i>	<i>Measure used</i>	<i>When measured</i>	<i>Results for controls/ before</i>	<i>Results for subjects/ after</i>	<i>Statistical significance</i>
			by therapist				'distinct difference in favour of subjects is claimed
		MS nurse specialist	N (%) of people seen by nurse	As above	9 (45)	20 (100)	As above
		Orthoptist	N (%) of people seen by orthoptist	As above	0 (0)	3 (15)	As above
		Further physiotherapy	N (%) of people referred	As above	3 (15)	13 (65)	As above
		Further OT	N (%) of people referred	As above	2 (10)	10 (50)	As above
Oeseburg 2004	Transmural care (same as Jansen?)	Neurologist	N (and mean frequency) of contacts	In 5m before and 10-15m after baseline	39 (1.1)	37 (1.0)	None reported
		GP	As above	As above	17 (3.3)	24 (2.7)	
		Rehabilitation specialist	As above	As above	3 (4.0)	19 (1.8)	
		Nurse specialist	As above	As above	3 (1.0)	36 (1.1)	
		OT	As above	As above	6 (11.0)	6 (5.2)	
		Physiotherapist	As above	As above	17 (31.6)	17 (20.4)	
		Social worker	As above	As above	3 (5.0)	4 (6.5)	
		Home care provider	As above	As above	11 (90.25)	15 (64.0)	
Jansen 2006	Trans-mural care model	Neurologist	N (%) consulting in past 10m	Baseline	68 (71)	66 (83)	Chi-squared value not reported, said

<i>First author and year</i>	<i>Model of care</i>	<i>Type of service</i>	<i>Measure used</i>	<i>When measured</i>	<i>Results for controls/ before</i>	<i>Results for subjects/ after</i>	<i>Statistical significance</i>
							to be NS
				10m later	47 (49)	64 (80)	Value not reported, p = .00
		GP	N (%) consulting in past 10m	Baseline	64 (67)	61 (76)	Not reported, NS
				10m later	51 (53)	59 (74)	Value not reported, p = .01
		Rehabilitation specialist	N (%) consulting in past 10m	Baseline	16 (17)	24 (30)	Value not reported, p=.03
				10m later	11 (12)	17 (21)	Value not reported, NS
		Nurse specialist	N (%) consulting in past 10m	Baseline	30 (31)	15 (19)	Value not reported, p=.05
				10m later	29 (30)	40 (50)	Value not reported, p=.01
		Physical therapist	N (%) consulting in past 10m	Baseline	36 (38)	41 (51)	Value not reported, p=.04
				10m later	37 (39%)	45 (56%)	Value not reported, p=.02
		OT	N (%) consulting in past 10m	Baseline	12 (13)	18 (23)	Value not reported, NS
				10m later	9 (9%)	15 (19%)	Value not reported, NS
		Social worker	N (%) consulting in past 10m	Baseline	5 (5)	9 (11)	Value not reported, NS
				10m later	8 (8)	12 (15)	Value not reported, NS
Verza 2006	Inter-disciplinary assessment protocol for assistive technology	Assistive aids	N (%) aids supplied but then not used	1997-1999 and 2000 -2002 (pre and post-	25/67 (37.3%)	8/84 (9.5%)	Chi-squared value not reported, p<.001

<i>First author and year</i>	<i>Model of care</i>	<i>Type of service</i>	<i>Measure used</i>	<i>When measured</i>	<i>Results for controls/ before</i>	<i>Results for subjects/ after</i>	<i>Statistical significance</i>
				intervention)			
Edmonds 2005 and 2006	Palliative care service	Paid carer	Days since last seen	At 4-6 weeks	3.9	0	Mann-Whitney, Z=-2.364, p=.018
				At 3 months	Not reported	Not reported	Not reported, said to be NS
Parkinson's disease							
Carne 2005	Multi-disciplinary assessment and management	Nurse visits	% of patients receiving	At follow-up (between 8 and 16m after initial assessment)	-	88%	None reported
		Neurology visits			-	100%	
		Neuro-psychology evaluations			-	42%	
		PM&R visits			-	93%	
		Diagnostic procedures			-	16%	
		Therapy visits			-	63%	
		Support group meetings			-	9%	
		Home exercise instruction			-	86%	
		Educational 'efforts'			-	84%	
Castleton 2005	Integrated care across health and social care	Residential care	N of admissions avoided	Not stated	-	4	None reported

<i>First author and year</i>	<i>Model of care</i>	<i>Type of service</i>	<i>Measure used</i>	<i>When measured</i>	<i>Results for controls/ before</i>	<i>Results for subjects/ after</i>	<i>Statistical significance</i>
	services						
		Use of local authority services not otherwise specified	Not reported	Not stated	-	Claim of overall reduction of demand on LA services	None reported
Montgomery 1994	Patient education and health promotion programme	Doctor not otherwise specified	Mean (SE) reported no of visits	6m before baseline	3.0 (0.2), n=150	3.1 (0.3), n=139	t-test value not reported, p=.9
				6m after baseline	3.1 (0.3) n=147	2.5 (0.2)	Value not reported, p=.06
			Mean (SE) difference	Between baseline and follow-up	0.07 (0.29)	0.62 (0.29)	Paired difference t-test value not reported, p=.09.
Jahanshahi 1994	Nurse practitioner	Physiotherapist	N (%) referred	At end of study	-	2 (6%)	n/a
		OT			-	6 (19%)	
		Dietician			-	2 (6%)	
		Speech therapist			-	3 (9%)	
		Contenance advisor			-	2 (6%)	
		Dentist			-	0	
		Optician			-	0	
		Chiropodist			-	1 (3%)	

<i>First author and year</i>	<i>Model of care</i>	<i>Type of service</i>	<i>Measure used</i>	<i>When measured</i>	<i>Results for controls/ before</i>	<i>Results for subjects/ after</i>	<i>Statistical significance</i>
		Psychologist/ psychiatrist			-	1 (3%)	
		Neurologist			-	5 (16%)	
		Driver assessment centre			-	1 (3%)	
Hurwitz 2004 and associated papers	Nurse specialist	Out-patients, day centre, or 'ancillary' therapists	N referred	24m after baseline	Not reported	Not reported	Proportions of subject and controls who were referred said not to vary significantly.
		Nurse assessments	Estimated mean carried out in one year	During 2 one week periods separated by 6m	n/a	8	n/a
Mixed neurological							
Ward 2004	Individualised patient education	GP	No (%) seeing >6 times	12m since baseline	10 (19)	17 (33)	Adjusted OR (95% CI) 2.12 (0.8 to 5.66) NS
		Specialist nurse	As above	As above	4 (8)	6 (11.5)	Adjusted OR (95%) 2.85 (0.59 to 13.73). NS
		Self-help group	No (%) in contact	As above	9 (17)	8 (15)	Adjusted OR (95% CI) 0.98 (0.34 to 2.88) NS

• Calculated by us

** Study followed up patients and reported outcomes for 9m. We have also reported 3m follow-up data to reflect whether recommended services were provided speedily.

2.3.1 RCTs

Two of the studies were RCTs of patient education or information (Montgomery, 1994; Ward, 2004) and showed no difference at follow-up between those receiving the intervention and those not in their contact with doctors, a specialist nurse or self-help groups. By contrast, an RCT of multi-disciplinary team (MDT) management of MS relapse (combined with IV steroid treatment) reported significantly higher levels of referral to and use of a range of therapy services and a nurse specialist at follow-up for those who had contact with the MDT (Craig, 2003). However, it is not clear whether the two groups had equivalent contact at baseline. The authors argue that the 'therapy input given to the control group reflects current practice on the wards' whereas the 'higher number of subjects referred on for further treatment in the intervention group is a reflection of the increased contact with therapists during admission' (p.1229).

There were two RCTs of a nurse specialist or nurse practitioner for people with PD. The first (Hurwitz, 2004) showed no difference between those who had and had not seen the nurse in their access to out-patient clinics, day centres or 'ancillary therapists' by 24 months after baseline. The second reported findings only for subjects and at the end of the study only. Similarly, an RCT of multi-disciplinary assessment and management for people with PD (Carne, 2005) reported findings on service use only for subjects, and only at follow-up.

The RCT of supported implementation of national care guidelines for epilepsy (Davis, 2004) reported the numbers of review consultations that primary care patients with epilepsy had with their GP and the number of GP consultations that involved discussion of epilepsy. In neither case were there any statistically significant differences between the control group (where primary care practices had simply received a copy of the guidelines through the post) and the two intervention groups (which had been offered different levels of support to implement the guidelines). Similarly, there were no differences between groups in the proportion of patients whose reviews conformed to the guidelines.

The pseudo-randomised trial of using a nurse specialist in a case manager role for people who had been admitted to hospital with epileptic seizures (Schull, 1992), showed an increase in the proportion of patients who kept appointments at an ambulatory (out-patient) clinic and a very small reduction in emergency department visits 90 days after the original admission. No statistical testing of the difference between the two groups was reported in the paper, however our reanalysis shows that, with the small numbers of patients involved (42 in total); the differences in relation to out-patient clinic compliance did not reach statistical significance.

Finally, the RCT of a palliative care service for people with MS (Edmonds, 2005; 2006), suggested that people receiving the service experienced a short-term

increase in access to the services of a paid carer, but that this difference did not persist to follow-up at three months.

2.3.2 Before and after studies

The before and after studies that reported access to or use of services varied in the extent to which they reported change over time.

For example, in a study of a nurse specialist in an epilepsy tertiary referral centre (Hosking, 2002), around a third of patients said that they had seen their GP less and a similar proportion their consultant less, since having access to the nurse specialist. However, there was no baseline information about contact with these doctors, or independent verification of numbers and frequency of contact.

Freeman (1999), a study of multi-disciplinary in-patient rehabilitation for people with MS, with recommendations for post-discharge services, did verify how many of the recommendations made at assessment had resulted in contact with services. Recommendations for contact from a wheelchair services clinic, community OT, district nurse, out-patient physiotherapy, community physiotherapy, psychology/counselling, home help, care management, and respite care had all been achieved by nine months of follow-up. By contrast, not everyone who had been recommended for contact with a social worker, day care services, re-housing, or housing adaptations had been contacted by nine months. Further, there was variation in the speed with which contact had been made. For example, contact about home help was made within three months in all cases where it had been recommended. By contrast, none of the three people recommended for re-housing had been contacted by three months.

A community-based MDT, also for people with MS (Makepeace, 2001) reported contacts with a range of service before and after people had received input from the team. Increases in the mean number of contacts over six months were evident¹ for district nursing, physiotherapy, psychology services, psychiatry, out-patient attendances, family counselling, OT, and social worker. There were also small decreases in the mean number of contacts with GPs and consultants.

Two studies of 'transmural care' in the Netherlands for people with MS, that was explicitly intended to increase co-operation across service boundaries, showed varying impact on service access and use (Oeseburg, 2004; Jansen, 2006). Both employed a form of follow-up, but only Jansen compared people who did and those who did not receive this model of care. Oeseburg (2004) suggests that, compared with average levels of contact in the five months before receiving transmural care,

¹ Calculated by us from data presented in the paper.

people had similar levels of contact with their neurologist but increased contact with their GP, rehabilitation specialists, nurse specialist and home care provider in the 10 to 15 months after starting to receive this model of care. By contrast, there was little difference in their contact with an OT, physiotherapist or social worker.

Jansen (2006) reports the numbers and proportions of people receiving transmural care who had contact with a range of services at baseline and 10 months later. Similar data are reported for people not receiving this model of care. However, the statistics reported compared the groups at baseline and then at follow-up but did not test whether or not the two groups' contact with services changed differentially over time. In places, this makes it difficult to understand the nature of the change. As they stand, the results suggest that people who did not receive transmural care reduced their contact with a neurologist and with a GP, while those who did receive this care maintained their pre-intervention level of contact. By contrast, while those receiving transmural care both started out and ended up with a higher level of contact with a rehabilitation specialist, 10 months later their level of contact was not significantly different from those who did not receive this model of care. A small increase in contact with a social worker and with a physiotherapist was experienced by both groups, as was a reduction in contact with an OT. Overall, then, it is difficult to take a consistent message from these two studies of transmural care in relation to access to and use of services.

Verza (2006) studied the impact of an inter-disciplinary assessment protocol for assistive technology. This examined the impact of introducing the assessment on the proportion of aids and equipment people with MS were supplied with but then did not use. Comparison of data from periods before and after introducing the assessment protocol showed a significant reduction in the proportion of supplied aids that were not subsequently used, from 37 per cent to 9.5 per cent.

Finally, Castleton (2005) examined the impact of 'integrated care' across health and social care services on the use of residential care and local authority services by people with Parkinson's disease. The model introduced involved a specialist treatment protocol, specialist clinics, meetings and seminars for patients and their carers, and a specialist nurse working as a key worker. Few data are reported directly in the study, but it is claimed that four admissions to residential care were avoided because of the new service organisation (out of 30 patients for whom information was collected). In addition, local authority staff felt that working in an integrated way had reduced demand for their care services.

2.3.3 Other studies

An audit of care for people with epilepsy in primary care (Redhead, 1996) showed a clear increase in the proportions of patients being seen in a 12 month period, from 83

per cent to 95 per cent, 22 months after the introduction of 'evidence-based care standards'. As the care standard introduced was that 75 per cent of epilepsy patients should be seen every year, it seems possible that it was the introduction of auditing, rather than the care standards themselves that increased the rate of call and recall of patients.

None of the remaining studies that reported access to or use of services included pre-baseline measures or comparison groups, and the apparent impact on service use varies between them. For example, over half of people with MND using a respite care service also received additional community support services (Hicks, 1993). By contrast, Van den Berg (2005) reported no differences in the number of times patients with MND saw a 'professional care giver' after attending multi-disciplinary clinics for symptomatic and palliative care. Similarly while 39 per cent of people with epilepsy seen by a nurse specialist and their GP took up an offer of consultant follow-up in one study (Lambert, 2001) only small proportions of people with epilepsy seeing a nurse specialist in a tertiary centre (Hosking, 2002) reported seeing their GP or consultant more often (6% and 4% respectively).

2.4 Service users' views of the model of care

Given that the impact on service use seems equivocal at best, how do those who use models of care that try to improve continuity feel about them?

Eighteen studies reported some quantitative assessment of service users' views of the model of care they had received (Table 2. 7). Two of these studies were RCTs of a nurse specialist (Ridsdale, 1996) or nurse practitioner (Jahanshahi, 1994) service. However, only the Ridsdale study reported findings for both the intervention and control groups, and here those who had been in contact with a nurse specialist and had access to a nurse-led clinic were asked about their experience of this care. Those in the control group were asked about their *expectations* of such care. Thus while the results are interesting in their own right, they do not allow us to compare the overall service experience of those with and without access to a nurse specialist.

A second RCT (Chataway, 2006) explored the impact of home-based versus hospital-based IV steroid administration. Measures of access to and co-ordination of care, access to information and experience of interpersonal care were used. Only in relation to co-ordination of care were there any statistically significant differences between those receiving treatment at home and the control group.

Table 2.7 Patients' views of model of care: quantitative results

<i>First author and year</i>	<i>Model of care</i>	<i>How views were assessed or measured</i>	<i>When assessed or measured</i>	<i>Results for controls/before</i>	<i>Results for subjects/ after</i>	<i>Statistical significance</i>
Epilepsy						
Ridsdale 1996 and associated papers	Nurse specialist and nurse-led clinic	Mean score (1 = excellent, 5= poor) about actual or anticipated (for controls) nurse specialist care ¹	6m after baseline			Not tested
		Investigation of condition		1.75	2.08	
		Diagnosis		1.83	1.87	
		Treatment		2.08	2.0	
		Information given		2.0	1.72	
		Advice/ counselling		1.92	1.72	
		Openness/ understanding		1.88	1.52	
		Continuity of care		1.87	2.0	
		Prognosis		2.32	2.0	
Ridsdale 2000	Two appointments with nurse specialist	% reporting sufficient advice given on: Driving	Baseline	82%	85%	$X^2 = 0.1, p=.70$
			6m	83%	96%	$X^2 = 3.8, p=.05$

<i>First author and year</i>	<i>Model of care</i>	<i>How views were assessed or measured</i>	<i>When assessed or measured</i>	<i>Results for controls/before</i>	<i>Results for subjects/ after</i>	<i>Statistical significance</i>
		Epilepsy types	Baseline	58%	46%	$X^2 = 1.2, p=.30$
			6m	55%	87%	$X^2 = 11.6, p<.01$
		Side effects of AEDs	Baseline	50%	41%	$X^2= 0.7, p= .40$
			6m	50%	81%	$X^2= 9.5, p<.01$
		Self-help groups	Baseline	49%	40%	$X^2=0.6, p=.40$
			6m	68%	87%	$X^2= 4.9, p= .03$
		Epilepsy causes	Baseline	44%	34%	$X^2= 1.0, p =.30$
			6m	51%	72%	$X^2= 4.3, p=.04$
		Problems with social activities	Baseline	49%	32%	$X^2= 2.6, p= .10$
			6m	48%	87%	$X^2= 15.9, p<.01$
		Problems with school/work	Baseline	45%	46%	$X^2= 0.0, p =.90$
			6m	50%	80%	$X^2= 7.9, p<.01$
		Problems with family life	Baseline	41%	23%	$X^2= 3.0, p=.10$

<i>First author and year</i>	<i>Model of care</i>	<i>How views were assessed or measured</i>	<i>When assessed or measured</i>	<i>Results for controls/before</i>	<i>Results for subjects/ after</i>	<i>Statistical significance</i>
			6m	44%	64%	$X^2 = 3.5, p = .06$
		Problems with other drugs	Baseline	36%	28%	$X^2 = 0.7, p = .40$
			6m	37%	77%	$X^2 = 14.3, p < .01$
Hosking 2002	Nurse specialist in tertiary referral centre	% reporting satisfaction with aspects of nurse specialist care: support and counselling	Not clear	-	54% extremely/ very helpful 26% helpful 3% unhelpful 17% invalid or n/a	None reported
		As above: improved management		-	45% significant/ a lot 23% some 14% none 1% worse 17% invalid/ nk	
		As above: satisfied with service		-	67% extremely/ very satisfied 19% satisfied 1% unsatisfied 13% invalid/ nk	
		As above: improvement on other services		-	68% significant improvement 6% unchanged 2% no change 11% nk 13% invalid	
		% reporting difficulty contacting nurse specialist		-	76% no difficulty 6% some 10% not attempted 2% invalid	
Upton 1996	Tertiary assessment centre	N (%) satisfied with services listed Drug changes	Before discharge from assessment centre	-	66/76 (87)	

<i>First author and year</i>	<i>Model of care</i>	<i>How views were assessed or measured</i>	<i>When assessed or measured</i>	<i>Results for controls/before</i>	<i>Results for subjects/ after</i>	<i>Statistical significance</i>
		Keyworker system		-	56/76 (74)	
		Medical services		-	71/76 (93)	
		Psychological services		-	68/76 (90)	
		Seizure control		-	43/76 (57)	
		Social work		-	71/76 (93)	
		N (%) rating services offered as 'very important'		-	59/76 (78)	
		Drug changes		-		
		Trying new drugs		-	33/76 (43)	
		Learning to become independent		-	27/76 (36)	
		Learning about epilepsy		-	36/76 (47)	
		Meeting others with epilepsy		-	36/76 (47)	
		Educational groups			34/76 (45)	
		Psychology services			34/76 (45)	
		Social work			27/76 (36)	
Gunter 2004	Disease management programme	Satisfaction questions in self-completed questionnaire: preference	While attending clinic or soon after	-	89% hospital clinic 4% GP 7% undecided	

<i>First author and year</i>	<i>Model of care</i>	<i>How views were assessed or measured</i>	<i>When assessed or measured</i>	<i>Results for controls/before</i>	<i>Results for subjects/ after</i>	<i>Statistical significance</i>
		for where epilepsy is managed				
		As above: % satisfied with clinic service	As above	-	63% satisfied 28% satisfied with some reservations 4% undecided 3% dissatisfied but with some positives 1% dissatisfied	
Multiple sclerosis						
Makepeace 2001	Multi-disciplinary community team	Mean score (range) on Client Satisfaction Questionnaire	Not clear	-	26.5 (10-32)	
D'Arcy 2006; Balaratnam nd	Multi-disciplinary community clinic	Questionnaire	1 week after appointment	-	77% clinic had been of great benefit 30% 'delighted' to see a specialist neurologist 30% 'pleased' to see whole MDT at one visit 70% thought action plans accurate 5% thought plans took too long to put into action N=27	None reported
Chataway 2006	Home-based IV steroid administration	Median score (IQR) on Multiple Sclerosis Relapse Management Scale: Access to care	1 week after treatment finished	11.1 (4.2 to 27.8)	11.1 (5.6 to 22.2)	Mann-Whitney U value not reported, p=.868
		As above: co-ordination of care		12.1 (3.0 to 18.6)	4.5 (3.0 to 11.4)	As above, p=.024
		As above: information		28.6 (9.5 to 45.2)	28.6 (14.3 to 47.6)	As above, p=.367
		As above: interpersonal care		5.6 (0 to 13.0)	7.4 (1.9 to 16.7)	As above, p=.130

<i>First author and year</i>	<i>Model of care</i>	<i>How views were assessed or measured</i>	<i>When assessed or measured</i>	<i>Results for controls/before</i>	<i>Results for subjects/ after</i>	<i>Statistical significance</i>
Oeseburg 2004	Transmural care (same as Jansen?)	% agreeing with statements. Not clear how data were collected	Not clear	90% visits from rehabilitation team were new 80% wanted to continue with visits because very useful 85% wanted to continue with nurse specialist visits because of care monitoring, listening and presenting practical solutions.		
Jansen 2006	Trans-mural care model	Questionnaire designed to assess continuity of care	Baseline and 10m later	Data not reported	-	None reported
MacLean 2005	Computer-based patient information	N (%) agreeing with statements. Not clear how data were collected. Information point easy to access	Not clear	27/31 (87)		
		Found all information looking for		19/31 (61)		
		Information in clear and understandable language		28/31 (90)		
		Information very useful or useful		14/31 (45) very useful 13/31 (42) useful		
		Information will help understanding and/or management of condition a great deal		20/31 (65)		
Parkinson's disease						
Castleton 2005	Integrated care across health and social care services	N reporting relative impact of services. Questionnaire.	At end of study – not clear when this was	-	9/37 no opinion 3/37 other services more beneficial 13/37 consultant clinics had greatest positive impact	

<i>First author and year</i>	<i>Model of care</i>	<i>How views were assessed or measured</i>	<i>When assessed or measured</i>	<i>Results for controls/before</i>	<i>Results for subjects/ after</i>	<i>Statistical significance</i>
					11/37 nurse specialist had greatest positive impact ²	
		Not clear	Not clear	-	4/19 patients who attended one or more of the seminars said they provided 'significant benefit' to their care.	
Simons 2006, Macht 2006	Patient education	% agreeing fully with selected items of evaluation questionnaire (11 items where 50% or more agreed fully) ³ :	After programme completed			
		Group atmosphere comfortable		-	100	
		Helpful exchange experiences		-	93.8	
		Group leader appropriately directive		-	93.8	
		Actively involved		-	93.8	
		Helpful information		-	87.5	
		Not alone with problems		-	81.3	
		Would recommend to others		-	81.3	
		Increased understanding		-	75	
		Information understandable		-	75	
		Information not too theoretical		-	75	
		Enough practical information		-	75	

<i>First author and year</i>	<i>Model of care</i>	<i>How views were assessed or measured</i>	<i>When assessed or measured</i>	<i>Results for controls/before</i>	<i>Results for subjects/ after</i>	<i>Statistical significance</i>
Macht 2006	As above					
Jahanshahi 1994	Nurse practitioner	Mean (SD) rating from questionnaire survey of satisfaction with nurse practitioner	At end of study	-	8.5 (2.0), n=26	n/a
Reynolds 2000	Nurse specialist	Change in score on satisfaction survey: waiting time at clinic	Baseline and end of study	Not reported	Not reported	Kruskall Wallis H=8.35, df=3, p=.04
		Information about medication				H=7.66, df=3, p=.05
		Overall satisfaction				H=7.75, df=3, p=.05
		23 other variables from survey				All reported as ns.
Mixed neurological						
Haig 1994	Multi-disciplinary team assessment	N rating programme as helpful. Telephone standardised questionnaire	1 year after end of study	-	20/ 40 very helpful 9/40 somewhat helpful 9/40 not helpful ⁴	
Barnes 1996	Multi-disciplinary out-patient clinic	Self-completion questionnaire: % agreeing with given statement	After discharge	-	88% useful having access to range of therapists 35% found environment inhibiting and could not talk freely 69% felt problems and questions properly addressed and were satisfied with outcome N= 62 ?	None reported
		As above: overall ranking of preferred clinic formats (1 is most desirable)	As above	-	1. Drop in system, without appointment and access to any therapist 2. Seeing 1 or 2	

<i>First author and year</i>	<i>Model of care</i>	<i>How views were assessed or measured</i>	<i>When assessed or measured</i>	<i>Results for controls/before</i>	<i>Results for subjects/ after</i>	<i>Statistical significance</i>
					professionals with expertise relevant to own problems 3. Doctor-based clinic with referral onto other therapists as appropriate 4. See all relevant therapists but on individual basis, not in group format 5. See all therapists and doctor together in same room at same time.	
Roy 1991	Integrated care across hospital and community services					

1. Questionnaire was used only with a sub-group from larger trial, selected from those in remission or with low seizure frequency.
2. Sums to 36, not the 37 said to have provided data.
3. UK results only reported. Seven item scores inverted by us to give the 'top 11' positive assessments.
4. Sums to 38, not the 40 said to have been followed-up.

None of the other studies reporting aspects of service users' views had comparison groups, or reported results both before and after implementation of the service. Overall, as one would expect, they report positive accounts of the model of care. For example, 90 per cent of those surveyed about transmural care (Oeseburg, 2004) had not previously received visits from a rehabilitation team and 80 per cent wanted them to continue because they found them very useful. Similarly, 85 per cent wanted to continue with visits from a nurse specialist because they valued the care monitoring provided, the practical solutions offered and the listening.

2.5 Disability and impairment

Seventeen studies reported some aspect of disability or impairment as an outcome (Table 2.8). Of these, 12 studies were RCTs. Thus, we potentially have relatively robust information about this outcome. However, there are several difficulties in synthesising the results reported in these studies.

Table 2.8 Summary synthesis of impact on impairment and/or disability and/or activities of daily living

<i>First author and year</i>	<i>Model of care</i>	<i>How measured</i>	<i>When measured</i>	<i>Results for controls/before</i>	<i>Results for subjects/after</i>	<i>Statistical significance</i>
Epilepsy						
Davis 2004	Supported implementation of national care guidelines	Mean (95% CI) ESI-55 cognitive function test	Baseline	21.0 (19.9 to 22.0)	Intermediate: 21.3 (20.6 to 22.0) Intensive: 20.7 (19.9 to 21.4)	
			12m	21.1 (20.2 to 22.0)	Intermediate: 20.9 (20.1 to 21.7) Intensive: 20.3 (19.6 to 21.1)	Paired t-tests value not reported. Said to be ns.
Multiple sclerosis						
Rossiter 1998 and 1995	Integrated care pathway	Mean FIM – motor score	As above	Cohort 1: 60 Cohort 2: 61 Cohort 3: 60	Cohort 1: 69 Cohort 2: 69 Cohort 3: 67	Not reported. Said to be no sig, diff between each cohort
		Mean FIM – cognitive score	As above	Cohort 1: 29 Cohort 2: 30 Cohort 3: 29	Cohort 1: 29 Cohort 2: 30 Cohort 3: 29	As above. Said to be ns.
Makepeace 2001	Multi-disciplinary community team	FIM motor score	As above	71.9	69.7	Wicoxon test. Not reported directly, $p < .05$ ¹
Craig 2003	Multi-disciplinary team management of relapse, combined with IV steroid treatment	Mean (SD) GNDS score ²	Baseline	21.5 (7.2)	21.1 (7.1)	
			3m	19.7 (10.6)	13.2 (8.9)	Univariate ANOVA on change from baseline to 3m. Result not reported, said to be significant.
Pozzilli 2002	Multi-disciplinary home care	FIM	Baseline and 12m	Not reported	Not reported	Results not reported. Said to be no sig. diff in change between subjects and controls

<i>First author and year</i>	<i>Model of care</i>	<i>How measured</i>	<i>When measured</i>	<i>Results for controls/before</i>	<i>Results for subjects/after</i>	<i>Statistical significance</i>
Chataway 2006	Home-based IV steroid administration	Mean (SD) EDSS score ²	As above	5.2 (1.3)	5.1 (1.5)	
				4.4 (1.9)	4.1 (2.0)	Repeated measures ANOVA of difference (95%CI) in mean score change. 0.2 (-0.2 to 0.6), p=.321
Oeseburg 2004	Transmural care (same as Jansen?)	Mean (range) EDSS score ²	Baseline and 15m	4.7 (0 to 8.5)	Not reported	Not reported. Said to be no sig. change over time
O'Hara 2002	Consumer focused, professional advice about self-care	Mean (SD) Barthel Index score	Baseline	15.73 (4.94)	15.5 (5.22)	
			6m	14.95 (5.44)	15.32 (5.57)	Wilcoxon test of difference from baseline to follow-up. Subjects z=0.49, p=.62. Controls z = -3.41, p=.001 ³
Parkinson's disease						
Trend 2002 and associated papers	Multi-disciplinary rehabilitation with group educational support	Mean (SD) PD Disability Questionnaire ²	Baseline	50.3 (18.0)	48.9 (14.4)	
			24 weeks	55.3 (19.5)	53.4 (17.4)	GLIM analysis of difference in change scores controlling for baseline differences. Not reported directly. p=.558
Carne 2005	Multi-disciplinary assessment and management	Mean (SD) UPDRS Part III Motor Examination Score ²	Baseline and follow-up (around 12m)	28.72 (13.16)	30/43 said to have improved with mean improvement of -11.28. 11/43 said to have deteriorated with mean deterioration of +9.72. Mean improvement of -5.38 ⁴	None reported
Montgomery 1994	Patient education and health promotion programme	Mean (SE) UPDRS summary score ²	Baseline	29.2 (1.1)	28.8 (1.3)	

<i>First author and year</i>	<i>Model of care</i>	<i>How measured</i>	<i>When measured</i>	<i>Results for controls/before</i>	<i>Results for subjects/after</i>	<i>Statistical significance</i>
			6m	31.9 (1.2)	28.9 (1.3)	Paired difference t-test on mean change score. Not reported directly, p said to be =.007 ⁵
Jahanshahi 1994	Nurse practitioner	Mean (SD) Functional Disability Questionnaire score ² PD patients	Baseline	49.7 (14.2)	53.1 (19.7)	
			6m	54.2 (19.4)	54.2 (19.4)	Not reported. Appears to be within group analysis. Reported as ns
		Mean (SD) Functional Disability Questionnaire score ² Dystonia patients	As above	56.8 (10.3)	55.7 (21.2)	
				56.4 (18.5)	56.6 (19.2)	As above.
Reynolds 2000	Nurse specialist	Functional Disability Questionnaire ² Social disability	Baseline and possibly 12m	Not reported	Not reported	Kruskall-Wallis test on change in score. H=3.91, df=3, ns
		Physical activity				H=3.18, df=3, ns
		Self-care				H=7.12, df=3, ns
		Leisure				H=2.67, df=3, ns
Mixed neurological						
Haig 1994	Multi-disciplinary team assessment	Reported change of overall function from telephone follow-up questionnaire	12m after evaluation	-	16/40 rated no change 13/40 rated better 8/40 rated worse	Chi-squared test of goodness of fit. $X^2 = 2.89$, ns.

<i>First author and year</i>	<i>Model of care</i>	<i>How measured</i>	<i>When measured</i>	<i>Results for controls/before</i>	<i>Results for subjects/after</i>	<i>Statistical significance</i>
					3 nk	
Sitzia 1998	Multi-disciplinary rehab with post-discharge follow-up	Median NHP (part 1) – physical mobility. PD patients ²	Baseline and one month after discharge	56.6	54.5	Wilcoxon Z=2.1, p<.05 ⁶
		As above, MS patients	As above	66.1	55.5	Wilcoxon Z=2.1, p<.05 ⁶
Ward 2004	Individualised patient education	Mean (SD) NEADL score	Baseline	6.15 (5.58)	7.83 (6.33)	
			12m	6.65 (6.07)	9.45 (7.13)	Paired difference t-test (within group) not reported directly. Controls ns, subjects p=.002. Mean difference for subjects (95% CI) 1.62 (0.69 to 2.55), p=.001

EDSS Kurtzke's Expanded Disability Status Scale

ESI 55

FIM Functional Independence Measure

GNDS Guys Neurological Disability Scale

NEADL Nottingham Extended Activities of Daily Living Scale

NHP Nottingham Health Profile

UPDRS Unified Parkinson's Disease Rating Scale

1. Performance declined over time.
2. Decrease in score indicates improvement
3. Based on analysis of median scores. Means and SDs provided directly by researchers.
4. Calculated by us.
5. The mean change for the control group is reported to be 29.7. This is very different from the apparent mean change reported in other tables in the paper – i.e. from 29.9 to 31.9 is a mean change of 2.0. It is not clear on which of these figures the apparently statistically significant change is based.
6. Reported values were identical for both groups. This is not explained in the paper.

First, the measures used were very varied. Some were straight measures of impairment – for example, tests of mobility or manual dexterity. Others, however, measured aspects of impairment alongside disability and, sometimes, activities of daily living.

Secondly, some studies reported more than one measure of impairment and/or disability (see Appendix 7 for all measures reported). In our analysis, we have confined ourselves to a single measure of impairment and/or disability from each RCT, and, where there was more than one to choose from, have tried to use a similar type of measure for each study.

Thirdly, not all papers reported results directly, but referred only to statistical test results or levels of significance. In all these cases, we attempted to contact the researchers to obtain results in a form that we could use for synthesis. In some cases this was successful, in others not.

Fourthly, we would have preferred to synthesise results using a social model of disability and thereby by distinguishing between:

- impairment of function (what someone is able or unable to do solely by virtue of their condition or physical state), and
- disability (what someone is able or unable to do by virtue of the help they may or may not get from others or from aids, or from adaptations to the physical environment).

However, almost none of the measures used in the sorts of studies reviewed here allowed such a distinction to be made.

Four RCTs - of multi-disciplinary team management of relapse for MS (Craig, 2003), of consumer-focused self-care advice for people with MS (O'Hara, 2002), of patient education and health promotion for people with Parkinson's disease (Montgomery, 1994) and of individualised patient education for people with mixed neurological conditions (Ward, 2004) - showed significant improvements on measures of impairment and/or disability in favour of the intervention groups. None of the other eight RCTs showed significant positive change on any of the measures used. However, even where statistically significant difference was not reached, the results did tend to favour the intervention groups.

Among the other studies, one (Makepeace, 2001, of a multi-disciplinary community team for MS) showed patients deteriorating significantly between baseline and six months follow-up, while a study of transmural (multi-disciplinary) care for MS (Oeseburg, 2004) claimed no significant changes between baseline and 15 months, although the quantitative details of this were not reported directly.

2.6 Clinical outcomes

Fifteen studies, seven of which were RCTs, reported some aspect of clinical outcomes. These outcomes varied considerably, from adverse events, through changes in drug treatment, to changes in clinical condition (see Table 2.9).

Three trials - the Ridsdale (1996) trial of a nurse specialist for people with epilepsy, the Davis (2004) trial of supported implementation of national guidelines for epilepsy, and the Hurwitz trial of a nurse specialist for PD - reported no significant differences in any of the clinical outcome measures used.

Chataway (2006) - an RCT of home-based IV steroid administration for MS - showed some differences between subjects and controls in reported adverse events. Where these differences were statistically significant (our analysis), they were in favour of the intervention, suggesting that home-based treatment was at least as safe as hospital-based treatment and perhaps associated with fewer side effects (metallic taste and mood disturbance).

Edmonds (2005), an RCT of palliative care for people with MS, showed that the intervention group were less likely to report nausea at the 'slight or worse' level. However, the subjects and controls were also significantly different on this variable at baseline (our analysis) so it seems likely that the difference at follow-up simply reflected the initial differences. Both groups had, in fact, deteriorated over time. Further, the intervention group reported significantly *poorer* sleep at final follow-up, compared to the controls. However, no baseline figures for this outcome were reported and, because the study employed a waiting list control group, by the time of final follow-up the control group had received the service (three months previously, compared to the intervention group six months previously).

A trial of a patient education and health promotion programme for people with PD (Montgomery, 1994), reported significant changes in mean levels of drug use for Levodopa in those receiving the intervention but for no other clinical outcomes reported.

Table 2.9 Clinical outcomes

<i>First author and year</i>	<i>Model of care</i>	<i>How measured</i>	<i>When measured</i>	<i>Results for controls/before</i>	<i>Results for subjects/after</i>	<i>Statistical significance</i>
ALS/MND						
Hicks 1993	Respite care	% of admissions leading to medication review	Retrospectively from records	n/a	81% of admissions	n/a
Epilepsy						
Ridsdale 2000	Nurse specialist	Median months since last seizure	Around 6m from baseline	4.9	6.5	Not reported, said to be ns
Davis 2004	Supported implementation of national guideline	Nature of seizures (mean (95% CI) ICTAL score)	Baseline	16.0 (15.2 to 16.7)	Intermediate: 15.5 (14.8 to 16.2) Intensive: 16.1 (15.3 to 16.8)	
			12 months	16.0 (15.4 to 16.9)	Intermediate: 16.1 (15.3 to 16.8) Intensive: 15.9 (15.3 to 16.5)	Not reported, said to be ns
		Mean score (95% CI) perceived severity of seizures	Baseline	30.6 (29.1 to 32.1)	Intermediate: 33.2 (32.2 to 34.1) Intensive: 31.5 (30.1 to 32.9)	
			12 months	32.0 (30.8 to 33.3)	Intermediate: 32.7 (31.1 to 34.2) Intensive: 31.3 (30.0 to 32.6)	Not reported, said to be ns.
		Mean score (95% CI) perceived adverse drug effects	Baseline	36.7 (35.3 to 38.2)	Intermediate: 37.9 (35.8 to 40.1) Intensive: 34.6 (31.9 to 37.3)	
			12 months	38.2 (36.0 to 40.5)	Intermediate: 35.9 (33.6 to 38.1) Intensive: 34.6 (32.9 to 36.3)	Not reported, said to be NS

<i>First author and year</i>	<i>Model of care</i>	<i>How measured</i>	<i>When measured</i>	<i>Results for controls/before</i>	<i>Results for subjects/after</i>	<i>Statistical significance</i>
Goodwin 2002	Multi-disciplinary review in primary care	N taking specified drug (out of 71 reviewed by specialist):	After review			
		Phenytoin		28	16	
		Phenobarbitone		5	2	
		Primidone		5	3	
		Carbamazepine		30	24	
		Sodium valproate		26	26	
		Clobazam		2	1	
		Diazepam		1	1	
		Lamotrigine		2	7	
		Ethosuzimide		1	1	
		N taking: no medication		1	10	
		Monotherapy		50	47	
		Polytherapy		20	14	
Leach 2005	Review and follow-up of patients previously 'unknown' to specialist services	Overall outcome of review, accepting treatment change and receiving continued specialist care. Those with diagnostic uncertainty (n=19)	Not clear	-	9 stopped AEDs, no events. 4 stopped AEDs, events but not seizures 2 stopped AEDs no further contact 3 treatment continued 1 reduced AEDs,	One sample chi-squared = 10.21, df=4, p=0.37 ¹

<i>First author and year</i>	<i>Model of care</i>	<i>How measured</i>	<i>When measured</i>	<i>Results for controls/before</i>	<i>Results for subjects/after</i>	<i>Statistical significance</i>
					definite seizure	
		Those in remission (n=13)		-	2 stopped AEDs, no relapse 4 changed treatment and side effects resolved 5 treatment continued 1 not in remission 1 stopped AEDs and relapsed	One sample chi-squared = 5.08, df=4, p=.279 ¹
		Those with active epilepsy (n=55)		-	17 new remission > 1 year 20 reduction in seizure frequency, severity or side effects 11 unchanged 4 lost to follow-up 2 epilepsy not active 1 transient deterioration in seizure control	One sample chi-squared = 36.66, df=5, p<.001 ¹
Upton 1996	Tertiary assessment centre	N and % reporting improvement in seizure control	Just before discharge and 6m later	52/76 (68%)	30/56 (54%)	
		N and % reporting improvement in drug side effects	As above	46/76 (61%)	N not reported. 82%	
Rasmusson 2005	Telemedicine clinic	Mean (SD) seizures	Record review over 3m period	4.58 (9.0)	4.81 (9.3)	t = - 0.19, p=.84, df=153 ²
		% with blood levels in	As above	89% (N=72)	82% (N=83)	Not reported.Said to

<i>First author and year</i>	<i>Model of care</i>	<i>How measured</i>	<i>When measured</i>	<i>Results for controls/before</i>	<i>Results for subjects/after</i>	<i>Statistical significance</i>
		therapeutic range by patient or provider report				be ns.
Redhead 1996	Evidence-based care standards	N and % with record of level of seizure control ³	At first audit cycle and 22m later	Poor: 12/150 (8%) Moderate: 13/150 (9%) Good : 50/150 (33%) All: 75/150 (50%)	Poor: 12/163 (7%) Moderate: 29/163 (18%) Good: 111/163 (68%) All: 152/163 (93%)	
		N and % taking AEDs no more than twice daily	As above	95/150 (63%)	107/163 (66%)	
Multiple sclerosis						
Chataway 2006	Home-based IV steroid administration	N and % adverse events: Metallic taste	During 3 days of treatment	37 (54%)	19 (28%)	Chi-squared ¹ = 9.74, df=1, p=.002
		Facial flushing		22 (32%)	21 (30%)	NS
		Sleep disturbance		19 (28%)	19 (28%)	NS
		Fatigue		4 (6%)	9 (13%)	NS
		Nausea		3 (4%)	7 (10%)	NS
		Mood disturbance		8 (12%)	2 (3%)	Chi-squared ¹ = 3.88, df=1, p=.049
		Light-headedness		3 (4%)	6 (9%)	NS
		Headache		0	4 (6%)	NS with continuity correction

<i>First author and year</i>	<i>Model of care</i>	<i>How measured</i>	<i>When measured</i>	<i>Results for controls/before</i>	<i>Results for subjects/after</i>	<i>Statistical significance</i>
		Reflux		1 (1%)	3 (4%)	NS
		Dry mouth		0	2 (3%)	NS
		Impaired concentration		1 (1%)	1 (1%)	NS
		Vomiting		0	1 (1%)	NS
		Arthralgia		1 (1%)	0	NS
		Palpitations		1 (1%)	0	NS
		Cutaneous reaction		0	1 (1%)	NS
		Mean no of adverse events ¹		1.45	1.38	
Edmonds 2005 and 2006	Palliative care service	POS – MS N reporting nausea slightly or worse	4-6 weeks	6/22	1/24	
			3 months	10/23	4/26	Not reported. Said to be 'borderline significant'.
		POS – MS N reporting sleeping problems slightly or worse ⁴	At 24-26 weeks	7/21	13/25	Mann-Whitney U, Z=1.138, p= 0.033
		MSIS N reporting problems sleeping slightly or worse ⁵	As above	5/21	13/25	As above. Z=2.229, p=0.026
Parkinson's disease						

<i>First author and year</i>	<i>Model of care</i>	<i>How measured</i>	<i>When measured</i>	<i>Results for controls/before</i>	<i>Results for subjects/after</i>	<i>Statistical significance</i>
Castleton 2005	Integrated care across health and social care services	% of cases where misdiagnoses detected (professional evaluation)	Not stated	8% (N=37)		
		% of cases where therapeutic effect of drug treatment was maximised and adverse events minimised (professional evaluation)	As above	30% (N=37)		
Montgomery 1994	Patient education and health promotion programme	% reporting end of dose exacerbations	Baseline	47.8 (N=138)	46.5 (N=129)	
			6 months	51.4 (N=138)	48.1 (N=133)	Not reported. Said to be ns
		% reporting 'on-off' problem	Baseline	26.9 (N=134)	35.2 (N=125)	
			6 months	30.5 (N=131)	32.1 (N=134)	As above
		% using Levodopa	Baseline	85 (N=150)	86 (N=140)	
			6 months	89 (N=150)	88 (N=140)	As above
		Change in mean (SE) dose of Levodopa (measure not reported)	From baseline to 6 months	61.22 (18.10)	-0.85 (19.05 - sic)	Result not reported, p=0.019
		% using Bromocriptine	Baseline	25 (N=150)	26 (N=140)	
			6 months	25	24	Not reported. Said to be ns.
		Change in mean (SE) dose of Bromocriptine	From baseline to 6 months	2.03 (1.05)	1.21 (0.66)	Result not reported. p=0.51

<i>First author and year</i>	<i>Model of care</i>	<i>How measured</i>	<i>When measured</i>	<i>Results for controls/before</i>	<i>Results for subjects/after</i>	<i>Statistical significance</i>
		% using Selegiline	Baseline	58 (N=150)	57 (N=140)	
			6 months	53	59	Not reported. Said to be ns.
		Change in mean (SE) dose	From baseline to 6 months	-0.04 (0.23)	0.04 (0.23)	Result not reported, p=0.8
		Mean (SE) change in side effects index	As above	3.04 (1.27)	0.79 (1.16)	Result not reported, p=0.19
Holloway 2006 and associated papers	User-led care pathway	Hoehn and Yahr scale estimate of severity of condition	Baseline and 12 months	3/22 mild 11/22 mild to moderate 7/22 moderate 1/22 moderate to severe	Not reported but said to reveal 'little change'	None reported
Hurwitz 2004 and associated papers	Nurse specialist	Fracture rate	12m before baseline	7% (50/702)	5.4% (55/1028)	
			During two year follow-up	11.1% (62/558) ⁶	13.2% (92/696)/2 ⁶	OR (95% CI) 1.20 (0.85 to 1.69), p=.31
		Various medication results – waiting for data from researchers				

<i>First author and year</i>	<i>Model of care</i>	<i>How measured</i>	<i>When measured</i>	<i>Results for controls/before</i>	<i>Results for subjects/after</i>	<i>Statistical significance</i>
Mixed neurological						
Ward 2004	Individualised patient education	n and % reporting falls	12m from baseline	24 (46%)	30 (56%)	OR (95% CI) adjusted for n of baseline events 2.83 (1.07 to 7.47), p=.036
		n and % reporting skin sores	As above	2 (4%)	7 (13.5%)	OR (95% CI) adjusted for n of baseline events 12.74 (1.14 to 142.6), p=0.039.

AEDs Anti-epileptic drugs

MSIS Multiple Sclerosis Impact Scale

POS-MS Palliative Outcome Scale – MS Version

1. Calculated by us
2. With no baseline figures it is difficult to know what this result signifies
3. 'Poor control' - one or more seizures in past month; 'moderate control' – 1-11 seizures in past 12 months; 'good control' – no seizures in past 12 months
4. No other POS-MS results reported, so presumably no others were significant
5. No other MSSSI results reported, so presumably no others were significant
6. The Ns on which these results are based are different from the Ns said to have survived and not been lost to follow-up (684 subjects and 541 controls)

The final trial (Ward, 2004) - of patient education for mixed neurological conditions, including PD - reported significant changes between the intervention and control groups in the proportions reporting falls and skin sores, but in both cases the changes were claimed to favour the control group, after adjusting for differences in baseline measures. After looking again at the results, we are not sure that this is correct. The proportion of people followed up in the control group who had experienced a fall in the previous 12 months changed from 22/52 (42.3%) at baseline to 24/52 (46.1%) at follow-up. In the intervention group the change was from 31/53 (58.5%) to 30/53 (56.6%). We do not see how adjustment for the differences at baseline could have generated an odds ratio that favoured the control group. By contrast, the change in proportions reporting a skin sore in the previous 12 months - from 6/52 (11.5%) to 2/52 (3.8%) for the controls and from 3/53 (5.7%) to 7/53 (13.2%)² - does clearly favour the control group.

Three further studies provided some comparative measurements.

Upton (1996) looked at improvements in epilepsy seizure control in patients who had attended a tertiary assessment centre. The results suggest that some gains in control (reported by 68% of patients just before leaving the centre) were lost later when only just over half (54%) were still reporting improvements.

Redhead (1996) explored the effect of introducing and then auditing evidence-based care standards for epilepsy in primary care and showed substantial improvements in record keeping between the first and second audits. In the first, only 50 per cent of records of patients with epilepsy included information about their level of seizure control. At the second audit, 93 per cent of patients had their level of control recorded. While the proportion of all epilepsy patients who were recorded as having good control increased between the two audits (from 33% to 68%) it seems that this had much to do with better recording about those with good control than any real clinical improvement. Another standard introduced was that medication should be taken once or twice daily to aid compliance. At the first audit, 63 per cent of patients were taking anti-epilepsy drugs no more than twice a day; by the second audit 66 per cent were.

The third before-and-after study (Holloway, 2006) explored the impact of a user-led care pathway on a PD severity measure. Although follow-up data were not reported directly, they were said to reveal little change between baseline and 12 months later.

² Not 13.5% as reported in the paper.

2.7 Mortality

Three studies formally reported mortality as an outcome.

Traynor (2003) compared people with ALS who attended a multi-disciplinary, specialist clinic with those who attended general neurology clinics. All patients with ALS in Ireland were identified and followed-up over a four-year period. Multivariate modelling explored the contribution of a range of variables, including attendance at the specialist clinic, to survival. Overall, median survival for those attending the specialist clinic was 677 days, compared with 448 days for those attending general neurology clinics. Cox proportional hazard modelling showed that the risk of death over the four year period in which death rates were tracked was significantly higher for those using general neurology clinics (hazard ratio 1.47, 95% CI 1.06 to 2.06, $p=.02$) than for those using the specialist service, once other influential variables had been controlled for. Patients with bulbar onset of ALS appeared to benefit particularly from the specialist clinics.

By contrast, Hurwitz (2004), in an RCT of a nurse specialist service for people with PD, showed no significant differences in mortality between the intervention group and the controls either two years or four years after baseline. Seventeen per cent of subjects and 18 per cent of controls had died by two years (hazard ratio 0.91, 95% CI 0.73 to 1.13, $p=.38$). By four years, 35 per cent and 38 per cent, respectively, had died (hazard ratio 0.89, 95% CI 0.76 to 1.03, $p=.12$).

Finally, the Edmonds (2005) RCT of a palliative care service for people with MS showed slightly higher death rates for controls than for the intervention group at final follow-up, between 24 and 26 weeks after baseline. One of the 26 in the intervention group and three of the 26 in the controls had died by this stage. No statistical analysis of these findings is presented.

2.8 Quality of life

Fifteen studies, nine of them RCTs, reported some measure of quality of life (QoL), usually using health-related quality of life measures or disease-specific measures. Again, then, we had some possibility of robust information about this outcome. However, even among the RCTs, the messages studies were mixed (see Table 2.10).

There were no significantly higher scores in any aspect of measured QoL in the Davis (2004) study of supported implementation of national guidelines for epilepsy.

Table 2.10 Quality of life outcomes

<i>First author and year</i>	<i>Model of care</i>	<i>How measured</i>	<i>When measured</i>	<i>Results for controls/before</i>	<i>Results for subjects/after</i>	<i>Statistical significance</i>
ALS/MND						
Van den Berg 2005	Multi-disciplinary clinics for symptomatic and palliative care	SF-36 Physical functioning summary score	At interview	Not reported	Not reported	Mean difference (95% CI) between groups, adjusted in regression for range of differences between groups: -1.22 (-4.2 to 1.7), p=.42
		Physical functioning				As above. -0.63 (-8.6 to 7.4), p=.88
		Role function, physical				As above. -1.1 (-11.5 to 9.3), p=.83
		General health				As above. 0.94 (-5.1 to 7.0), p=.76
		Bodily pain				As above. -2.49 (-10.9 to 5.9), p=.56
		Mental summary score				As above. 4.28 (1.2 to 7.8), p=.01
		Vitality				As above. 4.02 (-2.2 to 10.3), p=.21
		Social functioning				As above. 15.0 (6.8 to 23.3), p<.001
		Role functioning, emotional				As above. 5.1 (-7.7 to 18.0), p=.43
		Mental health				As above. 4.5 (-0.2 to 9.2), p=.06
Epilepsy						
Gunter 2004	Disease management programme	Composite mean score. Quality of Life in	Baseline	64 (n=30)	68.4 (n=138)	

<i>First author and year</i>	<i>Model of care</i>	<i>How measured</i>	<i>When measured</i>	<i>Results for controls/before</i>	<i>Results for subjects/after</i>	<i>Statistical significance</i>
		Epilepsy Inventory 31 ¹				
			'post-intervention'	65	69.9	Paired t-test change score value not reported, p=0.77
Davis 2004	Supported implementation of national care guidelines	SF-36. Mean (95% CI) score: mental component summary ²	Baseline	47.7 (45.2 to 50.2)	Intermediate: 49.7 (48.1 to 51.3)	
					Intensive: 49.8 (47.9 to 51.7)	
			12m	48.0 (46.0 to 50.0)	Intermediate: 50.2 (47.9 to 51.7)	
					Intensive: 49.0 (46.5 to 51.4)	Paired t-tests values not reported. Said to be ns
		Physical component summary	Baseline	44.4 (42.5 to 46.2)	Intermediate: 45.8 (43.2 to 48.4)	
					Intensive: 43.6 (41.5 to 45.6)	
			12m	43.2 (39.4 to 47.1)	Intermediate: 45.1 (42.7 to 47.4)	
					Intensive: 44.0 (41.8 to 46.1)	As above.
		Mean (95% CI) IMPACT score ??	Baseline	28.4 (27.1 to 29.6)	Intermediate: 29.1 (28.1 to 30.2) Intensive: 27.8 (26.0 to 29.7)	
			12m	28.8 (27.6 to 29.9)	Intermediate: 29.4 (28.3 to	As above

<i>First author and year</i>	<i>Model of care</i>	<i>How measured</i>	<i>When measured</i>	<i>Results for controls/before</i>	<i>Results for subjects/after</i>	<i>Statistical significance</i>
					30.5) Intensive: 28.1 (26.3 to 30.0)	
Multiple sclerosis						
Pozzilli 2002	Multi-disciplinary home care	SF36: Physical functioning	Baseline	Not reported	Not reported	
			12 m	Not reported	Not reported	Mean change (95% CI) in two groups, after adjusting for baseline values in regression model. 0.27 (-0.53 to 1.06), p=.55
		Role, physical	As above	As above	As above	As above. 3.67 (-1.19 to 8.53), p=.09
		Bodily pain				As above. 3.46 (2.38 to 4.54), p=.0001
		General Health				As above. 5.01 (4.50 to 5.51), p=.0001
		Vitality				As above. 0.28 (-0.38 to 0.94), p=.41
		Social functioning				As above, 1.09 (0.51 to 1.67), p=.001
		Role, emotional				As above. 12.39 (9.85 to 14.93), p=.0001
		Mental health				As above. -0.10 (-0.25 to 0.05), p=.19
		Physical component score				As above: 1.19 (1.04 to 1.34), p=.0001
		Mental component score				As above: 0.75 (0.58 to 0.91), p=.0001
Craig 2003	Multi-disciplinary team management of relapse, combined with IV steroid	SF36 – 8 domains reported separately.	Baseline and 3m	See paper	See paper	Mann-Whitney U analysis of mean change to 3m. No values reported, all p values ns.

<i>First author and year</i>	<i>Model of care</i>	<i>How measured</i>	<i>When measured</i>	<i>Results for controls/before</i>	<i>Results for subjects/after</i>	<i>Statistical significance</i>
	treatment					
Chataway 2006	Home-based IV steroid administration	Mean (SD) SF 36 scores: Role emotional	Baseline	42.2 (44.1)	44.4 (44.3)	Not reported but groups said to be similar
			6 weeks	43.5 (43.9)	55.1 (45.5)	Repeated measures ANOVA of difference in mean change score (95% CI) -9.3 (-25.9 to 7.3), p=.270
		Role physical	Baseline	12.2 (25.5)	13.6 (29.8)	
			6 weeks	19.8 (32.7)	31.1 (39.2)	As above. -9.8 (-22 to 2.4), p=.116
		Pain	Baseline	49.6 (29.5)	53.5 (34.3)	
			6 weeks	58.4 (27.6)	65.8 (28.3)	As above: -3.4 (-11.8 to 5), p=.420
		Energy and vitality	Baseline	29.7 (19.7)	29.7 (23.2)	
			6 weeks	38.2 (20.9)	39.0 (22.5)	As above: -0.9 (-7.1 to 5.2), p=.767
		General health perception	Baseline	46.0 (22.7)	48.4 (23.7)	
			6 weeks	50.7 (27.1)	49.5 (22.7)	As above: 3.6 (-2.4 to 9.7), p=.238
		Social functioning	Baseline	38.7 (26.2)	46.6 (29.5)	
			6 weeks	54.8 (31.9)	57.6 (27.6)	As above: 5.2 (-4.6 to 15), p=.298
		Physical functioning	Baseline	33.5 (26.3)	38.5 (31.8)	
			6 weeks	40.0 (27.7)	47.4 (29.5)	As above: -2.4 (-9.4 to 4.5), p=.493
		Mental health	Baseline	56.0 (20.4)	58.3 (24.7)	

<i>First author and year</i>	<i>Model of care</i>	<i>How measured</i>	<i>When measured</i>	<i>Results for controls/before</i>	<i>Results for subjects/after</i>	<i>Statistical significance</i>
			6 weeks	61.8 (21.8)	65.7 (21.1)	As above: -1.7 (-7.9 to 4.6), p=.599
		Mean (SD) MSIS-29 physical impact score *	Baseline	63.1 (21.0)	58.8 (25.5)	
			6 weeks	45.3 (26.2)	36.5 (23.5)	Repeated measures ANOVA of difference (95%CI) in mean score change. 4.5 (-3.2 to 12.2), p=.253
		Mean (SD) MSIS-29 psychological impact score	Baseline	55.9 (24.4)	54.0 (25.9)	
			6 weeks	38.5 (26.1)	36.8 (24.8)	As above. -0.2 (-8.9 to 8.5), p=.956
Oeseburg 2004	Transmural care (same as Jansen?)	Mean (range) RAND 36 score: Physical functioning	Baseline and 15m	34.9 (0 - 95)	Not reported	Not reported directly. Said to be no sig. change
		Social functioning	As above	60.3 (25 -100)	As above	As above
		Bodily pain		73.4 (22-100)		As above
		Role limitations physical		17.5 (0-100)		As above
		Role limitations social		54.2 (0-100)		As above
		Emotional well-being		64.5 (28-100)		As above
		Energy/fatigue		42.8 (15-95)		As above
		Overall health perception		40.5 (5-80)		As above
		Mean health changes		35.6 (25-100)		
Jansen 2006	Trans-mural care model	RAND 36 health – related QoL: Physical functioning	Baseline	Not reported	Not reported	

<i>First author and year</i>	<i>Model of care</i>	<i>How measured</i>	<i>When measured</i>	<i>Results for controls/before</i>	<i>Results for subjects/after</i>	<i>Statistical significance</i>
			10m			'Regression' not otherwise specified, controlling for baseline differences between the groups. Standardised regression coefficient (95% CI): -1.662 (-6.099 to 2.846), p=.476
		Social function (overall)	As above	As above	As above	As above: 2.532 (-3.836 to 8.901), p=.434
		Role limitations – physical				As above: 6.053 (-4.283 to 16.389), p=.249
		Role limitations - emotional				As above: 7.603 (-4.426 to 19.632), p=.214
		Mental health				As above: -0.37 (-4.313 to 4.239), p=.986
		Energy and vitality				As above: 4.698 (0.423 to 8.973), p=.031
		Bodily pain				As above: 0.497 (-5.869 to 6.863), p=.878
		General health				As above: -0.537 (-5.094 to 4.019) p=.816
		Reported health transition				As above: 7.678 (1.886 to 13.470), p=.01
O'Hara 2002	Consumer focused, professional advice about self-care	Mean (SD) scores on SF-36 subscales: mental health	Baseline	69.2 (22.4)	68.7 (20.1)	
			6m	68.0 (22.3)	72.4 (19.8)	ANOVA. F=4.54, p=.04
		Pain	Baseline	61.4 (27.1)	60.8 (29.2)	
			6m	60.3 (26.3)	63.2 (31.0)	F=0.98, p=.32
		Physical role	Baseline	24.3 (35.7)	34.5 (38.5)	

<i>First author and year</i>	<i>Model of care</i>	<i>How measured</i>	<i>When measured</i>	<i>Results for controls/before</i>	<i>Results for subjects/after</i>	<i>Statistical significance</i>
			6m	23.7 (35.2)	28.1 (35.3)	F=1.02, p=.31
		Physical function	Baseline	25.4 (23.4)	25.6 (25.2)	
			6m	24.1 (25.5)	26.2 (28.0)	F=0.53, p=.47
		Role emotional	Baseline	57.8 (44.4)	64.4 (43.2)	
			6m	54.7 (46.1)	60.2 (42.5)	F=0.02, p=.88
		Social function	Baseline	61.3 (27.2)	60.1 (30.7)	
			6m	58.0 (30.4)	60.9 (31.3)	F=0.95, p=.33
		Vitality	Baseline	38.6 (22.8)	38.9 (19.8)	
			6m	34.4 (22.1)	40.4 (22.3)	F=4.09, p=.05
		General health	Baseline	44.4 (18.0)	42.7 (21.4)	
			6m	49.2 (25.2)	50.1 (24.6)	F=0.99, p=.32
Parkinson's disease						
Trend 2002 and associated papers	Multi-disciplinary rehabilitation with group educational support	Mean (SD) Euroqol score	Baseline	0.74 (0.18)	0.73 (0.20)	
			24 weeks	0.67 (0.27)	0.66 (0.22)	GLIM modelling of difference in change scores, controlling for baseline score and group membership. Value not reported, p=.951
		Mean (SD) Euroqol Visual Analogue score	As above	71.4 (14.7)	72.7 (17.4)	
				68.7 (15.9)	68.2 (18.6)	As above, p=.633
		Means (SD) Parkinson's Disease Questionnaire - 39 score *	As above	27.6 (13.2)	26.1 (11.3)	

<i>First author and year</i>	<i>Model of care</i>	<i>How measured</i>	<i>When measured</i>	<i>Results for controls/before</i>	<i>Results for subjects/after</i>	<i>Statistical significance</i>
				26.2 (13.2)	26.7 (13.7)	As above, p=.439
		Mean (SD) SF36 score: physical component summary	As above	29.7 (9.7)	29.8 (10.8)	
				28.1 (11.8)	28.8 (10.8)	As above, p=.602
		As above: general health subscale	As above	43.8 (17.4)	50.4 (21.5)	
				48.0 (17.6)	42.7 (18.7)	As above, p=.002 ³
Simons 2006 ⁴	Patient education	Parkinson's Disease Questionnaire -39 *	Before and after programme	Not reported	Not reported	Paired t test. Value not reported, said to be ns
Macht 2006 ⁴	As above	Mean (SD) Parkinson's Disease Questionnaire -39 * score: Total	As above	30.8 (16.2), n=133	30.7 (7.7)	Paired t test. t=1.0, ns
		Emotional wellbeing		7.7 (5.2), n=133	7.8 (5.1)	t= -0.3, ns
		Stigma		3.4 (3.1), n=128	3.6 (3.4)	t= -1.2, ns
		Social support		2.3 (2.8), n=99	2.1 (2.6)	t= 1.0, ns
		Cognition		5.5 (3.2), n=120	5.2 (3.1)	t= 1.4, ns
		Communication		3.2 (2.6), n=126	3.5 (2.8)	t= 1.5, ns
		Bodily discomfort		5.0 (2.8), n=122	4.9 (3.1)	t= 0.6, ns
Montgomery 1994	Patient education and health promotion programme	Mean (SE) score on battery of 15 questions related to self-efficacy: Patient global	6m after baseline	43.5 (2.0)	41.0 (1.8)	Not clear. Assume t-test. Value not reported, said to be ns

<i>First author and year</i>	<i>Model of care</i>	<i>How measured</i>	<i>When measured</i>	<i>Results for controls/before</i>	<i>Results for subjects/after</i>	<i>Statistical significance</i>
		assessment				
		Self-efficacy (symptoms)		256.0 (11.0)	297.0 (10.0)	As above, p said to be <05
		Self-efficacy (timed function)		237.0 (10.0)	267.0 (11.0)	As above, p said to be <.05
		Self-efficacy (management)		302.0 (14.0)	340.0 (13.0)	As above, p said to be <.05
		Total self-efficacy		795.0 (22.0)	904.0 (24.0)	As above, p said to be <.01
Reynolds 2000	Nurse specialist	Change in score on SF-36. Physical functioning	Baseline and follow-up (possibly 12m)	Not reported directly	Not reported directly	Kruskall – Wallis on change in score. H=9.78, df=3, p=.02 ³
		Role emotional				H=4.15, df=3, ns
		Bodily pain				H=1.11, df=3, ns
		General health				H=10.51, df=3, p=.02 ³
		Vitality				H=4.96, df=3, ns
		Social functioning				H=5.35, df=3, ns
		Role emotional				H=0.98, df=3, ns
		Mental health				H=0.21, df=3, ns

<i>First author and year</i>	<i>Model of care</i>	<i>How measured</i>	<i>When measured</i>	<i>Results for controls/before</i>	<i>Results for subjects/after</i>	<i>Statistical significance</i>
		Change score on Parkinson's Disease Questionnaire *. Mobility	As above	As above	As above	H=6.36, df=3, ns
		Activities of Daily Living				H=3.62, df=3, ns
		Emotional well-being				H=2.62, df=3, ns
		Stigma				H=4.54, df=3, ns
		Social support				H=1.80, df=3, ns
		Cognition				H=6.66, df=3, ns
		Communication				H=2.69, df=3, ns ⁵
		Bodily discomfort				H=4.55, df=3, ns
Hurwitz 2004 and associated papers	Nurse specialist	Mean (SD) EuroQoL score	Baseline	0.43 (0.36)	0.43 (0.35)	
			2 years	0.39 (0.35)	0.37 (0.35)	Mean difference (95% CI) estimated using linear regression: -0.02 (-0.06 to 0.02), p=.30
		Mean (SD) Parkinson's Disease Questionnaire -	As above	38.2 (21.8)	37.9 (21.8)	

<i>First author and year</i>	<i>Model of care</i>	<i>How measured</i>	<i>When measured</i>	<i>Results for controls/before</i>	<i>Results for subjects/after</i>	<i>Statistical significance</i>
		39				
				39.2 (22.1)	39.7 (21.2)	As above. 0.47 (-2.72 to 3.66), p=.77
		Mean (SD) change in self-perceived global health questionnaire	At 1 and 2 year follow-up only	5.02 (1.38)	4.79 (1.5)	As above. -0.23 (-0.40 to -0.06), p=.008.
Mixed neurological						
Sitzia 1998	Multi-disciplinary rehab with post-discharge follow-up	Nottingham Health Profile (part 1) Total HRQOL score for PD patients *	1 week before admission and 1 m after	257.6	216.0	Wilcoxon Z = 2.6, p<.01 ⁶
		As above for MS patients *	As above	268.7	219.5	Wilcoxon Z = 2.6, p<.01 ⁶

* Higher scores indicate poorer outcomes

1. Domain scores were also reported for: seizure worry, overall QoL, emotional well-being, energy/fatigue, cognitive, medication effects, social function. In no case was the difference in change in mean score statistically significant different between the two groups.
2. All sub-scale results reported and also said to be ns.
3. Result favours control group
4. Macht 2006 reports results for all the countries involved in this project. Simons 2006 reports the results for the UK sub-study only.
5. Two groups were significantly different at baseline.
6. Z score and p values reported as identical, despite different scores and numbers for the two groups (PD and MS patients)

Three RCTs of different models of care for MS mostly showed no difference in QoL between intervention groups and controls - MDT management relapse (Craig, 2003), home-based IV steroid administration (Chataway, 2006), and consumer focused self-care advice (O'Hara, 2002). However, the latter study did report greater improvement in the mental health and vitality sub-scales of the SF-36 for those who had received self-care advice. By contrast, Pozzilli (2002), an RCT of multi-disciplinary home care for people with MS, reported significantly better sub-scale scores on the SF-36 for the intervention group for bodily pain, general health, social functioning and role emotional. Both the overall physical and mental component scores were thus better for the intervention group.

Among the RCTs related to PD, the Trend (2002) study of multi-disciplinary rehabilitation and group educational support showed no QoL benefit for the intervention group. Indeed, for one measure reported - the general health subscale of the SF-36 - the control group did significantly better than the intervention group. This was also true for two SF-36 sub-scales (physical functioning and general health) used in the Reynolds 2000 RCT of nurse specialists for PD patients. The third RCT related to PD, of a nurse specialist (Hurwitz, 2004) showed no significant differences on the validated QoL measures used (EuroQol and the PDQ-39) between those receiving the new model of care and those not. By contrast, an RCT of a patient education and health promotion programme for PD (Montgomery, 1994) showed significant differences in self-efficacy in relation to symptoms, timed function, management and total self-efficacy at six-month follow-up. However, it was not clear whether the measures used for this part of the study were valid or reliable, and no baseline data had been collected to ensure that the groups were equivalent at the start of the study.

Among the comparative studies, three showed no significant differences between the intervention and controls groups (Gunter, 2004, disease management programme for epilepsy; Oeseburg, 2004; Jansen, 2006, transmural care for MS; Simons, 2006/Macht, 2006, patient education for PD). By contrast, the fifth comparative study (Sitzia, 1998, multi-disciplinary rehabilitation with post-discharge follow-up) showed significant improvements for both PD and MS patients in their total health-related quality of life score, measured by the Nottingham Health Profile.

The last study reporting QoL outcomes was a survey of people attending multi-disciplinary clinics for symptomatic or palliative care for ALS, compared with those receiving usual care (Van den Berg, 2005). The researchers used regression analysis, adjusted for a range of socio-economic and impairment variables on which the two groups differed. This showed that those receiving multi-disciplinary care scored higher, all else being equal, on the mental summary and social functioning scores of the SF-36. However, without baseline measurement on the SF-36 it is difficult to ascribe these differences to the intervention.

The author of the one RCT that showed consistently positive results (Pozzilli, 2002) was unable to provide us with data that would have allowed us to include these results in our synthesis.

2.9 Mental health outcomes

Eleven studies, seven of which were RCTs, reported mental health outcomes (Table 2.11).

Two RCTs of nurse specialist support, both for people with epilepsy, used 'caseness' on the Hospital Anxiety and Depression Scale to assess mental health. In the first study (Ridsdale, 1996) results were analysed separately for those who had and those who had not had a seizure in the past six months. This was because earlier work by the researchers had shown that depression was significantly related to recent seizure. There were differences between the intervention and control groups on depression 'risk' at baseline. The follow-up analysis controlled for this and showed that people who had not had a seizure in the past six months and who were in the control group were more than three times as likely to be 'at risk' of depression as those who had seen a specialist nurse. By contrast, there was no significant difference in the risk of depression for those who had experienced a seizure in the past 6 months. A further trial of nurse specialist input by the same group, this time of two appointments only, showed no significant differences between the intervention and control groups on depression or anxiety 'caseness' or median score.

A single RCT, of multi-disciplinary care for people with MS showed no differences on mental health measures between intervention and control groups (Pozzilli, 2002).

Three of the RCTs involved people with PD and/or dystonia. None showed any differences in any of the mental health measures used between those who received multi-disciplinary rehabilitation with group educational support (Trend 2002) or nurse practitioner/specialist support (Jahanshahi, 1994; Reynolds, 2000) and those who did not.

The seventh RCT, of individualised patient education for people with mixed neurological conditions (Ward, 2004) similarly showed no differences between the intervention and control groups on 'caseness' on the General Health Questionnaire.

Two of the remaining studies used some element of comparative measurement and, as with the RCTs, demonstrated no statistically significant difference between those who did and did not receive the services of a multi-disciplinary community team for MS (Makepeace, 2001) or a patient education intervention for PD (Simons, 2006; Macht 2006).

Table 2.11 Mental health outcomes

<i>First author and year</i>	<i>Model of care</i>	<i>How measured</i>	<i>When measured</i>	<i>Results for controls/before</i>	<i>Results for subjects/after</i>	<i>Statistical significance</i>
Epilepsy						
Ridsdale 1996 and associated papers	Nurse specialist and nurse-led clinic	N and % 'at risk' on HAD depression score ¹	Baseline	Seizure in past 6m: 8/29 (28%) No seizure in past 6m: 5/60 (8%)	Seizure in past 6m: 8/31 (26%) No seizure in past 6m: 9/64 (14%)	
			Approx 6m later	Seizure in past 6m: 7/30 (23%) No seizure in past 6m: 12/62 (19%)	Seizure in past 6m: 10/31 (32%) No seizure in past 6m: 4/65 (6%)	Chi-squared controlling for depression status at baseline. Seizure in past 6m: $\chi^2 = 0.59$, $p=.44$. No seizure in past 6m: $\chi^2 = 4.98$, $p=0.03$ RR (95% CI) of depression in controls relative to intervention group. Seizure in past 6m: 0.72 (0.32 to 1.65) No seizure in past 6m: RR 3.15 (1.15 to 8.60)
Ridsdale 2000	Two appointments with a nurse specialist	N and % of HADS 'cases' – anxiety	Baseline	20/43 (47%)	20/47 (43%)	
			6m	18/43 (42%)	15/47 (32%)	$\chi^2 = 0.96$, $p=.33$
		Median HADS anxiety score	Baseline	7.2	6.3	

<i>First author and year</i>	<i>Model of care</i>	<i>How measured</i>	<i>When measured</i>	<i>Results for controls/before</i>	<i>Results for subjects/after</i>	<i>Statistical significance</i>
			6m	6	5.7	Mann-Whitney U. Not reported, p=.41
		N and % of HADS 'cases' – depression	Baseline	7/43 (16%)	9/47 (19%)	
			6m	8/43 (19%)	9/47 (19%)	X ² = 0.0, p=.95
		Median HADS depression score	Baseline	3.9	3.5	
			6m	3.7	2.7	Mann-Whitney U. Not reported, p=.27
Upton 1996	Tertiary assessment centre	N and % reporting improved mood	Before discharge and 6m later	38/76 (50%)	Not reported for follow-up	None reported
Multiple sclerosis						
Makepeace 2001	Multi-disciplinary community team	Mean GHQ score	Baseline and 6 months	7.0	6.5	T-test. Not reported directly. Said to be ns
Pozzilli 2002	Multi-disciplinary home care	STAXI	Baseline and 12m	Not reported	Not reported	Not clear what test used. Result not reported. Said to be ns.
		STAI	As above	As above	As above	As above
		% change in CDQ score	As above	+ 0.7%	-7.8%	As above. Claims a 'trend in favour of the intervention group' with a p of 0.11

<i>First author and year</i>	<i>Model of care</i>	<i>How measured</i>	<i>When measured</i>	<i>Results for controls/before</i>	<i>Results for subjects/after</i>	<i>Statistical significance</i>
Parkinson's disease						
Trend 2002 and associated papers	Multi-disciplinary rehabilitation with group educational support	Mean (SD) HAD anxiety score	Baseline	6.2 (3.4)	6.1 (3.5)	
			24 weeks	5.8 (3.6)	6.1 (3.4)	GLIM of difference in change scores. Not reported directly p=.472
		Mean (SD) HAD depression score	Baseline	5.0 (3.6)	5.6 (3.9)	
			24 weeks	4.9 (3.2)	5.2 (3.3)	As above. Not reported directly, p=.625
Simons 2006	Patient education	Self-rating depression scale	Before and after programme	Not reported	Not reported	Not reported, said to be ns
Macht 2006	As above	Mean (SD) as above	As above	42.4 (8.6) N=122	42.7 (10.6) N=122	t=-0.4, ns
Jahanshahi 1994	Nurse practitioner	Mean (SD) BDI for PD patients	Baseline	14.0 (5.7)	13.9 (6.7)	
			6m	13.1 (6.3)	12.6 (6.6)	Not reported. Said to be ns
		As above for dystonia patients	Baseline	15.7 (10.1)	9.9 (8.9)	
			6m	15.6 (13.9)	10.6 (6.5)	As above. Said to be ns
		Mean (SD) STAS for PD patients	Baseline	43.6 (11.8)	44.2 (8.4)	

<i>First author and year</i>	<i>Model of care</i>	<i>How measured</i>	<i>When measured</i>	<i>Results for controls/before</i>	<i>Results for subjects/after</i>	<i>Statistical significance</i>
			6m	43.9 (10.9)	43.2 (10.4)	As above. Said to be ns
		As above for dystonia patients	Baseline	49.5 (12.5)	40.6 (14.4)	
			6m	46.5 (12.9)	41.5 (13.9)	As above. Said to be ns
		Mean (SD) PFS – positive affect for PD patients	Baseline	11.2 (3.8)	11.5 (2.8)	
			6m	11.4 (3.1)	11.7 (3.6)	As above
		As above for dystonia patients	Baseline	11.0 (2.6)	12.3 (3.9)	
			6m	10.6 (2.3)	12.3 (2.6)	As above
Reynolds 2000	Nurse specialist	HADS – anxiety score ²	Not clear – baseline and possibly 12m	Not reported	Not reported	Kruskall- Wallis on change score. H=0.45, df=3, ns
		HADs – depression score	As above	As above	As above	As above. H=0.36, df=3, ns
Mixed neurological						
Roy 1991	Integrated care across hospital and community services	Retrospective judgement of care co-ordinators about psychological deterioration of all patients (n=296)	At the end of the study	-	11% deteriorated 40% unchanged 30% improved 5% died 14% not known	None reported

<i>First author and year</i>	<i>Model of care</i>	<i>How measured</i>	<i>When measured</i>	<i>Results for controls/before</i>	<i>Results for subjects/after</i>	<i>Statistical significance</i>
		As above for patients who had deteriorated physically (n=63)	As above	-	25% deteriorated ² 54% unchanged 16% improved 5% died	As above
		As above for patients referred specifically for rehabilitation (n=73)	As above	-	21% deteriorated 27% unchanged ³ 45% improved 7% died	As above
Ward 2004	Individualised patient education	N and % of GHQ 'cases' ⁴	Baseline	22/52 (41%)	27/53 (57%)	
			12m	21 (n unclear) ₅ (40% if n=52)	27 (n unclear) (51% if n=53) ⁶	Unadjusted OR (95% CI) 1.93 (0.86 to 4.31) Adjusted OR (95% CI) 1.60 (0.6 to 4.25)

BDI Beck Depression Inventory – higher score = poorer outcome

CDQ Clinical Depression Questionnaire – reference given in paper is actually to IPAT scale for anxiety

GHQ General Health Questionnaire

HAD Hospital Anxiety and Depression Scale – higher score = poorer outcome

PFS Bradburn's Present Feelings Scale

STAI State Trait Anxiety Inventory

STAS Spielberger Trait Anxiety Scale – higher score = poorer outcome

STAXI State Trait Anger Expression Inventory

1. Defined by a cut-off score of 8. Analysis conducted separately for those who had and had not had a seizure in the past 5m because previous research by this group showed risk of depression was significantly related to seizure in past 6m.
2. Anxiety scores were different between the groups at baseline.
3. Derived by us from figures given
4. 'Caseness' not defined
5. Table in paper reports 41.2%
6. Table in paper reports 57.4%

2.10 Coping or stress

Only one study used a coping or stress measure, so defined, as an outcome. Davis (2004), in testing the supported implementation of national guidelines on epilepsy care found no significant difference in change between baseline and follow-up between primary care patients in practices where the guidelines were implemented with varying degrees of support. The mean (95% CI) scores on what seems to be the Pearlin and Schooler coping scale at baseline were: controls 20.1 (19.4 to 20.8); intermediate support 20.2 (19.7 to 20.7); intensive support 19.9 (19.2 to 20.7). At follow up 12 months later the scores were: controls 20.3 (19.7 to 20.8); intermediate support 20.5 (19.9 to 21.0); intensive support 19.7 (19.1 to 20.4). The results of the statistical testing of these scores, by paired or un-paired t tests 'as appropriate', is not reported but is said to be not statistically significant.

2.11 Hospital admission

If integrated models of care aim to manage the boundaries between different parts of the health and care system, one might expect to see changes in the frequency with which people with LTNCs enter hospital and/or the amount of time they spend there when they do. Preventing, or reducing the length of, hospital stay has been a key issue in policy and practice for older people in the UK over the past 15 years, and has now moved up the agenda for people with long-term conditions, regardless of their age (Department of Health, 2005). However, only six of the evaluative studies that we included in the review, three of them RCTs, reported hospital admission and/or length of stay (see Table 2.12).

Four of the RCTs reported results for both intervention and control groups. Two of these showed no statistically significant benefit for intervention groups, whether for a nurse specialist case-manager for epilepsy (Schull, 1992) or for multi-disciplinary management of relapse in MS combined with IV steroid treatment (Craig, 2003), although the latter study did show a small improvement for the intervention groups. By contrast, Pozzilli (2002), evaluated a home-based service for people with MS against normal care and demonstrated a significant reduction in in-patient care 'events' for those receiving home care, as one might expect.

The fourth RCT was of home-based IV steroid administration for MS (Chataway, 2006) so, by definition, reduced use of *out*-patient resources, but this was not reported specifically. However, the main concern with this study was not so much with hospital admission, *per se*, but with hospital admission as an indicator of adverse events and, therefore, safety. One person out of the 69 treated at home was admitted to hospital for an overnight stay during the IV treatment.

Table 2.12 Hospital admission and length of stay

<i>First author and year</i>	<i>Model of care</i>	<i>Initial length of stay for controls/before</i>	<i>Initial length of stay for subjects/after</i>	<i>Statistical significance</i>	<i>Total length of stay for controls/before</i>	<i>Total length of stay for subjects/after</i>	<i>Statistical significance</i>
Epilepsy							
Schull 1992	Nurse specialist as case-manager	-	-	-	Mean days 6.79 ¹	Days 6.96 ¹	Not reported. Said to be 'very similar'
		-	-	-	N of seizure related readmissions: 3	N of seizure related readmissions: 0	
Rasmusson 2005	Telemedicine clinic	-	-	-	Mean ER visits: 0.125 SD 0.333 Total n of visits 9	Mean ER visits: 0.0963 SD 0.2969 Total n of visits 8	Wilcoxon rank sum test. Z=0.5634, df=153, p=.57
					Mean n of hospitalisations: 0.0417 SD 0.2012 Total n of admissions 9	Mean n of hospitalisations: 0.012 SD 0.109 Total n of admissions 2	Wilcoxon rank sum test. Z=1.15, df=153, p=.25
Multiple sclerosis							
Makepeace 2001	Multi-disciplinary community team	-	-	-	Mean over previous 6m: 2.53 ²	Mean 0.37 ² over 6m while in contact with team	None reported. NHS cost difference of - £15,368
D'Arcy 2006; Balaratnam	Multi-disciplinary community clinic	-	-	-	Not reported	Not reported. Said to be 38% lower in three years clinic running than in previous three years	None reported
Craig 2003	Multi-disciplinary team management of relapse, combined with	-	-	-	Mean 4.8 SD 3.07	Mean 3.45 SD 1.15	None reported

<i>First author and year</i>	<i>Model of care</i>	<i>Initial length of stay for controls/before</i>	<i>Initial length of stay for subjects/after</i>	<i>Statistical significance</i>	<i>Total length of stay for controls/before</i>	<i>Total length of stay for subjects/after</i>	<i>Statistical significance</i>
	IV steroid treatment						
Chataway 2006	Home-based IV steroid administration	-	-	-		1/69 patients admitted during 3 days of treatment – overnight stay	
Pozzilli 2002	Multi-disciplinary home care	-	-	-	Mean n of inpatient care 'events'. 1.01	Mean n of inpatient care 'events' 0.34	Difference of the mean (95% CI) -0.67 (-1.15 to -0.19), p=.0001

1. LOS includes original length of stay in hospital plus readmission within 30 days of discharge.
2. Calculated by us

Of the three remaining studies, two provided comparative data on hospital admission. The study of a telemedicine clinic for people with epilepsy (Rasmusson, 2005) showed reductions in hospital admissions or visits to emergency departments for those using the clinic and the study of a multi-disciplinary community team for people with MS (Makepeace 2001) showed reductions in days of hospital bed use after the introduction of the multi-disciplinary team. The differences in the tele-medicine clinic did not reach statistical significance, and the difference was not tested in the other study. However, the latter did claim a saving on hospital bed costs of £15,363 (an average of £404.29 per patient surveyed) when comparing use in the six months before and six months after new referral to the team.

Finally, an audit of a multi-disciplinary clinic for MS, based on retrospective record review (D'Arcy, 2006), claimed a 38 per cent decrease in days in hospital for MS patients in the three years after the clinic was introduced, compared with the three years before. However, with no information about the number of patients with MS in the hospital record system over the two periods, it is difficult to interpret this apparent reduction.

The small reductions in hospital admission and/or length of stay for the models of care evaluated, particularly those that are multi-disciplinary, look promising. However, the low number of studies and the small numbers of participants within them suggest that the impact of these models of integrated care remains to be evaluated in relation to these particular outcomes.

2.12 Costs to health services

Eight studies reported some aspect of costs to health services of implementing new models of care (Table 2.13).

Five of the studies were RCTs – one was of multi-disciplinary rehabilitation with group educational support for people with MS (Trend, 2002); one of multi-disciplinary home care for people with MS (Pozzilli, 2002); one of home-based IV steroid administration for people with MS (Chataway, 2006); and two of nurse specialists for people with PD (Reynolds, 2000; Hurwitz, 2004).

Different methods of health economics analysis were used in the RCTs, depending upon their focus. Trend (2002) presented a cost-consequence analysis, and Chataway (2006) and Hurwitz (2004) cost-minimisation analyses. The approach adopted by Reynolds (2000) and Pozzilli (2002) is not clear. The studies also adopted different approaches to identifying costs; some used bottom-up costing, some top-down costing, and others estimated costs.

Table 2.13 Costs to health services

<i>First author and year</i>	<i>Model of care</i>	<i>How calculated</i>	<i>Over what period?</i>	<i>Results for controls/before</i>	<i>Results for subjects/after</i>	<i>Overall conclusion</i>
Multiple sclerosis						
Verza 2006	Inter-disciplinary assessment protocol for assistive technology	Comparison of total expenditure and expenditures for abandoned equipment. Bottom-up costing for pre-intervention period. Extrapolation from assistive technologies database for intervention period.	Pre-intervention 1997-99 Intervention 2000-2002	Total cost 43,597 Euros. Abandoned equipment 14,920 Euros (34% of total)	Total cost 84,219 Euros Abandoned equipment 3,882 Euros (4.6% of total)	No statistics applied.
Trend 2002 and associated papers	Multi-disciplinary rehabilitation with group educational support	Bottom-up costing based on 1999/2000 financial year. Cost-consequence analysis	Annual cost	Not calculated – waiting list control group	£1069 pa for treatment (staff £360, consumables £24, space and overheads £685) £455 transport	Judgement 'depends upon the value attached' by patients, carers and funders to the mobility gains made.
Makepeace 2001	Multi-disciplinary community team	Bottom-up costing of services used by patients. Annual cost of service	6m before and 6m after contact with team	£28,797 total cost of services for 38 patients (mean ¹ £757.82 or £126.30 per month)	£22,804.50 total cost of services for 38 patients (mean ¹ £600.12 or £100.02 per month). £120,000 per annum cost of team.	Despite increased contact with most services costs reduced because of fewer contacts with GPs and consultants and fewer hospital bed days. Claims that costs of service would be offset by savings if service used by all people with MS in Newcastle.
Pozzilli 2002	Multi-disciplinary home care	Top-down and estimated costs. Drugs and aids to daily living not included.	12m period	Cost per patient 2265 Euros	Cost per patient 1443 Euros	Intervention patients had significantly fewer inpatient stays but more 'medical care', nursing, social and psychological support. Best case scenario in sensitivity analysis predicts a saving of

<i>First author and year</i>	<i>Model of care</i>	<i>How calculated</i>	<i>Over what period?</i>	<i>Results for controls/before</i>	<i>Results for subjects/after</i>	<i>Overall conclusion</i>
						2086 Euros per patient; worst case increased costs of 234 Euros per patient.
Chataway 2006	Home-based IV steroid administration	Mean (CI) costs. Bottom-up costing. Cost minimisation analysis.	Not clear. During 3 days of treatment but also refers to 'clinical events and resource use after study period'. Possibly 6 weeks after treatment.	£499 (£471-534) direct medical costs £61 (£49 – 76) non-medical costs. £560 (£531-598) total costs	£354 (fixed) direct medical costs £1 (0-2) non-medical costs. £355 (£354-356) total costs	Direct medical costs significantly higher for out-patient compared to home group. Non-medical costs significantly lower for home group.
Parkinson's disease						
Reynolds 2000	Nurse specialist	Not clear. Primary analysis carried out on only 47 (30 subjects and 17 controls) of 185 randomised	Not clear – two follow-up periods 1 and 2. No baseline assessment of costs	Period 1 mean monthly costs of care £4.76 Period 2 mean monthly costs of care £5.41	Period 1 mean monthly costs of care £53.96 Period 2 mean monthly costs of care £66.77	Says that change in costs between two periods 'was not significantly different between the two groups'.
Hurwitz 2004 and associated papers	Nurse specialist	Appears to be based on patient recall of service use, costed using average unit costs.	Annualised using 1996 costs	Mean patient cost, year preceding study £3480 ² Year 2 £5530 ³ Individual mean increase in cost ³ £2800	Mean patient cost, year preceding study £4050 ² Year 2 £5860 ³ Individual mean increase in cost ³ £2540	Difference in individual mean increase (95% CI) -£260 (-£980 to £450) p=.47. Tested with unpaired t test with unequal variances. P value and 95% CI checked with bootstrapped samples. Improvements in patient well-being 'achieved without an increase in healthcare costs'.
Hobson nd	Nurse specialist	Costed services that in absence of nurse specialist would have taken place in out-patient setting. Costed all nurse	12m	-	On basis of nurse specialist having 321 patients and carrying out 881 'interventions' claims saving of £54,992 on out-	Many untested assumptions made about substitution of nurse specialist follow-up for consultant-led follow-up.

<i>First author and year</i>	<i>Model of care</i>	<i>How calculated</i>	<i>Over what period?</i>	<i>Results for controls/before</i>	<i>Results for subjects/after</i>	<i>Overall conclusion</i>
		specialist interventions that in her absence would have been done by someone else. Then deducted cost of nurse specialist.			patient clinics, £8296 on community assessments and £1203 on in-patient assessments. Total saving of £64491 claimed.	

1. Calculated by us
2. All patients entering study
3. Patients at end of study

Trend 2002 did not collect cost data for the waiting list control group so no assumptions about the relative costs of multi-disciplinary rehabilitation with group educational support can be made.

Pozzilli 2002 claims substantial reductions in costs for a home-care service but largely on the basis of estimated costs for the new model of care. Chataway (2006) also demonstrates considerable savings to health services for a home-based model of care, using bottom-up costing.

Reynolds (2000) carried out no baseline assessment of costs so all that can be said about the nurse specialist service evaluation is that between two periods of follow-up increases in costs were not different for those with and those without a nurse specialist. However, the mean monthly costs for those having access to a nurse specialist in this study appeared to be substantially higher than for the controls, but it is not clear exactly which costs were included in the analysis. By contrast, Hurwitz (2004) found no significant difference in the mean increase of costs between baseline and follow-up for those receiving nurse specialist care compared with those who were not, although the costs of health care for both the intervention and control groups had increased substantially.

Hobson (nd) was a simple costing study of a nurse specialist but based on many untested assumptions about the substitution of nurse-specialist follow-up for consultant-led follow-up. On this basis, substantial savings are claimed, but with no demonstration of outcomes, it is difficult to know how to interpret this finding.

Makepeace (2001) assessed the health service costs associated with introducing a multi-disciplinary community team for people with MS. Services for 38 patients were costed, using a bottom-up approach, for the year before and the year after the service was introduced. Although people increased their contact with most services after the team was introduced, the overall costs reduced because they had fewer contacts with GPs and consultants and spent fewer days in hospital. However, the service itself cost £120,000 per annum. The researchers claim that these costs could be offset if the savings demonstrated by the 38 patients could be replicated when the service was extended to all people in the area where the study took place. The assumption that such savings would be replicated across the board is untested. The paper itself points out that only 66 per cent of the people known to have MS in the area had actually been referred to the service. Adding the rest presumably would require additional staff or lower levels of service input, which might weaken the apparent cost-saving effect.

The final study that reports cost is Verza (2006), who compared the costs of abandoned assistive equipment for people with MS before and after an inter-disciplinary assessment protocol was introduced. Using predominantly bottom-up

costing, this study suggests a considerable reduction of the costs of abandoned equipment within the context of an overall increase in the total equipment budget.

Overall, these studies suggest, as one might expect, that home-based services are cheaper than out-patient services, without any increase in adverse events (see section on in-patient admission). However, this is based on only two studies. Neither nurse specialist services for people with LTNCs nor multi-disciplinary team approaches appear yet to have been adequately researched in relation to outcomes as against costs.

2.13 Impact on family or carers

Eight studies, four of which were RCTs, reported the impact of the model of care on the families or informal carers of people with a LTNC (Table 2.14).

Two of the RCTs were of models of care for people with multiple sclerosis. One - of multi-disciplinary rehabilitation with group educational support (Trend 2002) - reported no significant effects on patients or carers. By contrast, the RCT of a palliative care service (Edmonds, 2005) reported significant improvements in three outcomes for families or carers when the person with MS was receiving specialist palliative care.

The other two trials were of models of care for people with PD (a patient education and health promotion programme, Montgomery, 1994) or for mixed neurological conditions, including PD (individualised patient education, Ward, 2004). In neither case were any statistically significant differences reported between the families or carers of those who did and did not receive the intervention.

Two comparative studies were both related to PD. One evaluated patient education (Simons, 2006) and the other a user-led care pathway (Holloway, 2006). Simons (2006) reports no significant differences at follow-up while Holloway (2006) reports that the number of carers stating that they 'could not carry on' had fallen between baseline and follow-up 12 months later.

Van den Berg (2005) compared the families and carers of people with ALS/MND who were attending specialist multi-disciplinary clinics with those who were not, using a survey design at a single point in time. Scores were adjusted for a range of variables on which the two groups differed; after adjustment there were no significant differences between the two groups of family members or carers.

Table 2.14 Impact on family or carers

<i>First author and year</i>	<i>Model of care</i>	<i>How measured</i>	<i>When measured</i>	<i>Results for controls/before</i>	<i>Results for subjects/after</i>	<i>Statistical significance</i>
ALS/MND						
Van den Berg 2005	Multi-disciplinary clinics for symptomatic and palliative care	CSI? ¹	At interview	Not reported	Not reported	Not reported. Said to be no difference in adjusted scores.
Epilepsy						
Upton 1996	Tertiary assessment centre	N and % reporting improvement in patient	Immediately after discharge	-	48/52 (92%) reported improvement 60% reported improvements in seizure control 45% reported improvements in drug side effects	None reported
Multiple sclerosis						
Trend 2002 and associated papers	Multi-disciplinary rehabilitation with group educational support	Mean (SD) CSI	Baseline	3.6 (3.4) n=28	3.0 (2.7) n=40	
			24 weeks	3.3 (3.0) n=28	3.7 (3.0) n=39	GLIM of difference in change scores, controlling for differences in baseline scores. Result not reported, p=0.086
		Mean (SD) Euroqol	Baseline	0.83 (0.33) n=27	0.86 (0.21) n=40	
			24 weeks	0.81 (0.18) n=29	0.82 (0.20) n=39	As above. Not reported, p=.592

<i>First author and year</i>	<i>Model of care</i>	<i>How measured</i>	<i>When measured</i>	<i>Results for controls/before</i>	<i>Results for subjects/after</i>	<i>Statistical significance</i>
		Mean (SD) Euroqol visual analogue scale	Baseline	79.0 (14.5) n=27	78.4 (17.2) n=40	
			24 weeks	80.8 (14.5) n=29	77.8 (19.8) n=39	As above. Not reported, p=.996
Edmonds 2005 and 2006	Palliative care service	Mean ZBI score ² : suffering of health	Baseline	1.63 (n=19)	1.15 (n=13)	
			3m	1.67 (n=15)	0.56 (n=16)	Mann-Whitney U. Z=2.372, p=0.018
		Mean ZBI score ² : loss of control over life	Baseline	1.84 (n=19)	1.54 (n=13)	
			3m	2.00 (n=15)	1.06 (n=16)	As above. Z=2.334, p=0.02
		ZBI: n (%) reporting learning new skills	Baseline	12/18 (67%)	8/13 (61%)	
			3m	7/15 (47%)	15/16 (94%)	As above. Z=2.19, p=0.029
Parkinson's disease						
Simons 2006	Patient education	EQ-5D	Before and after programme	Not reported	Not reported	Students t not reported, ns
		BELA-A-k	As above	As above	As above	As above
Montgomery 1994	Patient education and health promotion programme	Patient questionnaire on self-efficacy: questions about spousal relationship ³ Mean (SE) 'spousal stress'	6m after baseline	38.2 (1.8)	35.0 (1.8)	Not reported, ns
		Mean (SE) 'spousal assessment'	As above	11.3 (0.5)	12.1 (0.6)	As above

<i>First author and year</i>	<i>Model of care</i>	<i>How measured</i>	<i>When measured</i>	<i>Results for controls/before</i>	<i>Results for subjects/after</i>	<i>Statistical significance</i>
Holloway 2006 and associated papers	User-led care pathway	Interviews with carers	Baseline and 12m	-	Number of carers stating that they did not know if they could carry on said to have fallen. Numbers not given.	
Mixed neurological						
Ward 2004	Individualised patient education	N and % of GHQ-28 'cases	12m after baseline	14 (41%)	6 (23%)	Unadjusted OR (95% CI) 2.36 (0.83 to 6.71) Adjusted OR 2.35 (0.65 to 7.73)

BELA-A-k Measure of disease specific psychosocial problems – version for carers

CSI Carers Stain Index

EQ-5D Euroqol quality of life scale

GHQ General Health Questionnaire

ZBI Zarit Burden Inventory

1. The test refers to carers' quality of life, but only the CSI appears to have been used.
2. Not clear whether or not groups were statistically equivalent at baseline
3. Not clear how the questions asked relate to the results reported

Finally, Upton (1996) surveyed the families or carers of people with epilepsy just after they had been discharged from a tertiary assessment centre. While most (92%) reported improvement in the condition of the person with epilepsy, only 60 per cent reported improvements in seizure control and 45 per cent improvements in drug side effects.

Overall, then, except in relation to specialist palliative care services for people with MS, there is no evidence from the studies reviewed here of the families or carers of people with LTNCs benefitting from the models of care evaluated. However, many of the studies were small and, given that few of the studies included in the review attempted to assess outcomes for families or carers, we have to conclude that this issue remains to be researched adequately.

2.14 Costs to service users and families

Only two studies, both of them RCTs, reported any aspect of the costs borne by patients or their families (Table 2.15). Trend (2002) reported costs for all patients who eventually used multi-disciplinary rehabilitation services with group educational support for people with MS, so there are no comparisons with the waiting list control group from the RCT. Chataway (2006) reports 'non-medical costs' from a study of home versus out-patient IV steroid administration that could include transport and child-care costs, but not wider costs such as loss of income from paid work. The results suggest that home-based IV is significantly less costly for patients and their families, although the transport costs reported for those who had out-patient treatment do not seem to take into account any reimbursement received.

2.15 Social and economic outcomes for service users

Three studies, none of them RCTs, reported some aspect of socio-economic outcomes (Table 2.16). Upton (1996) reported the perceived importance of a tertiary assessment centre's services for helping people with epilepsy to be independent and giving them opportunities to meet other people with epilepsy. Sitzia (1998) explored social isolation for people with mixed neurological conditions using a multi-disciplinary service with post-discharge follow-up, via the Nottingham Health Profile. Roy (1991) asked care co-ordinators to make judgements about 'social deterioration' among people with mixed neurological conditions after they had received integrated care across hospital and community services.

None of the studies had a control group of any sort, but Sitzia (1998) did assess social isolation before and after people used the service being evaluated, but found no change over time.

Table 2.15 Costs to patients or families

<i>First author and year</i>	<i>Model of care</i>	<i>How measured</i>	<i>When measured</i>	<i>Results for controls/before</i>	<i>Results for subjects/after</i>	<i>Statistical significance</i>
Multiple sclerosis						
Trend 2002 and associated papers	Multi-disciplinary rehabilitation with group educational support	Annual cost per patient of travel to hospital using estimated mileage multiplied by mileage allowance paid to volunteer hospital drivers	Not clear	Not reported	£46	None done
Chataway 2006	Home-based IV steroid administration	Mean (95% CI) direct non-medical costs arising because of treatment, identified via CSRI	Not clear. During 3 days of treatment but also refers to 'clinical events and resource use after study period'. Possibly 6 weeks after treatment.	Transport: £59 (£47 to £74) Non-transport £2 (0-6)	Transport £0 (all cases) Non-transport £1 (£0to £2)	Says that there were 'significant savings' to the patients receiving home IV. ¹

CSRI Client Service Receipt Inventory

1. But did not record what % of transport costs were reimbursed to control patients.

Table 2.16 Socio-economic outcomes

<i>First author and year</i>	<i>Model of care</i>	<i>How measured</i>	<i>When measured</i>	<i>Results for controls/before</i>	<i>Results for subjects/after</i>	<i>Statistical significance</i>
Epilepsy						
Upton 1996	Tertiary assessment centre	N (%) rating service offered as 'very important': Learning to become independent	Before discharge	-	27/76 (36%)	None reported
		Meeting others with epilepsy	As above	-	36/76 (47%)	As above
		N (%) of family members rating service offered as 'very important': Learning to become independent	Immediately after discharge of patient	-	39/52 (75%)	As above
		Meeting others with epilepsy	As above	-	33/52 (63%)	As above
Mixed neurological						
Sitzia 1998	Multi-disciplinary rehab with post-discharge follow-up	Social isolation dimension of NHP. Median score for PD patients	1 week before admission and 1 month after discharge	22.5	22.5	Wilcoxon Z, not reported., p=0.4 ₁
		As above for MS patients	As above	22.5	22.5	As above, p=0.4 ₁
Roy 1991	Integrated care across hospital and community services	Care co-ordinators were asked to make a judgement about outcome for patients	Retrospectively	-	Social deterioration in 8% overall. Among those whose physical condition had deteriorated, 31% improved socially, 44% unchanged. Among rehabilitation patients only, 12% deteriorated socially	N/a

1. It is not clear that the results reported for the two groups were actually analysed separately as both the scores and the p values are identical.

The one interesting finding from these studies is in relation to the tertiary assessment centre for people with epilepsy. Here family members were much more likely than patients to rate the services of the centre as very important in relation to helping the patient become independent and meeting others with epilepsy.

2.16 Expressed need

Only four studies made any kind of assessment of the needs that people with LTNCs had and whether the model of care being evaluated had had any effect on these (Table 2.17). None of these studies was a RCT and only two allowed any judgement about impact of the intervention.

Both Oeseburg (2004) and Jansen (2006) evaluated a model of 'trans-mural' care for people with MS in the Netherlands. As discussed earlier, it is not entirely clear whether the same areas and/or service users were included in both studies. Oeseburg showed overall reductions between baseline and final follow-up in most areas of expressed needs among the 40 people included in this case study. However, with no control group to compare, it is difficult to ascribe this change to the model of care. By contrast, the Jansen (2006) study did compare those who had and had not received trans-mural care in relation to change in expressed needs between baseline and follow-up. Odds ratios were calculated, adjusting for the significantly different levels of need that the intervention and comparison groups had expressed at baseline. After this adjustment, people who had received transmural care were significantly less likely to express need at follow-up in relation to personal care, defecation and vision. The paper does not refer to the apparently *greater* likelihood of those who received trans-mural care expressing a need in relation to communication; a difference that almost reached conventional levels of statistical significance.

The remaining studies were of two different ways of assessing people with epilepsy – the review and follow-up of patients previously 'unknown' to specialist services (Leach, 2005) and an out-patient clinic in a tertiary referral centre (Goldstein, 1997). In both cases, need was assessed at initial contact with the service, but not subsequently, meaning that no judgement about impact of the service can be made.

Table 2.17 Expressed need

<i>First author and year</i>	<i>Model of care</i>	<i>How measured</i>	<i>When measured</i>	<i>Results for controls/before</i>	<i>Results for subjects/after</i>	<i>Statistical significance</i>
Epilepsy						
Leach 2005	Review and follow-up of patients previously 'unknown' to specialist services	N mentioning need for information on: Discontinuing drugs	When assessed	-	58/275 ²	n/a
		Driving regulations	As above	-	27/275	n/a
		Reproduction or fertility	As above	-	14/275	n/a
		Doubts over diagnosis	As above	-	3/275	n/a
		Side effects and interactions of long-term AEDs	As above	-	4/275	n/a
		Safety, including alcohol consumption	As above	-	3/275	n/a
Goldstein 1997	Out-patient clinic in tertiary referral centre	% wanting to talk about epilepsy to specified professional in more detail than currently possible	While at clinic or soon after	-	15% social worker 24% psychologist 40% nurse specialist 19% epilepsy voluntary organisation	None reported
		% ¹ expressing need for information about epilepsy	As above	-	33% basic information 44% extensive information 19% basic and extensive information 5% no information	As above

<i>First author and year</i>	<i>Model of care</i>	<i>How measured</i>	<i>When measured</i>	<i>Results for controls/before</i>	<i>Results for subjects/after</i>	<i>Statistical significance</i>
		% requesting advice about specific topics	As above	-	33% advice/support/counselling for patients and families 21% social security benefits 19% driving/insurance 17% employment 17% home safety 14% holidays 13% leisure activities 9% accommodation 9% vocational training 7% education matters 5% sheltered employment 5% action groups	As above
Multiple sclerosis						
Oeseburg 2004	Transmural care (same as Jansen?)	Mean n of needs ¹ expressed for: Information	Baseline and 15m	0.55	0.24	None reported
		Equipment		0.225	0.079	
		Services		0.575	0.132	
		Finance		0	0	
		Self-actualisation		0.003	0.026	
		Other		0.001	0.026	
		Total needs expressed		1.425	0.500	
Jansen 2006	Trans-mural care model	Health care need: communication	Baseline and 10m	Not reported	Not reported	OR (95% CI) 2.413 (0.991 to 5.872), p=.052
		Motion	As above	As above	As above	OR (95% CI). 0.40 (0.109 to

<i>First author and year</i>	<i>Model of care</i>	<i>How measured</i>	<i>When measured</i>	<i>Results for controls/before</i>	<i>Results for subjects/after</i>	<i>Statistical significance</i>
						1.464), p=.166
		Movement	As above	As above	As above	OR (95% CI). 0.607 (0.219 to 1.688), p=.339
		Personal care	As above	As above	As above	OR (95% CI). 0.364 (0.168 to 0.790), p=.011
		Defecation	As above	As above	As above	β (95% CI). -.446 (-.881 to -.010) p=.45
		Pattern of urination	As above	As above	As above	β (95% CI). 0.185 (-.202 to .571) p=.349
		Fatigue	As above	As above	As above	β (95% CI). -.007 (-.356 to .341) p=.967
		Pain	As above	As above	As above	β (95% CI). -.172 (-.537 to .194), p=.357
		Sleep	As above	As above	As above	β (95% CI). .200 (-.237 to .636) p=.370
		Vision	As above	As above	As above	β (95% CI). .522 (-1.009 to -.035) p=.035
		Cognition	As above	As above	As above	β (95% CI). .020 (-.473 to .512) p=.937
		Psyche	As above	As above	As above	β (95% CI). .358 (-.124

<i>First author and year</i>	<i>Model of care</i>	<i>How measured</i>	<i>When measured</i>	<i>Results for controls/before</i>	<i>Results for subjects/after</i>	<i>Statistical significance</i>
						to .840) p=.145
		Sexuality	As above	As above	As above	β (95% CI). .223 (-.277 to .724) p=.382

1. Calculated by us
2. N in paper is not entirely clear. We have assumed it is the number of people who attended for review, rather than the number who subsequently saw a consultant (see p.515)

2.17 Knowledge of condition

Six of the models of care included in the review had explicit aims of providing information or education to people with LTNCs. These were:

- Trend (2002) - a model of care that included group educational support for people with MS.
- Simons (2006), Macht (2006) - patient education for people with PD.
- Montgomery (1994) - a patient education and health promotion programme for people with PD.
- Ward (2004) - individualised patient education for people with varied neurological conditions.
- O'Hara (2002) - consumer-focused, professional advice about self-care for people with MS.
- Maclean (2005) - a computer-based patient education programme for people with MS.

In addition, there were nine studies of nurse practitioner or nurse specialist services, where one might have expected information giving and education about the condition to be a key part of the nurses' activity (see, for example, Kwan *et al.*, 2000).

Despite this, only four studies (Table 2.18) actually reported anything about knowledge of the condition among individuals with LTNCs and/or their family members or carers (Ridsdale, 1996; 2000; Upton, 1996; Goldstein, 1997). Further, none of the models of care evaluated in these four studies was *specifically* about patient education or information giving. Two evaluated nurse specialist services for people with established or newly diagnosed epilepsy (Ridsdale, 1996; 2000 respectively), one a tertiary assessment centre for people with epilepsy (Upton, 1996) and one an outpatient clinic in a tertiary centre (Goldstein, 1997).

The Ridsdale (1996) RCT of a nurse specialist service for people with established epilepsy showed no impact on knowledge of the condition. By contrast, Ridsdale (2000), which was an RCT of a nurse specialist service for newly diagnosed people, showed that people who were less well informed at baseline seemed to benefit. Those in the lowest quartile of knowledge scores at baseline improved their knowledge levels significantly 6 months later, relative to the least well-informed people who had not seen the nurse specialist. This suggests, perhaps, that people who are already well-informed have less scope for improving their knowledge and that, therefore, the additional information that a nurse specialist might provide adds little. By contrast, when people are relatively poorly informed about epilepsy there is more scope for change.

Table 2.18 Knowledge of condition

<i>First author and year</i>	<i>Model of care</i>	<i>How measured</i>	<i>When measured</i>	<i>Results for controls/before</i>	<i>Results for subjects/after</i>	<i>Statistical significance</i>
Epilepsy						
Ridsdale 1996 and associated papers	Nurse specialist and nurse-led clinic	EKP-G: medical, social and total score	Baseline and c. 6m later	Not reported	Not reported	Said to be ns
Ridsdale 2000	Two appointments with a nurse specialist	Median EKP-G total score ¹	Baseline	Quartile 1 48.5 Quartile 2 43.4 Quartile 3 41.2 Quartile 4 36	Quartile 1 47.1 Quartile 2 44.2 Quartile 3 41.1 Quartile 4 38.2	Mann-Whitney U, value not reported. Quartile 1 p=.05 ² Quartile 2 p=.19 Quartile 3 p=.84 Quartile 4 p=.25
			6m later	Quartile 1 46.5 Quartile 2 43.2 Quartile 3 42.5 Quartile 4 37.2	Quartile 1 45.5 Quartile 2 44.5 Quartile 3 41.7 Quartile 4 42.7	As above Quartile 1 p=.49 Quartile 2 p=.56 Quartile 3 p=.73 Quartile 4 p<.01
Upton 1996	Tertiary assessment centre	N (%) of patients rating service offered as 'very important' in relation to learning about epilepsy	Immediately before discharge	36/76 (47%)	n/a	
		N (%) of families/carers rating service offered as 'very important' in relation to learning about epilepsy	Immediately after discharge	33/52 (63%)	n/a	
Goldstein 1997	Out-patient clinic in tertiary referral centre	Mean (SD) EKP-G total score. Max possible =55	At clinic or soon after	-	40.94 (5.85)	n/a
		Mean (SD) EKP-P (questions 3-8 only – max possible =15)	As above	-	8.77 (2.51)	

EKP-G Epilepsy Knowledge Profile - General
EKP-P Epilepsy Knowledge Profile – Personal

1. Analysed by quartile scores at baseline
2. This p value seems unlikely given the median scores reported.

Neither of the other two studies formally explored change over time, although Upton 1996 reported that 47 per cent of patients discharged from a tertiary assessment centre had found the service 'very important' in relation to learning about epilepsy. This was a lower proportion than was recorded for family members or carers (63%). Goldstein 1997 simply tested patients' knowledge about epilepsy at a single point - when they attended an outpatient clinic in a tertiary centre or soon after.

2.18 Communication

Five studies, none of them RCTs, reported some aspect of communication, either between professionals, or between the person with a LTNC and professionals (Table 2.19).

Only one of the studies (Castleton, 2005) was about multi-disciplinary team working or integrated care (so described), in this case for people with PD. The others were about GP care with access to a nurse specialist for people with epilepsy (Lambert, 2001); the personal list system in general practice and its effect on epilepsy care (Freeman, 1994); an epilepsy out-patient clinic in a tertiary referral centre (Goldstein, 1997); and a user-led care pathway for people with PD that had an explicit focus on information transfer between patients and professionals (Holloway, 2006). Again, then, we find a lack of information about an outcome that might be assumed to be central to many of the models of care – and specifically those about multi-disciplinary working – evaluated in the studies we reviewed.

Of the three comparative studies only one (Castleton, 2005) formally assessed communication before and after the integrated model of care was introduced. No results were reported directly but the authors suggest that professionals 'in general' reported more effective communication between themselves, with a PD nurse specialist being the main channel through which this was achieved. A 'slight increase' in informal discussion and meetings was also mentioned.

Holloway (2006) explored with 22 PD patients their use and the perceived usefulness of two paper-based systems introduced specifically to improve communication. Seventeen people reported that the 'Problems/Needs form' provided an accurate description of their symptoms and problems, and 15 that it had helped them make the most of their consultation with their neurologist. Fewer - 14 - had found the Clinic Summary (a summary of need, with identification of issues for monitoring and a note of any referrals to be made) useful. Further, professionals outside of the outpatient clinic where it was completed had rarely consulted the Clinic Summary (Holloway, 2006: 68).

Table 2.19 Communication in team or with patient

<i>First author and year</i>	<i>Model of care</i>	<i>How measured</i>	<i>When measured</i>	<i>Results for controls/before</i>	<i>Results for subjects/after</i>	<i>Statistical significance</i>
Epilepsy						
Lambert 2001	GP care with access to nurse specialist	% of GPs without or with access to nurse specialist wanting: Joint clinics with specialist epilepsy services	One-off survey	16% yes 60% no 24% unsure (n=302)	2/10 yes 3/10 no 5/10 unsure	$X^2= 4.11, df=2,$ $p=.128^1$
		'Co-operation cards'	As above	66% yes 22% no 13% unsure	8/10 yes 0/10 no 2/10 unsure	$X^2= 2.85, df=2,$ $p=.240^1$
		Regular teaching on epilepsy	As above	65% yes 25% no 11% unsure	5/10 yes 2/10 no 3/10 unsure	$X^2= 3.66, df=2,$ $p=.160^1$
Freeman 1994	Personal list system in general practice	% ² mentioning discussion of: Stopping treatment	At interview	n/a	55% no one 35% usual GP 7% other GP (42% any GP) 3% specialist	
		Stigma	As above		82% no one 9% usual GP 5% other GP (15% any GP) 3% specialist	
		Concealment	As above		64% no one 28% usual GP	

<i>First author and year</i>	<i>Model of care</i>	<i>How measured</i>	<i>When measured</i>	<i>Results for controls/before</i>	<i>Results for subjects/after</i>	<i>Statistical significance</i>
					5% other GP (33% any GP) 3% specialist	
		'Question most wants to ask'	As above		14% no one 43% usual GP 9% other GP (52% any GP) 22% specialist 12% other	
Goldstein 1997	Out-patient clinic in tertiary referral centre	% of patients reporting being given information on side-effects of AEDs	At the clinic	n/a	40% never given information 33% given a little but not enough information 25% given sufficient information	
Parkinson's disease						
Castleton 2005	Integrated care across health and social care services	Questionnaire to health and LA staff about patterns of communication	Pre- and post-implementation	Not reported	Not reported directly. 'General' report of more effective communication with PD nurse being main channel. Also 'slight increase' in informal discussion and meetings as tool for problem solving.	
Holloway 2006 and associated papers	User-led care pathway	N who felt that 'Problems/Needs form' : Provided accurate description of	12m after implementation of care pathway	n/a	17/22	

<i>First author and year</i>	<i>Model of care</i>	<i>How measured</i>	<i>When measured</i>	<i>Results for controls/before</i>	<i>Results for subjects/after</i>	<i>Statistical significance</i>
		symptoms and problems				
		Helped them to make most of consultation with neurologist	As above	n/a	15/22	
		N reporting usefulness of Clinic Summary form	As above	n/a	9/22 very useful 5/22 quite useful 5/22 not very useful ³	

AEDs Anti-epileptic drugs
LA Local authority

1. Our analysis
2. Calculated by us
3. Not clear what the other 2/22 felt

Freeman (1994) simply surveyed the proportions of patients who mentioned discussing a range of epilepsy-related issues with their GP or specialist. However, the data were also analysed to explore whether increased continuity of care in primary care³ was associated with patients being more likely to discuss these issues with their usual GP or any GP in the practice. The analysis suggested that this form of continuity of care was associated with a significantly greater likelihood (expressed an odds ratio) of discussing the issues with the 'usual' GP, but not with discussing the issues with 'any GP' in the practice. It is difficult to understand what conclusion to draw from this analysis. By definition, if someone has had two or more recent consultations with the same GP (presumably their 'usual' GP) this, of itself, will have increased the opportunities to have discussed the issues *with* their usual GP. The analysis thus seems circular.

Goldstein (1997) also surveyed epilepsy patients at a single point, while they were attending an outpatient clinic. Only 25 per cent of those surveyed felt that they had ever been given sufficient information about the side effects of their AEDs. However, without comparative data it is difficult to know how to interpret this finding in relation to communication with patients.

Finally, Lambert (2001) surveyed GPs with and without access to an epilepsy nurse specialist to identify whether they felt they needed additional support in providing epilepsy care. GPs with access to a specialist nurse were slightly more likely to say that they would like joint clinics with specialist epilepsy services or to use 'co-operation cards'⁴ and slightly less likely to say that they wanted regular teaching on epilepsy. None of these differences was large enough to reach statistical significance, although the numbers of GPs who had access to a nurse specialist was very much smaller than those who did not (10 and 302 respectively).

2.19 Staff views about the model of care

Three studies, none of them RCTs, reported some aspect of staff views about the model of care being evaluated (Table 2.20). Oeseburg (2004) interviewed nurse specialists about transmurial care for people with MS; Castleton (2005) used a questionnaire to survey health and local authority staff about an integrated care system for people with PD, and Holloway (2006) carried out interviews with a neurologist and a nurse specialist about their views of a user-led care pathway for PD.

³ Defined as two or more of the last 12 GP consultations being with the *same* doctor.

⁴ Medical notes shared between the GP and hospital, similar to those used for ante-natal care.

Table 2.20 Staff views

<i>First author and year</i>	<i>Model of care</i>	<i>How measured</i>	<i>When measured</i>	<i>Results for controls/before</i>	<i>Results for subjects/after</i>	<i>Statistical significance</i>
Multiple sclerosis						
Oeseburg 2004	Transmural care (same as Jansen?)	Interviews with nurse specialists	Not stated	-	Were positive about model of care but identified some problem areas. 1. Patient care file improved information exchange between professionals and between professionals and patients, but was additional to other records and was time-consuming to use. 2. Despite existing records, transfer of information between professionals was scarce. Nurse specialist sometime found it difficult to get information from relevant professional, some of whom were reluctant to co-operate because co-ordination is usually GP's task.	n/a
Parkinson's disease						
Castleton 2005	Integrated care across health and social care services	Questionnaire to health and LA staff	At end of study	-	Team said to have learned to work together in non-competitive, non-judgemental way. Availability of specialist help via nurses and consultant seen as helpful. PD nurse allowed increased ownership of service and allowed better co-ordination. Clinics at health centre facilitated information exchange and advice. Access to GP notes by consultant was beneficial. Protocol eliminated inappropriate diagnosis and prescribing by GPs. Patients received more personalised service from consultant at local health centre and actively sought information about condition. More accurate information available to all.	
Holloway 2006 and associated papers	User-led care pathway	Face to face Interview with neurologist.	At 12m follow-up	-	Felt intervention facilitated development of partnership with patients, assisting in better treatment and management of disease.	n/a
		Telephone interview with nurse specialist	As above	-	Most important benefit identified as patient and carer empowerment, through increasing capacity for self-management and helping them to access more effective treatment	n/a

All three studies identified positive staff views about the model of care, but these positives tended to be different for each. However, there were some commonalities in two of the studies. For example, those working in an integrated care system (Castleton, 2005) referred to improvements in joint working, improved information exchange, and increase personalisation of care that, in its turn, seemed to increase the active participation of patients in seeking information about their care. Similarly, professionals involved in the user-led care pathway (Holloway, 2006) felt that it had increased the sense of partnership between patients and professionals, and empowered patients and carers by increasing their capacity for self-management.

2.20 Discussion

Despite recent growth in the evaluative literature on models of care for people with LTNCs that might enhance their experience of continuity of care, the evidence base about the best models to adopt remains under-developed. Because of the range of models evaluated, across different LTNCs, the number of high quality, controlled evaluations of any individual model is limited.

The overall picture from studies that reported access to or use of services as an outcome of the model of care was very mixed. However, this confused picture is partly because service use was not always adequately reported before and after the introduction of a new model of care, even when the evaluation was an RCT. Further, providing additional services was sometimes the *point* of the model of care, especially in multi-disciplinary teams, so the demonstrated increases were expected. Where models were less service-oriented (for example, patient education or information giving) less or even no impact was evident.

Introducing care standards, even with offers of support, made little difference to epilepsy care in a large RCT, mainly because so few of the primary care practices in the study implemented any aspect of the standards. By contrast, a much simpler set of epilepsy care standards, implemented and *audited*, did achieve change in a non-randomised study. This suggests that different mechanisms may have been at play (not least the sense of ownership of the standards when they are developed and introduced locally) which deserve to be tested more closely.

Fewer than half of the studies we reviewed included any assessment of service users' views about the model of care. Overall, the results reviewed suggested that service users valued the new models of care that they were being offered, but with so little comparative information it is difficult to judge whether this reflects their gratitude for receiving *any* service, or whether the model being evaluated really was better than anything else.

Seventeen studies reported some aspect of disability or impairment but there was no consistent or conclusive evidence across the studies about positive or negative impact on this outcome. However, three RCTs of models that involved some aspect of education or training for service users did suggest better outcomes for intervention groups; this seems to be a potentially valuable avenue of future research.

There was no evidence from the studies reviewed that integrated models of care had better clinical outcomes than 'usual care', but neither was there any secure evidence that they had worse clinical outcomes. In terms of those models of care that involve changes in skill-mix (for example, substitution of medical specialist by nurse specialist care) or which involve delivery of care closer to the service user's home (the home-based IV service) the apparent similarity of clinical outcomes is encouraging.

Only three studies reported mortality as an outcome. Both specialist care for people with MND/ALS and specialist palliative care for people with MS were associated with somewhat longer survival, compared to usual care. There was no difference in mortality outcomes in a study of nurse specialist care for people with PD.

Although reported in nine RCTs and six other types of study, there was little secure evidence of any beneficial effect on quality of life, as measured by the particular instruments used, from any of the models of care evaluated.

Similarly, there was little suggestion that any of the models of care studied improved (or, indeed, worsened) mental health, although there were some small changes in favour of intervention groups on a range of depression measures. Only one study reported impact on coping or stress and, again, with no evidence of positive or negative effects.

The small reductions in hospital admission and/or length of stay for the models of care evaluated, particularly those that are multi-disciplinary, look promising. However, the low number of studies and the small numbers of participants within them suggest that the impact of these models of care remains to be evaluated in relation to these particular outcomes. Related to this, the included studies that reported any type of health economics data suggest, as one might expect, that home-based services are cheaper than out-patient services, without any increase in adverse events (see above). However, this is based on only two studies. Neither nurse specialist services for people with LTNCs nor multi-disciplinary team approaches appear yet to have been adequately researched in relation to outcomes as against costs.

The one study that reported comparative costs for service users or their families suggest that home-based IV is less costly for patients and their families, although

there was a question mark over whether re-imburement of transport costs for those who had out-patient treatment had been taken into account.

The very few studies that looked at wider social or economic impacts on service users or their families came to no clear conclusions overall. Similarly, the lack of comparative data makes it impossible to say anything secure about the effect of the evaluated models of care on service users' expressed needs for support.

None of the interventions included in our review that provided some element of patient education or advice included the service users' knowledge of their condition as an outcome. This is a puzzling gap, especially in the context of increased emphasis on self-care and 'personalisation' and flags up an area that deserves further research. Only two of the four studies that did report patient knowledge as an outcome (and both of which were about nurse specialists) provided comparative data. One showed no overall improvement of knowledge levels for those receiving a nurse specialist service, while the second showed that people who started out with a low level of knowledge about their newly diagnosed epilepsy did increase their knowledge if they had received the service. Again, this suggests a potentially fruitful area for future research.

There were no clear messages overall from the studies reviewed about whether models of care that might deliver better continuity of care promoted better communication, either between professionals, or between professionals and service users. However, relatively few studies actually considered communication as a possible outcome. This relative neglect in the evaluative literature of this important issue for people with long-term conditions is puzzling.

The findings about professionals' views about the models of care that were evaluated, albeit from only a few studies, confirm what other literature on joint or integrated working has suggested over many years - that professionals seem to like working in this way. The lack of high quality, comparative evidence about *service users'* views about these ways of delivering care and services remains.

3. Descriptive studies

One hundred and twenty-seven descriptions of models of care were included in this part of the review. These were taken from publications that were exclusively descriptive, as well as papers related to the 48 models of care included in the evaluative part of the review (see Chapter 2). Full bibliographical details of papers reviewed are in Appendices 5 and 6.

The focus of this element of the review was the content of service models that might deliver continuity of care (see Chapter 1). We therefore extracted data that described the model of care, where it was delivered, the conditions it covered, who was involved in delivering the model of care, what service elements were included, aspects of service delivery and organisation, and what type of continuity of care it delivered. In order to address the last question, we used the conceptual framework of continuity of care developed by Freeman and colleagues (Freeman *et al.*, 2001; 2002) as the basis for our analysis. This model has developed over time, and in the report of the full project we describe how these developments influenced our analysis of material in the case studies. However, the review described here was carried out relatively early in the project and we therefore used the model of continuity originally outlined in our research proposal. Our work on the review also suggested a further type of continuity of care – that of personal agency – not covered by the Freeman model. We defined this as continuity that enabled people to retain control over their own lives and to manage their own health and well-being, and we have included it in the analysis of the descriptive material that we present here.

3.1 Conditions covered

The conditions that the models of care targeted varied. None of the papers included was about migraine, muscular dystrophy, or stroke in younger people. The most commonly mentioned condition was multiple sclerosis (41 papers) followed by epilepsy (36 papers), and Parkinson's disease (36 papers). There were 17 papers about models of care for motor neurone disease, five about dystonia or ataxia, and one each about cerebral palsy, Huntington's disease, head injury, and spinal injury. Four papers mentioned 'general' neurological conditions, 18 all or any neurological conditions, and four other, named conditions. As these figures suggest, some models of care dealt with more than one condition – 20 with two conditions, three with three and four with four conditions. Multiple sclerosis and Parkinson's Disease were the conditions most likely to be covered by models of care targeting more than one disease.

3.2 Models of care

There was a wide range of models of care reported. Overall, 59 per cent of papers (n=74) reported a single approach to delivering continuity of care. Of these, the majority were accounts of multi-disciplinary teams or clinics (26) or clinical nurse specialists (12). The other models were self-care interventions (7), assessment and disease management initiatives (6), methods to facilitate access to care (5), disease registers (3), and nurse-led clinics (2). There were 13 separate 'other' models of care, ranging from a clinical managed network to a project that explored the effect on continuity of care of always seeing the same general practitioner.

Among the 52 papers reporting models of care with more than one aspect to them, assessment and disease management initiatives were the most commonly mentioned (23), followed by clinical nurse specialists (18) and multi-disciplinary teams or clinics (15). The other models mentioned were nurse-led clinics (9), disease registers (7), methods to facilitate access to care (6), self-care initiatives (5), professional-led care pathways (2), GPs with special interests (3), palliative care (2), professional training (2) and a user-led care pathway. There were 32 separate 'other' models of care, ranging from a rapid response team for administering intra-venous therapy at home to a specialist transition clinic for young people moving onto adult services.

There was little common overlap in provision among the papers reporting more than one aspect to the model of care. Some multi-disciplinary teams and clinical nurse specialists were associated with assessment and disease management (4 and 5 cases respectively). Some initiatives to improve access to care were also associated with assessment and disease management (6 cases). Beyond these, however, there were few obvious patterns among the models of care.

Overall, then, the most commonly reported models of care were multi-disciplinary teams or clinics (41 in total), clinical nurse specialists (30 in total) and assessment and disease management initiatives (29 in total). For the purposes of the analysis that follows, we explore these three models and their characteristics separately.

3.3 Multi-disciplinary teams or clinics

Twenty-two of the 41 multi-disciplinary teams (MDTs) or clinics described were based in the UK. The next largest group was in the USA (6), followed by Australia (4), France (3), Canada (2), Ireland (2), Denmark (1) and Italy.

It was not wholly clear in seven of the 41 papers where the model of care was based or delivered. Of the remainder, 16 were delivered in a single setting, nine in two settings, six in three settings and three in four or more settings. As might be expected, multi-disciplinary teams or clinics were somewhat more likely to work in outpatient and in-patient settings although 12 also delivered services in patients' own homes (Table 3.1). However, as Table 3.1 also shows, it was unusual for a multi-disciplinary model of care to be delivered exclusively at home; it was much more likely to be in conjunction with in-patient or/and outpatient or community delivery.

Table 3.1 Settings for multi-disciplinary teams or clinics

<i>Type of setting</i>	<i>Team or clinic in one setting</i>	<i>Team or clinic in two settings</i>	<i>Team or clinic in three settings</i>	<i>Team or clinic in four settings</i>	<i>Not known or unclear</i>	<i>Total N (% of teams or clinics)¹</i>
In-patient	4	3	3	3	-	13 (32)
Out-patient	7	5	4	3	-	19 (46)
Home	1	4	6	3	-	14 (34)
Other community	2	3	3	3	-	11 (27)
Any other	2	3	2	0	-	7 (17)
Not known/unclear	-	-	-	-	7	7 (17)
N of teams	16	9	6	3	7	41 (100)

1. Sums to more than 100% because of multiple coding.

Some conditions were more and some less likely to be associated with MDTs or clinics than were others. Ten of the 17 papers on motor neurone disease (MND) and 19 of the 41 papers on multiple sclerosis (MS) reported MDTs or clinics. By contrast, only three of the 36 papers on epilepsy were about MDTs or clinics. In all these cases, the differences were statistically significant.

There were 13 accounts of MDTs or clinics for Parkinson's Disease (PD), one for cerebral palsy, and head injury, and none for Huntington's disease or spinal injury. In none of these conditions were MDTs or clinics more or less likely to be reported than other models of care.

Our data extraction for the descriptive review included the question, 'What is this model of care?' Although all the papers in this section were MDTs or clinics, some also included elements of other models of care. So, for example, four MDTs or clinics also provided assessment services, two maintained a disease register, two included a clinical nurse specialist, one a general practitioner with a special interest (GPSI), one a nurse-led clinic, and one provided palliative care. Other elements reported

included annual review (1), clinical team meetings (1), continence advisors (1), a hospital discharge and follow-up system (1), and a rehabilitation service (1).

We also extracted information on staffing of the MDTs or clinics, where given. These data need to be interpreted with care. First, if a particular profession was not mentioned in a paper, it was not always clear whether this was because this profession was not actually represented in the MDT or clinic, or was because the authors of the paper had not reported all types of staff involved. Phrases such as 'staff involved included ...' were common. Secondly, papers did not always include detailed information about the staff. For example, a 'specialist nurse', with no other details reported, could have been a neurological specialist, a continence specialist, or could have had some other specialist training. Similar issues arose with doctors and therapists. In all cases where specialism was referred to but the type of specialty was not reported, we recorded 'specialty not specified'. The proportions in Table 3.2, therefore, represent the *minimum* levels of different staff in each MDT or clinic and the *minimum* levels of neurological specialist staff in each.

Table 3.2 Number and proportion of MDTs or clinics with specified staff compared with other models of care

<i>Staff</i>	<i>N (%) of MDTs or clinics</i>	<i>N (%) of other models of care</i>	<i>p =</i>
Doctors:			
Neurology	18 (44)	28 (33)	0.214
Rehabilitation	9 (22)	6 (7)	0.014
Other specialty	10 (24)	9 (11)	0.040
Specialty not specified	6 (15)	6 (7)	0.168
Nurses:			
Neurology community	6 (15)	20 (23)	0.260
Neurology acute	6 (15)	16 (19)	0.511
Other specialist community	4 (10)	5 (6)	0.418
Other specialist acute	7 (17)	5 (6)	0.43
Specialty not specified	9 (22)	8 (9)	0.050
General community	2 (5)	8 (9)	0.387
General acute	2 (5)	4 (5)	0.955
General not specified	5 (12)	9 (11)	0.771
Therapists:			
Physiotherapist	31 (76)	16 (19)	0.000
Occupational therapist	30 (73)	16 (19)	0.000
Speech and language therapist	24 (59)	13 (15)	0.000

<i>Staff</i>	<i>N (%) of MDTs or clinics</i>	<i>N (%) of other models of care</i>	<i>p =</i>
Dietician	13 (32)	8 (9)	0.001
Other therapist	7 (17)	5 (6)	0.043
Specialty not specified	2 (5)	0	0.039
<i>Other staff:</i>			
Psychologist	14 (34)	11 (13)	0.005
Counsellor	4 (10)	4 (5)	0.268
Social worker	18 (44)	18 (21)	0.007
Social Services, so described	3 (7)	2 (2)	0.176
Voluntary organisation	8 (20)	8 (9)	0.105
Coordinator/care manager	7 (17)	7 (8)	0.133
General practitioner	2 (5)	13 (15)	0.095
Any other member of staff	11 (27)	17 (20)	0.369
N (100%)	41	86	

p using Pearson chi-squared (two-sided)

Despite these provisos, as Table 3.2 shows, MDTs and clinics were significantly different from other models of care in ways that one might have expected. All types of therapy staff, psychologists, social workers and care co-ordinators or care managers were more likely to be mentioned in papers describing MDTs and clinics than papers describing other models. Rehabilitation medicine specialists were also more likely in MDT teams, but they were no more or less likely to contain neurologists.

Also as might be expected in models of care described as multi-disciplinary, there were significantly higher numbers of different types of professionals working in MDTs and clinics than in other models of care; over two-thirds contained at least six different types of professional (Table 3.3).

Table 3.3 Number of different type of professionals in MDTs or clinics, compared with other models of care

<i>Model of care</i>	<i>N (%) of models of care with different types of professionals by number of professionals</i>			
	1	2-5	6 or more	Total
MDT or clinic	1 (3)	12 (29)	28 (68)	41 (100)
Other	35 (42)	32 (38)	17 (20)	84 (100)
Total	36 (29)	44 (35)	45 (36)	125 (100)

Missing = 2

$\chi^2 = 33.005$, $df=2$, $p<.000$

Data extracted from the papers about the elements of service provided by models of care covered diagnosis, assessment, care plans, care co-ordination and care management, drugs monitoring and review, equipment supply, providing information, goal setting, overall monitoring, and multi-disciplinary meetings, among others. As Table 3.4 shows, there were relatively few significant differences in the elements reported for MDTs and clinics, compared to other models of care. As might be expected, given the higher representation of therapists in the MDTs and clinics, rehabilitation input was much more likely to be reported, alongside the assessment of disability or impairment. MDTs were also more likely, again as would be expected, to involve multi-disciplinary meetings or consultation. Other elements of care that MDTs were more likely to be providing were diagnosis of a condition and palliative care. Beyond these factors, MDTs or clinics were no more likely than other models of care to provide any other elements of care. By contrast, they were apparently *less* likely to provide information, education or training for professionals than were other models.

Table 3.4 Number and proportion of MDTs or clinics providing different elements of care compared with other models of care

<i>Elements provided</i>	<i>N (%) of MDTs or clinics</i>	<i>N (%) of other models of care</i>	<i>p =</i>
Diagnosis	7 (17)	5 (6)	0.043
<i>Assessment of:</i>			
Condition	16 (39)	23 (27)	0.161
Disability/impairment	13 (32)	8 (9)	0.001
Service need	10 (24)	18 (21)	0.660
Nursing need	3 (7)	9 (11)	0.571
Other	12 (29)	24 (28)	0.874
Patient-held care file ¹	0	5 (6)	0.115
Professional-held care file	1 (2)	11 (13)	0.062
Patient-held care plan ²	3 (7)	3 (4)	0.342
Professional-held care plan ³	5 (12)	11 (13)	0.925
Care or service co-ordination	10 (24)	22 (26)	0.885
Care management	3 (7)	9 (11)	0.571
Drug/medication review	7 (17)	18 (21)	0.609
Equipment/aids supply	5 (12)	4 (5)	0.121
Goal setting	7 (17)	8 (9)	0.205
Information/education/training for carer	16 (39)	31 (36)	0.745
Information/education/training for patient	23 (56)	49 (57)	0.926
Information/education/training for professionals	5 (12)	27 (31)	0.020
Monitoring and review	15 (37)	27 (31)	0.561

<i>Elements provided</i>	<i>N (%) of MDTs or clinics</i>	<i>N (%) of other models of care</i>	<i>p =</i>
Multi-disciplinary meeting/consultation	16 (39)	16 (19)	0.013
Other clinical care	29 (71)	56 (65)	0.529
Palliative care	6 (15)	3 (4)	0.022
Advice/contact/help line	6 (15)	16 (19)	0.580
Rehabilitation care	17 (42)	10 (12)	0.000
Specialist clinics	7 (17)	12 (14)	0.645
Carers' support group	3 (7)	5 (6)	0.744
Patients' support group	5 (12)	8 (9)	0.615
Telemedicine	0	3 (4)	0.226
Counselling care	10 (24)	11 (13)	0.100
N (100%)	41	86	

p using Pearson chi-squared (two-sided)

1. 1 case in other model of care: not clear who holds case file
2. 2 cases in MDTs or clinics and 2 cases in other model of care: not clear who holds care plan
3. 2 cases in MDTs or clinics: not clear who holds care plan

Finally, in this section about MDTs and clinics we turn to the issue of what type of continuity of care was delivered by this model. This was the most subjective part of our review, because while papers might use the concept of continuity of care as a way of describing what the models of care did, none were based on the Freeman conceptual framework (Freeman *et al.*, 2001; 2002). Further, our judgements about what type of continuity might be involved in the model were necessarily limited by the details presented in the papers. Despite this, there were apparent differences in the descriptions of MDTs and clinics and other models of care (Table 3.5).

Table 3.5 Number and proportion of MDTs and clinics delivering different types of continuity of care compared with other models of care

<i>Type of continuity of care</i>	<i>N (%) of MDTs or clinics</i>	<i>N (%) of other models of care</i>	<i>p =</i>
Cross-boundary, team	31 (76)	44 (51)	0.009
Flexible	5 (12)	17 (20)	0.292
Informational	8 (20)	32 (37)	0.045
Longitudinal	15 (37)	5 (6)	0.000
Long-term	6 (15)	7 (8)	0.259
Personal agency	10 (24)	29 (34)	0.287
Relational, personal, therapeutic	8 (20)	19 (22)	0.740
Social context	7 (17)	11 (13)	0.518
Experienced	1 (2)	3 (3)	0.752

N (100%)	35	75
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p using Pearson chi-squared (two-sided)

MDTs and clinics were significantly more likely to deliver cross-boundary or team continuity (as would be expected). They were also more likely to deliver longitudinal continuity; the continuity that comes with care provided from as few professionals as possible, over time, consistent with need. There was no obvious relationship between the two types of continuity in the papers reviewed. In relation to most other types of continuity, MDTs and clinics seemed *less* likely than other models of care to deliver them, although, with the exception of informational continuity, not at a level that reached statistical significance.

3.4 Clinical nurse specialists

Thirty models of care in total involved clinical nurse specialists (CNSs) either as a stand-alone model or in combination with some other aspect of care. The majority of papers (22) described CNS services in the UK, four in the USA, three in France and in one it was not entirely clear where the service was based.

It was not wholly clear in two papers where the CNS service was delivered. Among the remainder, 17 services were delivered in a single setting, seven in two settings, and four in three or more settings. CNSs were no more or less likely than other models of care to be working in in-patient (30% for both), out-patient (37% and 45% respectively) and community settings (45% and 27%), but were significantly less likely to be working in patients' own homes (17% and 39%, $\chi^2 = 5.073$, $df=2$, $p=0.024$). As Table 3.6 shows, hospital settings, whether in-patient or out-patient were the most common settings for CNSs, followed by community settings, other settings and patients' own homes.

Table 3.6 Settings for clinical nurse specialists

Type of setting	CNS in one setting	CNS in two settings	CNS in three settings	CNS in four settings	Not known or not clear	Total N (%) of CNSs ¹
In-patient	3	3	2	1	-	9 (30)
Out-patient	5	2	2	2	-	11 (37)
Home	0	2	1	2	-	5 (17)
Other community	7	4	0	2	-	13 (43)
Any other	2	3	1	1	-	7 (23)
Not known or not clear	-	-	-	-	2	1 (3)
N of CNSs	17	7	2	2	2	30 (100%)

1. Sums to more than 100% because of multiple coding

Twelve (40%) CNS services were associated with epilepsy, 14 (47%) with PD five (17%) with MS, three with any or all neurological conditions and one with another specific condition (dystonia/ataxia). As this suggests, some services were associated with two conditions – two for both PD and any/all neurological conditions, one for MS and any/all neurological conditions, one for both epilepsy and MS, and one for both PD and dystonia/ataxia. There were no CNS services for any other condition. Difference in provision for different conditions was statistically significant in relation to MND ($\chi^2= 6.07$, $df=1$, $p=0.014$) and MS ($\chi^2=4.382$, $df=1$, $p=0.036$) where there were fewer papers about CNS services than other models of care. By contrast, there was a higher than expected proportion of papers about CNS services for PD ($\chi^2 = 6.409$, $df=1$, $p=0.011$).

As with MDTs and clinics, some CNSs provided or were associated with other models of care. Thus, two papers mentioned a model that provided screening or 'prescription' for access to care, five an assessment and management model, three a disease register, two a GP with special interest in neurology, five a nurse-led clinic, and two a MDT or clinic. Other elements reported (in each case once only) included self care, audit and review by a specialist team in primary care, a clinical management programme, an epilepsy liaison service, a multi-disciplinary care protocol, a national guideline, a team for younger people with physical impairments, and a rapid response service for outpatient IV treatment.

CNS services are, by definition, often uni-professional. This is reflected in the findings in Table 3.7. Here we see that CNSs were, as one would expect, significantly more likely than other models of care to involve neurology specialist nurses, whether acute- or community-based. By contrast, they were significantly less likely than other models of care to be working in teams that included neurologists, therapy professionals, psychologists and social workers. This is not to say that CNSs did not work with such professionals, of course, or that they were not seen as members of teams. Rather it reflects the intention of many of the papers reporting CNS services, which tended to focus on the single clinical role, rather than its place in a multi-professional context. However, it was the case that some CNS services, and particularly those in primary care, were effectively lone workers, albeit that they might be providing outreach from or in-reach to a hospital-based neurology service.

Table 3.7 Number and proportion of CNS services with specified staff compared with other models of care

<i>Staff</i>	<i>N (%) of CNS services</i>	<i>N (%) of other models of care</i>	<i>p =</i>
<i>Doctors:</i>			
Neurology	6 (20)	40 (41)	0.034
Rehabilitation	1 (3)	14 (14)	0.100
Other specialty	2 (7)	17 (18)	0.145
Specialty not specified	1 (3)	11 (11)	0.190
<i>Nurses:</i>			
Neurology community	15 (50)	11 (11)	0.000
Neurology acute	12 (40)	10 (10)	0.000
Other specialist community	1 (3)	8 (8)	0.359
Other specialist acute	2 (7)	10 (10)	0.551
Specialty not specified	1 (3)	17 (18)	0.051
General community	3 (10)	7 (7)	0.621
General acute	0	6 (6)	0.163
General not specified	1 (3)	13 (13)	0.124
<i>Therapists:</i>			
Physiotherapist	3 (10)	44 (45)	0.000
Occupational therapist	3 (10)	43 (44)	0.001
Speech and language therapist	3 (10)	34 (35)	0.008
Dietician	1 (3)	20 (21)	0.026
Other therapist	1 (3)	11 (11)	0.190
Specialty not specified	0	2 (2)	0.428
<i>Other staff:</i>			
Psychologist	0	25 (26)	0.002
Counsellor	1 (3)	7 (7)	0.444
Social worker	3 (10)	33 (34)	0.011
Social Services, so described	0	5 (5)	0.205
Voluntary organisation	2 (7)	14 (14)	0.263
Coordinator/care manager	1 (3)	13 (13)	0.124
General practitioner	4 (13)	11 (11)	0.768
Any other member of staff	3 (10)	25 (26)	0.069
N (100%)	30	97	

p using Pearson chi-squared (two-sided)

The results in Table 3.8 further underline the uni-professional nature of CNS services. This shows that they were more likely to involve teams containing only one type of professional (47% compared to 23% of other models of care) and much less likely to

involve teams containing six or more different types of professional (10% compared with 44%).

Table 3.8 Number of different type of professionals in CNS services, compared with other models of care

<i>Model of care</i>	<i>N (%) of models of care with different types of professionals by number of professionals</i>			
	1	2-5	6 or more	Total
CNS service	14 (47)	12 (43)	3 (10)	30 (100)
Other	22 (23)	31 (33)	42 (44)	95 (100)
Total	36 (29)	44 (35)	45 (36)	125 (100)

Missing cases =2
 $\chi^2 = 12.529$, $df=2$, $p=.002$

Table 3.9 shows the elements of care provided by CNS services, as described in the papers. This shows only a few significant differences in the care provided by CNS services compared to other models of care. CNS services were less likely to include multi-disciplinary team meetings, reflecting the uni-professional picture described above. No CNS services involved diagnosis of condition, as might be expected, and rather more were involved in providing advice, contact or a help-line service (33% compared to 12% in other models of care).

Table 3.9 Number and proportion of CNS services providing different elements of care compared with other models of care

<i>Elements provided</i>	<i>N (%) of CNS services</i>	<i>N (%) of other models of care</i>	<i>p =</i>
Diagnosis	0	12 (12)	0.043
<i>Assessment of:</i>			
Condition	8 (27)	31 (32)	0.583
Disability/impairment	3 (10)	18 (19)	0.270
Service need	5 (17)	23 (24)	0.416
Nursing need	4 (13)	8 (8)	0.405
Other	7 (23)	29 (29)	0.486
Patient-held care file ¹	0	5 (5)	0.205
Professional-held care file	4 (13)	8 (8)	0.405
Patient-held care plan ²	1 (3)	5 (5)	0.681
Professional-held care plan ³	3 (10)	13 (13)	0.624
Care or service co-ordination	9 (30)	23 (23)	0.488
Care management	2 (7)	10 (10)	0.551
Drug/medication review	7 (23)	18 (19)	0.565

<i>Elements provided</i>	<i>N (%) of CNS services</i>	<i>N (%) of other models of care</i>	<i>p =</i>
Equipment/aids supply	0	9 (9)	0.083
Goal setting	1 (3)	14 (14)	0.100
Information/education/training for carer	11 (37)	36 (37)	0.965
Information/education/training for patient	16 (53)	56 (58)	0.671
Information/education/training for professionals	10 (33)	22 (23)	0.240
Monitoring and review	12 (40)	30 (31)	0.356
Multi-disciplinary meeting/consultation	3 (10)	29 (30)	0.028
Other clinical care	10 (33)	32 (33)	0.972
Palliative care	0	9 (9)	0.083
Advice/contact/help line	10 (33)	12 (12)	0.008
Rehabilitation care	3 (10)	24 (25)	0.085
Specialist clinics	7 (23)	12 (12)	0.141
Carers' support group	1 (3)	7 (7)	0.444
Patients' support group	2 (7)	11 (11)	0.461
Telemedicine	0	3 (3)	0.330
Counselling care	4 (13)	17 (17)	0.589
N (100%)	30	97	

p using Pearson chi-squared (two-sided)

1. 1 case in other model of care: not clear who holds case file
2. 4 cases in other model of care: not clear who holds care plan
3. 2 cases in other model of care: not clear who holds care plan

Despite relatively few differences between CNS services and other models in terms of the elements of care delivered, a different pattern of provision of continuity of care was evident from the papers reviewed. As Table 3.10 shows, the papers about CNS services were much more likely to describe delivering relational, personal, therapeutic continuity and flexible continuity of care. This first difference is not entirely surprising, given that the definition of this type of continuity relates to one or more, named, individual professionals with whom the service user can establish and maintain a consistent, therapeutic relationship. Nonetheless, it does suggest that this is what CNS services are, indeed, able to do. Further, it is not something that the descriptions of MDTs referred to in any numbers.

One might have assumed that flexible continuity – where input can adjust to the needs of the individual over time – would be related to relational continuity but no pattern of this sort was obvious from these descriptive papers. Those describing relational continuity were no more or less likely also to describe flexible continuity.

Table 3.10 Number and proportion of CNS services delivering different types of continuity of care compared with other models of care

<i>Type of continuity of care</i>	<i>N (%) of CNS services</i>	<i>N (%) of other models of care</i>	<i>p =</i>
Cross-boundary, team	17 (57)	58 (60)	0.761
Flexible	11 (37)	11 (11)	0.001
Informational	6 (20)	34 (35)	0.121
Longitudinal	2 (7)	18 (19)	0.118
Long-term	2 (7)	11 (11)	0.461
Personal agency	8 (27)	31 (32)	0.583
Relational, personal, therapeutic	15 (50)	12 (12)	0.000
Social context	3 (10)	15 (16)	0.453
Experienced	2 (7)	2 (2)	0.207
N (100%)	35	75	

p using Pearson chi-squared (two-sided)

3.5 Assessment and disease management models of care

Thirteen of the 29 assessment and disease management models (ADMMs) of care included in the descriptive review were based in the UK. Six were in the USA, four in Canada, two in France, two in the Netherlands, and one each in Denmark and Ireland.

Over a third (11) of the models were delivered in a single setting, ten in two settings, and eight in three or more settings (Table 3.11). These models were no more or less likely than other models of care to be delivered in in-patient (35% and 29% respectively), out-patient (55% and 39%), home (45% and 30%), or other community settings (38% and 29%). They were slightly more likely to be delivered in any other setting (41% and 23%) although this, and the slightly higher proportion of ADMMs in each setting, reflects that they were somewhat more likely than other models to be delivered in three or more settings.

Table 3.11 Settings for assessment and disease management models

<i>Type of setting</i>	<i>Model in one setting</i>	<i>Model in two settings</i>	<i>Model in three settings</i>	<i>Model in four settings</i>	<i>Model in five settings</i>	<i>Total N (%) assessment and disease management models¹</i>
In-patient	2	3	0	4	1	10 (35)
Out-patient	4	4	2	5	1	16 (55)
Home	1	5	2	4	1	13 (45)
Other community	3	3	1	3	1	11 (38)
Any other	1	5	1	4	1	12 (41)
N of models	11	10	2	5	1	29 (100)

1. Sums to more than 100% because of multiple coding

None of the ADMMs described were for people with cerebral palsy, head injury, Huntington's Disease, MND, or spinal injury. The largest number (12) focused on epilepsy, followed by MS (10), and PD (6). Three models were for general neurological conditions, five for any or all long-term neurological conditions and one specifically for dystonia/ataxia. As these figures suggest, some ADMMs provided services for more than one condition. Two targeted PD and any or another neurological conditions, two had a general neurological focus, dealing with any or all conditions, one had a general neurological focus but mentioned dystonia/ataxia specifically, one targeted epilepsy and MS, one MS and PD, and one MS with other neurological conditions. Ten per cent of ADMMs were for general neurology, compared to only one per cent of other models ($\chi^2 = 6.378$, $df=2$, $p=0.012$). By contrast, there were no ADMMs for MND, compared to 17 per cent of other models ($\chi^2 = 5.808$, $df=2$, $P=0.016$). There were no other significant differences in relation to condition targeted.

Like other models of care reviewed in this chapter, ADMMs were sometimes associated with other types of provision. Six provided access to other services, five were also associated with a CNS service and four a MDT or clinic, three were associated with self-care, two a nurse-led clinic, two with disease registers, one with a professionally-led care pathway, and one with professional training. Several (7) were also associated with specialist clinics or centres that delivered a range of services.

The staff most commonly involved in assessment and disease management models of care were, as might be expected, neurologists (Table 3.12). Further, neurologists were significantly more likely to be involved in these models of care than in others. These models were slightly less likely than others were to involve general practitioners, and a higher proportion included social workers, although neither difference was large enough to reach statistical significance. There were no other

differences in the types of professionals involved in assessment and disease management models.

Table 3.12 Number and proportion of assessment and disease management models with specified staff compared with other models of care

<i>Staff</i>	<i>N (%) of assessment and disease management models</i>	<i>N (%) of other models of care</i>	<i>p =</i>
Doctors:			
Neurology	15 (52)	31 (32)	0.048
Rehabilitation	5 (17)	10 (10)	0.302
Other specialty	2 (7)	17 (17)	0.166
Specialty not specified	5 (17)	7 (7)	0.102
Nurses:			
Neurology ¹ community	5 (17)	21 (21)	0.624
Neurology acute	3 (10)	19 (19)	0.258
Other specialist community	2 (7)	7 (7)	0.964
Other specialist acute	2 (7)	10 (10)	0.593
Specialty not specified	3 (10)	15 (15)	0.501
General community	4 (14)	6 (6)	0.178
General acute	3 (10)	3 (3)	0.104
General not specified	4 (14)	10 (10)	0.588
Therapists:			
Physiotherapist	11 (38)	36 (37)	0.907
Occupational therapist	11 (38)	35 (36)	0.827
Speech and language therapist	8 (28)	29 (30)	0.835
Dietician	5 (17)	16 (16)	0.907
Other therapist	5 (17)	7 (7)	0.102
Specialty not specified	0	2 (2)	0.438
Other staff:			
Psychologist	7 (24)	18 (18)	0.492
Counsellor	2 (7)	6 (6)	0.880
Social worker	12 (41)	24 (25)	0.076
Social Services, so described	1 (3)	4 (4)	0.878
Voluntary organisation	3 (10)	13 (13)	0.677
Coordinator/care manager	5 (17)	9 (9)	0.224
General practitioner	1 (3)	14 (14)	0.112
Any other member of staff	7 (24)	21 (21)	0.757
N (100%)	29	98	

p using Pearson chi-squared (two-sided)

1. 2 cases not known

Assessment and disease management models of care were no more or less likely than other models to be uni- or multi-professional in composition (Table 3.13). Most teams (44%) had between two and five different types of professionals involved.

Table 3.13 Number of different type of professionals in assessment and disease management models, compared with other models of care

<i>Model of care</i>	<i>N (%) of models with different types of professionals by number of professionals</i>			
	1	2-5	6 or more	Total
Assessment and disease management	6 (21)	11 (38)	12 (41)	29 (100)
Other	30 (31)	33 (34)	33 (34)	96 (100)
Total	36 (29)	44 (35)	45 (36)	125 (100)

$\chi^2 = 1.246$, $df=2$, $p= 0.536$

As one might expect, assessment and disease management models of care were more likely than other models of care to provide diagnoses and to assess service users' condition (Table 3.14). Beyond this, however, there were few other differences. Assessment and disease management models were slightly more likely than other models to assess nursing need, and to provide information, education or training for professionals than were other models of care but neither difference reached conventional levels of statistical significance. They were also somewhat more likely to provide other forms of assessment. These included home safety assessment (1), multi-disciplinary assessment (1), pre-operative assessment (1), psychosocial assessment (2), and assessment of side-effects of treatment (1).

Table 3.14 Number and proportion of assessment and disease management models providing different elements of care compared with other models of care

<i>Elements provided</i>	<i>N (%) of assessment and disease management models</i>	<i>N (%) of other models of care</i>	<i>p =</i>
Diagnosis	6 (21)	6 (6)	.018
<i>Assessment of:</i>			
Condition	13 (45)	26 (26)	.061
Disability/impairment	6 (21)	15 (15)	.493
Service need	8 (28)	20 (20)	.413
Nursing need	5 (17)	7 (7)	.102
Other	12 (41)	24 (25)	.076
Patient-held care file ¹	1 (3)	4 (4)	.878
Professional-held care file	3 (10)	9 (9)	.851
Patient-held care plan ²	2 (7)	4 (4)	.530
Professional-held care plan ³	4 (14)	12 (12)	.825

<i>Elements provided</i>	<i>N (%) of assessment and disease management models</i>	<i>N (%) of other models of care</i>	<i>p =</i>
Care or service co-ordination	9 (31)	23 (24)	.410
Care management	3 (10)	9 (9)	.851
Drug/medication review	6 (21)	19 (19)	.877
Equipment/aids supply	1 (3)	8 (8)	.385
Goal setting	2 (7)	13 (13)	.351
Information/education/training for carer	10 (35)	37 (38)	.749
Information/education/training for patient	14 (48)	58 (59)	.298
Information/education/training for professionals	11 (38)	21 (21)	.072
Monitoring and review	10 (35)	32 (33)	.854
Multi-disciplinary meeting/consultation	7 (24)	25 (26)	.881
Other clinical care	11 (38)	31 (32)	.527
Palliative care	0	9 (9)	.090
Advice/contact/help line	4 (14)	18 (18)	.567
Rehabilitation care	6 (21)	21 (21)	.932
Specialist clinics	6 (21)	13 (13)	.325
Carers' support group	1 (3)	7 (7)	.472
Patients' support group	3 (10)	10 (10)	.982
Telemedicine	0	3 (3)	.340
Counselling care	3 (10)	18 (18)	.307
N (100%)	29	98	

p using Pearson chi-squared (two-sided)

1. 1 case in other model of care: not clear who holds case file
2. 4 cases in other model of care: not clear who holds care plan
3. 2 cases in other model of care: not clear who holds care plan

There were few differences between the type of continuity of care described in accounts of assessment and disease management models of care and other models of care (Table 3.15). The one statistically significant difference was in relation to experienced care – three of the four models described as delivering this were assessment and disease management models. However, the numbers involved here were very small. Other differences that approached conventional levels of statistical significance were flexible (adjusting to the needs of the person over time) and cross-boundary or team continuity, both of which were more likely to be described in papers about assessment and disease management models. By contrast, assessment and disease management models were somewhat less likely to be described as providing relational, personal or therapeutic continuity (provision of one or more named professionals with whom the service user can establish and maintain a consistent therapeutic relationship). This difference, again, was not statistically significant.

Table 3.15 Number and proportion of assessment and disease management models delivering different types of continuity of care compared with other models of care

<i>Type of continuity of care</i>	<i>N (%) of assessment and disease management models</i>	<i>N (%) of other models of care</i>	<i>p =</i>
Cross-boundary, team	21 (72)	54 (55)	.096
Flexible	8 (28)	14 (14)	.096
Informational	12 (41)	28 (29)	.192
Longitudinal	3 (10)	17 (17)	.363
Long-term	5 (17)	8 (8)	.157
Personal agency	9 (31)	30 (31)	.965
Relational, personal, therapeutic	3 (10)	24 (25)	.102
Social context	4 (14)	14 (14)	.947
Experienced	3 (10)	1 (1)	.012
N (100%)			

p using Pearson chi-squared (two-sided)

3.6 Aspects of service delivery and organisation

As well as the characteristics of the different models of care described above, we extracted information from the reviewed papers about aspects of service delivery and organisation, where mentioned. This covered who was able to refer to the service (including patient or carer referral), what type of access arrangements were in place, what exclusion criteria, if any, were in place to manage access to the service, the age range served, whether access was time-limited, and who funded and who provided the service. Statements about most of these aspects of the models of care were relatively uncommon; in most cases, at least half of the papers reported nothing about these aspects of the model of care. Given this, we did not carry out any further analysis of this material.

3.7 Discussion

The literature on models of care for people with LTNCs seems to be dominated by three main conditions – MS, epilepsy and PD. To some extent, this reflects the epidemiology of these conditions but means that there is little evidence about models of care for people with some of the most challenging conditions, for example Huntington’s Disease and brain injury.

The material reviewed here shows, as one might expect, that the three predominant models of care for people with LTNCs described in the literature – multi-disciplinary teams or clinics, clinical nurse specialists, and assessment and disease management models – are different in their professional composition, size and operational bases. However, they also varied in their condition focus; for example, almost two-thirds of the included papers on models of care for people with MND were on MDTs and clinics, but fewer than one in ten of the papers on epilepsy. It is difficult to know whether this reflects real differences in service provision, or simply that papers about certain models of care for particular conditions may appear more novel or interesting and are therefore more likely to be published.

The descriptions of the three main models and the elements of care that they delivered were more similar than might have been expected, and the differences that were evident were largely ones that were easily explained. For example, descriptions of MDTs were more likely to refer to diagnosis, those of CNSs to providing advice, and those of ADMMs diagnosis and assessment of condition. Beyond these, there were few major differences in the elements of care provided.

Despite the similarities, the descriptions of the models did suggest that they facilitated somewhat different types of continuity of care. Accounts of MDTs and clinics were more likely to mention aspects of cross-boundary or team continuity and longitudinal continuity. CNSs were more often associated with relational, personal and therapeutic continuity and with flexible continuity. By contrast, there were no obvious differences between the descriptions of ADMMs and other models of care. These differences, if real, do suggest that MDTs working with or alongside CNSs could facilitate a wider range of types of continuity of care for people with LTNCs than either could alone.

Our analysis of the material here was inevitably limited by the detail about the models of care being described or evaluated in the papers reviewed. Reporting of details of service delivery or organisation was particularly poor and we were unable to take our analysis of this any further.

4. Summary and conclusions

A 'rapid' systematic review of evidence about the outcomes of models of integrated care for people with long-term neurological conditions (LTNCs) reported here was the first stage of a larger project evaluating the National Service Framework for Long-Term Neurological Conditions. The full report of this work, its methods and findings is available (Bernard et al, 2010). This working paper is the technical report of the review.

4.1 Objectives

The first objective was to identify models of integrated service provision for people with LTNCs from the research literature and to evaluate their impact on different types of continuity of care. The second objective was to understand what the evaluative and descriptive research literature suggested about how best to achieve models of integrated care that delivered continuity.

4.2 Methods

A 'rapid' review searches systematically but not necessarily exhaustively for available evidence, critically appraises studies and sifts out those that are of poor quality. The material is then used to collate descriptive outlines of the evidence, provide an overview of it and what it says (Davies, 2003). We divided the work on our review into two parts. In the first, we dealt with the evaluative literature, and messages about the outcomes that models of integrated care could deliver. In the second part, we analysed descriptions of models of integrated care included in both the evaluative literature reviewed in the first part and in the wider descriptive literature. This reviewed evidence on how integrated models of care operated, who worked in them, what elements of service provision they included, and what types of continuity they appeared to deliver. Here and in the technical report, we called these two different approaches the 'evaluative review' and the 'descriptive review'.

Full details of our main search strategy, including the electronic databases searched, the keyword strategy, search restrictions, additional searching strategies, inclusion and exclusion criteria and how these were developed, the selection of material for review, data extraction and quality assessment are all included in the technical report. Overall, we followed CRD guidance for systematic reviews (CRD, 2001) in all elements of both reviews, working together as a team to develop common understandings and checking our decision making throughout.

4.3 Analysis and outcomes

The evaluative review presented a narrative synthesis of quantitative findings from the primary studies reviewed. The outcomes reported were: access to and use of services; service users' views of the model of care; disability and impairment; quality of life; clinical outcomes; mental health outcomes; hospital admission and length of stay; impact on family or carers; expressed need; knowledge of the condition; communication; costs to the health service, costs to service users and families; socio-economic outcomes; staff views about the model of care; coping or stress; and mortality.

The descriptive review converted text statements from publications that described models of integrated care into two categories – 'clearly present in the description' and 'not clearly present in the description'. These data were then subject to simple frequency analysis and cross-tabulation by model of care. The main issues covered were: What is the model of care? Where is it delivered? What conditions does it cover? Who delivers it? What service elements are included? What type of continuity of care does it deliver? For this last question, we used the Freeman *et al.* (2000) model as our starting point.

4.4 Included studies

Two thousand four hundred and seven publications were identified in the searching, 573 of which were initially selected as of potential relevance.

Of these, 49 separate studies, covering 47 models of care and reported in 68 publications were eventually included in the **evaluative review**. Fourteen randomised controlled trials (RCTs) and one pseudo-randomised study were included, alongside 14 other studies using a comparative design of some type. There were also four studies based on surveys, nine based on audit or retrospective record review and five based on 'other' designs. The majority of studies (33), 12 of which were RCTs, had been carried out in the UK. Most studies were about epilepsy (15), MS (14) or Parkinson's Disease (11).

One hundred and twenty-seven descriptions of models of care, including the 47 models included in the evaluative review, were included in the **descriptive review**. The majority of descriptions were about models of care for MS (41), epilepsy (36) or Parkinson's Disease (36).

4.5 Findings of the evaluative review

Table 4.1 summarises the findings from the evaluative review. As the table shows, there is little conclusive or consistent evidence of positive or negative impact on the service user or family outcomes reported in the evaluative research we reviewed. However, there is some limited evidence that home-based models of integrated care may reduce health service costs and, possibly, those of service users and their families as well. However, there is a substantial research agenda here, with few existing studies reporting these economic outcomes.

Table 4.1 Summary findings from studies included in evaluative review

<i>Outcome</i>	<i>Number of studies reporting</i>	<i>Overall findings</i>
Use of or contact with services	21	No consistent evidence about improved access to or use of services
Service users' view of model of care	18	Service users value new models of care but with little comparative information it is difficult to know whether this reflects gratitude for any service
Disability/impairment	17	Half of RCTs showed significant improvement, others did not. Evidence from other types of studies inconsistent.
Quality of life	15	Little secure evidence of positive impact on QoL for any model evaluated
Clinical outcomes	15	Inconsistent evidence
Mental health	11	Small but not statistically significant improvements in depression
Impact on family and/or carers	8	Specialist palliative care services for people with MS may improve care outcomes (1 RCT only), no evidence of positive impact from any other study or model
Costs to health services	8	Some limited evidence of reduced costs for home-based services. No adequate research re: nurse specialists or multidisciplinary teams
Hospital admission	6	Small but promising reductions in admission/length of stay, particularly for multidisciplinary care. Needs further research.
Communication in team or with patient	5	No conclusive evidence and lack of comparative data.
Patient or carer expressed need	4	Evidence of benefit is unclear
Knowledge of condition	4	Some evidence from single study of epilepsy that those with low levels of initial knowledge benefit from nurse specialist input.

<i>Outcome</i>	<i>Number of studies reporting</i>	<i>Overall findings</i>
Socio-economic outcome e.g. education, employment	3	No controlled studies.
Staff views of model of care	3	Positive views in all three studies. Integrated care systems and user-led care pathway said by staff to improve joint working, information exchange, and personalisation of care
Mortality	3	One study of multidisciplinary specialist clinic for motor neurone disease suggests improvement in mortality over general neurological care. No evidence of impact in other studies.
Costs to service users or families	2	One study only provided comparative data. Home-based IV may be less costly for service users and families.
Coping or stress	1	No evidence of impact.

The lack of evidence of impact from these studies does not mean that there is no impact to be found. Many studies were of relatively poor methodological quality and, where of better quality, too small to demonstrate impact. Further, the choice of outcome measures for many of the studies was limited to the conventional. Given the nature of many of the conditions studied here, looking for differences in clinical or impairment outcomes is probably always going to be relatively fruitless although, when the research is of high quality and large enough, lack of difference can mean that the new model is no worse than usual care. By contrast, outcomes that might have real meaning to service users were largely notable by their absence. For example, while two studies showed that professionals felt that integrated care models increased the active participation of service users in their care, or increased their empowerment, no study seems to have asked service users themselves about these important types of outcome!

4.6 Findings of the descriptive review

Three main models of integrated care were identified in the descriptive review – multi-disciplinary teams or clinics (MDTs), clinical nurse specialists (CNSs) and assessment and disease management models (ADMMs). Some were delivered as a single approach, others in combination with another model or aspect of integrated care. In total, 41 descriptions involved MDTs, 20 CNSs, and 29 assessment and disease management initiatives. There were 32 separate ‘other’ models of care, ranging from a rapid response team for administering IV therapy at home, to a specialist transition clinic for young people moving onto adult services. The three main models were used to analyse the descriptive material, thus allowing us to compare and contrast different ways of delivering integrated care.

4.6.1 Multi-disciplinary teams or clinics

The 41 descriptions and evaluations of MDTs showed that they were most often based in hospital (in-patient and out-patient) settings. However, 12 of the described teams also delivered care in service users' own homes. MDTs were significantly more likely to be associated with care for people with motor neurone disease or multiple sclerosis than were other models of care, and less likely to be associated with epilepsy. Although reporting of which staff were involved in MDTs and how many was variable across the descriptions, as one might expect, MDTs were more likely to include certain types of professionals than were other models of care. All types of therapists, psychologists, social workers, and care co-ordinators or care managers were significantly more likely to be mentioned in publications about MDTs than in those about other models. However, while rehabilitation medicine specialists were also significantly more likely to be mentioned, MDTs were no more or less likely to include neurologists. Over two-thirds of the described MDTs involved at least six different types of professional staff and, again, this was significantly different (higher) than in other models of care.

Despite these differences, the service elements described as part of MDTs were not very different from those described in other models of care. MDTs were more likely to be reported as providing diagnosis, rehabilitation input, assessment of disability or impairment, and palliative care, and to involve multi-disciplinary meetings or consultation. By contrast, the descriptions were less likely than those for other models of care to refer to providing information, education or training for professionals. Beyond these differences, the service elements involved were similar to those provided in the other models of care.

The descriptions of MDTs were significantly more likely to suggest that they provided cross-boundary or team continuity (as would be expected) and longitudinal continuity (care provided from as few professionals as possible, over time, consistent with need). However, the descriptions were less likely to suggest that MDTs provided any of the other types of continuity in the Freeman model although with the exception of information continuity, the differences were not at a level that reached statistical significance.

4.6.2 Clinical nurse specialists

We included 30 descriptions or evaluations of CNSs, either as a stand-alone model or in combination with some other aspect of care, were no more or less likely than other models of care to be based in hospital (in-patient or outpatient) or community health settings. However, they were significantly less likely than other models to be working in patients' own homes. CNSs were significantly more likely to be described

in relation to Parkinson's disease, and less likely in relation to Motor Neurone Disease or MS, than were other models of care.

CNSs are, by definition, uni-disciplinary so it is not surprising to find that the descriptive literature reflects this, referring less often to working in teams involving neurologists, therapy professionals, psychologists and social workers. This does not mean that CNSs do not work with other professionals or as members of wider teams, rather that the descriptive literature tends to concentrate on their clinical role, rather than their place in a multi-professional context. However, some CNSs, and particularly those in primary care, were effectively lone workers, albeit that they might be providing out-reach from or in-reach to a hospital-based neurology service.

Despite their uni-professional and often solitary role, the descriptions of CNSs suggest that they were no less likely than other models of care to provide a wide range of elements of care (see footnote 1). No CNS services involved diagnostic services, as one might expect, but they were significantly more likely than other models of care to be involved in providing advice, contact or a help-line service.

There were clear differences in the types of continuity of care that the descriptions of CNSs included, compared to other models of care, with aspects of relational, personal and therapeutic continuity, and flexible continuity referred to significantly more often.

4.6.3 Assessment and disease management models of care

There were 29 descriptions or evaluations of ADMMs in the descriptive review. These were no more or less likely than other models to be delivered in hospital (in-patient and outpatient), community health settings or service users' own homes. They were slightly different from other models in that the condition focus of the largest group was epilepsy (12), though followed by MS (10) and Parkinson's Disease (6). ADMMs were also significantly more likely than other models to report a focus on general or 'all and any' neurological conditions and less likely to focus on Motor Neurone Disease.

Neurologists were more likely to be part of the staffing of ADMMs, compared to other models but there were few other differences in the types of staff involved. They were as likely as other models of care to be uni- or multi-professional; most teams involved between two and five different types of professional.

ADMMs were more likely to provide diagnosis and to assess service users' condition, but there were few other differences in the elements of care provided.

With the relatively small numbers of ADMMs included in the review, identifying any significant differences in the types of continuity described was difficult. However, of the four descriptions that clearly outlined experienced continuity of care, three were of ADMMs and this difference did reach statistical significance. Other indicative, though not significant differences, included more descriptions of flexible continuity and of cross-boundary or team continuity. By contrast, relational, personal or therapeutic continuity was less often described.

4.6.4 Aspects of service delivery and organisation

Reporting of aspects of service delivery and organisation – such as referral and access routes, exclusion criteria, and funding – was rare in both the descriptive and evaluative accounts that we included in the descriptive review. We therefore did not carry out any further analysis of this material.

4.7 Strengths and limitations of the review

Although characterised as a ‘rapid’ systematic review, the evaluative review reported here had many of the features of a full systematic review. We carried out extensive electronic searches, systematically selected material for relevance and then for review, extracted data systematically, and carried out a full narrative synthesis of findings. We confined the evaluative review to studies that allowed some form of comparison to be made between people receiving the model of care being evaluated and those not, thus enhancing the opportunities for robust messages to emerge. We did not search exhaustively for material from the grey literature and relevant websites, and we did not include all additional material identified in the reference lists of included studies. However, we did include any RCTs of models of integrated care identified through this route. Overall, then we feel that the review was comprehensive but not exhaustive.

A conceptual limitation applies to this work. We were interested in models of care that could be described as integrated in some way and which might thereby deliver one of more types of continuity of care. Our decisions about whether the material we found through the search strategies was relevant, given this focus, were thus perhaps more subjective than would be the case with, say, a review of a clearly defined clinical intervention. However, we reduced this subjectivity to a minimum by using algorithms to guide selection and by extensive discussion between the review team members.

A related issue was how to decide whether the papers we identified through the searches could facilitate continuity of care and, if so, of which type. Again, we dealt

with this by discussion in the team, but we were inevitably restricted in our decisions by the type and extent of detail provided in the selected material.

The main limitation of the review, however, is the quality of the research we found. For example, while many of the RCTs in the evaluative review had been carried out since the CONSORT guidelines were published (Begg *et al.*, 1996), few were of high quality. Further, the choice of 'routine' clinical outcomes in the evaluative literature leaves a large part of service users' experiences of models of integrated care un-researched.

4.8 Conclusion

Our overall conclusion from the 'rapid' systematic review is that the evidence base, about both the impact and costs of integrated models of care for people with LTNCs and about the service delivery and organisation elements that need to be in place to make these models operate well, is weak. The evaluative literature is characterised by relatively poor quality research, regardless of its design, while the descriptive literature is variable in what it describes about how these models of care work in practice. Further, there is little sense in the evaluative research that outcomes that would be valued by service users and their families have informed the choice of outcome measures in the evaluations. Issues of personal choice, empowerment and, indeed, the experience of continuity of care (in any of its guises) are largely absent.

Despite this, the descriptive literature does suggest that multi-disciplinary team or clinics, alongside clinical nurse specialists, would provide a wider range of types of continuity of care for people with LTNCs than would either alone.

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Mays, N., Pope, C. and Popay, J. (2005) Systematically reviewing qualitative and quantitative evidence to inform management and policy-making in the health field. *Journal of Health Services Research and Policy*, 10, S1, 6-20.

Parker, G., Bhakta. P., Katbamna. S., Lovett. C., Paisley. S., Parker S. *et.al.* (2000) Best place of care for older people after acute and during subacute illness: a systematic review, *Journal of Health Services Research and Policy*, 5, 3, 176-189.

Appendix 1 Search strategies for long-term neurological conditions

The following databases were searched:

- MEDLINE
- CINAHL
- EMBASE
- HMIC
- DARE
- HTA
- NHSEED
- SIGLE
- Social Policy and Practice
- Social Science Citation Index
- ASSIA, Social Services Abstracts
- Sociological Abstracts
- NRR SOSIG
- The Cochrane Database of Systematic Reviews.

MEDLINE (Ovid Online – <http://www.ovid.com/>)

1966 to March Week 4 2006

Searched on 4/4/2006

Retrieved 334 hits

Search strategy:

1. ((Integrate\$ adj3 care) or (Integrate\$ adj3 healthcare) or (Integrate\$ adj3 health care)).ti,ab.
2. (Integrat\$ adj3 working).ti,ab.
3. (Integrat\$ adj3 provision).ti,ab.
4. (Integrat\$ adj3 provider organisation\$).ti,ab.
5. (Integrat\$ adj3 assessment\$).ti,ab.
6. (Integrat\$ adj3 team\$).ti,ab.
7. (Integrat\$ adj3 management).ti,ab.
8. Horizontal integration.ti,ab.
9. Vertical integration.ti,ab.
10. (Integrat\$ adj3 primary adj3 community).ti,ab.
11. (Integrat\$ adj3 health adj3 social).ti,ab.
12. (Cluster\$ adj3 health adj3 social).ti,ab.
13. (Integrat\$ adj3 service\$).ti,ab.

14. (Structured care or Structured healthcare or Structured health care).ti,ab.
15. Structured service\$.ti,ab.
16. (Joint\$ adj3 working).ti,ab.
17. Joined-up partnership\$.ti,ab.
18. (Partnership\$ adj3 working).ti,ab.
19. (Joint service\$ adj3 development\$).ti,ab.
20. Horizontal communication\$.ti,ab.
21. Partnership project\$.ti,ab.
22. Horizontal partnership\$.ti,ab.
23. Flexible partnership\$.ti,ab.
24. (Joint\$ adj3 service\$).ti,ab.
25. Joined-up service\$.ti,ab.
26. ((Joint\$ adj3 care) or (Joint\$ adj3 healthcare) or (Joint\$ adj3 health care)).ti,ab.
27. (Joined-up care or Joined-up health care or Joined-up healthcare).ti,ab.
28. ((Co-ordinat\$ adj3 care\$) or (Co-ordinat\$ adj3 health care\$) or (Co-ordinat\$ adj3 healthcare\$)).ti,ab.
29. ((Coordinat\$ adj3 care\$) or (Coordinat\$ adj3 healthcare\$) or (Coordinat\$ adj3 health care\$)).ti,ab.
30. (Co-ordinat\$ adj3 service\$).ti,ab.
31. (Coordinat\$ adj3 service\$).ti,ab.
32. Seamless service\$.ti,ab.
33. Seamless care.ti,ab.
34. (Contin\$ adj3 service\$).ti,ab.
35. ((contin\$ adj3 care) or (contin\$ adj3 healthcare) or (contin\$. adj3 health care)).ti,ab.
36. ((Progression adj3 care) or (Progression adj3 healthcare) or (Progression adj3 health care)).ti,ab.
37. (Uninterrupted care or Uninterrupted healthcare or Uninterrupted health care).ti,ab.
38. Uninterrupted service\$.ti,ab.
39. ((Inter-organisation\$ or Inter-organization\$) adj3 (care or healthcare or health care or service\$ or team\$ or work\$ or collaboration\$ or co-ordinat\$ or coordinat\$)).ti,ab.
40. (Holistic adj3 (care or health care or healthcare or service\$ or team\$ or work\$ or collaboration\$ or co-ordinat\$ or coordinat\$)).ti,ab.
41. ((Interoragnisation\$ or Interoragnization\$) adj3 (care or health care or healthcare or service\$ or team\$ or work\$ or collaboration\$ or co-ordinat\$ or coordinat\$)).ti,ab.
42. (Multidisciplinary adj3 (care or healthcare or health care or service\$ or team\$ or work\$ or collaboration\$ or co-ordinat\$ or coordinat\$)).ti,ab.

43. (Multiprofessional adj3 (care or healthcare or health care or service\$ or team\$ or work\$ or collaboration\$ or co-ordinat\$ or coordinat\$)).ti,ab.
44. (Multi-disciplinary adj3 (care or health care or healthcare or service\$ or team\$ or work\$ or collaboration\$ or co-ordinat\$ or coordinat\$)).ti,ab.
45. (Multi-professional adj3 (care or health care or healthcare or service\$ or team\$ or work\$ or collaboration\$ or co-ordinat\$ or coordinat\$)).ti,ab.
46. (Multi-agency adj3 (care or healthcare or health care or service\$ or team\$ or work\$ or collaboration\$ or co-ordinat\$ or coordinat\$)).ti,ab.
47. (Inter-agency adj3 (care or healthcare or health care or service\$ or team\$ or work\$ or collaboration\$ or co-ordinat\$ or coordinat\$)).ti,ab.
48. (Inter-professional adj3 (care health care or healthcare or service\$ or team\$ or work\$ or collaboration\$ or co-ordinat\$ or coordinat\$)).ti,ab.
49. (Interdisciplinary adj3 (care or healthcare or health care or ervice\$ or team\$ or work\$ or collaboration\$ or co-ordinat\$ or coordinat\$)).ti,ab.
50. (Inter-disciplinary adj3 (care or health care or healthcare or service\$ or team\$ or work\$ or collaboration\$ or co-ordinat\$ or coordinat\$)).ti,ab.
51. (Holistic adj3 (care or healthcare or health care or service\$ or team\$ or work\$ or collaboration\$ or co-ordinat\$ or coordinat\$)).ti,ab.
52. (Collaborat\$ adj3 servic\$).ti,ab.
53. Multidisciplinary assessment\$.ti,ab.
54. single assessment\$.ti,ab.
55. Care trust\$.ti,ab.
56. Strategic collaboration\$.ti,ab.
57. Provider partnership\$.ti,ab.
58. (Pool\$ adj3 budget\$).ti,ab.
59. Overlapping commissioning.ti,ab.
60. Contiguous commissioning.ti,ab.
61. Joint commissioning.ti,ab.
62. Integrated commissioning.ti,ab.
63. linkwork\$.ti,ab.
64. Co-located team\$.ti,ab.
65. co-location.ti,ab.
66. One stop shop\$.ti,ab.
67. exp "Delivery of Health Care, Integrated"/ (4591)
68. exp ambulatory care/
69. (ambulatory care or ambulatory health care or ambulatory healthcare).ti,ab.
70. (ambulatory service\$ or ambulatory health service\$).ti,ab. (366)
71. case management.ti,ab.
72. care management.ti,ab.
73. Case Management/
74. Managed Care Program\$.ti,ab.
75. Patient Care Plan\$.ti,ab.

76. or/1-75
77. Motor Neuron Disease/
78. lou gehrig disease.ti,ab.
79. lou gehrig's disease.ti,ab.
80. motor neuron disease.ti,ab.
81. motor neurone disease.ti,ab.
82. MND.ti,ab.
83. lateral sclerosis.ti,ab.
84. ALS.ti,ab.
85. anterior horn cell disease.ti,ab.
86. Bulbar Palsy.ti,ab.
87. Spinal Muscular Atrophy.ti,ab.
88. PARKINSON DISEASE/
89. paralysis agitans.ti,ab.
90. Parkinson disease.ti,ab.
91. Parkinson syndrome.ti,ab.
92. Parkinson s.ti,ab.
93. parkinsonism.ti,ab.
94. Ms.ti,ab.
95. Multiple sclerosis.ti,ab.
96. exp Multiple Sclerosis/
97. degenerative neurologic\$ disease\$.ti,ab.
98. degenerative neurologic\$ condition\$.ti,ab.
99. long term neurologic\$ disease\$.ti,ab.
100. long-term neurologic\$ disease\$.ti,ab.
101. long term neurologic\$ condition\$.ti,ab.
102. evolving neurologic\$ disease\$.ti,ab.
103. evolving neurologic\$ condition\$.ti,ab.
104. LTNC\$.ti,ab.
105. or/77-104
106. 76 and 105
107. 106
108. limit 107 to yr="1985 - 2006"

CINAHL - Cumulative Index to Nursing & Allied Health Literature (Ovid Online - <http://www.ovid.com/>)

1982 to March Week 5 2006

Searched on 4/4/2006

Retrieved 169 hits

Search strategy:

1. ((Integrate\$ adj3 care) or (Integrate\$ adj3 healthcare) or (Integrate\$ adj3 health care)).ti,ab.

2. (Integrat\$ adj3 working).ti,ab.
3. (Integrat\$ adj3 provision).ti,ab.
4. (Integrat\$ adj3 provider organisation\$).ti,ab.
5. (Integrat\$ adj3 assessment\$).ti,ab.
6. (Integrat\$ adj3 team\$).ti,ab.
7. (Integrat\$ adj3 management).ti,ab.
8. Horizontal integration.ti,ab.
9. Vertical integration.ti,ab.
10. (Integrat\$ adj3 primary adj3 community).ti,ab.
11. (Integrat\$ adj3 health adj3 social).ti,ab.
12. (Cluster\$ adj3 health adj3 social).ti,ab.
13. (Integrat\$ adj3 service\$).ti,ab.
14. (Structured care or Structured healthcare or Structured health care).ti,ab.
15. Structured service\$.ti,ab.
16. (Joint\$ adj3 working).ti,ab.
17. Joined-up partnership\$.ti,ab.
18. (Partnership\$ adj3 working).ti,ab.
19. (Joint service\$ adj3 development\$).ti,ab.
20. Horizontal communication\$.ti,ab.
21. Partnership project\$.ti,ab.
22. Horizontal partnership\$.ti,ab.
23. Flexible partnership\$.ti,ab.
24. (Joint\$ adj3 service\$).ti,ab.
25. Joined-up service\$.ti,ab.
26. ((Joint\$ adj3 care) or (Joint\$ adj3 healthcare) or (Joint\$ adj3 health care)).ti,ab.
27. (Joined-up care or Joined-up health care or Joined-up healthcare).ti,ab.
28. ((Co-ordinat\$ adj3 care\$) or (Co-ordinat\$ adj3 health care\$) or (Co-ordinat\$ adj3 healthcare\$)).ti,ab.
29. ((Coordinat\$ adj3 care\$) or (Coordinat\$ adj3 healthcare\$) or (Coordinat\$ adj3 health care\$)).ti,ab.
30. (Co-ordinat\$ adj3 service\$).ti,ab.
31. (Coordinat\$ adj3 service\$).ti,ab.
32. Seamless service\$.ti,ab.
33. Seamless care.ti,ab.
34. (Contin\$ adj3 service\$).ti,ab.
35. ((contin\$ adj3 care) or (contin\$ adj3 healthcare) or (contin\$ adj3 health care)).ti,ab.
36. ((Progression adj3 care) or (Progression adj3 healthcare) or (Progression adj3 health care)).ti,ab.

37. (Uninterrupted care or Uninterrupted healthcare or Uninterrupted health care).ti,ab.
38. Uninterrupted service\$.ti,ab.
39. ((Inter-organisation\$ or Inter-organization\$) adj3 (care or healthcare or health care or service\$ or team\$ or work\$ or collaboration\$ or co-ordinat\$ or coordinat\$)).ti,ab.
40. (Holistic adj3 (care or health care or healthcare or service\$ or team\$ or work\$ or collaboration\$ or co-ordinat\$ or coordinat\$)).ti,ab.
41. ((Interoragnisation\$ or Interoragnization\$) adj3 (care or health care or healthcare or service\$ or team\$ or work\$ or collaboration\$ or co-ordinat\$ or coordinat\$)).ti,ab.
42. (Multidisciplinary adj3 (care or healthcare or health care or service\$ or team\$ or work\$ or collaboration\$ or co-ordinat\$ or coordinat\$)).ti,ab.
43. (Multiprofessional adj3 (care or healthcare or health care or service\$ or team\$ or work\$ or collaboration\$ or co-ordinat\$ or coordinat\$)).ti,ab.
44. (Multi-disciplinary adj3 (care or health care or healthcare or service\$ or team\$ or work\$ or collaboration\$ or co-ordinat\$ or coordinat\$)).ti,ab.
45. (Multi-professional adj3 (care or health care or healthcare or service\$ or team\$ or work\$ or collaboration\$ or co-ordinat\$ or coordinat\$)).ti,ab.
46. (Multi-agency adj3 (care or healthcare or health care or service\$ or team\$ or work\$ or collaboration\$ or co-ordinat\$ or coordinat\$)).ti,ab.
47. (Inter-agency adj3 (care or healthcare or health care or service\$ or team\$ or work\$ or collaboration\$ or co-ordinat\$ or coordinat\$)).ti,ab.
48. (Inter-professional adj3 (care health care or healthcare or service\$ or team\$ or work\$ or collaboration\$ or co-ordinat\$ or coordinat\$)).ti,ab.
49. (Interdisciplinary adj3 (care or healthcare or health care or service\$ or team\$ or work\$ or collaboration\$ or co-ordinat\$ or coordinat\$)).ti,ab.
50. (Inter-disciplinary adj3 (care or health care or healthcare or service\$ or team\$ or work\$ or collaboration\$ or co-ordinat\$ or coordinat\$)).ti,ab.
51. (Holistic adj3 (care or healthcare or health care or service\$ or team\$ or work\$ or collaboration\$ or co-ordinat\$ or coordinat\$)).ti,ab.
52. (Collaborat\$ adj3 servic\$).ti,ab.
53. Multidisciplinary assessment\$.ti,ab.
54. single assessment\$.ti,ab.
55. Care trust\$.ti,ab.
56. Strategic collaboration\$.ti,ab.
57. Provider partnership\$.ti,ab.
58. (Pool\$ adj3 budget\$).ti,ab.
59. Overlapping commissioning.ti,ab.
60. Contiguous commissioning.ti,ab.
61. Joint commissioning.ti,ab.
62. Integrated commissioning.ti,ab.
63. linkwork\$.ti,ab.
64. Co-located team\$.ti,ab.

65. co-location.ti,ab.
66. One stop shop\$.ti,ab.
67. Health Care Delivery, Integrated/
68. ambulatory care/
69. (ambulatory care or ambulatory health care or ambulatory healthcare).ti,ab.
70. (ambulatory service\$ or ambulatory health service\$.ti,ab.
71. case management.ti,ab.
72. care management.ti,ab.
73. Case Management/
74. Managed Care Program\$.ti,ab.
75. Patient Care Plan\$.ti,ab.
76. or/1-75
77. exp Motor Neuron Diseases/
78. lou gehrig disease.ti,ab.
79. lou gehrig's disease.ti,ab.
80. motor neuron disease.ti,ab.
81. motor neurone disease.ti,ab.
82. MND.ti,ab.
83. lateral sclerosis.ti,ab.
84. ALS.ti,ab.
85. anterior horn cell disease.ti,ab.
86. Bulbar Palsy.ti,ab.
87. Spinal Muscular Atrophy.ti,ab.
88. PARKINSON DISEASE/
89. paralysis agitans.ti,ab.
90. Parkinson disease.ti,ab.
91. Parkinson syndrome.ti,ab.
92. Parkinson s.ti,ab.
93. parkinsonism.ti,ab.
94. Ms.ti,ab.
95. Multiple sclerosis.ti,ab.
96. Multiple Sclerosis/
97. degenerative neurologic\$ disease\$.ti,ab.
98. degenerative neurologic\$ condition\$.ti,ab.
99. long term neurologic\$ disease\$.ti,ab.
100. long-term neurologic\$ disease\$.ti,ab.
101. long term neurologic\$ condition\$.ti,ab.
102. evolving neurologic\$ disease\$.ti,ab.
103. evolving neurologic\$ condition\$.ti,ab.
104. LTNC\$.ti,ab.
105. or/77-104
106. 76 and 105

107. 106
 108. limit 107 to yr="1985 - 2006"

EMBASE (Ovid Online – <http://www.ovid.com/>)

1980 to 2006 Week 13

Searched on 4/4/2006

Retrieved 254 hits

Search strategy:

1. ((Integrate\$ adj3 care) or (Integrate\$ adj3 healthcare) or (Integrate\$ adj3 health care)).ti,ab. (2146)
2. (Integrat\$ adj3 working).ti,ab. (226)
3. (Integrat\$ adj3 provision).ti,ab. (86)
4. (Integrat\$ adj3 provider organisation\$).ti,ab. (0)
5. (Integrat\$ adj3 assessment\$).ti,ab. (907)
6. (Integrat\$ adj3 team\$).ti,ab. (320)
7. (Integrat\$ adj3 management).ti,ab. (1898)
8. Horizontal integration.ti,ab. (44)
9. Vertical integration.ti,ab. (104)
10. (Integrat\$ adj3 primary adj3 community).ti,ab. (0)
11. (Integrat\$ adj3 health adj3 social).ti,ab. (154)
12. (Cluster\$ adj3 health adj3 social).ti,ab. (4)
13. (Integrat\$ adj3 service\$).ti,ab. (1566)
14. (Structured care or Structured healthcare or Structured health care).ti,ab. (71)
15. Structured service\$.ti,ab. (10)
16. (Joint\$ adj3 working).ti,ab. (227)
17. Joined-up partnership\$.ti,ab. (1)
18. (Partnership\$ adj3 working).ti,ab. (148)
19. (Joint service\$ adj3 development\$).ti,ab. (1)
20. Horizontal communication\$.ti,ab. (2)
21. Partnership project\$.ti,ab. (16)
22. Horizontal partnership\$.ti,ab. (0)
23. Flexible partnership\$.ti,ab. (2)
24. (Joint\$ adj3 service\$).ti,ab. (175)
25. Joined-up service\$.ti,ab. (2)
26. ((Joint\$ adj3 care) or (Joint\$ adj3 healthcare) or (Joint\$ adj3 health care)).ti,ab. (600)
27. (Joined-up care or Joined-up health care or Joined-up healthcare).ti,ab. (7)
28. ((Co-ordinat\$ adj3 care\$) or (Co-ordinat\$ adj3 health care\$) or (Co-ordinat\$ adj3 healthcare\$)).ti,ab. (156)
29. ((Coordinat\$ adj3 care\$) or (Coordinat\$ adj3 healthcare\$) or (Coordinat\$ adj3 health care\$)).ti,ab. (1640)

30. (Co-ordinat\$ adj3 service\$).ti,ab. (135)
31. (Coordinat\$ adj3 service\$).ti,ab. (772)
32. Seamless service\$.ti,ab. (13)
33. Seamless care.ti,ab. (43)
34. (Contin\$ adj3 service\$).ti,ab. (1236)
35. ((contin\$ adj3 care) or (contin\$ adj3 healthcare) or (contin\$ adj3 health care)).ti,ab. (5888)
36. ((Progression adj3 care) or (Progression adj3 healthcare) or (Progression adj3 health care)).ti,ab. (99)
37. (Uninterrupted care or Uninterrupted healthcare or Uninterrupted health care).ti,ab. (7)
38. Uninterrupted service\$.ti,ab. (2)
39. ((Inter-organisation\$ or Inter-organization\$) adj3 (care or healthcare or health care or service\$ or team\$ or work\$ or collaboration\$ or co-ordinat\$ or coordinat\$)).ti,ab. (0)
40. (Holistic adj3 (care or health care or healthcare or service\$ or team\$ or work\$ or collaboration\$ or co-ordinat\$ or coordinat\$)).ti,ab. (328)
41. ((Interoragnisation\$ or Interoragnization\$) adj3 (care or health care or healthcare or service\$ or team\$ or work\$ or collaboration\$ or co-ordinat\$ or coordinat\$)).ti,ab. (0)
42. (Multidisciplinary adj3 (care or healthcare or health care or service\$ or team\$ or work\$ or collaboration\$ or co-ordinat\$ or coordinat\$)).ti,ab. (4837)
43. (Multiprofessional adj3 (care or healthcare or health care or service\$ or team\$ or work\$ or collaboration\$ or co-ordinat\$ or coordinat\$)).ti,ab. (158)
44. (Multi-disciplinary adj3 (care or health care or healthcare or service\$ or team\$ or work\$ or collaboration\$ or co-ordinat\$ or coordinat\$)).ti,ab. (454)
45. (Multi-professional adj3 (care or health care or healthcare or service\$ or team\$ or work\$ or collaboration\$ or co-ordinat\$ or coordinat\$)).ti,ab. (77)
46. (Multi-agency adj3 (care or healthcare or health care or service\$ or team\$ or work\$ or collaboration\$ or co-ordinat\$ or coordinat\$)).ti,ab. (40)
47. (Inter-agency adj3 (care or healthcare or health care or service\$ or team\$ or work\$ or collaboration\$ or co-ordinat\$ or coordinat\$)).ti,ab. (53)
48. (Inter-professional adj3 (care health care or healthcare or service\$ or team\$ or work\$ or collaboration\$ or co-ordinat\$ or coordinat\$)).ti,ab. (36)

49. (Interdisciplinary adj3 (care or healthcare or health care or service\$ or team\$ or work\$ or collaboration\$ or co-ordinat\$ or coordinat\$)).ti,ab. (2056)
50. (Inter-disciplinary adj3 (care or health care or healthcare or service\$ or team\$ or work\$ or collaboration\$ or co-ordinat\$ or coordinat\$)).ti,ab. (31)
51. (Holistic adj3 (care or healthcare or health care or service\$ or team\$ or work\$ or collaboration\$ or co-ordinat\$ or coordinat\$)).ti,ab. (328)
52. (Collaborat\$ adj3 servic\$).ti,ab. (477)
53. Multidisciplinary assessment\$.ti,ab. (150)
54. single assessment\$.ti,ab. (101)
55. Care trust\$.ti,ab. (324)
56. Strategic collaboration\$.ti,ab. (4)
57. Provider partnership\$.ti,ab. (12)
58. (Pool\$ adj3 budget\$).ti,ab. (7)
59. Overlapping commissioning.ti,ab. (0)
60. Contiguous commissioning.ti,ab. (0)
61. Joint commissioning.ti,ab. (13)
62. Integrated commissioning.ti,ab. (1)
63. linkwork\$.ti,ab. (10)
64. Co-located team\$.ti,ab. (0)
65. co-location.ti,ab. (42)
66. One stop shop\$.ti,ab. (78)
67. ambulatory care/ (5424)
68. (ambulatory care or ambulatory health care or ambulatory healthcare).ti,ab. (2655)
69. (ambulatory service\$ or ambulatory health service\$).ti,ab. (184)
70. case management.ti,ab. (2566)
71. care management.ti,ab. (1853)
72. Managed Care Program\$.ti,ab. (200)
73. Patient Care Plan\$.ti,ab. (52)
74. or/1-73 (34989)
75. exp Motor Neuron Diseases/ (0)
76. lou gehrig disease.ti,ab. (5)
77. lou gehrig's disease.ti,ab. (27)
78. motor neuron disease.ti,ab. (1581)
79. motor neurone disease.ti,ab. (370)
80. MND.ti,ab. (731)
81. lateral sclerosis.ti,ab. (5537)
82. ALS.ti,ab. (5839)
83. anterior horn cell disease.ti,ab. (42)
84. Bulbar Palsy.ti,ab. (210)
85. Spinal Muscular Atrophy.ti,ab. (1466)
86. PARKINSON DISEASE/ (28917)

87. paralysis agitans.ti,ab. (30)
88. Parkinson disease.ti,ab. (1830)
89. Parkinson syndrome.ti,ab. (130)
90. Parkinson s.ti,ab. (41)
91. parkinsonism.ti,ab. (6222)
92. Ms.ti,ab. (81283)
93. Multiple sclerosis.ti,ab. (21233)
94. Multiple Sclerosis/ (24693)
95. degenerative neurologic\$ disease\$.ti,ab. (114)
96. degenerative neurologic\$ condition\$.ti,ab. (22)
97. long term neurologic\$ disease\$.ti,ab. (1)
98. long-term neurologic\$ disease\$.ti,ab. (1)
99. long term neurologic\$ condition\$.ti,ab. (0)
100. evolving neurologic\$ disease\$.ti,ab. (0)
101. evolving neurologic\$ condition\$.ti,ab. (2)
102. LTNC\$.ti,ab. (1)
103. or/75-102 (140114)
104. 74 and 103 (266)
105. 104 (266)
106. limit 105 to yr="1985 - 2006" (254)

HMIC (Ovid Online – <http://www.ovid.com/>)

March 2006

Searched on 5/4/2006

Retrieved 23 hits

Search strategy:

1. ((Integrate\$ adj3 care) or (Integrate\$ adj3 healthcare) or (Integrate\$ adj3 health care)).ti,ab.
2. (Integrat\$ adj3 working).ti,ab.
3. (Integrat\$ adj3 provision).ti,ab.
4. (Integrat\$ adj3 provider organisation\$.ti,ab.
5. (Integrat\$ adj3 assessment\$.ti,ab.
6. (Integrat\$ adj3 team\$.ti,ab.
7. (Integrat\$ adj3 management).ti,ab.
8. Horizontal integration.ti,ab.
9. Vertical integration.ti,ab.
10. (Integrat\$ adj3 primary adj3 community).ti,ab.
11. (Integrat\$ adj3 health adj3 social).ti,ab.
12. (Cluster\$ adj3 health adj3 social).ti,ab.
13. (Integrat\$ adj3 service\$.ti,ab.

14. (Structured care or Structured healthcare or Structured health care).ti,ab.
15. Structured service\$.ti,ab.
16. (Joint\$ adj3 working).ti,ab.
17. Joined-up partnership\$.ti,ab.
18. (Partnership\$ adj3 working).ti,ab.
19. (Joint service\$ adj3 development\$).ti,ab.
20. Horizontal communication\$.ti,ab.
21. Partnership project\$.ti,ab.
22. Horizontal partnership\$.ti,ab.
23. Flexible partnership\$.ti,ab.
24. (Joint\$ adj3 service\$).ti,ab.
25. Joined-up service\$.ti,ab.
26. ((Joint\$ adj3 care) or (Joint\$ adj3 healthcare) or (Joint\$ adj3 health care)).ti,ab.
27. (Joined-up care or Joined-up health care or Joined-up healthcare).ti,ab.
28. ((Co-ordinat\$ adj3 care\$) or (Co-ordinat\$ adj3 health care\$) or (Co-ordinat\$ adj3 healthcare\$)).ti,ab.
29. ((Coordinat\$ adj3 care\$) or (Coordinat\$ adj3 healthcare\$) or (Coordinat\$ adj3 health care\$)).ti,ab.
30. (Co-ordinat\$ adj3 service\$).ti,ab.
31. (Coordinat\$ adj3 service\$).ti,ab.
32. Seamless service\$.ti,ab.
33. Seamless care.ti,ab.
34. (Contin\$ adj3 service\$).ti,ab.
35. ((contin\$ adj3 care) or (contin\$ adj3 healthcare) or (contin\$ adj3 health care)).ti,ab.
36. ((Progression adj3 care) or (Progression adj3 healthcare) or (Progression adj3 health care)).ti,ab.
37. (Uninterrupted care or Uninterrupted healthcare or Uninterrupted health care).ti,ab.
38. Uninterrupted service\$.ti,ab.
39. ((Inter-organisation\$ or Inter-organization\$) adj3 (care or healthcare or health care or service\$ or team\$ or work\$ or collaboration\$ or co-ordinat\$ or coordinat\$)).ti,ab.
40. (Holistic adj3 (care or health care or healthcare or service\$ or team\$ or work\$ or collaboration\$ or co-ordinat\$ or coordinat\$)).ti,ab.
41. ((Interoragnisation\$ or Interoragnization\$) adj3 (care or health care or healthcare or service\$ or team\$ or work\$ or collaboration\$ or co-ordinat\$ or coordinat\$)).ti,ab.
42. (Multidisciplinary adj3 (care or healthcare or health care or service\$ or team\$ or work\$ or collaboration\$ or co-ordinat\$ or coordinat\$)).ti,ab.

43. (Multiprofessional adj3 (care or healthcare or health care or service\$ or team\$ or work\$ or collaboration\$ or co-ordinat\$ or coordinat\$)).ti,ab.
44. (Multi-disciplinary adj3 (care or health care or healthcare or service\$ or team\$ or work\$ or collaboration\$ or co-ordinat\$ or coordinat\$)).ti,ab.
45. (Multi-professional adj3 (care or health care or healthcare or service\$ or team\$ or work\$ or collaboration\$ or co-ordinat\$ or coordinat\$)).ti,ab.
46. (Multi-agency adj3 (care or healthcare or health care or service\$ or team\$ or work\$ or collaboration\$ or co-ordinat\$ or coordinat\$)).ti,ab.
47. (Inter-agency adj3 (care or healthcare or health care or service\$ or team\$ or work\$ or collaboration\$ or co-ordinat\$ or coordinat\$)).ti,ab.
48. (Inter-professional adj3 (care health care or healthcare or service\$ or team\$ or work\$ or collaboration\$ or co-ordinat\$ or coordinat\$)).ti,ab.
49. (Interdisciplinary adj3 (care or healthcare or health care or service\$ or team\$ or work\$ or collaboration\$ or co-ordinat\$ or coordinat\$)).ti,ab.
50. (Inter-disciplinary adj3 (care or health care or healthcare or service\$ or team\$ or work\$ or collaboration\$ or co-ordinat\$ or coordinat\$)).ti,ab.
51. (Holistic adj3 (care or healthcare or health care or service\$ or team\$ or work\$ or collaboration\$ or co-ordinat\$ or coordinat\$)).ti,ab.
52. (Collaborat\$ adj3 servic\$).ti,ab.
53. Multidisciplinary assessment\$.ti,ab.
54. single assessment\$.ti,ab.
55. Care trust\$.ti,ab.
56. Strategic collaboration\$.ti,ab.
57. Provider partnership\$.ti,ab.
58. (Pool\$ adj3 budget\$).ti,ab.
59. Overlapping commissioning.ti,ab.
60. Contiguous commissioning.ti,ab.
61. Joint commissioning.ti,ab.
62. Integrated commissioning.ti,ab.
63. linkwork\$.ti,ab.
64. Co-located team\$.ti,ab.
65. co-location.ti,ab.
66. One stop shop\$.ti,ab.
67. exp AMBULATORY CARE/
68. AMBULATORY CARE SERVICES/
69. (ambulatory care or ambulatory health care or ambulatory healthcare).ti,ab.
70. (ambulatory service\$ or ambulatory health service\$).ti,ab.
71. case management.ti,ab.
72. care management.ti,ab.
73. Case Management/ or care management/
74. Managed Care Program\$.ti,ab.
75. Patient Care Plan\$.ti,ab.

76. or/1-75
77. Motor Neuron Diseases/
78. lou gehrig disease.ti,ab.
79. lou gehrig's disease.ti,ab.
80. motor neuron disease.ti,ab.
81. motor neurone disease.ti,ab.
82. MND.ti,ab.
83. lateral sclerosis.ti,ab.
84. ALS.ti,ab.
85. anterior horn cell disease.ti,ab.
86. Bulbar Palsy.ti,ab.
87. Spinal Muscular Atrophy.ti,ab.
88. parkinsons disease/
89. paralysis agitans.ti,ab.
90. Parkinson disease.ti,ab.
91. Parkinson syndrome.ti,ab.
92. Parkinson s.ti,ab.
93. parkinsonism.ti,ab.
94. Ms.ti,ab.
95. Multiple sclerosis.ti,ab.
96. multiple sclerosis/
97. degenerative neurologic\$ disease\$.ti,ab.
98. degenerative neurologic\$ condition\$.ti,ab.
99. long term neurologic\$ disease\$.ti,ab.
100. long-term neurologic\$ disease\$.ti,ab.
101. long term neurologic\$ condition\$.ti,ab.
102. evolving neurologic\$ disease\$.ti,ab.
103. evolving neurologic\$ condition\$.ti,ab.
104. LTNC\$.ti,ab.
105. or/77-104
106. 76 and 105
107. 106
108. limit 107 to yr="1985 - 2006"

DARE – Database of Abstracts of Reviews of Effects, HTA (Health Technology Assessment Database and NHSEED (NHS Economic Evaluation Database) (CRD administration database))

Searched on 6/4/2006

Retrieved 28 hits from DARE, 3 hits from HTA and 14 hits from NHSEED

Search strategy:

1. s Integrate\$(3w)care or Integrate\$(3w)healthcare or Integrate\$(3w)health(w)care

2. s Integrat\$(3w)working
3. s Integrat\$(3w)provision
4. s Integrat\$(3w)provider(w)organisation\$
5. s Integrat\$(3w)assessment
6. s Integrat\$(3w)team
7. s Integrat\$(3w)management
8. s Horizontal(w)integration
9. s Vertical(w)integration
10. s Integrat\$(3w)primary(3w)community
11. s Integrat\$(3w)health(3w)social
12. s Cluster\$(3w)health(3w)social
13. s Integrated(3w)service or Integrated(3w)services or Integration(3w)service or Integration(3w)services
14. s Structured(w)care or Structured(w)healthcare or Structured(w)health(w)care
15. s Structured(w)service or Structured(w)services
16. s Joint\$(3w)working
17. s Joined(w)up(w)partnership\$
18. s Partnership\$(3w)working
19. s Joint(w)service(3w)development or Joint(w)services(3w)development
20. s Horizontal(w)communication\$
21. s Partnership(w)project\$
22. s Horizontal(w)partnership\$
23. s Flexible(w)partnership\$
24. s Joint(3w)service or Joint(3w)service or Jointly(3w)service or Jointly(3w)services
25. s Joined(w)up(w)service or Joined(w)up(w)services
26. s Joint(3w)care or Joint(3w)healthcare or Joint(3w)health(w)care or Jointly(3w)care or Jointly(3w)healthcare or Jointly(3w)health(w)care
27. s Joined(w)up(w)care or Joined(w)up(w)health(w)care or Joined(w)up(w)healthcare
28. s Co(w)ordinate(3w)care or Co(w)ordinate(3w)health(w)care or Co(w)ordinate(3w)healthcare or Co(w)ordination(3w)care or Co(w)ordination(3w)health(w)care or Co(w)ordination(3w)healthcare
29. s Coordinat\$(3w)care or Coordinat\$ (3w)healthcare or Coordinat\$(3w)health(w)care
30. s Co(w)ordinate(3w)service or s Co(w)ordinate(3w)services or Co(w)ordination(3w)service or s Co(w)ordination(3w)service
31. s Coordinate(3w)service or Coordinate(3w)services or Coordination(3w)service or Coordination(3w)services
32. s Seamless(w)service or Seamless(w)services

33. s Seamless(w)care
34. s Continuous(w)service or Continuous(w)services or Continuity(3w)service or Continuity(3w)services
35. s contin\$(3w)care or contin\$(3w)healthcare or contin\$(3w)health(w)care
36. s Progression(3w)care or Progression(3w)healthcare or Progression(3w)health(w)care
37. s Uninterrupted(w)care or Uninterrupted(w)healthcare or Uninterrupted(w)health(w)care
38. s Uninterrupted(w)service or Uninterrupted(w)services
39. s Inter(w)organisation(3w)(care or healthcare or health(w)care or service or services or team or teams or work or working or workers or collaboration or collaborate or collaborations or co(W)ordinate or co(W)ordination or coordinate or coordination) or Inter(w)organisational(3w)(care or healthcare or health(w)care or service or services or team or teams or work or working or workers or collaboration or collaborate or collaborations or co(W)ordinate or co(W)ordination or coordinate or coordination)
40. s Holistic(3w)(care or health care or healthcare or service or services or team or teams or work or workers or working or collaboration\$ or co(w)ordinate or co(w)ordination or coordinate or coordination)
41. s ((Interoragnisation or Interoragnisational or Interoragnization or Interoragnizational)(3w)(care or health care or healthcare or service or services or team or teams or work or working or workers or collaboration or collaborations or co(w)ordinate or co(w)ordination or coordinate or coordination))
42. s Multidisciplinary(3w)(care or healthcare or health(w)care or service or services or team or teams or work or workers or working or collaboration or collaborations or co(w)ordinate or co(w)ordination or coordinate or coordination)
43. s Multiprofessional(3w)(care or healthcare or health(w)care or service or services or team or teams or work or workers or working or collaboration or collaborations or co(w)ordinate or co(w)ordination or coordinate or coordination)
44. s Multi(w)disciplinary(3w)(care or healthcare or health(w)care or service or services or team or teams or work or workers or working or collaboration or collaborations or co(w)ordinate or co(w)ordination or coordinate or coordination)
45. s Multi(w)professional(3w)(care or healthcare or health(w)care or service or services or team or teams or work or workers or working or collaboration or collaborations or co(w)ordinate or co(w)ordination or coordinate or coordination)
46. s Multi(w)agency(3w)(care or healthcare or health(w)care or service or services or team or teams or work or workers or working or

- collaboration or collaborations or co(w)ordinate or co(w)ordination or coordinate or coordination)
47. s Inter(w)agency(3w)(care or healthcare or health(w)care or service or services or team or teams or work or workers or working or collaboration or collaborations or co(w)ordinate or co(w)ordination or coordinate or coordination)
 48. s Inter(w)professional(3w)(care or healthcare or health(w)care or service or services or team or teams or work or workers or working or collaboration or collaborations or co(w)ordinate or co(w)ordination or coordinate or coordination)
 49. s Interdisciplinary(3w)(care or healthcare or health(w)care or service or services or team or teams or work or workers or working or collaboration or collaborations or co(w)ordinate or co(w)ordination or coordinate or coordination)
 50. s Inter(w)disciplinary(3w)(care or healthcare or health(w)care or service or services or team or teams or work or workers or working or collaboration or collaborations or co(w)ordinate or co(w)ordination or coordinate or coordination)
 51. s Holistic(3w)(care or healthcare or health(w)care or service or services or team or teams or work or workers or working or collaboration or collaborations or co(w)ordinate or co(w)ordination or coordinate or coordination)
 52. s (Collaborate or collaboration or collaborations)(3w)(service or services)
 53. s Multidisciplinary(w)assessment\$
 54. s single(w)assessment\$
 55. s Care(w)trust\$
 56. s Strategic(w)collaboration\$
 57. s Provider(w)partnership\$
 58. s Pool\$(3w)budget\$
 59. s Overlapping(w)commissioning
 60. s Contiguous(w)commissioning
 61. s Joint(w)commissioning
 62. s Integrated(w)commissioning
 63. s linkwork\$
 64. s Co(w)located(w)team\$
 65. s co(w)location
 66. s One(w)stop(w)shop\$
 67. s ambulatory(w)care or ambulatory(w)health(w)care or ambulatory(w)healthcare
 68. s ambulatory(w)service or ambulatory(w)services or ambulatory(w)health(w)service or ambulatory(w)health(w)services
 69. s case(w)management

- 70. s care(w)management
- 71. s Managed(w)Care(w)Program\$
- 72. s Patient(w)Care(w)Plan\$
- 73. s s1 or s2 or s3 or s4 or s5 or s6 or s7 or s8 or s9 or s10 or s11 or s12 or s13 or s14 or s15 or s16 or s17 or s18 or s19 or s20 or s21 or s22 or s23 or s24 or s25 or s26 or s27 or s28 or s29 or s30 or s31 or s32 or s33 or s34 or s35 or s36 or s37 or s38 or s39 or s40 or s41 or s42 or s43 or s44 or s45 or s46 or s47 or s48 or s49 or s50 or s51 or s52 or s53 or s54 or s55 or s56 or s57 or s58 or s59 or s60 or s61 or s62 or s63 or s64 or s65 or s66 or s67 or s68 or s69 or s70 or s71 or s72
- 74. s lou(w)gehrig(w)disease
- 75. s lou(w)gehrig(w)s(w)disease
- 76. s motor(w)neuron(w)disease
- 77. s motor(w)neurone(w)disease
- 78. s MND
- 79. s lateral(w)sclerosis
- 80. s ALS
- 81. s anterior(w)horn(w)cell(w)disease
- 82. s Bulbar(w)Palsy
- 83. s Spinal(w)Muscular(w)Atrophy
- 84. s paralysis(w)agitans
- 85. s Parkinson(w)disease
- 86. s Parkinson(w)syndrome
- 87. s Parkinson(w)s
- 88. s parkinsonism
- 89. s Ms
- 90. s Multiple(w)sclerosis
- 91. s degenerative(w)neurologic(w)disease or degenerative(w)neurological(w)disease or degenerative(w)neurologic(w)diseases or degenerative(w)neurological(w)diseases
- 92. s degenerative(w)neurologic(w)condition or degenerative(w)neurological(w)condition or degenerative(w)neurologic(w)conditions or degenerative(w)neurological(w)conditions
- 93. s long(w)term(w)neurologic(w)disease or long(w)term(w)neurological(w)disease or long(w)term(w)neurologic(w)diseases or long(w)term(w)neurological(w)diseases
- 94. s long(w)term(w)neurologic(w)condition or long(w)term(w)neurological(w)condition or long(w)term(w)neurologic(w)conditions or long(w)term(w)neurological(w)conditions

95. s evolving(w)neurologic(w)disease or
evolving(w)neurological(w)disease or
evolving(w)neurologic(w)diseases or
evolving(w)neurological(w)diseases
96. s evolving(w)neurologic(w)condition or
evolving(w)neurological(w)condition or
evolving(w)neurologic(w)conditions or
evolving(w)neurological(w)conditions
97. s LTNC\$
98. s s74 or s75 or s76 or s77 or s78 or s79 or s80 or s81 or s82 or s83 or
s84 or s85 or s86 or s87 or s88 or s89 or s90 or s91 or s92 or s93 or
s94 or s95 or s96 or s97
99. s s98 and s73
100. s @1985:2006
101. s s99 and s100

SIGLE (Silverplatter ERL WebSPIRS – <http://www.arc.uk.ovid.com/>)

1980-2005/03

Searched on 6/4/2006

Retrieved 40 hits

and:

**Social Policy and Practice (Silverplatter ERL WebSPIRS –
<http://www.arc.uk.ovid.com/>)**

1890-

Searched on 6/4/2006

Retrieved 23 hits

Search strategy:

- #1. (Integrate* near3 care) or (Integrate* near3 healthcare) or
(Integrate* near3 health care)
- #2. Integrat* near3 working
- #3. Integrat* near3 provision
- #4. Integrat* near3 provider organisation*
- #5. Integrat* near3 assessment*
- #6. Integrat* near3 team*
- #7. Integrat* near3 management
- #8. Horizontal integration
- #9. Vertical integration
- #10. Integrat* near3 primary near3 community
- #11. Integrat* near3 health near3 social

- #12. Cluster* near3 health near3 social
- #13. Integrat* near3 service*
- #14. Structured care or Structured healthcare or Structured health care
- #15. Structured service*
- #16. Joint* near3 working
- #17. Joined-up partnership*
- #18. Partnership* near3 working
- #19. Joint service* near3 development*
- #20. Horizontal communication*
- #21. Partnership project*
- #22. Horizontal partnership*
- #23. Flexible partnership*
- #24. Joint* near3 service*
- #25. Joined-up service*
- #26. (Joint* near3 care) or (Joint* near3 healthcare) or (Joint* near3 health care)
- #27. Joined-up care or Joined-up health care or Joined-up healthcare
- #28. (Co-ordinat* near3 care*) or (Co-ordinat* near3 health care*) or (Co-ordinat* near3 healthcare*)
- #29. (Coordinat* near3 care*) or (Coordinat* near3 healthcare*) or (Coordinat* near3 health care*)
- #30. Co-ordinat* near3 service*
- #31. Coordinat* near3 service*
- #32. Seamless service*
- #33. Seamless care
- #34. Contin* near3 service*
- #35. (contin* near3 care) or (contin* near3 healthcare) or (contin* near3 health care)
- #36. (Progression near3 care) or (Progression near3 healthcare) or (Progression near3 health care)
- #37. Uninterrupted care or Uninterrupted healthcare or Uninterrupted health care
- #38. Uninterrupted service*
- #39. (Inter-oragnisation* or Inter-oragnization*) near3 (care or healthcare or health care or service* or team* or work* or collaboration* or co-ordinat* or coordinat*)
- #40. Holistic near3 (care or health care or healthcare or service* or team* or work* or collaboration* or co-ordinat* or coordinat*)
- #41. (Interoragnisation* or Interoragnization*) near3 (care or health care or healthcare or service* or team* or work* or collaboration* or co-ordinat* or coordinat*)
- #42. Multidisciplinary near3 (care or healthcare or health care or service* or team* or work* or collaboration* or co-ordinat* or coordinat*)

- #43. Multiprofessional near3 (care or healthcare or health care or service* or team* or work* or collaboration* or co-ordinat* or coordinat*)
- #44. Multi-disciplinary near3 (care or health care or healthcare or service* or team* or work* or collaboration* or co-ordinat* or coordinat*)
- #45. Multi-professional near3 (care or health care or healthcare or service* or team* or work* or collaboration* or co-ordinat* or coordinat*)
- #46. Multi-agency near3 (care or healthcare or health care or service* or team* or work* or collaboration* or co-ordinat* or coordinat*)
- #47. Inter-agency near3 (care or healthcare or health care or service* or team* or work* or collaboration* or co-ordinat* or coordinat*)
- #48. Inter-professional near3 (care health care or healthcare or service* or team* or work* or collaboration* or co-ordinat* or coordinat*)
- #49. Interdisciplinary near3 (care or healthcare or health care or service* or team* or work* or collaboration* or co-ordinat* or coordinat*)
- #50. Inter-disciplinary near3 (care or health care or healthcare or service* or team* or work* or collaboration* or co-ordinat* or coordinat*)
- #51. Holistic near3 (care or healthcare or health care or service* or team* or work* or collaboration* or co-ordinat* or coordinat*)
- #52. Collaborat* near3 servic*
- #53. Multidisciplinary assessment*
- #54. single assessment*
- #55. Care trust*
- #56. Strategic collaboration*
- #57. Provider partnership*
- #58. Pool* near3 budget*
- #59. Overlapping commissioning
- #60. Contiguous commissioning
- #61. Joint commissioning
- #62. Integrated commissioning
- #63. linkwork*
- #64. Co-located team*
- #65. co-location
- #66. One stop shop*
- #67. ambulatory care or ambulatory health care or ambulatory healthcare
- #68. ambulatory service* or ambulatory health service*
- #69. case management
- #70. care management
- #71. Managed Care Program*
- #72. Patient Care Plan*
- #73. #1 or #2 or #3 or #4 or #5 or #6 or #7 or #8 or #9 or #10 or #11 or #12 or #13 or #14 or #15 or #16 or #17 or #18 or #19 or #20 or #21 or #22

- or #23 or #24 or #25 or #26 or #27 or #28 or #29 or #30 or #31 or #32
 or #33 or #34 or #35 or #36 or #37 or #38 or #39 or #40 or #41 or #42
 or #43 or #44 or #45 or #46 or #47 or #48 or #49 or #50 or #51 or #52
 or #53 or #54 or #55 or #56 or #57 or #58 or #59 or #60 or #61 or #62
 or #63 or #64 or #65 or #66 or #67 or #68 or #69 or #70 or #71 or #72
- #74. lou gehrig disease
 - #75. lou gehrig's disease
 - #76. motor neuron disease
 - #77. motor neurone disease
 - #78. MND
 - #79. lateral sclerosis
 - #80. ALS
 - #81. anterior horn cell disease
 - #82. Bulbar Palsy
 - #83. Spinal Muscular Atrophy
 - #84. paralysis agitans
 - #85. Parkinson disease
 - #86. Parkinson syndrome
 - #87. Parkinson s or parkinson's
 - #88. parkinsonism
 - #89. Ms
 - #90. Multiple sclerosis
 - #91. degenerative neurologic* disease*
 - #92. degenerative neurologic* condition*
 - #93. long term neurologic* disease*
 - #94. long-term neurologic* disease*
 - #95. long term neurologic* condition*
 - #96. evolving neurologic* disease*
 - #97. evolving neurologic* condition*
 - #98. LTNC*
 - #99. #74 or #75 or #76 or #77 or #78 or #79 or #80 or #81 or #82 or
 #83 or #84 or #85 or #86 or #87 or #88 or #89 or #90 or #91 or
 #92 or #93 or #94 or #95 or #96 or #97 or #98
 - #100. #73 and #99

**Social Science Citation Index (SSCI) (Web Of Knowledge –
<http://wos.mimas.ac.uk/>)**

(limited to)1985-2006

Searched on 6/4/2006

Retrieved 96 hits

Search strategy:

All lines listed as follows:

DocType=All document types; Language=All languages; Database=SSCI;
Timespan=1985-2006

- #1. TS=(Integrate* same health care))
- #2. TS=((Integrat* same working))
- #3. TS=(Integrat* same provision)
- #4. TS=(Integrat* same provider organisation*)
- #5. TS=(Integrat* same assessment*)
- #6. TS=(Integrat* same team*)
- #7. TS=(Integrat* same management)
- #8. TS=(Horizontal integration)
- #9. TS=(Vertical integration)
- #10. TS=(Integrat* same primary same community)
- #11. TS=(Integrat* same health same social)
- #12. TS=(Cluster* same health same social)
- #13. TS=(Integrat* same service*)
- #14. TS=(Structured care or Structured healthcare or Structured health care)
- #15. TS=(Structured service*)
- #16. TS=(Joint* same working)
- #17. TS=(Joined-up partnership*)
- #18. TS=(Partnership* same working)
- #19. TS=(Joint service* same development*)
- #20. TS=(Horizontal communication*)
- #21. TS=(Partnership project*)
- #22. TS=(Horizontal partnership*)
- #23. TS=(Flexible partnership*)
- #24. TS=(Joint* same service*)
- #25. TS=(Joined-up service*)
- #26. TS=((Joint* same care) or (Joint* same healthcare) or (Joint* same health care))
- #27. TS=(Joined-up care or Joined-up health care or Joined-up healthcare)
- #28. TS=((Co-ordinat* same care*) or (Co-ordinat* same health care*) or (Co-ordinat* same healthcare*))
- #29. TS=((Coordinat* same care*) or (Coordinat* same healthcare*) or (Coordinat* same health care*))
- #30. TS=(Co-ordinat* same service*)
- #31. TS=(Coordinat* same service*)
- #32. TS=(Seamless service*)
- #33. TS=(Seamless care)
- #34. TS=(Contin* same service*)

- #35. TS=((contin* same care) or (contin* same healthcare) or (contin* same health care))
- #36. TS=((Progression same care) or (Progression same healthcare) or (Progression same health care))
- #37. TS=(Uninterrupted care or Uninterrupted healthcare or Uninterrupted health care)
- #38. TS=(Uninterrupted service*)
- #39. TS=((Inter-oragnisation* or Inter-oragnization*) same (care or healthcare or health care or service* or team* or work* or collaboration* or co-ordinat* or coordinat*))
- #40. TS=((Holistic same (care or health care or healthcare or service* or team* or work* or collaboration* or co-ordinat* or coordinat*))
- #41. TS((((Interoragnisation* or Interoragnization*) same (care or health care or healthcare or service* or team* or work* or collaboration* or co-ordinat* or coordinat*)))
- #42. TS=(Multidisciplinary same (care or healthcare or health care or service* or team* or work* or collaboration* or co-ordinat* or coordinat*))
- #43. TS=(Multiprofessional same (care or healthcare or health care or service* or team* or work* or collaboration* or co-ordinat* or coordinat*))
- #44. TS=(Multi-disciplinary same (care or health care or healthcare or service* or team* or work* or collaboration* or co-ordinat* or coordinat*))
- #45. TS=(Multi-professional same (care or health care or healthcare or service* or team* or work* or collaboration* or co-ordinat* or coordinat*))
- #46. TS=(Multi-agency same (care or healthcare or health care or service* or team* or work* or collaboration* or co-ordinat* or coordinat*))
- #47. TS=(Inter-agency same (care or healthcare or health care or service* or team* or work* or collaboration* or co-ordinat* or coordinat*))
- #48. TS=(Inter-professional same (care health care or healthcare or service* or team* or work* or collaboration* or co-ordinat* or coordinat*))
- #49. TS=(Interdisciplinary same (care or healthcare or health care or service* or team* or work* or collaboration* or co-ordinat* or coordinat*))
- #50. TS=(Inter-disciplinary same (care or health care or healthcare or service* or team* or work* or collaboration* or co-ordinat* or coordinat*))
- #51. TS=(Holistic same (care or healthcare or health care or service* or team* or work* or collaboration* or co-ordinat* or coordinat*))
- #52. TS=(Collaborat* same servic*)

- #53. TS=(Multidisciplinary assessment*)
- #54. TS=(single assessment*)
- #55. TS=(Care trust*)
- #56. TS=(Strategic collaboration*)
- #57. TS=(Provider partnership*)
- #58. TS=(Pool* same budget*)
- #59. TS=(Overlapping commissioning)
- #60. TS=(Contiguous commissioning)
- #61. TS=(Joint commissioning)
- #62. TS=(Integrated commissioning)
- #63. TS=(linkwork*)
- #64. TS=(Co-located team*)
- #65. TS=(co-location)
- #66. TS=(One stop shop*)
- #67. TS=(ambulatory care or ambulatory health care or ambulatory healthcare)
- #68. TS=(ambulatory service* or ambulatory health service*)
- #69. TS=(case management)
- #70. TS=(care management)
- #71. TS=(Managed Care Program*)
- #72. TS=(Patient Care Plan*)
- #73. #1 or #2 or #3 or #4 or #5 or #6 or #7 or #8 or #9 or #10 or #11 or #12 or #13 or #14 or #15 or #16 or #17 or #18 or #19 or #20 or #21 or #22 or #23 or #24
- #74. #25 or #26 or #27 or #28 or #29 or #30 or #31 or #32 or #33 or #34 or #35 or #36 or #37 or #38 or #39 or #40 or #41 or #42 or #43 or #44 or #45 or #46 or #47 or #48 or #49 or #50
- #75. #51 or #52 or #53 or #54 or #55 or #56 or #57 or #58 or #59 or #60 or #61 or #62 or #63 or #64 or #65 or #66 or #67 or #68 or #69 or #70 or #71 or #72
- #76. #73 or #74 or #75
- #77. TS=(lou gehrig disease)
- #78. TS=(lou gehrig's disease)
- #79. TS=(motor neuron disease)
- #80. TS=(motor neurone disease)
- #81. TS=(MND)
- #82. TS=(lateral sclerosis)
- #83. TS=(ALS)
- #84. TS=(anterior horn cell disease)
- #85. TS=(Bulbar Palsy)
- #86. TS=(Spinal Muscular Atrophy)
- #87. TS=(paralysis agitans)
- #88. TS=(Parkinson disease)

- #89. TS=(Parkinson syndrome)
- #90. TS=(Parkinson s or Parkinson's)
- #91. TS=(parkinsonism)
- #92. TS=(Ms)
- #93. TS=(Multiple sclerosis)
- #94. TS=(degenerative neurologic* disease*)
- #95. TS=(degenerative neurologic* condition*)
- #96. TS=(long term neurologic* condition*)
- #97. #77 or #78 or #79 or #80 or #81 or #82 or #83 or #84 or #85 or #86 or #87 or #88 or #89 or #90 or #91 or #92 or #93 or #94 or #95 or #96
- #98. #97 and #76

Due to limitations of the database, it was not possible to include all the desired terms in this search. The following terms retrieved no hits on the database and so were omitted from the final search:

evolving neurologic* disease*
 evolving neurologic* condition*
 LTNC*
 Long term neurologic* disease*

ASSIA (CSA Illumina – <http://ca2.csa.com/>)

1987 to 2006
 Searched on 7/4/2006
 Retrieved 23 hits

and

Social Services Abstracts (CSA Illumina – <http://ca2.csa.com/>)

1979 to 2006
 Searched on 7/4/2006
 Retrieved 28 hits

and

Sociological Abstracts (CSA Illumina – <http://ca2.csa.com/>)

1952 to 2006
 Searched on 7/4/2006
 Retrieved 34 hits

Search strategy:

1. (Integrate* within 3 care) or (Integrate* within 3 healthcare) or (Integrate* within 3 health care)

2. Integrat* within 3 working
3. Integrat* within 3 provision
4. Integrat* within 3 provider organisation*
5. Integrat* within 3 assessment*
6. Integrat* within 3 team*
7. Integrat* within 3 management
8. Horizontal integration
9. Vertical integration
10. Integrat* within 3 primary within 3 community
11. Integrat* within 3 health within 3 social
12. Cluster* within 3 health within 3 social
13. Integrat* within 3 service*
14. Structured care or Structured healthcare or Structured health care
15. Structured service*
16. Joint* within 3 working
17. Joined-up partnership*
18. Partnership* within 3 working
19. Joint service* within 3 development*
20. Horizontal communication*
21. Partnership project*
22. Horizontal partnership*
23. Flexible partnership*
24. Joint* within 3 service*
25. Joined-up service*
26. (Joint* within 3 care) or (Joint* within 3 healthcare) or (Joint* within 3 health care)
27. Joined-up care or Joined-up health care or Joined-up healthcare
28. (Co-ordinat* within 3 care*) or (Co-ordinat* within 3 health care*) or (Co-ordinat* within 3 healthcare*)
29. (Coordinat* within 3 care*) or (Coordinat* within 3 healthcare*) or (Coordinat* within 3 health care*)
30. Co-ordinat* within 3 service*
31. Coordinat* within 3 service*
32. Seamless service*
33. Seamless care
34. Contin* within 3 service*
35. (contin* within 3 care) or (contin* within 3 healthcare) or (contin* within 3 health care)
36. (Progression within 3 care) or (Progression within 3 healthcare) or (Progression within 3 health care)
37. Uninterrupted care or Uninterrupted healthcare or Uninterrupted health care

38. Uninterrupted service*
39. (Inter-organisation* or Inter-organization*) within 3 (care or healthcare or health care or service* or team* or work* or collaboration* or co-ordinat* or coordinat*)
40. Holistic within 3 (care or health care or healthcare or service* or team* or work* or collaboration* or co-ordinat* or coordinat*)
41. (Interorganisation* or Interorganization*) within 3 (care or health care or healthcare or service* or team* or work* or collaboration* or co-ordinat* or coordinat*)
42. Multidisciplinary within 3 (care or healthcare or health care or service* or team* or work* or collaboration* or co-ordinat* or coordinat*)
43. Multiprofessional within 3 (care or healthcare or health care or service* or team* or work* or collaboration* or co-ordinat* or coordinat*)
44. Multi-disciplinary within 3 (care or health care or healthcare or service* or team* or work* or collaboration* or co-ordinat* or coordinat*)
45. Multi-professional within 3 (care or health care or healthcare or service* or team* or work* or collaboration* or co-ordinat* or coordinat*)
46. Multi-agency within 3 (care or healthcare or health care or service* or team* or work* or collaboration* or co-ordinat* or coordinat*)
47. Inter-agency within 3 (care or healthcare or health care or service* or team* or work* or collaboration* or co-ordinat* or coordinat*)
48. Inter-professional within 3 (care health care or healthcare or service* or team* or work* or collaboration* or co-ordinat* or coordinat*)
49. Interdisciplinary within 3 (care or healthcare or health care or service* or team* or work* or collaboration* or co-ordinat* or coordinat*)
50. Inter-disciplinary within 3 (care or health care or healthcare or service* or team* or work* or collaboration* or co-ordinat* or coordinat*)
51. Holistic within 3 (care or healthcare or health care or service* or team* or work* or collaboration* or co-ordinat* or coordinat*)
52. Collaborat* within 3 servic*
53. Multidisciplinary assessment*
54. single assessment*
55. Care trust*
56. Strategic collaboration*
57. Provider partnership*
58. Pool* within 3 budget*
59. Overlapping commissioning
60. Contiguous commissioning
61. Joint commissioning
62. Integrated commissioning
63. linkwork*
64. Co-located team*
65. co-location
66. One stop shop*

67. DE="Integrated management"
68. DE="Ambulatory health care"
69. ambulatory care or ambulatory health care or ambulatory healthcare
70. ambulatory service* or ambulatory health service*
71. case management
72. care management
73. DE="Integrated care pathways"
74. Managed Care Program*
75. Patient Care Plan*
76. #1 or #2 or #3 or #4 or #5 or #6 or #7 or #8 or #9 or #10 or #11 or #12 or #13 or #14 or #15 or #16 or #17 or #18 or #19 or #20 or #21 or #22 or #23 or #24 or #25 or #26 or #27 or #28 or #29 or #30 or #31 or #32 or #33 or #34 or #35 or #36 or #37 or #38 or #39 or #40 or #41 or #42 or #43 or #44 or #45 or #46 or #47 or #48 or #49 or #50 or #51 or #52 or #53 or #54 or #55 or #56 or #57 or #58 or #59 or #60 or #61 or #62 or #63 or #64 or #65 or #66 or #67 or #68 or #69 or #70 or #71 or #72 or #73 or #74 or #75
77. DE="Motor neurone disease" or "bell s palsy"
78. lou gehrig disease
79. lou gehrig's disease
80. motor neuron disease
81. motor neurone disease
82. MND
83. lateral sclerosis
84. ALS
85. anterior horn cell disease
86. Bulbar Palsy
87. Spinal Muscular Atrophy
88. DE="Parkinson's disease"
89. paralysis agitans
90. Parkinson disease
91. Parkinson syndrome
92. Parkinson s
93. parkinsonism
94. Ms
95. Multiple sclerosis
96. DE="Multiple sclerosis"
97. degenerative neurologic* disease*
98. degenerative neurologic* condition*
99. long term neurologic* disease*
100. long-term neurologic* disease*
101. long term neurologic* condition*

- 102. evolving neurologic* disease*
- 103. evolving neurologic* condition*
- 104. LTNC*
- 105. #77 or #78 or #79 or #80 or #81 or #82 or #83 or #84 or #85 or
#86 or #87 or #88 or #89 or #90 or #91 or #92 or #93 or #94 or
#95 or #96 or #97 or #98 or #99 or #100 or #101 or #102 or #103 or
#104
- 106. #76 and #105

Date range = 1985-2006

NRR (<http://www.nrr.nhs.uk/>)

2006: Issue 1

Searched on 7/4/2006

Retrieved 46 hits

Search strategy:

- #1. (integrate* near care) or (integrate* near healthcare) or (integrate* near health care)
- #2. integrat* near working
- #3. (integrat* near provision)
- #4. (integrat* near (provider next organisation*))
- #5. (integrat* near assessment*)
- #6. (integrat* near team*)
- #7. (integrat* near management)
- #8. (horizontal next integration)
- #9. (vertical next integration)
- #10. (integrat* near primary near community)
- #11. (integrat* near health near social)
- #12. (cluster* near health near social)
- #13. (integrat* near service*)
- #14. ((structured next care) or (structured next healthcare) or (structured next health next care))
- #15. (structured next service*)
- #16. (joint* near working)
- #17. (joined next up next partnership*)
- #18. partnership* working
- #19. joint near service* near development*
- #20. (horizontal next communication*)
- #21. (partnership next project*)
- #22. (horizontal next partnership*)
- #23. (flexible next partnership*)
- #24. (joint* near service*)
- #25. (joined next up next service*)
- #26. joint* care or joint* healthcare or joint* health care
- #27. ((joined next up next care) or (joined next up next health next care) or (joined next up next healthcare))
- #28. ((co-ordinat* near care*) or (co-ordinat* near (health next care*)) or (co-ordinat* near healthcare*))
- #29. ((coordinat* near care*) or (coordinat* near healthcare*) or (coordinat* near (health next care*)))
- #30. (co-ordinat* near service*)
- #31. (coordinat* near service*)
- #32. (seamless next service*)

- #33. (seamless next care)
- #34. (contin* near service*)
- #35. contin* care or contin* healthcare or contin* health care
- #36. ((progression near care) or (progression near healthcare) or (progression near (health next care)))
- #37. ((uninterrupted next care) or (uninterrupted next healthcare) or (uninterrupted next health next care))
- #38. (uninterrupted next service*)
- #39. (((inter next oragnisation*) or (inter next oragnization*)) and (care or healthcare or (health next care) or service* or team* or work* or collaboration* or (co next ordinat*) or coordinat*))
- #40. (holistic and (care or (health next care) or healthcare or service* or team* or work* or collaboration* or co-ordinat* or coordinat*))
- #41. ((interoragnisation* or interoragnization*) and (care or (health next care) or healthcare or service* or team* or work* or collaboration* or co-ordinat* or coordinat*))
- #42. (Multidisciplinary near care) or (Multidisciplinary near healthcare) or (Multidisciplinary near health care) or (Multidisciplinary near service*) or (Multidisciplinary near team*) or (Multidisciplinary near work*) or (Multidisciplinary near collaboration*) or (Multidisciplinary near co-ordinat*) or (Multidisciplinary near coordinat*)
- #43. (multiprofessional and (care or healthcare or (health next care) or service* or team* or work* or collaboration* or co-ordinat* or coordinat*))
- #44. ((multi next disciplinary) and (care or (health next care) or healthcare or service* or team* or work* or collaboration* or co-ordinat* or coordinat*))
- #45. ((multi next professional) and (care or (health next care) or healthcare or service* or team* or work* or collaboration* or co-ordinat* or coordinat*))
- #46. ((multi next agency) and (care or healthcare or (health next care) or service* or team* or work* or collaboration* or co-ordinat* or coordinat*))
- #47. ((inter next agency) and (care or healthcare or (health next care) or service* or team* or work* or collaboration* or co-ordinat* or coordinat*))
- #48. ((inter next professional) and ((care next health next care) or healthcare or service* or team* or work* or collaboration* or co-ordinat* or coordinat*))
- #49. (interdisciplinary and (care or healthcare or (health next care) or service* or team* or work* or collaboration* or co-ordinat* or coordinat*))
- #50. ((inter next disciplinary) and (care or (health next care) or healthcare or service* or team* or work* or collaboration* or co-ordinat* or coordinat*))
- #51. (holistic and (care or healthcare or (health next care) or service* or team* or work* or collaboration* or co-ordinat* or coordinat*))
- #52. (collaborat* near servic*)

- #53. (multidisciplinary next assessment*)
- #54. (single next assessment*)
- #55. care next trust*:ti
- #56. (strategic next collaboration*)
- #57. (provider next partnership*)
- #58. (pool* near budget*)
- #59. (overlapping next commissioning)
- #60. (contiguous next commissioning)
- #61. (joint next commissioning)
- #62. (integrated next commissioning)
- #63. linkwork*
- #64. (co-located next team*)
- #65. co-location
- #66. (one next stop next shop*)
- #67. DELIVERY OF HEALTH CARE INTEGRATED explode all trees (MeSH)
- #68. AMBULATORY CARE explode all trees (MeSH)
- #69. ((ambulatory next care) or (ambulatory next health next care) or (ambulatory next healthcare))
- #70. ((ambulatory next service*) or (ambulatory next health next service*))
- #71. (case next management)
- #72. (care next management)
- #73. CASE MANAGEMENT single term (MeSH)
- #74. (managed next care next program*)
- #75. (patient next care next plan*)
- #76. (#1 or #2 or #3 or #4 or #5 or #6 or #7 or #8 or #9 or #10 or #11 or #12 or #13 or #14 or #15 or #16 or #17 or #18 or #19 or #20 or #21 or #22 or #23 or #24 or #25 or #26 or #27 or #28 or #29 or #30 or #31 or #32 or #33 or #34 or #35 or #36 or #37 or #38 or #39 or #40 or #41 or #42 or #43 or #44 or #45 or #46 or #47 or #48 or #49 or #50 or #51 or #52 or #53 or #54 or #55 or #56 or #57 or #58 or #59 or #60 or #61 or #62 or #63 or #64 or #65 or #66 or #67 or #68 or #69 or #70 or #71 or #72 or #73 or #74 or #75)
- #77. MOTOR NEURON DISEASE explode all trees (MeSH)
- #78. (lou next gehrig next disease)
- #79. (lou next gehrig next s next disease)
- #80. (motor next neuron next disease)
- #81. (motor next neurone next disease)
- #82. mnd
- #83. (lateral next sclerosis)
- #84. als
- #85. (anterior next horn next cell next disease)
- #86. (bulbar next palsy)
- #87. (spinal next muscular next atrophy)

- #88. PARKINSON DISEASE single term (MeSH)
- #89. (paralysis next agitans)
- #90. (parkinson next disease)
- #91. (parkinson next syndrome)
- #92. (parkinson next s)
- #93. parkinsonism
- #94. ms:ti
- #95. (multiple next sclerosis)
- #96. MULTIPLE SCLEROSIS explode all trees (MeSH)
- #97. (degenerative next neurologic* next disease*)
- #98. (degenerative next neurologic* next condition*)
- #99. (long next term next neurologic* next disease*)
- #100. (long next term next neurologic* next disease*)
- #101. (long next term next neurologic* next condition*)
- #102. (evolving next neurologic* next disease*)
- #103. (evolving next neurologic* next condition*)
- #104. Itnc*
- #105. (#77 or #78 or #79 or #80 or #81 or #82 or #83 or #84 or #85 or
#86 or #87 or #88 or #89 or #90 or #91 or #92 or #93 or #94 or
#95 or #96 or #97 or #98 or #99 or #100 or #101 or #102 or #103 or
#104)
- #106. (#76 and #105)

SOSIG (<http://www.sosig.ac.uk/>)

Searched on 10/4/2006

Retrieved 96 hits

Search strategy:

This is a very simple search interface and the following lines were run as separate searches on both the Social Welfare section and the Government Policy section.

- “Integrated care”
- “Integrated service” or “integrated services”
- “Integrated work” or “integrated working”
- “Integrated health” or “Integrated healthcare”
- “Integrated team” or “Integrated teams”
- “integrated management”
- “structured care”
- “managed care”
- “Case management”
- “care management”

“Ambulatory care”
“ambulatory service” or “ambulatory services”
collaborate and (care or service or services)
collaborate and (work or health or team or teams)
collaborate and (assessment or management)
collaboration and (care or service or services)
collaboration and (work or health or team)
collaboration and teams
collaboration and (assessment or management)

**Cochrane Database of Systematic Reviews (The Cochrane Library –
<http://www.thecochranelibrary.com/>)**

Issue 2 2006

Searched on 15/5/2006

Retrieved 6 hits

Search strategy:

- #1. ((integrate* near/3 care) or (integrate* near/3 healthcare) or (integrate* near/3 health care)) in Record Title or ((integrate* near/3 care) or (integrate* near/3 healthcare) or (integrate* near/3 health care)) in Abstract in all products
- #2. (integrat* near/3 working) in Record Title or (integrat* near/3 working) in Abstract in all products
- #3. (integrat* near/3 provision) in Record Title or (integrat* near/3 provision) in Abstract in all products
- #4. (integrat* near/3 provider organisation*) in Record Title or (integrat* near/3 provider organisation*) in Abstract in all products
- #5. (integrat* near/3 assessment*) in Record Title or (integrat* near/3 assessment*) in Abstract in all products
- #6. (integrat* near/3 team*) in Record Title or (integrat* near/3 team*) in Abstract in all products
- #7. (integrat* near/3 management) in Record Title or (integrat* near/3 management) in Abstract in all products
- #8. horizontal integration in Record Title or horizontal integration in Abstract in all products
- #9. vertical integration in Record Title or vertical integration in Abstract in all products
- #10. (integrat* near/3 primary near/3 community) in Record Title or (integrat* near/3 primary near/3 community) in Abstract in all products
- #11. (integrat* near/3 health near/3 social) in Record Title or (integrat* near/3 health near/3 social) in Abstract in all products

- #12. (cluster* near/3 health near/3 social) in Record Title or (cluster* near/3 health near/3 social) in Abstract in all products
- #13. (integrat* near/3 service*) in Record Title or (integrat* near/3 service*) in Abstract in all products
- #14. (structured care or structured healthcare or structured health care) in Record Title or (structured care or structured healthcare or structured health care) in Abstract in all products
- #15. structured service* in Record Title or structured service* in Abstract in all products
- #16. (joint* near/3 working) in Record Title or (joint* near/3 working) in Abstract in all products
- #17. joined up partnership* in Record Title or joined up partnership* in Abstract in all products
- #18. (partnership* near/3 working) in Record Title or (partnership* near/3 working) in Abstract in all products
- #19. (joint service* near/3 development*) in Record Title or (joint service* near/3 development*) in Abstract in all products
- #20. horizontal communication* in Record Title or horizontal communication* in Abstract in all products
- #21. partnership project* in Record Title or partnership project* in Abstract in all products
- #22. horizontal partnership* in Record Title or horizontal partnership* in Abstract in all products
- #23. flexible partnership* in Record Title or flexible partnership* in Abstract in all products
- #24. (joint* near/3 service*) in Record Title or (joint* near/3 service*) in Abstract in all products
- #25. joined up service* in Record Title or joined up service* in Abstract in all products
- #26. ((joint* near/3 care) or (joint* near/3 healthcare) or (joint* near/3 health care)) in Record Title or ((joint* near/3 care) or (joint* near/3 healthcare) or (joint* near/3 health care)) in Abstract in all products
- #27. (joined up care or joined up health care or joined up healthcare) in Record Title or (joined up care or joined up health care or joined up healthcare) in Abstract in all products
- #28. ((co ordinat* near/3 care*) or (co ordinat* near/3 health care*) or (co ordinat* near/3 healthcare*)) in Record Title or ((co ordinat* near/3 care*) or (co ordinat* near/3 health care*) or (co ordinat* near/3 healthcare*)) in Abstract in all products
- #29. ((coordinat* near/3 care*) or (coordinat* near/3 healthcare*) or (coordinat* near/3 health care*)) in Record Title or ((coordinat* near/3 care*) or (coordinat* near/3 healthcare*) or (coordinat* near/3 health care*)) in Abstract in all products

- #30. (co ordinat* near/3 service*) in Record Title or (co ordinat* near/3 service*) in Abstract in all products
- #31. (coordinat* near/3 service*) in Record Title or (coordinat* near/3 service*) in Abstract in all products
- #32. seamless service* in Record Title or seamless service* in Abstract in all products
- #33. seamless care in Record Title or seamless care in Abstract in all products
- #34. (contin* near/3 service*) in Record Title or (contin* near/3 service*) in Abstract in all products
- #35. ((contin* near/3 care) or (contin* near/3 healthcare) or (contin* near/3 health care)) in Record Title or ((contin* near/3 care) or (contin* near/3 healthcare) or (contin* near/3 health care)) in Abstract in all products
- #36. ((progression near/3 care) or (progression near/3 healthcare) or (progression near/3 health care)) in Record Title or ((progression near/3 care) or (progression near/3 healthcare) or (progression near/3 health care)) in Abstract in all products
- #37. (uninterrupted care or uninterrupted healthcare or uninterrupted health care) in Record Title or (uninterrupted care or uninterrupted healthcare or uninterrupted health care) in Abstract in all products
- #38. uninterrupted service* in Record Title or uninterrupted service* in Abstract in all products
- #39. ((inter oragnisation* or inter oragnization*) near/3 (care or healthcare or health care or service* or team* or work* or collaboration* or co ordinat* or coordinat*)) in Record Title or ((inter oragnisation* or inter oragnization*) near/3 (care or healthcare or health care or service* or team* or work* or collaboration* or co ordinat* or coordinat*)) in Abstract in all products
- #40. (holistic near/3 (care or health care or healthcare or service* or team* or work* or collaboration* or co ordinat* or coordinat*)) in Record Title or (holistic near/3 (care or health care or healthcare or service* or team* or work* or collaboration* or co ordinat* or coordinat*)) in Abstract in all products
- #41. ((interoragnisation* or interoragnization*) near/3 (care or health care or healthcare or service* or team* or work* or collaboration* or co ordinat* or coordinat*)) in Record Title or ((interoragnisation* or interoragnization*) near/3 (care or health care or healthcare or service* or team* or work* or collaboration* or co ordinat* or coordinat*)) in Abstract in all products
- #42. (multidisciplinary near/3 (care or healthcare or health care or service* or team* or work* or collaboration* or co ordinat* or coordinat*)) in Record Title or (multidisciplinary near/3 (care or healthcare or health

- care or service* or team* or work* or collaboration* or co ordinat* or coordinat*) in Abstract in all products
- #43. (multiprofessional near/3 (care or healthcare or health care or service* or team* or work* or collaboration* or co ordinat* or coordinat*)) in Record Title or (multiprofessional near/3 (care or healthcare or health care or service* or team* or work* or collaboration* or co ordinat* or coordinat*)) in Abstract in all products
- #44. (multi disciplinary near/3 (care or health care or healthcare or service* or team* or work* or collaboration* or co ordinat* or coordinat*)) in Record Title or (multi disciplinary near/3 (care or health care or healthcare or service* or team* or work* or collaboration* or co ordinat* or coordinat*)) in Abstract in all products
- #45. (multi professional near/3 (care or health care or healthcare or service* or team* or work* or collaboration* or co ordinat* or coordinat*)) in Record Title or (multi professional near/3 (care or health care or healthcare or service* or team* or work* or collaboration* or co ordinat* or coordinat*)) in Abstract in all products
- #46. (multi agency near/3 (care or healthcare or health care or service* or team* or work* or collaboration* or co ordinat* or coordinat*)) in Record Title or (multi agency near/3 (care or healthcare or health care or service* or team* or work* or collaboration* or co ordinat* or coordinat*)) in Abstract in all products
- #47. (inter agency near/3 (care or healthcare or health care or service* or team* or work* or collaboration* or co ordinat* or coordinat*)) in Record Title or (inter agency near/3 (care or healthcare or health care or service* or team* or work* or collaboration* or co ordinat* or coordinat*)) in Abstract in all products
- #48. (inter professional near/3 (care health care or healthcare or service* or team* or work* or collaboration* or co ordinat* or coordinat*)) in Record Title or (inter professional near/3 (care health care or healthcare or service* or team* or work* or collaboration* or co ordinat* or coordinat*)) in Abstract in all products
- #49. (interdisciplinary near/3 (care or healthcare or health care or service* or team* or work* or collaboration* or co ordinat* or coordinat*)) in Record Title or (interdisciplinary near/3 (care or healthcare or health care or service* or team* or work* or collaboration* or co ordinat* or coordinat*)) in Abstract in all products
- #50. (inter disciplinary near/3 (care or health care or healthcare or service* or team* or work* or collaboration* or co ordinat* or coordinat*)) in Record Title or (inter disciplinary near/3 (care or health care or healthcare or service* or team* or work* or collaboration* or co ordinat* or coordinat*)) in Abstract in all products
- #51. (holistic near/3 (care or healthcare or health care or service* or team* or work* or collaboration* or co ordinat* or coordinat*)) in Record Title

- or (holistic near/3 (care or healthcare or health care or service* or team* or work* or collaboration* or co ordinat* or coordinat*)) in Abstract in all products
- #52. (collaborat* near/3 servic*) in Record Title or (collaborat* near/3 servic*) in Abstract in all products
- #53. multidisciplinary assessment* in Record Title or multidisciplinary assessment* in Abstract in all products
- #54. single assessment* in Record Title or single assessment* in Abstract in all products
- #55. care trust* in Record Title or care trust* in Abstract in all products
- #56. strategic collaboration* in Record Title or strategic collaboration* in Abstract in all products
- #57. provider partnership* in Record Title or provider partnership* in Abstract in all products
- #58. (pool* near/3 budget*) in Record Title or (pool* near/3 budget*) in Abstract in all products
- #59. overlapping commissioning in Record Title or overlapping commissioning in Abstract in all products
- #60. contiguous commissioning in Record Title or contiguous commissioning in Abstract in all products
- #61. joint commissioning in Record Title or joint commissioning in Abstract in all products
- #62. integrated commissioning in Record Title or integrated commissioning in Abstract in all products
- #63. linkwork* in Record Title or linkwork* in Abstract in all products
- #64. co located team* in Record Title or co located team* in Abstract in all products
- #65. co location in Record Title or co location in Abstract in all products
- #66. one stop shop* in Record Title or one stop shop* in Abstract in all products
- #67. MeSH descriptor Delivery of Health Care, Integrated explode all trees in MeSH products
- #68. MeSH descriptor Ambulatory Care explode all trees in MeSH products
- #69. (ambulatory care or ambulatory health care or ambulatory healthcare) in Record Title or (ambulatory care or ambulatory health care or ambulatory healthcare) in Abstract in all products
- #70. (ambulatory service* or ambulatory health service*) in Record Title or (ambulatory service* or ambulatory health service*) in Abstract in all products
- #71. case management in Record Title or case management in Abstract in all products

- #72. care management in Record Title or care management in Abstract in all products
- #73. MeSH descriptor Case Management, this term only in MeSH products
- #74. managed care program* in Record Title or managed care program* in Abstract in all products
- #75. patient care plan* in Record Title or patient care plan* in Abstract in all products
- #76. (#1 OR #2 OR #3 OR #4 OR #5 OR #6 OR #7 OR #8 OR #9 OR #10 OR #11 OR #12 OR #13 OR #14 OR #15 OR #16 OR #17 OR #18 OR #19 OR #20 OR #21 OR #22 OR #23 OR #24 OR #25 OR #26 OR #27 OR #28 OR #29 OR #30 OR #31 OR #32 OR #33 OR #34 OR #35 OR #36 OR #37 OR #38 OR #39 OR #40 OR #41 OR #42 OR #43 OR #44 OR #45 OR #46 OR #47 OR #48 OR #49 OR #50 OR #51 OR #52 OR #53 OR #54 OR #55 OR #56 OR #57 OR #58 OR #59 OR #60 OR #61 OR #62 OR #63 OR #64 OR #65 OR #66 OR #67 OR #68 OR #69 OR #70 OR #71 OR #72 OR #73 OR #74 OR #75)
- #77. MeSH descriptor Motor Neuron Disease explode all trees in MeSH products
- #78. lou gehrig disease in Record Title or lou gehrig disease in Abstract in all products
- #79. lou gehrig s disease in Record Title or lou gehrig s disease in Abstract in all products
- #80. motor neuron disease in Record Title or motor neuron disease in Abstract in all products
- #81. motor neurone disease in Record Title or motor neurone disease in Abstract in all products
- #82. mnd in Record Title or mnd in Abstract in all products
- #83. lateral sclerosis in Record Title or lateral sclerosis in Abstract in all products
- #84. als in Record Title or als in Abstract in all products
- #85. anterior horn cell disease in Record Title or anterior horn cell disease in Abstract in all products
- #86. bulbar palsy in Record Title or bulbar palsy in Abstract in all products
- #87. spinal muscular atrophy in Record Title or spinal muscular atrophy in Abstract in all products
- #88. MeSH descriptor Parkinson Disease, this term only in MeSH products
- #89. paralysis agitans in Record Title or paralysis agitans in Abstract in all products
- #90. parkinson disease in Record Title or parkinson disease in Abstract in all products
- #91. parkinson syndrome in Record Title or parkinson syndrome in Abstract in all products
- #92. parkinson s in Record Title or parkinson s in Abstract in all products

- #93. parkinsonism in Record Title or parkinsonism in Abstract in all products
- #94. ms in Record Title or ms in Abstract in all products
- #95. multiple sclerosis in Record Title or multiple sclerosis in Abstract in all products
- #96. MeSH descriptor Multiple Sclerosis explode all trees in MeSH products
- #97. degenerative neurologic* disease* in Record Title or degenerative neurologic* disease* in Abstract in all products
- #98. degenerative neurologic* condition* in Record Title or degenerative neurologic* condition* in Abstract in all products
- #99. long term neurologic* disease* in Record Title or long term neurologic* disease* in Abstract in all products
- #100. long term neurologic* disease* in Record Title or long term neurologic* disease* in Abstract in all products
- #101. long term neurologic* condition* in Record Title or long term neurologic* condition* in Abstract in all products
- #102. evolving neurologic* disease* in Record Title or evolving neurologic* disease* in Abstract in all products
- #103. evolving neurologic* condition* in Record Title or evolving neurologic* condition* in Abstract in all products
- #104. Itnc* in Record Title or Itnc* in Abstract in all products
- #105. (#77 OR #78 OR #79 OR #80 OR #81 OR #82 OR #83 OR #84 OR #85 OR #86 OR #87 OR #88 OR #89 OR #90 OR #91 OR #92 OR #93 OR #94 OR #95 OR #96 OR #97 OR #98 OR #99 OR #100 OR #101 OR #102 OR #103 OR #104)
- #106. (#76 AND #105)
- #107. (#76 AND #105)

Appendix 2 Search strategies for long-term neurological conditions – new search terms and update searching (December 2006)

The following databases were searched:

- MEDLINE
- CINAHL
- EMBASE
- HMIC
- DARE
- HTA
- NHSEED
- SIGLE
- Social Policy and Practice
- Social Science Citation Index
- ASSIA, Social Services Abstracts
- Sociological Abstracts
- NRR SOSIG
- The Cochrane Database of Systematic Reviews.

Terminology

These searches included extra terms for multidisciplinary working which has been identified from the results of previous searches.

In an attempt to increase the amount of relevant literature retrieved, terms for epilepsy and cerebral palsy were also included.

Dates

The strategies were run to pick up any material from the new terms using the original date restrictions (1985 onwards).

Since it was 9 months since the original searches had been conducted, a top up search was also run on the original terms.

All results were deduplicated against the material retrieved from the main searches.

MEDLINE (Ovid Online – <http://www.ovid.com/>)

1966 to November Week 3 2006

Searched on 1/12/2006

Retrieved 749 hits

Search strategy:

1. ((Integrate\$ adj3 care) or (Integrate\$ adj3 healthcare) or (Integrate\$ adj3 health care)).ti,ab.
2. (Integrat\$ adj3 working).ti,ab.
3. (Integrat\$ adj3 provision).ti,ab.
4. (Integrat\$ adj3 provider organisation\$).ti,ab.
5. (Integrat\$ adj3 assessment\$).ti,ab.
6. (Integrat\$ adj3 team\$).ti,ab.
7. (Integrat\$ adj3 management).ti,ab.
8. Horizontal integration.ti,ab.
9. Vertical integration.ti,ab.
10. (Integrat\$ adj3 primary adj3 community).ti,ab.
11. (Integrat\$ adj3 health adj3 social).ti,ab.
12. (Cluster\$ adj3 health adj3 social).ti,ab.
13. (Integrat\$ adj3 service\$).ti,ab.
14. (Structured care or Structured healthcare or Structured health care).ti,ab.
15. Structured service\$.ti,ab.
16. (Joint\$ adj3 working).ti,ab.
17. Joined-up partnership\$.ti,ab.
18. (Partnership\$ adj3 working).ti,ab.
19. (Joint service\$ adj3 development\$).ti,ab.
20. Horizontal communication\$.ti,ab.
21. Partnership project\$.ti,ab.
22. Horizontal partnership\$.ti,ab.
23. Flexible partnership\$.ti,ab.
24. (Joint\$ adj3 service\$).ti,ab.
25. Joined-up service\$.ti,ab.
26. ((Joint\$ adj3 care) or (Joint\$ adj3 healthcare) or (Joint\$ adj3 health care)).ti,ab.
27. (Joined-up care or Joined-up health care or Joined-up healthcare).ti,ab.
28. ((Co-ordinat\$ adj3 care\$) or (Co-ordinat\$ adj3 health care\$) or (Co-ordinat\$ adj3 healthcare\$)).ti,ab.
29. ((Coordinat\$ adj3 care\$) or (Coordinat\$ adj3 healthcare\$) or (Coordinat\$ adj3 health care\$)).ti,ab.
30. (Co-ordinat\$ adj3 service\$).ti,ab.
31. (Coordinat\$ adj3 service\$).ti,ab.
32. Seamless service\$.ti,ab.
33. Seamless care.ti,ab.
34. (Contin\$ adj3 service\$).ti,ab.
35. ((contin\$ adj3 care) or (contin\$ adj3 healthcare) or (contin\$ adj3 health care)).ti,ab.
36. ((Progression adj3 care) or (Progression adj3 healthcare) or (Progression adj3 health care)).ti,ab.

37. (Uninterrupted care or Uninterrupted healthcare or Uninterrupted health care).ti,ab.
38. Uninterrupted service\$.ti,ab.
39. ((Inter-organisation\$ or Inter-organization\$) adj3 (care or healthcare or health care or service\$ or team\$ or work\$ or collaboration\$ or co-ordinat\$ or coordinat\$)).ti,ab.
40. (Holistic adj3 (care or health care or healthcare or service\$ or team\$ or work\$ or collaboration\$ or co-ordinat\$ or coordinat\$)).ti,ab.
41. ((Interoragnisation\$ or Interoragnization\$) adj3 (care or health care or healthcare or service\$ or team\$ or work\$ or collaboration\$ or co-ordinat\$ or coordinat\$)).ti,ab.
42. (Multidisciplinary adj3 (care or healthcare or health care or service\$ or team\$ or work\$ or collaboration\$ or co-ordinat\$ or coordinat\$)).ti,ab.
43. (Multiprofessional adj3 (care or healthcare or health care or service\$ or team\$ or work\$ or collaboration\$ or co-ordinat\$ or coordinat\$)).ti,ab.
44. (Multi-disciplinary adj3 (care or health care or healthcare or service\$ or team\$ or work\$ or collaboration\$ or co-ordinat\$ or coordinat\$)).ti,ab.
45. (Multi-professional adj3 (care or health care or healthcare or service\$ or team\$ or work\$ or collaboration\$ or co-ordinat\$ or coordinat\$)).ti,ab.
46. (Multi-agency adj3 (care or healthcare or health care or service\$ or team\$ or work\$ or collaboration\$ or co-ordinat\$ or coordinat\$)).ti,ab.
47. (Inter-agency adj3 (care or healthcare or health care or service\$ or team\$ or work\$ or collaboration\$ or co-ordinat\$ or coordinat\$)).ti,ab.
48. (Inter-professional adj3 (care health care or healthcare or service\$ or team\$ or work\$ or collaboration\$ or co-ordinat\$ or coordinat\$)).ti,ab.
49. (Interdisciplinary adj3 (care or healthcare or health care or service\$ or team\$ or work\$ or collaboration\$ or co-ordinat\$ or coordinat\$)).ti,ab.
50. (Inter-disciplinary adj3 (care or health care or healthcare or service\$ or team\$ or work\$ or collaboration\$ or co-ordinat\$ or coordinat\$)).ti,ab.
51. (Holistic adj3 (care or healthcare or health care or service\$ or team\$ or work\$ or collaboration\$ or co-ordinat\$ or coordinat\$)).ti,ab.
52. (Collaborat\$ adj3 servic\$).ti,ab.
53. Multidisciplinary assessment\$.ti,ab.
54. single assessment\$.ti,ab.
55. Care trust\$.ti,ab.
56. Strategic collaboration\$.ti,ab.
57. Provider partnership\$.ti,ab.
58. (Pool\$ adj3 budget\$).ti,ab.
59. Overlapping commissioning.ti,ab.
60. Contiguous commissioning.ti,ab.
61. Joint commissioning.ti,ab.
62. Integrated commissioning.ti,ab.
63. linkwork\$.ti,ab.
64. Co-located team\$.ti,ab.
65. co-location.ti,ab.
66. One stop shop\$.ti,ab.
67. exp "Delivery of Health Care, Integrated"/
68. exp ambulatory care/
69. (ambulatory care or ambulatory health care or ambulatory healthcare).ti,ab.

70. (ambulatory service\$ or ambulatory health service\$.ti,ab.
71. case management.ti,ab.
72. care management.ti,ab.
73. Case Management/
74. Managed Care Program\$.ti,ab.
75. Patient Care Plan\$.ti,ab.
76. Patient Care Team/
77. care team\$.ti,ab.
78. or/1-77
79. Motor Neuron Disease/
80. lou gehrig disease.ti,ab.
81. lou gehrig's disease.ti,ab.
82. motor neuron disease.ti,ab.
83. motor neurone disease.ti,ab.
84. MND.ti,ab.
85. lateral sclerosis.ti,ab.
86. ALS.ti,ab.
87. anterior horn cell disease.ti,ab.
88. Bulbar Palsy.ti,ab.
89. Spinal Muscular Atrophy.ti,ab.
90. PARKINSON DISEASE/
91. paralysis agitans.ti,ab.
92. Parkinson disease.ti,ab.
93. Parkinson syndrome.ti,ab.
94. Parkinson s.ti,ab.
95. parkinsonism.ti,ab.
96. Ms.ti,ab.
97. Multiple sclerosis.ti,ab.
98. exp Multiple Sclerosis/
99. degenerative neurologic\$ disease\$.ti,ab.
100. degenerative neurologic\$ condition\$.ti,ab.
101. long term neurologic\$ disease\$.ti,ab.
102. long-term neurologic\$ disease\$.ti,ab.
103. long term neurologic\$ condition\$.ti,ab.
104. evolving neurologic\$ disease\$.ti,ab.
105. evolving neurologic\$ condition\$.ti,ab.
106. LTNC\$.ti,ab.
107. Epilepsy/
108. epilepsy.ti,ab.
109. epileptic.ti,ab.
110. seizure disorder\$.ti,ab.
111. landau kleffner syndrome.ti,ab.
112. cerebral palsy.ti,ab.
113. spastic diplegia.ti,ab.
114. little disease.ti,ab.
115. cp.ti,ab.
116. diplegia spastic.ti,ab.
117. little's disease.ti,ab.
118. cerebral palsy/
119. or/79-118

120. 78 and 119
121. 120
122. 2006\$.ed.
123. 121 and 122
124. or/79-106
125. or/107-118
126. 125 not 124
127. 126 and 78
128. 127
129. limit 128 to yr="1985 - 2006"
130. 129 or 123

CINAHL - Cumulative Index to Nursing & Allied Health Literature (Ovid Online – <http://www.ovid.com/>)

1982 to December Week 1 2006

Searched on 7/12/2006

Retrieved 156 hits

Search strategy:

1. ((Integrate\$ adj3 care) or (Integrate\$ adj3 healthcare) or (Integrate\$ adj3 health care)).ti,ab.
2. (Integrat\$ adj3 working).ti,ab.
3. (Integrat\$ adj3 provision).ti,ab.
4. (Integrat\$ adj3 provider organisation\$).ti,ab.
5. (Integrat\$ adj3 assessment\$).ti,ab.
6. (Integrat\$ adj3 team\$).ti,ab.
7. (Integrat\$ adj3 management).ti,ab.
8. Horizontal integration.ti,ab.
9. Vertical integration.ti,ab.
10. (Integrat\$ adj3 primary adj3 community).ti,ab.
11. (Integrat\$ adj3 health adj3 social).ti,ab.
12. (Cluster\$ adj3 health adj3 social).ti,ab.
13. (Integrat\$ adj3 service\$).ti,ab.
14. (Structured care or Structured healthcare or Structured health care).ti,ab.
15. Structured service\$.ti,ab.
16. (Joint\$ adj3 working).ti,ab.
17. Joined-up partnership\$.ti,ab.
18. (Partnership\$ adj3 working).ti,ab.
19. (Joint service\$ adj3 development\$).ti,ab.
20. Horizontal communication\$.ti,ab.
21. Partnership project\$.ti,ab.
22. Horizontal partnership\$.ti,ab.
23. Flexible partnership\$.ti,ab.
24. (Joint\$ adj3 service\$).ti,ab.
25. Joined-up service\$.ti,ab.
26. ((Joint\$ adj3 care) or (Joint\$ adj3 healthcare) or (Joint\$ adj3 health care)).ti,ab.
27. (Joined-up care or Joined-up health care or Joined-up healthcare).ti,ab.

28. ((Co-ordinat\$ adj3 care\$) or (Co-ordinat\$ adj3 health care\$) or (Co-ordinat\$ adj3 healthcare\$)).ti,ab.
29. ((Coordinat\$ adj3 care\$) or (Coordinat\$ adj3 healthcare\$) or (Coordinat\$ adj3 health care\$)).ti,ab.
30. (Co-ordinat\$ adj3 service\$).ti,ab.
31. (Coordinat\$ adj3 service\$).ti,ab.
32. Seamless service\$.ti,ab.
33. Seamless care.ti,ab.
34. (Contin\$ adj3 service\$).ti,ab.
35. ((contin\$ adj3 care) or (contin\$ adj3 healthcare) or (contin\$ adj3 health care)).ti,ab.
36. ((Progression adj3 care) or (Progression adj3 healthcare) or (Progression adj3 health care)).ti,ab.
37. (Uninterrupted care or Uninterrupted healthcare or Uninterrupted health care).ti,ab.
38. Uninterrupted service\$.ti,ab.
39. ((Inter-organisation\$ or Inter-organization\$) adj3 (care or healthcare or health care or service\$ or team\$ or work\$ or collaboration\$ or co-ordinat\$ or coordinat\$)).ti,ab.
40. (Holistic adj3 (care or health care or healthcare or service\$ or team\$ or work\$ or collaboration\$ or co-ordinat\$ or coordinat\$)).ti,ab.
41. ((Interoragnisation\$ or Interoragnization\$) adj3 (care or health care or healthcare or service\$ or team\$ or work\$ or collaboration\$ or co-ordinat\$ or coordinat\$)).ti,ab.
42. (Multidisciplinary adj3 (care or healthcare or health care or service\$ or team\$ or work\$ or collaboration\$ or co-ordinat\$ or coordinat\$)).ti,ab.
43. (Multiprofessional adj3 (care or healthcare or health care or service\$ or team\$ or work\$ or collaboration\$ or co-ordinat\$ or coordinat\$)).ti,ab.
44. (Multi-disciplinary adj3 (care or health care or healthcare or service\$ or team\$ or work\$ or collaboration\$ or co-ordinat\$ or coordinat\$)).ti,ab.
45. (Multi-professional adj3 (care or health care or healthcare or service\$ or team\$ or work\$ or collaboration\$ or co-ordinat\$ or coordinat\$)).ti,ab.
46. (Multi-agency adj3 (care or healthcare or health care or service\$ or team\$ or work\$ or collaboration\$ or co-ordinat\$ or coordinat\$)).ti,ab.
47. (Inter-agency adj3 (care or healthcare or health care or service\$ or team\$ or work\$ or collaboration\$ or co-ordinat\$ or coordinat\$)).ti,ab.
48. (Inter-professional adj3 (care health care or healthcare or service\$ or team\$ or work\$ or collaboration\$ or co-ordinat\$ or coordinat\$)).ti,ab.
49. (Interdisciplinary adj3 (care or healthcare or health care or service\$ or team\$ or work\$ or collaboration\$ or co-ordinat\$ or coordinat\$)).ti,ab.
50. (Inter-disciplinary adj3 (care or health care or healthcare or service\$ or team\$ or work\$ or collaboration\$ or co-ordinat\$ or coordinat\$)).ti,ab.
51. (Holistic adj3 (care or healthcare or health care or service\$ or team\$ or work\$ or collaboration\$ or co-ordinat\$ or coordinat\$)).ti,ab.
52. (Collaborat\$ adj3 servic\$).ti,ab.
53. Multidisciplinary assessment\$.ti,ab.
54. single assessment\$.ti,ab.
55. Care trust\$.ti,ab.
56. Strategic collaboration\$.ti,ab.
57. Provider partnership\$.ti,ab.

58. (Pool\$ adj3 budget\$.ti,ab.
59. Overlapping commissioning.ti,ab.
60. Contiguous commissioning.ti,ab.
61. Joint commissioning.ti,ab.
62. Integrated commissioning.ti,ab.
63. linkwork\$.ti,ab.
64. Co-located team\$.ti,ab.
65. co-location.ti,ab.
66. One stop shop\$.ti,ab.
67. Health Care Delivery, Integrated/
68. ambulatory care/
69. (ambulatory care or ambulatory health care or ambulatory healthcare).ti,ab.
70. (ambulatory service\$ or ambulatory health service\$.ti,ab.
71. case management.ti,ab.
72. care management.ti,ab.
73. Case Management/
74. Managed Care Program\$.ti,ab.
75. Patient Care Plan\$.ti,ab.
76. care team\$.ti,ab.
77. multidisciplinary care team/
78. or/1-77
79. exp Motor Neuron Diseases/
80. lou gehrig disease.ti,ab.
81. lou gehrig's disease.ti,ab.
82. motor neuron disease.ti,ab.
83. motor neurone disease.ti,ab.
84. MND.ti,ab.
85. lateral sclerosis.ti,ab.
86. ALS.ti,ab.
87. anterior horn cell disease.ti,ab.
88. Bulbar Palsy.ti,ab.
89. Spinal Muscular Atrophy.ti,ab.
90. PARKINSON DISEASE/
91. paralysis agitans.ti,ab.
92. Parkinson disease.ti,ab.
93. Parkinson syndrome.ti,ab.
94. Parkinson s.ti,ab.
95. parkinsonism.ti,ab.
96. Ms.ti,ab.
97. Multiple sclerosis.ti,ab.
98. Multiple Sclerosis/
99. degenerative neurologic\$ disease\$.ti,ab.
100. degenerative neurologic\$ condition\$.ti,ab.
101. long term neurologic\$ disease\$.ti,ab.
102. long-term neurologic\$ disease\$.ti,ab.
103. long term neurologic\$ condition\$.ti,ab.
104. evolving neurologic\$ disease\$.ti,ab.
105. evolving neurologic\$ condition\$.ti,ab.
106. LTNC\$.ti,ab.

107. Epilepsy/
108. epilepsy.ti,ab.
109. epileptic.ti,ab.
110. seizure disorder\$.ti,ab.
111. landau kleffner syndrome.ti,ab.
112. cerebral palsy.ti,ab.
113. spastic diplegia.ti,ab.
114. little disease.ti,ab.
115. little's disease.ti,ab.
116. cerebral palsy/
117. cp.ti,ab.
118. diplegia spastic.ti,ab.
119. or/79-118
120. 78 and 119
121. 120
122. 2006\$.ew.
123. 121 and 122
124. or/79-106
125. or/107-118
126. 125 not 124
127. 126 and 78
128. 127
129. limit 128 to yr="1985 - 2006"
130. 129 or 123

EMBASE (Ovid Online – <http://www.ovid.com/>)

1980 to 2006 Week 48

Searched on 7/12/2006

Retrieved 357 hits

Search strategy:

1. ((Integrate\$ adj3 care) or (Integrate\$ adj3 healthcare) or (Integrate\$ adj3 health care)).ti,ab.
2. (Integrat\$ adj3 working).ti,ab.
3. (Integrat\$ adj3 provision).ti,ab.
4. (Integrat\$ adj3 provider organisation\$).ti,ab.
5. (Integrat\$ adj3 assessment\$).ti,ab.
6. (Integrat\$ adj3 team\$).ti,ab.
7. (Integrat\$ adj3 management).ti,ab.
8. Horizontal integration.ti,ab.
9. Vertical integration.ti,ab.
10. (Integrat\$ adj3 primary adj3 community).ti,ab.
11. (Integrat\$ adj3 health adj3 social).ti,ab.
12. (Cluster\$ adj3 health adj3 social).ti,ab.
13. (Integrat\$ adj3 service\$).ti,ab.
14. (Structured care or Structured healthcare or Structured health care).ti,ab.
15. Structured service\$.ti,ab.
16. (Joint\$ adj3 working).ti,ab.

17. Joined-up partnership\$.ti,ab.
18. (Partnership\$ adj3 working).ti,ab.
19. (Joint service\$ adj3 development\$.ti,ab.
20. Horizontal communication\$.ti,ab.
21. Partnership project\$.ti,ab.
22. Horizontal partnership\$.ti,ab.
23. Flexible partnership\$.ti,ab.
24. (Joint\$ adj3 service\$.ti,ab.
25. Joined-up service\$.ti,ab.
26. ((Joint\$ adj3 care) or (Joint\$ adj3 healthcare) or (Joint\$ adj3 health care)).ti,ab.
27. (Joined-up care or Joined-up health care or Joined-up healthcare).ti,ab.
28. ((Co-ordinat\$ adj3 care\$) or (Co-ordinat\$ adj3 health care\$) or (Co-ordinat\$ adj3 healthcare\$)).ti,ab.
29. ((Coordinat\$ adj3 care\$) or (Coordinat\$ adj3 healthcare\$) or (Coordinat\$ adj3 health care\$)).ti,ab.
30. (Co-ordinat\$ adj3 service\$.ti,ab.
31. (Coordinat\$ adj3 service\$.ti,ab.
32. Seamless service\$.ti,ab.
33. Seamless care.ti,ab.
34. (Contin\$ adj3 service\$.ti,ab.
35. ((contin\$ adj3 care) or (contin\$ adj3 healthcare) or (contin\$ adj3 health care)).ti,ab.
36. ((Progression adj3 care) or (Progression adj3 healthcare) or (Progression adj3 health care)).ti,ab.
37. (Uninterrupted care or Uninterrupted healthcare or Uninterrupted health care).ti,ab.
38. Uninterrupted service\$.ti,ab.
39. ((Inter-organisation\$ or Inter-organization\$) adj3 (care or healthcare or health care or service\$ or team\$ or work\$ or collaboration\$ or co-ordinat\$ or coordinat\$)).ti,ab.
40. (Holistic adj3 (care or health care or healthcare or service\$ or team\$ or work\$ or collaboration\$ or co-ordinat\$ or coordinat\$)).ti,ab.
41. ((Interoragnisation\$ or Interoragnization\$) adj3 (care or health care or healthcare or service\$ or team\$ or work\$ or collaboration\$ or co-ordinat\$ or coordinat\$)).ti,ab.
42. (Multidisciplinary adj3 (care or healthcare or health care or service\$ or team\$ or work\$ or collaboration\$ or co-ordinat\$ or coordinat\$)).ti,ab.
43. (Multiprofessional adj3 (care or healthcare or health care or service\$ or team\$ or work\$ or collaboration\$ or co-ordinat\$ or coordinat\$)).ti,ab.
44. (Multi-disciplinary adj3 (care or health care or healthcare or service\$ or team\$ or work\$ or collaboration\$ or co-ordinat\$ or coordinat\$)).ti,ab.
45. (Multi-professional adj3 (care or health care or healthcare or service\$ or team\$ or work\$ or collaboration\$ or co-ordinat\$ or coordinat\$)).ti,ab.
46. (Multi-agency adj3 (care or healthcare or health care or service\$ or team\$ or work\$ or collaboration\$ or co-ordinat\$ or coordinat\$)).ti,ab.
47. (Inter-agency adj3 (care or healthcare or health care or service\$ or team\$ or work\$ or collaboration\$ or co-ordinat\$ or coordinat\$)).ti,ab.
48. (Inter-professional adj3 (care health care or healthcare or service\$ or team\$ or work\$ or collaboration\$ or co-ordinat\$ or coordinat\$)).ti,ab.

49. (Interdisciplinary adj3 (care or healthcare or health care or service\$ or team\$ or work\$ or collaboration\$ or co-ordinat\$ or coordinat\$)).ti,ab.
50. (Inter-disciplinary adj3 (care or health care or healthcare or service\$ or team\$ or work\$ or collaboration\$ or co-ordinat\$ or coordinat\$)).ti,ab.
51. (Holistic adj3 (care or healthcare or health care or service\$ or team\$ or work\$ or collaboration\$ or co-ordinat\$ or coordinat\$)).ti,ab.
52. (Collaborat\$ adj3 servic\$).ti,ab.
53. Multidisciplinary assessment\$.ti,ab.
54. single assessment\$.ti,ab.
55. Care trust\$.ti,ab.
56. Strategic collaboration\$.ti,ab.
57. Provider partnership\$.ti,ab.
58. (Pool\$ adj3 budget\$).ti,ab.
59. Overlapping commissioning.ti,ab.
60. Contiguous commissioning.ti,ab.
61. Joint commissioning.ti,ab.
62. Integrated commissioning.ti,ab.
63. linkwork\$.ti,ab.
64. Co-located team\$.ti,ab.
65. co-location.ti,ab.
66. One stop shop\$.ti,ab.
67. ambulatory care/
68. (ambulatory care or ambulatory health care or ambulatory healthcare).ti,ab.
69. (ambulatory service\$ or ambulatory health service\$).ti,ab.
70. case management.ti,ab.
71. care management.ti,ab.
72. Managed Care Program\$.ti,ab.
73. Patient Care Plan\$.ti,ab.
74. care team\$.ti,ab.
75. or/1-74
76. exp Motor Neuron Diseases/
77. lou gehrig disease.ti,ab.
78. lou gehrig's disease.ti,ab.
79. motor neuron disease.ti,ab.
80. motor neurone disease.ti,ab.
81. MND.ti,ab.
82. lateral sclerosis.ti,ab.
83. ALS.ti,ab.
84. anterior horn cell disease.ti,ab.
85. Bulbar Palsy.ti,ab.
86. Spinal Muscular Atrophy.ti,ab.
87. PARKINSON DISEASE/
88. paralysis agitans.ti,ab.
89. Parkinson disease.ti,ab.
90. Parkinson syndrome.ti,ab.
91. Parkinson s.ti,ab.
92. parkinsonism.ti,ab.
93. Ms.ti,ab.
94. Multiple sclerosis.ti,ab.

95. Multiple Sclerosis/
96. degenerative neurologic\$ disease\$.ti,ab.
97. degenerative neurologic\$ condition\$.ti,ab.
98. long term neurologic\$ disease\$.ti,ab.
99. long-term neurologic\$ disease\$.ti,ab.
100. long term neurologic\$ condition\$.ti,ab.
101. evolving neurologic\$ disease\$.ti,ab.
102. evolving neurologic\$ condition\$.ti,ab.
103. LTNC\$.ti,ab.
104. epilepsy/ or generalized epilepsy/
105. epilepsy.ti,ab.
106. epileptic.ti,ab.
107. seizure disorder\$.ti,ab.
108. landau kleffner syndrome.ti,ab.
109. cerebral palsy.ti,ab.
110. spastic diplegia.ti,ab.
111. little disease.ti,ab.
112. cp.ti,ab.
113. diplegia spastic.ti,ab.
114. little's disease.ti,ab.
115. Cerebral Palsy/
116. or/76-115
117. 116 and 75
118. 2006\$.em.
119. 117 and 118
120. or/76-103
121. or/104-115
122. 121 not 120
123. 122 and 75
124. 123
125. limit 124 to yr="1985 - 2006"
126. 125 or 119

HMIC (Ovid Online – <http://www.ovid.com/>)

November 2006

Searched on 7/12/2006

Retrieved 32 hits

Search strategy:

1. ((Integrate\$ adj3 care) or (Integrate\$ adj3 healthcare) or (Integrate\$ adj3 health care)).ti,ab.
2. (Integrat\$ adj3 working).ti,ab.
3. (Integrat\$ adj3 provision).ti,ab.
4. (Integrat\$ adj3 provider organisation\$).ti,ab.
5. (Integrat\$ adj3 assessment\$).ti,ab.
6. (Integrat\$ adj3 team\$).ti,ab.
7. (Integrat\$ adj3 management).ti,ab.
8. Horizontal integration.ti,ab.
9. Vertical integration.ti,ab.

10. (Integrat\$ adj3 primary adj3 community).ti,ab.
11. (Integrat\$ adj3 health adj3 social).ti,ab.
12. (Cluster\$ adj3 health adj3 social).ti,ab.
13. (Integrat\$ adj3 service\$).ti,ab.
14. (Structured care or Structured healthcare or Structured health care).ti,ab.
15. Structured service\$.ti,ab.
16. (Joint\$ adj3 working).ti,ab.
17. Joined-up partnership\$.ti,ab.
18. (Partnership\$ adj3 working).ti,ab.
19. (Joint service\$ adj3 development\$).ti,ab.
20. Horizontal communication\$.ti,ab.
21. Partnership project\$.ti,ab.
22. Horizontal partnership\$.ti,ab.
23. Flexible partnership\$.ti,ab.
24. (Joint\$ adj3 service\$).ti,ab.
25. Joined-up service\$.ti,ab.
26. ((Joint\$ adj3 care) or (Joint\$ adj3 healthcare) or (Joint\$ adj3 health care)).ti,ab.
27. (Joined-up care or Joined-up health care or Joined-up healthcare).ti,ab.
28. ((Co-ordinat\$ adj3 care\$) or (Co-ordinat\$ adj3 health care\$) or (Co-ordinat\$ adj3 healthcare\$)).ti,ab.
29. ((Coordinat\$ adj3 care\$) or (Coordinat\$ adj3 healthcare\$) or (Coordinat\$ adj3 health care\$)).ti,ab.
30. (Co-ordinat\$ adj3 service\$).ti,ab.
31. (Coordinat\$ adj3 service\$).ti,ab.
32. Seamless service\$.ti,ab.
33. Seamless care.ti,ab.
34. (Contin\$ adj3 service\$).ti,ab.
35. ((contin\$ adj3 care) or (contin\$ adj3 healthcare) or (contin\$ adj3 health care)).ti,ab.
36. ((Progression adj3 care) or (Progression adj3 healthcare) or (Progression adj3 health care)).ti,ab.
37. (Uninterrupted care or Uninterrupted healthcare or Uninterrupted health care).ti,ab.
38. Uninterrupted service\$.ti,ab.
39. ((Inter-organisation\$ or Inter-organization\$) adj3 (care or healthcare or health care or service\$ or team\$ or work\$ or collaboration\$ or co-ordinat\$ or coordinat\$)).ti,ab.
40. (Holistic adj3 (care or health care or healthcare or service\$ or team\$ or work\$ or collaboration\$ or co-ordinat\$ or coordinat\$)).ti,ab.
41. ((Interoragnisation\$ or Interoragnization\$) adj3 (care or health care or healthcare or service\$ or team\$ or work\$ or collaboration\$ or co-ordinat\$ or coordinat\$)).ti,ab.
42. (Multidisciplinary adj3 (care or healthcare or health care or service\$ or team\$ or work\$ or collaboration\$ or co-ordinat\$ or coordinat\$)).ti,ab.
43. (Multiprofessional adj3 (care or healthcare or health care or service\$ or team\$ or work\$ or collaboration\$ or co-ordinat\$ or coordinat\$)).ti,ab.
44. (Multi-disciplinary adj3 (care or health care or healthcare or service\$ or team\$ or work\$ or collaboration\$ or co-ordinat\$ or coordinat\$)).ti,ab.

45. (Multi-professional adj3 (care or health care or healthcare or service\$ or team\$ or work\$ or collaboration\$ or co-ordinat\$ or coordinat\$)).ti,ab.
46. (Multi-agency adj3 (care or healthcare or health care or service\$ or team\$ or work\$ or collaboration\$ or co-ordinat\$ or coordinat\$)).ti,ab.
47. (Inter-agency adj3 (care or healthcare or health care or service\$ or team\$ or work\$ or collaboration\$ or co-ordinat\$ or coordinat\$)).ti,ab.
48. (Inter-professional adj3 (care health care or healthcare or service\$ or team\$ or work\$ or collaboration\$ or co-ordinat\$ or coordinat\$)).ti,ab.
49. (Interdisciplinary adj3 (care or healthcare or health care or service\$ or team\$ or work\$ or collaboration\$ or co-ordinat\$ or coordinat\$)).ti,ab.
50. (Inter-disciplinary adj3 (care or health care or healthcare or service\$ or team\$ or work\$ or collaboration\$ or co-ordinat\$ or coordinat\$)).ti,ab.
51. (Holistic adj3 (care or healthcare or health care or service\$ or team\$ or work\$ or collaboration\$ or co-ordinat\$ or coordinat\$)).ti,ab.
52. (Collaborat\$ adj3 servic\$).ti,ab.
53. Multidisciplinary assessment\$.ti,ab.
54. single assessment\$.ti,ab.
55. Care trust\$.ti,ab.
56. Strategic collaboration\$.ti,ab.
57. Provider partnership\$.ti,ab.
58. (Pool\$ adj3 budget\$).ti,ab.
59. Overlapping commissioning.ti,ab.
60. Contiguous commissioning.ti,ab.
61. Joint commissioning.ti,ab.
62. Integrated commissioning.ti,ab.
63. linkwork\$.ti,ab.
64. Co-located team\$.ti,ab.
65. co-location.ti,ab.
66. One stop shop\$.ti,ab.
67. exp AMBULATORY CARE/
68. AMBULATORY CARE SERVICES/
69. (ambulatory care or ambulatory health care or ambulatory healthcare).ti,ab.
70. (ambulatory service\$ or ambulatory health service\$).ti,ab.
71. case management.ti,ab.
72. care management.ti,ab.
73. Case Management/ or care management/
74. Managed Care Program\$.ti,ab.
75. Patient Care Plan\$.ti,ab.
76. Health care teams/
77. care team\$.ti,ab.
78. or/1-77
79. Motor Neuron Diseases/
80. lou gehrig disease.ti,ab.
81. lou gehrig's disease.ti,ab.
82. motor neuron disease.ti,ab.
83. motor neurone disease.ti,ab.
84. MND.ti,ab.
85. lateral sclerosis.ti,ab.
86. ALS.ti,ab.

87. anterior horn cell disease.ti,ab.
88. Bulbar Palsy.ti,ab.
89. Spinal Muscular Atrophy.ti,ab.
90. parkinsons disease/
91. paralysis agitans.ti,ab.
92. Parkinson disease.ti,ab.
93. Parkinson syndrome.ti,ab.
94. Parkinson s.ti,ab.
95. parkinsonism.ti,ab.
96. Ms.ti,ab.
97. Multiple sclerosis.ti,ab.
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99. degenerative neurologic\$ disease\$.ti,ab.
100. degenerative neurologic\$ condition\$.ti,ab.
101. long term neurologic\$ disease\$.ti,ab.
102. long-term neurologic\$ disease\$.ti,ab.
103. long term neurologic\$ condition\$.ti,ab.
104. evolving neurologic\$ disease\$.ti,ab.
105. evolving neurologic\$ condition\$.ti,ab.
106. LTNC\$.ti,ab.
107. epilepsy/
108. epilepsy.ti,ab.
109. epileptic.ti,ab.
110. seizure disorder\$.ti,ab.
111. landau kleffner syndrome.ti,ab.
112. cerebral palsy.ti,ab.
113. spastic diplegia.ti,ab.
114. little disease.ti,ab.
115. cp.ti,ab.
116. diplegia spastic.ti,ab.
117. little's disease.ti,ab.
118. cerebral palsy/
119. or/79-118
120. 78 and 119
121. 2006\$.up.
122. 120 and 121
123. or/79-106
124. or/107-118
125. 124 not 123
126. 125 and 78
127. 126
128. limit 127 to yr="1985 - 2006"
129. 128 or 122

DARE – Database of Abstracts of Reviews of Effects, HTA (Health Technology Assessment Database and NHSEED (NHS Economic Evaluation Database) (CRD administration database))

Searched on 7/12/2006

Retrieved 5 hits from DARE, 4 hits from HTA and 22 hits from NHSEED

Search strategy:

1. s Integrate\$(3w)care or Integrate\$(3w)healthcare or Integrate\$(3w)health(w)care
2. s Integrat\$(3w)working
3. s Integrat\$(3w)provision
4. s Integrat\$(3w)provider(w)organisation\$
5. s Integrat\$(3w)assessment
6. s Integrat\$(3w)team
7. s Integrat\$(3w)management
8. s Horizontal(w)integration
9. s Vertical(w)integration
10. s Integrat\$(3w)primary(3w)community
11. s Integrat\$(3w)health(3w)social
12. s Cluster\$(3w)health(3w)social
13. s Integrated(3w)service or Integrated(3w)services or Integration(3w)service or Integration(3w)services
14. s Structured(w)care or Structured(w)healthcare or Structured(w)health(w)care
15. s Structured(w)service or Structured(w)services
16. s Joint\$(3w)working
17. s Joined(w)up(w)partnership\$
18. s Partnership\$(3w)working
19. s Joint(w)service(3w)development or Joint(w)services(3w)development
20. s Horizontal(w)communication\$
21. s Partnership(w)project\$
22. s Horizontal(w)partnership\$
23. s Flexible(w)partnership\$
24. s Joint(3w)service or Joint(3w)service or Jointly(3w)service or Jointly(3w)services
25. s Joined(w)up(w)service or Joined(w)up(w)services
26. s Joint(3w)care or Joint(3w)healthcare or Joint(3w)health(w)care or Jointly(3w)care or Jointly(3w)healthcare or Jointly(3w)health(w)care
27. s Joined(w)up(w)care or Joined(w)up(w)health(w)care or Joined(w)up(w)healthcare
28. s Co(w)ordinate(3w)care or Co(w)ordinate(3w)health(w)care or Co(w)ordinate(3w)healthcare or Co(w)ordination(3w)care or Co(w)ordination(3w)health(w)care or Co(w)ordination(3w)healthcare
29. s Coordinat\$(3w)care or Coordinat\$(3w)healthcare or Coordinat\$(3w)health(w)care
30. s Co(w)ordinate(3w)service or s Co(w)ordinate(3w)services or Co(w)ordination(3w)service or s Co(w)ordination(3w)service
31. s Coordinate(3w)service or Coordinate(3w)services or Coordination(3w)service or Coordination(3w)services
32. s Seamless(w)service or Seamless(w)services

33. s Seamless(w)care
34. s Continuous(w)service or Continuous(w)services or Continuity(3w)service or Continuity(3w)services
35. s contin\$(3w)care or contin\$(3w)healthcare or contin\$(3w)health(w)care
36. s Progression(3w)care or Progression(3w)healthcare or Progression(3w)health(w)care
37. s Uninterrupted(w)care or Uninterrupted(w)healthcare or Uninterrupted(w)health(w)care
38. s Uninterrupted(w)service or Uninterrupted(w)services
39. s Inter(w)organisation(3w)(care or healthcare or health(w)care or service or services or team or teams or work or working or workers or collaboration or collaborate or collaborations or co(W)ordinate or co(W)ordination or coordinate or coordination) or Inter(w)organisational(3w)(care or healthcare or health(w)care or service or services or team or teams or work or working or workers or collaboration or collaborate or collaborations or co(W)ordinate or co(W)ordination or coordinate or coordination)
40. s Holistic(3w)(care or health care or healthcare or service or services or team or teams or work or workers or working or collaboration\$ or co(w)ordinate or co(w)ordination or coordinate or coordination)
41. s ((Interoragnisation or Interoragnisational or Interoragnization or Interoragnizational)(3w)(care or health care or healthcare or service or services or team or teams or work or working or workers or collaboration or collaborations or co(w)ordinate or co(w)ordination or coordinate or coordination))
42. s Multidisciplinary(3w)(care or healthcare or health(w)care or service or services or team or teams or work or workers or working or collaboration or collaborations or co(w)ordinate or co(w)ordination or coordinate or coordination)
43. s Multiprofessional(3w)(care or healthcare or health(w)care or service or services or team or teams or work or workers or working or collaboration or collaborations or co(w)ordinate or co(w)ordination or coordinate or coordination)
44. s Multi(w)disciplinary(3w)(care or healthcare or health(w)care or service or services or team or teams or work or workers or working or collaboration or collaborations or co(w)ordinate or co(w)ordination or coordinate or coordination)
45. s Multi(w)professional(3w)(care or healthcare or health(w)care or service or services or team or teams or work or workers or working or collaboration or collaborations or co(w)ordinate or co(w)ordination or coordinate or coordination)
46. s Multi(w)agency(3w)(care or healthcare or health(w)care or service or services or team or teams or work or workers or working or collaboration or collaborations or co(w)ordinate or co(w)ordination or coordinate or coordination)
47. s Inter(w)agency(3w)(care or healthcare or health(w)care or service or services or team or teams or work or workers or working or collaboration or collaborations or co(w)ordinate or co(w)ordination or coordinate or coordination)

48. s Inter(w)professional(3w)(care or healthcare or health(w)care or service or services or team or teams or work or workers or working or collaboration or collaborations or co(w)ordinate or co(w)ordination or coordinate or coordination)
49. s Interdisciplinary(3w)(care or healthcare or health(w)care or service or services or team or teams or work or workers or working or collaboration or collaborations or co(w)ordinate or co(w)ordination or coordinate or coordination)
50. s Inter(w)disciplinary(3w)(care or healthcare or health(w)care or service or services or team or teams or work or workers or working or collaboration or collaborations or co(w)ordinate or co(w)ordination or coordinate or coordination)
51. s Holistic(3w)(care or healthcare or health(w)care or service or services or team or teams or work or workers or working or collaboration or collaborations or co(w)ordinate or co(w)ordination or coordinate or coordination)
52. s (Collaborate or collaboration or collaborations)(3w)(service or services)
53. s Multidisciplinary(w)assessment\$
54. s single(w)assessment\$
55. s Care(w)trust\$
56. s Strategic(w)collaboration\$
57. s Provider(w)partnership\$
58. s Pool\$(3w)budget\$
59. s Overlapping(w)commissioning
60. s Contiguous(w)commissioning
61. s Joint(w)commissioning
62. s Integrated(w)commissioning
63. s linkwork\$
64. s Co(w)located(w)team\$
65. s co(w)location
66. s One(w)stop(w)shop\$
67. s ambulatory(w)care or ambulatory(w)health(w)care or ambulatory(w)healthcare
68. s ambulatory(w)service or ambulatory(w)services or ambulatory(w)health(w)service or ambulatory(w)health(w)services
69. s case(w)management
70. s care(w)management
71. s Managed(w)Care(w)Program\$
72. s Patient(w)Care(w)Plan\$
73. s care(w)team\$
74. s s1 or s2 or s3 or s4 or s5 or s6 or s7 or s8 or s9 or s10 or s11 or s12 or s13 or s14 or s15 or s16 or s17 or s18 or s19 or s20 or s21 or s22 or s23 or s24 or s25 or s26 or s27 or s28 or s29 or s30 or s31 or s32 or s33 or s34 or s35 or s36 or s37 or s38 or s39 or s40 or s41 or s42 or s43 or s44 or s45 or s46 or s47 or s48 or s49 or s50 or s51 or s52 or s53 or s54 or s55 or s56 or s57 or s58 or s59 or s60 or s61 or s62 or s63 or s64 or s65 or s66 or s67 or s68 or s69 or s70 or s71 or s72 or s73
75. s lou(w)gehrig(w)disease

76. s lou(w)gehrig(w)s(w)disease
77. s motor(w)neuron(w)disease
78. s motor(w)neurone(w)disease
79. s MND
80. s lateral(w)sclerosis
81. s ALS
82. s anterior(w)horn(w)cell(w)disease
83. s Bulbar(w)Palsy
84. s Spinal(w)Muscular(w)Atrophy
85. s paralysis(w)agitans
86. s Parkinson(w)disease
87. s Parkinson(w)syndrome
88. s Parkinson(w)s
89. s parkinsonism
90. s Ms
91. s Multiple(w)sclerosis
92. s degenerative(w)neurologic(w)disease or
degenerative(w)neurological(w)disease or
degenerative(w)neurologic(w)diseases or
degenerative(w)neurological(w)diseases
93. s degenerative(w)neurologic(w)condition or
degenerative(w)neurological(w)condition or
degenerative(w)neurologic(w)conditions or
degenerative(w)neurological(w)conditions
94. s long(w)term(w)neurologic(w)disease or
long(w)term(w)neurological(w)disease or
long(w)term(w)neurologic(w)diseases or
long(w)term(w)neurological(w)diseases
95. s long(w)term(w)neurologic(w)condition or
long(w)term(w)neurological(w)condition or
long(w)term(w)neurologic(w)conditions or
long(w)term(w)neurological(w)conditions
96. s evolving(w)neurologic(w)disease or
evolving(w)neurological(w)disease or
evolving(w)neurologic(w)diseases or
evolving(w)neurological(w)diseases
97. s evolving(w)neurologic(w)condition or
evolving(w)neurological(w)condition or
evolving(w)neurologic(w)conditions or
evolving(w)neurological(w)conditions
98. s LTNC\$
99. s epilepsy
100. s epileptic
101. s seizure(w)disorder\$
102. s landau(w)kleffner(w)syndrome
103. s cerebral(w)palsy
104. s spastic(w)diplegia
105. s little(w)disease
106. s cp
107. s diplegia(w)spastic

- 108. s little(w)s(w)disease
- 109. s s75 or s76 or s77 or s78 or s79 or s80 or s81 or s82 or s83 or s84 or s85 or s86 or s87 or s88 or s89 or s90 or s91 or s92 or s93 or s94 or s95 or s96 or s97 or s98 or s99 or s100 or s101 or s102 or s103 or s104 or s105 or s106 or s107 or s108
- 110. s s74 and s109
- 111. s @2006
- 112. s s110 and s111
- 113. s s75 or s76 or s77 or s78 or s79 or s80 or s81 or s82 or s83 or s84 or s85 or s86 or s87 or s88 or s89 or s90 or s91 or s92 or s93 or s94 or s95 or s96 or s97 or s98
- 114. s s99 or s100 or s101 or s102 or s103 or s104 or s105 or s106 or s107 or s108
- 115. s s114 andnot s113
- 116. s s115 and s74
- 117. s @1985:2006
- 118. s s116 and s117
- 119. s s118 or s112

SIGLE (Silverplatter ERL WebSPIRS – <http://www.arc.uk.ovid.com/>)

1980-2005/03

Searched on 8/12/2006

Retrieved 0 hits

and:

Social Policy and Practice (Silverplatter ERL WebSPIRS – <http://www.arc.uk.ovid.com/>)

1890-

Searched on 812/2006

Retrieved 19 hits

Search strategy:

- #1 (Integrate* near3 care) or (Integrate* near3 healthcare) or (Integrate* near3 health care)
- #2 Integrat* near3 working
- #3 Integrat* near3 provision
- #4 Integrat* near3 provider organisation*
- #5 Integrat* near3 assessment*
- #6 Integrat* near3 team*
- #7 Integrat* near3 management
- #8 Horizontal integration
- #9 Vertical integration
- #10 Integrat* near3 primary near3 community
- #11 Integrat* near3 health near3 social
- #12 Cluster* near3 health near3 social
- #13 Integrat* near3 service*
- #14 Structured care or Structured healthcare or Structured health care
- #15 Structured service*

- #16 Joint* near3 working
- #17 Joined-up partnership*
- #18 Partnership* near3 working
- #19 Joint service* near3 development*
- #20 Horizontal communication*
- #21 Partnership project*
- #22 Horizontal partnership*
- #23 Flexible partnership*
- #24 Joint* near3 service*
- #25 Joined-up service*
- #26 (Joint* near3 care) or (Joint* near3 healthcare) or (Joint* near3 health care)
- #27 Joined-up care or Joined-up health care or Joined-up healthcare
- #28 (Co-ordinat* near3 care*) or (Co-ordinat* near3 health care*) or (Co-ordinat* near3 healthcare*)
- #29 (Coordinat* near3 care*) or (Coordinat* near3 healthcare*) or (Coordinat* near3 health care*)
- #30 Co-ordinat* near3 service*
- #31 Coordinat* near3 service*
- #32 Seamless service*
- #33 Seamless care
- #34 Contin* near3 service*
- #35 (contin* near3 care) or (contin* near3 healthcare) or (contin* near3 health care)
- #36 (Progression near3 care) or (Progression near3 healthcare) or (Progression near3 health care)
- #37 Uninterrupted care or Uninterrupted healthcare or Uninterrupted health care
- #38 Uninterrupted service*
- #39 (Inter-organisation* or Inter-oragnization*) near3 (care or healthcare or health care or service* or team* or work* or collaboration* or co-ordinat* or coordinat*)
- #40 Holistic near3 (care or health care or healthcare or service* or team* or work* or collaboration* or co-ordinat* or coordinat*)
- #41 (Interoragnosis* or Interoragnization*) near3 (care or health care or healthcare or service* or team* or work* or collaboration* or co-ordinat* or coordinat*)
- #42 Multidisciplinary near3 (care or healthcare or health care or service* or team* or work* or collaboration* or co-ordinat* or coordinat*)
- #43 Multiprofessional near3 (care or healthcare or health care or service* or team* or work* or collaboration* or co-ordinat* or coordinat*)
- #44 Multi-disciplinary near3 (care or health care or healthcare or service* or team* or work* or collaboration* or co-ordinat* or coordinat*)
- #45 Multi-professional near3 (care or health care or healthcare or service* or team* or work* or collaboration* or co-ordinat* or coordinat*)
- #46 Multi-agency near3 (care or healthcare or health care or service* or team* or work* or collaboration* or co-ordinat* or coordinat*)
- #47 Inter-agency near3 (care or healthcare or health care or service* or team* or work* or collaboration* or co-ordinat* or coordinat*)

- #48 Inter-professional near3 (care health care or healthcare or service* or team* or work* or collaboration* or co-ordinat* or coordinat*)
- #49 Interdisciplinary near3 (care or healthcare or health care or service* or team* or work* or collaboration* or co-ordinat* or coordinat*)
- #50 Inter-disciplinary near3 (care or health care or healthcare or service* or team* or work* or collaboration* or co-ordinat* or coordinat*)
- #51 Holistic near3 (care or healthcare or health care or service* or team* or work* or collaboration* or co-ordinat* or coordinat*)
- #52 Collaborat* near3 servic*
- #53 Multidisciplinary assessment*
- #54 single assessment*
- #55 Care trust*
- #56 Strategic collaboration*
- #57 Provider partnership*
- #58 Pool* near3 budget*
- #59 Overlapping commissioning
- #60 Contiguous commissioning
- #61 Joint commissioning
- #62 Integrated commissioning
- #63 linkwork*
- #64 Co-located team*
- #65 co-location
- #66 One stop shop*
- #67 ambulatory care or ambulatory health care or ambulatory healthcare
- #68 ambulatory service* or ambulatory health service*
- #69 case management
- #70 care management
- #71 Managed Care Program*
- #72 Patient Care Plan*
- #73 #1 or #2 or #3 or #4 or #5 or #6 or #7 or #8 or #9 or #10 or #11 or #12 or #13 or #14 or #15 or #16 or #17 or #18 or #19 or #20 or #21 or #22 or #23 or #24 or #25 or #26 or #27 or #28 or #29 or #30 or #31 or #32 or #33 or #34 or #35 or #36 or #37 or #38 or #39 or #40 or #41 or #42 or #43 or #44 or #45 or #46 or #47 or #48 or #49 or #50 or #51 or #52 or #53 or #54 or #55 or #56 or #57 or #58 or #59 or #60 or #61 or #62 or #63 or #64 or #65 or #66 or #67 or #68 or #69 or #70 or #71 or #72
- #74 lou gehrig disease
- #75 lou gehrig's disease
- #76 motor neuron disease
- #77 motor neurone disease
- #78 MND
- #79 lateral sclerosis
- #80 ALS
- #81 anterior horn cell disease
- #82 Bulbar Palsy
- #83 Spinal Muscular Atrophy
- #84 paralysis agitans
- #85 Parkinson disease
- #86 Parkinson syndrome
- #87 Parkinson s or parkinson's

- #88 parkinsonism
- #89 Ms
- #90 Multiple sclerosis
- #91 degenerative neurologic* disease*
- #92 degenerative neurologic* condition*
- #93 long term neurologic* disease*
- #94 long-term neurologic* disease*
- #95 long term neurologic* condition*
- #96 evolving neurologic* disease*
- #97 evolving neurologic* condition*
- #98 LTNC*
- #99 #74 or #75 or #76 or #77 or #78 or #79 or #80 or #81 or #81 or #83 or #84 or #85 or #86 or #87 or #88 or #89 or #90 or #91 or #92 or #92 or #94 or #95 or #96 or #97 or #98
- #100 #99 and #73
- #101 care team*
- #102 #101 and #99
- #103 #73 or #101
- #104 epilepsy
- #105 epileptic
- #106 seizure disorder*
- #107 landau kleffner syndrome
- #108 cerebral palsy
- #109 spastic diplegia
- #110 little disease
- #111 cp
- #112 diplegia spastic
- #113 little's disease
- #114 #104 or #105 or #106 or #107 or #108 or #109 or #110 or #111 or #112 or #113
- #115 #103 and #99 and (PY = 2006)
- #116 #103 and #114
- #117 #115 or #116

Social Science Citation Index (SSCI) (Web Of Knowledge – <http://wos.mimas.ac.uk/>)

(limited to)1985-2006

Searched on 11/12/2006

Retrieved 95 hits

Search strategy:

All lines limited as follows:

DocType=All document types; Language=All languages; Database=SSCI; Timespan=1985-2006 (except where otherwise stated)

- #1 TS=(Integrate* same "health care")
- #2 TS=(Integrat* same working)
- #3 TS=(Integrat* same provision)

- #4 TS=(Integrat* same "provider organisation*")
- #5 TS=(Integrat* same assessment*)
- #6 TS=(Integrat* same team*)
- #7 TS=(Integrat* same management)
- #8 TS=("Horizontal integration")
- #9 TS=("Vertical integration")
- #10 TS=(Integrat* same primary same community)
- #11 TS=(Integrat* same health same social)
- #12 TS=(Cluster* same health same social)
- #13 TS=(Integrat* same service*)
- #14 TS=("Structured care" or "Structured healthcare" or "Structured health care")
- #15 TS=("Structured service*")
- #16 TS=(Joint* same working)
- #17 TS=("Joined-up partnership*" or "Joined up partnership*")
- #18 TS=(Partnership* same working)
- #19 TS=("Joint service*" same development*)
- #20 TS=("Horizontal communication*")
- #21 TS=("Partnership project*")
- #22 TS=("Horizontal partnership*")
- #23 TS=("Flexible partnership*")
- #24 TS=(Joint* same service*)
- #25 TS=("Joined-up service*" or "Joined up service*")
- #26 TS=((Joint* same care) or (Joint* same healthcare) or (Joint* same "health care"))
- #27 TS=("Joined-up care" or "Joined-up health care" or "Joined-up healthcare")
- #28 TS=((Co-ordinat* same care*) or (Co-ordinat* same "health care*") or (Co-ordinat* same healthcare*))
- #29 TS=((Coordinat* same care*) or (Coordinat* same healthcare*) or (Coordinat* same "health care*"))
- #30 TS=(Co-ordinat* same service*)
- #31 TS=(Coordinat* same service*)
- #32 TS=("Seamless service*")
- #33 TS=("Seamless care")
- #34 TS=(Contin* same service*)
- #35 TS=((contin* same care) or (contin* same healthcare) or (contin* same "health care"))
- #36 TS=((Progression same care) or (Progression same healthcare) or (Progression same "health care"))
- #37 TS=("Uninterrupted care" or "Uninterrupted healthcare" or "Uninterrupted health care")
- #38 TS=("Uninterrupted service*")
- #39 TS=((Inter-oragnisation* or Inter-oragnization*) same (care or healthcare or "health care" or service* or team* or work* or collaboration* or co-ordinat* or coordinat*))
- #40 TS=(Holistic same (care or health care or healthcare or service* or team* or work* or collaboration* or co-ordinat* or coordinat*))

- #41 TS=((Interoragnisation* or Interoragnization*) same (care or "health care" or healthcare or service* or team* or work* or collaboration* or co-ordinat* or coordinat*))
- #42 TS=(Multidisciplinary same (care or healthcare or "health care" or service* or team* or work* or collaboration* or co-ordinat* or coordinat*))
- #43 TS=(Multiprofessional same (care or healthcare or "health care" or service* or team* or work* or collaboration* or co-ordinat* or coordinat*))
- #44 TS=(Multi-disciplinary same (care or "health care" or healthcare or service* or team* or work* or collaboration* or co-ordinat* or coordinat*))
- #45 TS=(Multi-professional same (care or "health care" or healthcare or service* or team* or work* or collaboration* or co-ordinat* or coordinat*))
- #46 TS=(Multi-agency same (care or healthcare or "health care" or service* or team* or work* or collaboration* or co-ordinat* or coordinat*))
- #47 TS=(Inter-agency same (care or healthcare or "health care" or service* or team* or work* or collaboration* or co-ordinat* or coordinat*))
- #48 TS=(Inter-professional same (care or healthcare or "health care" or service* or team* or work* or collaboration* or co-ordinat* or coordinat*))
- #49 TS=(Interdisciplinary same (care or healthcare or "health care" or service* or team* or work* or collaboration* or co-ordinat* or coordinat*))
- #50 TS=(Inter-disciplinary same (care or healthcare or "health care" or service* or team* or work* or collaboration* or co-ordinat* or coordinat*))
- #51 TS=(Holistic same (care or healthcare or "health care" or service* or team* or work* or collaboration* or co-ordinat* or coordinat*))
- #52 TS=(Collaborat* same servic*)
- #53 TS=("Multidisciplinary assessment*")
- #54 TS=("single assessment*")
- #55 TS=("Care trust*")
- #56 TS=("Strategic collaboration*")
- #57 TS=("Provider partnership*")
- #58 TS=(Pool* same budget*)
- #59 TS=("Overlapping commissioning")
- #60 TS=("Contiguous commissioning")
- #61 TS=("Joint commissioning")
- #62 TS=("Integrated commissioning")
- #63 TS=(linkwork*)
- #64 TS=("Co-located team*")
- #65 TS=(co-location)
- #66 TS=("One stop shop*")
- #67 TS=("ambulatory care" or "ambulatory health care" or "ambulatory healthcare")
- #68 TS=("ambulatory service*" or "ambulatory health service*")
- #69 TS=("case management")
- #70 TS=("care management")
- #71 TS=("Managed Care Program*")
- #72 TS=("Patient Care Plan*" or "care team*")
- #73 TS=(#1 or #2 or #3 or #4 or #5 or #6 or #7 or #8 or #9 or #10 or #11 or #12 or #13 or #14 or #15 or #16 or #17 or #18 or #19 or #20 or #21 or #22 or #23 or #24)

- #74 TS=(#25 or #26 or #27 or #28 or #29 or #30 or #31 or #32 or #33 or #34 or #35 or #36 or #37 or #38 or #39 or #40 or #41 or #42 or #43 or #44 or #45 or #46 or #47 or #48 or #49 or #50)
- #75 TS=(#51 or #52 or #53 or #54 or #55 or #56 or #57 or #58 or #59 or #60 or #61 or #62 or #63 or #64 or #65 or #66 or #67 or #68 or #69 or #70 or #71 or #72)
- #76 TS=(#73 or #74 or #75)
- #77 TS=("lou gehrig disease")
- #78 TS=("lou gehrig's disease")
- #79 TS=("motor neuron disease")
- #80 TS=("motor neurone disease")
- #81 TS=(MND)
- #82 TS=("lateral sclerosis")
- #83 TS=(ALS)
- #84 TS=("anterior horn cell disease")
- #85 TS=("Bulbar Palsy")
- #86 TS=("Spinal Muscular Atrophy")
- #87 TS=("paralysis agitans")
- #88 TS=("Parkinson disease")
- #89 TS=("Parkinson syndrome")
- #90 TS=("Parkinson s" or "Parkinson's")
- #91 TS=(parkinsonism)
- #92 TS=(Ms or LTNC*)
- #93 TS=("Multiple sclerosis" or "Long term neurologic* disease**")
- #94 TS=("degenerative neurologic* disease**" or "evolving neurologic* disease**" or "degenerative neurologic* condition**" or "evolving neurologic* condition**")
- #95 TS=("long term neurologic* condition**")
- #96 TS=(#77 or #78 or #79 or #80 or #81 or #82 or #83 or #84 or #85 or #86 or #87 or #88 or #89 or #90 or #91 or #92 or #93 or #94 or #95 or #95)
- #97 TS=(epilepsy or epileptic or "seizure disorder**" or "landau kleffner syndrome" or "cerebral palsy" or "spastic diplegia" or "diplegia spastic or cp")
- #98 TS=(#96 and #76)(*Timespan=2006*)
- #99 TS=(#97 and #76)
- #100 TS=(#98 or #99)

ASSIA (CSA Illumina – <http://ca2.csa.com/>)

1987 to 2006

Searched on 11/12/2006

Retrieved 43 hits

and

Social Services Abstracts (CSA Illumina – <http://ca2.csa.com/>)

1979 to 2006

Searched on 11/12/2006

Retrieved 12 hits

and

Sociological Abstracts (CSA Illumina – <http://ca2.csa.com/>)

1952 to 2006

Searched on 11/12/2006

Retrieved 18 hits

Search strategy:

1. Integrate* within 3 care
2. Integrate* within 3 healthcare
3. Integrate* within 3 health care
4. Integrat* within 3 working
5. Integrat* within 3 provision
6. Integrat* within 3 provider organisation*
7. Integrat* within 3 assessment*
8. Integrat* within 3 team*
9. Integrat* within 3 management
10. Horizontal integration
11. Vertical integration
12. Integrat* within 3 primary within 3 community
13. Integrat* within 3 health within 3 social
14. Cluster* within 3 health within 3 social
15. Cluster* within 3 health within 3 social
16. Structured care or Structured healthcare or Structured health care
17. Structured service*
18. Joint* within 3 working
19. Joined-up partnership*
20. Partnership* within 3 working
21. Joint service* within 3 development*
22. Horizontal communication*
23. Partnership project*
24. Horizontal partnership*
25. Flexible partnership*
26. Joint* within 3 service*
27. Joined-up service*
28. Joint* within 3 care
29. Joint* within 3 healthcare
30. Joint* within 3 health care
31. Joined-up care or Joined-up health care or Joined-up healthcare
32. Co-ordinat* within 3 care*
33. Co-ordinat* within 3 health care*
34. Co-ordinat* within 3 healthcare*
35. Coordinat* within 3 care*
36. Coordinat* within 3 healthcare*
37. Coordinat* within 3 health care*
38. Co-ordinat* within 3 service*
39. Coordinat* within 3 service*
40. Seamless service*
41. Seamless care
42. Contin* within 3 service*

43. contin* within 3 care
44. contin* within 3 healthcare
45. contin* within 3 health care
46. Progression within 3 care
47. Progression within 3 healthcare
48. (Progression within 3 health care)) or
49. Uninterrupted care or Uninterrupted healthcare or Uninterrupted health care)
50. Uninterrupted service*
51. (Inter-organisation* or Inter-organization*) within 3 (care or healthcare or health care or service* or team* or work* or collaboration* or co-ordinat* or coordinat*)
52. (Holistic within 3 (care or health care or healthcare or service* or team* or work* or collaboration* or co-ordinat* or coordinat*))
53. (Interorganisation* or Interorganization*) within 3 (care or health care or healthcare or service* or team* or work* or collaboration* or co-ordinat* or coordinat*)
54. (Multidisciplinary within 3 (care or healthcare or health care or service* or team* or work* or collaboration* or co-ordinat* or coordinat*))
55. (Multiprofessional within 3 (care or healthcare or health care or service* or team* or work* or collaboration* or co-ordinat* or coordinat*))
56. (Multi-disciplinary within 3 (care or health care or healthcare or service* or team* or work* or collaboration* or co-ordinat* or coordinat*))
57. (Multi-professional within 3 (care or health care or healthcare or service* or team* or work* or collaboration* or co-ordinat* or coordinat*))
58. (Multi-agency within 3 (care or healthcare or health care or service* or team* or work* or collaboration* or co-ordinat* or coordinat*))
59. (Inter-agency within 3 (care or healthcare or health care or service* or team* or work* or collaboration* or co-ordinat* or coordinat*))
60. (Inter-professional within 3 (care health care or healthcare or service* or team* or work* or collaboration* or co-ordinat* or coordinat*))
61. (Interdisciplinary within 3 (care or healthcare or health care or service* or team* or work* or collaboration* or co-ordinat* or coordinat*))
62. (Inter-disciplinary within 3 (care or health care or healthcare or service* or team* or work* or collaboration* or co-ordinat* or coordinat*))
63. (Holistic within 3 (care or healthcare or health care or service* or team* or work* or collaboration* or co-ordinat* or coordinat*))
64. Collaborat* within 3 servic*)
65. Multidisciplinary assessment*)
66. single assessment*)
67. Care trust*)
68. Strategic collaboration*)
69. Provider partnership*)
70. Pool* within 3 budget*)
71. Overlapping commissioning)
72. Contiguous commissioning)
73. Joint commissioning)
74. Integrated commissioning)
75. linkwork*)
76. Co-located team*)

77. co-location)
78. care team*)
79. One stop shop*)
80. DE="integrated management")
81. DE="ambulatory health care")
82. ambulatory care or ambulatory health care or ambulatory healthcare)
83. ambulatory service* or ambulatory health service*)
84. case management)
85. care management)
86. DE="integrated care pathways")
87. Managed Care Program*)
88. Patient Care Plan*
89. #1 or #2 or #3 or #4 or #5 or #6 or #7 or #8 or #9 or #10 or #11 or #12
or #13 or #14 or #15 or #16 or #17 or #18 or #19 or #20 or #21 or #22
or #23 or #24 or #25 or #26 or #27 or #28 or #29 or #30 or #31 or #32
or #33 or #34 or #35 or #36 or #37 or #38 or #39 or #40 or #41 or #42
or #43 or #44 or #45 or #46 or #47 or #48 or #49 or #50 or #51 or #52
or #53 or #54 or #55 or #56 or #57 or #58 or #59 or #60 or #61 or #62
or #63 or #64 or #65 or #66 or #67 or #68 or #69 or #70 or #71 or #72
or #73 or #74 or #75 or #76 or #77 or #78 or #79 or #80 or #81 or #82
or #83 or #84 or #85 or #86 or #87 or #88
90. (DE=("motor neurone disease" or "bell s palsy"))
91. lou gehrig disease)
92. lou gehrig's disease)
93. motor neuron disease)
94. motor neurone disease)
95. MND)
96. lateral sclerosis)
97. ALS)
98. anterior horn cell disease)
99. Bulbar Palsy)
100. Spinal Muscular Atrophy)
101. DE="parkinson s disease")
102. paralysis agitans)
103. Parkinson disease)
104. Parkinson syndrome)
105. Parkinson s or Parkinson's
106. parkinsonism)
107. Ms)
108. Multiple sclerosis)
109. DE="multiple sclerosis")
110. degenerative neurologic* disease*)
112. degenerative neurologic* condition*)
113. long term neurologic* disease*)
114. long-term neurologic* disease*)
115. long term neurologic* condition*)
116. evolving neurologic* disease*)
117. evolving neurologic* condition*)
118. LTNC*

119. #90 or #91 or #92 or #93 or #94 or #95 or #96 or #97 or #98 or #99 or #100 or #101 or #102 or #103 or #104 or #105 or #116 or #117 or #118
120. #89 and #119 (2006-2007)
121. DE=("epilepsy" or "complex partial seizure disorder" or "landau kleffner syndrome" or "temporal lobe epilepsy" or "cerebral palsy")
122. epilepsy
123. epileptic
124. seizure disorder*
125. landau kleffner syndrome
126. cerebral palsy
127. spastic diplegia
128. little disease
129. cp
130. diplegia spastic
131. little's disease
132. #121 or #122 or #123 or #124 or #125 or #126 or #127 or #128 or #129 or #130 or #131
133. #89 and #132 (1985-2007)

Due to the restrictions on combining searches for different dates, sets #120 and #133 were downloaded separately and deduplicated in Endnote.

NRR (<http://www.nrr.nhs.uk/>)

2006: Issue 4

Searched on 12/12/2006

Retrieved 94 hits

Search strategy:

- #1. (integrate* near care) or (integrate* near healthcare) or (integrate* near health care)
- #2. (integrat* near working)
- #3. (integrat* near provision)
- #4. (integrat* near (provider next organisation*))
- #5. (integrat* near assessment*)
- #6. (integrat* near team*)
- #7. (integrat* near management)
- #8. (horizontal next integration)
- #9. (vertical next integration)
- #10. (integrat* near primary near community)
- #11. (integrat* near health near social)
- #12. (cluster* near health near social)
- #13. (integrat* near service*)
- #14. ((structured next care) or (structured next healthcare) or (structured next health next care))
- #15. (structured next service*)
- #16. (joint* near working)
- #17. (joined next up next partnership*)
- #18. partnership* working
- #19. joint near service* near development*

- #20. (horizontal next communication*)
- #21. (partnership next project*)
- #22. (horizontal next partnership*)
- #23. (flexible next partnership*)
- #24. (joint* near service*)
- #25. (joined next up next service*)
- #26. (joint* next care) or (joint* next healthcare) or (joint* next health next care)
- #27. ((joined next up next care) or (joined next up next health next care) or (joined next up next healthcare))
- #28. ((co-ordinat* near care*) or (co-ordinat* near (health next care*)) or (co-ordinat* near healthcare*))
- #29. ((coordinat* near care*) or (coordinat* near healthcare*) or (coordinat* near (health next care*)))
- #30. (co-ordinat* near service*)
- #31. (coordinat* near service*)
- #32. (seamless next service*)
- #33. (seamless next care)
- #34. (contin* near service*)
- #35. (contin* next care) or (contin* next healthcare) or (contin* next health next care)
- #36. ((progression near care) or (progression near healthcare) or (progression near (health next care)))
- #37. ((uninterrupted next care) or (uninterrupted next healthcare) or (uninterrupted next health next care))
- #38. (uninterrupted next service*)
- #39. (((inter next oragnisation*) or (inter next oragnization*)) and (care or healthcare or (health next care) or service* or team* or work* or collaboration* or (co next ordinat*) or coordinat*))
- #40. (holistic and (care or (health next care) or healthcare or service* or team* or work* or collaboration* or co-ordinat* or coordinat*))
- #41. ((interoragnisation* or interoragnization*) and (care or (health next care) or healthcare or service* or team* or work* or collaboration* or co-ordinat* or coordinat*))
- #42. (Multidisciplinary near care) or (Multidisciplinary near healthcare) or (Multidisciplinary near health care) or (Multidisciplinary near service*) or (Multidisciplinary near team*) or (Multidisciplinary near work*) or (Multidisciplinary near collaboration*) or (Multidisciplinary near co-ordinat*) or (Multidisciplinary near coordinat*)
- #43. (multiprofessional and (care or healthcare or (health next care) or service* or team* or work* or collaboration* or co-ordinat* or coordinat*))
- #44. ((multi next disciplinary) and (care or (health next care) or healthcare or service* or team* or work* or collaboration* or co-ordinat* or coordinat*))
- #45. ((multi next professional) and (care or (health next care) or healthcare or service* or team* or work* or collaboration* or co-ordinat* or coordinat*))
- #46. ((multi next agency) and (care or healthcare or (health next care) or service* or team* or work* or collaboration* or co-ordinat* or coordinat*))
- #47. ((inter next agency) and (care or healthcare or (health next care) or service* or team* or work* or collaboration* or co-ordinat* or coordinat*))

- #48. ((inter next professional) and ((care next health next care) or healthcare or service* or team* or work* or collaboration* or co-ordinat* or coordinat*))
- #49. (interdisciplinary and (care or healthcare or (health next care) or service* or team* or work* or collaboration* or co-ordinat* or coordinat*))
- #50. ((inter next disciplinary) and (care or (health next care) or healthcare or service* or team* or work* or collaboration* or co-ordinat* or coordinat*))
- #51. (holistic and (care or healthcare or (health next care) or service* or team* or work* or collaboration* or co-ordinat* or coordinat*))
- #52. (collaborat* near servic*)
- #53. (multidisciplinary next assessment*)
- #54. (single next assessment*)
- #55. care next trust*:ti
- #56. (strategic next collaboration*)
- #57. (provider next partnership*)
- #58. (pool* near budget*)
- #59. (overlapping next commissioning)
- #60. (contiguous next commissioning)
- #61. (joint next commissioning)
- #62. (integrated next commissioning)
- #63. linkwork*
- #64. (co-located next team*)
- #65. co-location
- #66. (one next stop next shop*)
- #67. DELIVERY OF HEALTH CARE INTEGRATED explode all trees (MeSH)
- #68. AMBULATORY CARE explode all trees (MeSH)
- #69. ((ambulatory next care) or (ambulatory next health next care) or (ambulatory next healthcare))
- #70. ((ambulatory next service*) or (ambulatory next health next service*))
- #71. (case next management)
- #72. (care next management)
- #73. CASE MANAGEMENT single term (MeSH)
- #74. (managed next care next program*)
- #75. (patient next care next plan*)
- #76. PATIENT CARE TEAM explode all trees (MeSH)
- #77. care next team*
- #78. (#1 or #2 or #3 or #4 or #5 or #6 or #7 or #8 or #9 or #10 or #11 or #12 or #13 or #14 or #15 or #16 or #17 or #18 or #19 or #20 or #21 or #22 or #23 or #24 or #25 or #26 or #27 or #28 or #29 or #30 or #31 or #32 or #33 or #34 or #35 or #36 or #37 or #38 or #39 or #40 or #41 or #42 or #43 or #44 or #45 or #46 or #47 or #48 or #49 or #50 or #51 or #52 or #53 or #54 or #55 or #56 or #57 or #58 or #59 or #60 or #61 or #62 or #63 or #64 or #65 or #66 or #67 or #68 or #69 or #70 or #71 or #72 or #73 or #74 or #75 or #76 or #77)
- #79. MOTOR NEURON DISEASE explode all trees (MeSH)
- #80. (lou next gehrig next disease)
- #81. (lou next gehrig next s next disease)
- #82. (motor next neuron next disease)
- #83. (motor next neurone next disease)
- #84. mnd

- #85. (lateral next sclerosis)
- #86. als
- #87. (anterior next horn next cell next disease)
- #88. (bulbar next palsy)
- #89. (spinal next muscular next atrophy)
- #90. PARKINSON DISEASE single term (MeSH)
- #91. (paralysis next agitans)
- #92. (parkinson next disease)
- #93. (parkinson next syndrome)
- #94. (parkinson next s)
- #95. parkinsonism
- #96. ms:ti
- #97. (multiple next sclerosis)
- #98. MULTIPLE SCLEROSIS explode all trees (MeSH)
- #99. (degenerative next neurologic* next disease*)
- #100. (degenerative next neurologic* next condition*)
- #101. (long next term next neurologic* next disease*)
- #102. (long next term next neurologic* next disease*)
- #103. (long next term next neurologic* next condition*)
- #104. (evolving next neurologic* next disease*)
- #105. (evolving next neurologic* next condition*)
- #106. Itnc*
- #107. EPILEPSY single term (MeSH)
- #108. epilepsy
- #109. epileptic
- #110. seizure next disorder*
- #111. landau next kleffner next syndrome
- #112. cerebral next palsy
- #113. spastic next diplegia
- #114. little next disease
- #115. cp
- #116. diplegia next spastic
- #117. little next s next disease
- #118. CEREBRAL PALSY single term (MeSH)
- #119. (# 79 or #80 or #81 or #82 or #83 or #84 or #85 or #86 or #87 or #88 or #89 or #90 or #91 or #92 or #93 or #94 or #95 or #96 or #97 or #98 or #99 or #100 or #101 or #102 or #103 or #104 or #105 or #106 or #107 or #108 or #109 or #110 or #112 or #113 or #114 or #115 or #116 or #117 or #118)
- #120.(#78 and #119)

INTUTE (formerly SOSIG) (<http://www.intute.ac.uk/socialsciences/>)

Searched on 12/12/2006

Retrieved 10 new hits

Search strategy:

This is a very simple search interface and the following lines were run as separate searches on both the Social Welfare section and the Government Policy section.

“Integrated care”
“Integrated service” or “integrated services”
“Integrated work” or “integrated working”
“Integrated health” or “Integrated healthcare”
“Integrated team” or “Integrated teams”
“integrated management”
“structured care”
“managed care”
“Case management”
“care management”
“Ambulatory care”
“ambulatory service” or “ambulatory services”
collaborate and (care or service or services)
collaborate and (work or health or team or teams)
collaborate and (assessment or management)
collaboration and (care or service or services)
collaboration and (work or health or team)
collaboration and teams
collaboration and (assessment or management)
“care teams” or “care team”

Cochrane Database of Systematic Reviews (The Cochrane Library – <http://www.thecochranelibrary.com/>)

Issue 4 2006

Searched on 12/12/2006

Retrieved 11 hits

Search strategy:

- #1 ((integrate* near/3 care) or (integrate* near/3 healthcare) or (integrate* near/3 health care)) in Record Title or ((integrate* near/3 care) or (integrate* near/3 healthcare) or (integrate* near/3 health care)) in Abstract in all products
- #2 (integrat* near/3 working) in Record Title or (integrat* near/3 working) in Abstract in all products
- #3 (integrat* near/3 provision) in Record Title or (integrat* near/3 provision) in Abstract in all products
- #4 (integrat* near/3 provider organisation*) in Record Title or (integrat* near/3 provider organisation*) in Abstract in all products
- #5 (integrat* near/3 assessment*) in Record Title or (integrat* near/3 assessment*) in Abstract in all products

- #6 (integrat* near/3 team*) in Record Title or (integrat* near/3 team*) in Abstract in all products
- #7 (integrat* near/3 management) in Record Title or (integrat* near/3 management) in Abstract in all products
- #8 horizontal integration in Record Title or horizontal integration in Abstract in all products
- #9 vertical integration in Record Title or vertical integration in Abstract in all products
- #10 (integrat* near/3 primary near/3 community) in Record Title or (integrat* near/3 primary near/3 community) in Abstract in all products
- #11 (integrat* near/3 health near/3 social) in Record Title or (integrat* near/3 health near/3 social) in Abstract in all products
- #12 (cluster* near/3 health near/3 social) in Record Title or (cluster* near/3 health near/3 social) in Abstract in all products
- #13 (integrat* near/3 service*) in Record Title or (integrat* near/3 service*) in Abstract in all products
- #14 (structured care or structured healthcare or structured health care) in Record Title or (structured care or structured healthcare or structured health care) in Abstract in all products
- #15 structured service* in Record Title or structured service* in Abstract in all products
- #16 (joint* near/3 working) in Record Title or (joint* near/3 working) in Abstract in all products
- #17 joined up partnership* in Record Title or joined up partnership* in Abstract in all products
- #18 (partnership* near/3 working) in Record Title or (partnership* near/3 working) in Abstract in all products
- #19 (joint service* near/3 development*) in Record Title or (joint service* near/3 development*) in Abstract in all products
- #20 horizontal communication* in Record Title or horizontal communication* in Abstract in all products
- #21 partnership project* in Record Title or partnership project* in Abstract in all products
- #22 horizontal partnership* in Record Title or horizontal partnership* in Abstract in all products
- #23 flexible partnership* in Record Title or flexible partnership* in Abstract in all products
- #24 (joint* near/3 service*) in Record Title or (joint* near/3 service*) in Abstract in all products
- #25 joined up service* in Record Title or joined up service* in Abstract in all products
- #26 ((joint* near/3 care) or (joint* near/3 healthcare) or (joint* near/3 health care)) in Record Title or ((joint* near/3 care) or (joint* near/3 healthcare) or (joint* near/3 health care)) in Abstract in all products
- #27 (joined up care or joined up health care or joined up healthcare) in Record Title or (joined up care or joined up health care or joined up healthcare) in Abstract in all products
- #28 ((co ordinat* near/3 care*) or (co ordinat* near/3 health care*) or (co ordinat* near/3 healthcare*)) in Record Title or ((co ordinat* near/3

- care*) or (co ordinat* near/3 health care*) or (co ordinat* near/3 healthcare*)) in Abstract in all products
- #29 ((coordinat* near/3 care*) or (coordinat* near/3 healthcare*) or (coordinat* near/3 health care*)) in Record Title or ((coordinat* near/3 care*) or (coordinat* near/3 healthcare*) or (coordinat* near/3 health care*)) in Abstract in all products
- #30 (co ordinat* near/3 service*) in Record Title or (co ordinat* near/3 service*) in Abstract in all products
- #31 (coordinat* near/3 service*) in Record Title or (coordinat* near/3 service*) in Abstract in all products
- #32 seamless service* in Record Title or seamless service* in Abstract in all products
- #33 seamless care in Record Title or seamless care in Abstract in all products
- #34 (contin* near/3 service*) in Record Title or (contin* near/3 service*) in Abstract in all products
- #35 ((contin* near/3 care) or (contin* near/3 healthcare) or (contin* near/3 health care)) in Record Title or ((contin* near/3 care) or (contin* near/3 healthcare) or (contin* near/3 health care)) in Abstract in all products
- #36 ((progression near/3 care) or (progression near/3 healthcare) or (progression near/3 health care)) in Record Title or ((progression near/3 care) or (progression near/3 healthcare) or (progression near/3 health care)) in Abstract in all products
- #37 (uninterrupted care or uninterrupted healthcare or uninterrupted health care) in Record Title or (uninterrupted care or uninterrupted healthcare or uninterrupted health care) in Abstract in all products
- #38 uninterrupted service* in Record Title or uninterrupted service* in Abstract in all products
- #39 ((inter oragnisation* or inter oragnization*) near/3 (care or healthcare or health care or service* or team* or work* or collaboration* or co ordinat* or coordinat*)) in Record Title or ((inter oragnisation* or inter oragnization*) near/3 (care or healthcare or health care or service* or team* or work* or collaboration* or co ordinat* or coordinat*)) in Abstract in all products
- #40 (holistic near/3 (care or health care or healthcare or service* or team* or work* or collaboration* or co ordinat* or coordinat*)) in Record Title or (holistic near/3 (care or health care or healthcare or service* or team* or work* or collaboration* or co ordinat* or coordinat*)) in Abstract in all products
- #41 ((interoragnisation* or interoragnization*) near/3 (care or health care or healthcare or service* or team* or work* or collaboration* or co ordinat* or coordinat*)) in Record Title or ((interoragnisation* or interoragnization*) near/3 (care or health care or healthcare or service* or team* or work* or collaboration* or co ordinat* or coordinat*)) in Abstract in all products
- #42 (multidisciplinary near/3 (care or healthcare or health care or service* or team* or work* or collaboration* or co ordinat* or coordinat*)) in Record Title or (multidisciplinary near/3 (care or healthcare or health care or service* or team* or work* or collaboration* or co ordinat* or coordinat*)) in Abstract in all products

- #43 (multiprofessional near/3 (care or healthcare or health care or service* or team* or work* or collaboration* or co ordinat* or coordinat*)) in Record Title or (multiprofessional near/3 (care or healthcare or health care or service* or team* or work* or collaboration* or co ordinat* or coordinat*)) in Abstract in all products
- #44 (multi disciplinary near/3 (care or health care or healthcare or service* or team* or work* or collaboration* or co ordinat* or coordinat*)) in Record Title or (multi disciplinary near/3 (care or health care or healthcare or service* or team* or work* or collaboration* or co ordinat* or coordinat*)) in Abstract in all products
- #45 (multi professional near/3 (care or health care or healthcare or service* or team* or work* or collaboration* or co ordinat* or coordinat*)) in Record Title or (multi professional near/3 (care or health care or healthcare or service* or team* or work* or collaboration* or co ordinat* or coordinat*)) in Abstract in all products
- #46 (multi agency near/3 (care or healthcare or health care or service* or team* or work* or collaboration* or co ordinat* or coordinat*)) in Record Title or (multi agency near/3 (care or healthcare or health care or service* or team* or work* or collaboration* or co ordinat* or coordinat*)) in Abstract in all products
- #47 (inter agency near/3 (care or healthcare or health care or service* or team* or work* or collaboration* or co ordinat* or coordinat*)) in Record Title or (inter agency near/3 (care or healthcare or health care or service* or team* or work* or collaboration* or co ordinat* or coordinat*)) in Abstract in all products
- #48 (inter professional near/3 (care health care or healthcare or service* or team* or work* or collaboration* or co ordinat* or coordinat*)) in Record Title or (inter professional near/3 (care health care or healthcare or service* or team* or work* or collaboration* or co ordinat* or coordinat*)) in Abstract in all products
- #49 (interdisciplinary near/3 (care or healthcare or health care or service* or team* or work* or collaboration* or co ordinat* or coordinat*)) in Record Title or (interdisciplinary near/3 (care or healthcare or health care or service* or team* or work* or collaboration* or co ordinat* or coordinat*)) in Abstract in all products
- #50 (inter disciplinary near/3 (care or health care or healthcare or service* or team* or work* or collaboration* or co ordinat* or coordinat*)) in Record Title or (inter disciplinary near/3 (care or health care or healthcare or service* or team* or work* or collaboration* or co ordinat* or coordinat*)) in Abstract in all products
- #51 (holistic near/3 (care or healthcare or health care or service* or team* or work* or collaboration* or co ordinat* or coordinat*)) in Record Title or (holistic near/3 (care or healthcare or health care or service* or team* or work* or collaboration* or co ordinat* or coordinat*)) in Abstract in all products
- #52 (collaborat* near/3 servic*) in Record Title or (collaborat* near/3 servic*) in Abstract in all products
- #53 multidisciplinary assessment* in Record Title or multidisciplinary assessment* in Abstract in all products

- #54 single assessment* in Record Title or single assessment* in Abstract in all products
- #55 care trust* in Record Title or care trust* in Abstract in all products
- #56 strategic collaboration* in Record Title or strategic collaboration* in Abstract in all products
- #57 provider partnership* in Record Title or provider partnership* in Abstract in all products
- #58 (pool* near/3 budget*) in Record Title or (pool* near/3 budget*) in Abstract in all products
- #59 overlapping commissioning in Record Title or overlapping commissioning in Abstract in all products
- #60 contiguous commissioning in Record Title or contiguous commissioning in Abstract in all products
- #61 joint commissioning in Record Title or joint commissioning in Abstract in all products
- #62 integrated commissioning in Record Title or integrated commissioning in Abstract in all products
- #63 linkwork* in Record Title or linkwork* in Abstract in all products
- #64 co located team* in Record Title or co located team* in Abstract in all products
- #65 co location in Record Title or co location in Abstract in all products
- #66 one stop shop* in Record Title or one stop shop* in Abstract in all products
- #67 MeSH descriptor Delivery of Health Care, Integrated explode all trees in MeSH products
- #68 MeSH descriptor Ambulatory Care explode all trees in MeSH products
- #69 (ambulatory care or ambulatory health care or ambulatory healthcare) in Record Title or (ambulatory care or ambulatory health care or ambulatory healthcare) in Abstract in all products
- #70 (ambulatory service* or ambulatory health service*) in Record Title or (ambulatory service* or ambulatory health service*) in Abstract in all products
- #71 case management in Record Title or case management in Abstract in all products
- #72 care management in Record Title or care management in Abstract in all products
- #73 MeSH descriptor Case Management, this term only in MeSH products
- #74 managed care program* in Record Title or managed care program* in Abstract in all products
- #75 patient care plan* in Record Title or patient care plan* in Abstract in all products
- #76 (#1 OR #2 OR #3 OR #4 OR #5 OR #6 OR #7 OR #8 OR #9 OR #10 OR #11 OR #12 OR #13 OR #14 OR #15 OR #16 OR #17 OR #18 OR #19 OR #20 OR #21 OR #22 OR #23 OR #24 OR #25 OR #26 OR #27 OR #28 OR #29 OR #30 OR #31 OR #32 OR #33 OR #34 OR #35 OR #36 OR #37 OR #38 OR #39 OR #40 OR #41 OR #42 OR #43 OR #44 OR #45 OR #46 OR #47 OR #48 OR #49 OR #50 OR #51 OR #52 OR #53 OR #54 OR #55 OR #56 OR #57 OR #58 OR #59 OR #60 OR #61 OR #62 OR #63 OR #64 OR #65 OR #66 OR #67 OR #68 OR #69 OR #70 OR #71 OR #72 OR #73 OR #74 OR #75)

- #77 MeSH descriptor Motor Neuron Disease explode all trees in MeSH products
- #78 lou gehrig disease in Record Title or lou gehrig disease in Abstract in all products
- #79 lou gehrig s disease in Record Title or lou gehrig s disease in Abstract in all products
- #80 motor neuron disease in Record Title or motor neuron disease in Abstract in all products
- #81 motor neurone disease in Record Title or motor neurone disease in Abstract in all products
- #82 mnd in Record Title or mnd in Abstract in all products
- #83 lateral sclerosis in Record Title or lateral sclerosis in Abstract in all products
- #84 als in Record Title or als in Abstract in all products
- #85 anterior horn cell disease in Record Title or anterior horn cell disease in Abstract in all products
- #86 bulbar palsy in Record Title or bulbar palsy in Abstract in all products
- #87 spinal muscular atrophy in Record Title or spinal muscular atrophy in Abstract in all products
- #88 MeSH descriptor Parkinson Disease, this term only in MeSH products
- #89 paralysis agitans in Record Title or paralysis agitans in Abstract in all products
- #90 parkinson disease in Record Title or parkinson disease in Abstract in all products
- #91 parkinson syndrome in Record Title or parkinson syndrome in Abstract in all products
- #92 parkinson s in Record Title or parkinson s in Abstract in all products
- #93 parkinsonism in Record Title or parkinsonism in Abstract in all products
- #94 ms in Record Title or ms in Abstract in all products
- #95 multiple sclerosis in Record Title or multiple sclerosis in Abstract in all products
- #96 MeSH descriptor Multiple Sclerosis explode all trees in MeSH products
- #97 degenerative neurologic* disease* in Record Title or degenerative neurologic* disease* in Abstract in all products
- #98 degenerative neurologic* condition* in Record Title or degenerative neurologic* condition* in Abstract in all products
- #99 long term neurologic* disease* in Record Title or long term neurologic* disease* in Abstract in all products
- #100 long term neurologic* disease* in Record Title or long term neurologic* disease* in Abstract in all products
- #101 long term neurologic* condition* in Record Title or long term neurologic* condition* in Abstract in all products
- #102 evolving neurologic* disease* in Record Title or evolving neurologic* disease* in Abstract in all products
- #103 evolving neurologic* condition* in Record Title or evolving neurologic* condition* in Abstract in all products
- #104 Itnc* in Record Title or Itnc* in Abstract in all products
- #105 (#77 OR #78 OR #79 OR #80 OR #81 OR #82 OR #83 OR #84 OR #85 OR #86 OR #87 OR #88 OR #89 OR #90 OR #91 OR #92 OR #93

OR #94 OR #95 OR #96 OR #97 OR #98 OR #99 OR #100 OR #101
 OR #102 OR #103 OR #104)
 #106 (#76 AND #105)
 #107 MeSH descriptor Patient Care Team, this term only
 #108 (care team*):ti or (care team*):ab
 #109 (#76 OR #107 OR #108)
 #110 MeSH descriptor Epilepsy, this term only
 #111 (epilepsy):ti or (epilepsy):ab
 #112 (epileptic):ti or (epileptic):ab
 #113 (seizure disorder*):ti or (seizure disorder*):ab
 #114 (landau kleffner syndrome):ti or (landau kleffner syndrome):ab
 #115 (cerebral palsy):ti or (cerebral palsy):ab
 #116 (spastic diplegia):ti or (spastic diplegia):ab
 #117 ("little disease"):ti or ("little disease"):ab
 #118 (cp):ti or (cp):ab
 #119 (diplegia spastic):ti or (diplegia spastic):ab
 #120 (little s disease):ti or (little s disease):ab
 #121 MeSH descriptor Cerebral Palsy, this term only
 #122 (#110 OR #111 OR #112 OR #113 OR #114 OR #115 OR #116 OR
 #117 OR #118 OR #119 OR #120 OR #121)
 #123 (#122 AND #109)
 #124 (#123 AND NOT #106)

Appendix 3 Definitions for selection for review/data extraction

Method to ensure or improve continuity of care

(based on Freeman *et al.* (2001, 2002) with carers added as a group who might also experience continuity of care).

Any service, any aspect of service organisation or delivery, or any model of care intended to ensure or improve any of the following:

- Co-ordinated and smooth progression of care from service user's or informal carer's point of view (*experienced continuity*).
- Care that sustains a person's preferred social and personal relationships in the community and enhances their quality of life (*continuity of social context*).
- Provision of one or more named, individual professionals with whom the service user or informal carer can establish and maintain a consistent therapeutic relationship (*relational, personal and therapeutic continuity*).
- Care provided by as few professionals [over time] as possible, consistent with need (*longitudinal continuity*).
- Flexibility and adjustment to the needs of the individual over time (*flexible continuity*).
- Provision of care for as long as the service user needs it (*long-term continuity*).
- Excellent transfer of information that follows the service user and informal carer (*continuity of information*).
- Excellent transfer of information between professionals working in statutory and non-statutory agencies, working in primary and secondary [and tertiary] care and with service users and their informal care networks (*cross-boundary continuity; team continuity*).

Evaluation

Any form of research (qualitative or quantitative) or other form of structured enquiry (such as audit or inspection) that reports the *effect* or *outcomes* of a method of ensuring or improving continuity of care.

Description

Any material that describes any organisational or delivery features (e.g. provider, staffing, skill mix, location) of a method of ensuring or improving continuity of care.

Systematic review/meta-analysis

Any paper that describes itself as a systematic review and/or a meta-analysis. The team will make judgements subsequently about whether it is accurately described.

Appendix 4 Data extraction headings for the descriptive review

What is the model of care?

Self-care intervention
Screening/prescription/access to care
Assessment and management
Register
Prof led care pathway
User-led care pathway
Specialist nurse
GP with special interest
Nurse-led clinic
MD rehab
Palliative care
Prof training re: continuity of care
other(specify)

Where is it delivered?

In-patient setting
Out-patient setting
Home
Community
Other (specify)

What condition(s) does it cover?

Cerebral Palsy
Epilepsy
Generic neurology
Head injury
Huntington's Disease
Migraine
MND/ALS
Multiple Sclerosis
Muscular Dystrophy
Parkinson's Disease
Spinal injury
Stroke
Other (specify)

Who delivers the model?

Specialist doctors:

Neurology
Rehabilitation
Other (specify)
Speciality not mentioned

Nurses:

Neurology community based
Neurology acute based
Other specialist community based (specify)
Other specialist acute based (specify)
Specialty not mentioned
General community based
General acute based
Nurse not otherwise specified

Therapists:

Physiotherapist
Occupational therapist
Speech and language therapist
Dietician/nutritionist
Other (specify)
Therapist not otherwise specified

Other:

Psychologist
Counsellor
Social worker
Social services
Voluntary organisation
Co-ordinator/care manager
GP

Any other (specify)

What elements are included in this model of care?

Diagnosis
Assessment of:
 condition
 disability/impairment
 service need
 nursing need
 other
Care file - patient held
Care file - professional held
Care plan - patient held

Care plan - professional held
Care/service co-ordination
Data management system
Drug/medication review
Equipment/aids supply
Goal setting
Information/education/training - carer
Information/education/training - patient
Information/education/training - professional
Monitoring/review
Multi-disciplinary meeting/consultation
Other clinical input (specify)
Palliative care
Phone helpline/advice line/contact line
Rehabilitation input
Specialist clinics
Support group - carer
Support group - patient
Telemedicine/video link
Other (specify)

Aspects of service delivery and organisation

Who can refer:

- acute health care professional
- community health care professional
- patient
- voluntary organisation
- other (specify)

Type of access

Size of caseload

Other case load characteristics

Age of patients

Time-limited or ongoing service?

Funded by

Which agency provides?

Exclusion criteria for service:

- age
- mental capacity
- physical capacity/condition
- language
- co-morbidity
- other (specify)
- none reported

Type of continuity of care

Personal agency

Experienced

Social context
Relational, personal, therapeutic
Longitudinal
Flexible
Long-term
Information continuity
Cross-boundary/team

Appendix 5 Evaluation papers

Balaratnam, M., Adib-Sami, P., D'arcy, C., Nicholas, R. and Malik, O. (2007) *Community-based Multidisciplinary MS Clinics Reduce Hospital Bed Occupancy and Enhance Patient Satisfaction*, Hammersmith and Fulham Social Services Community Rehabilitation Team; Hammersmith and Fulham Branch of UK MS Society.

Barnes, M.P. and Skeil, D.A. (1996) Outpatients in neurological rehabilitation, *International Journal of Rehabilitation Research*, 19, 39-45.

Bhatt, H., Matharu, M.S., Henderson, K. and Greenwood, R. (2005) An audit of first seizures presenting to an Accident and Emergency department, *Seizure*, 14, 58-61.

Carne, W., Cifu, D., Marcinko, P., Pickett, T., Baron, M., Qutubbudin, A., Calabrese, V., Roberge, P., Holloway, K. and Mutchler, B. (2005) Efficacy of a multidisciplinary treatment program on one-year outcomes of individuals with Parkinson's disease, *Neurorehabilitation*, 20, 161-167.

Castleton, B., Dunstan, C., Nicholas, V., Titheridge, E., Bouckley, S., Crawhurst, P. and Friggens, W. (2005) Improving care for patients with Parkinson's disease, *British Journal of Health Care Management*, 11, 111-115.

Chataway, J., Porter, B., Riazi, A., Heaney, D., Watt, H., Hobart, J. and Thompson, A. (2006) Home versus outpatient administration of intravenous steroids for multiple-sclerosis relapses: a randomised controlled trial, *Lancet Neurology*, 5, 565-571.

Corr, B., Frost, E., Traynor, B. J. and Hardiman, O. (1998) Service provision for patients with ALS/MND: a cost-effective multidisciplinary approach, *Journal of the Neurological Sciences*, 160 Suppl 1, S141-145.

Craig, J., Young, C. A., Ennis, M., Baker, G. and Boggild, M. (2003) A randomised controlled trial comparing rehabilitation against standard therapy in multiple sclerosis patients receiving intravenous steroid treatment, *Journal of Neurology, Neurosurgery and Psychiatry*, 74, 1225-1230.

D'arcy, C. (2005) Managing multiple sclerosis: working in partnership, *Nursing Management (Harrow)*, 12, 32-35.

Davis, J., Roberts, R., Davidson, D., Norman, A., Osgston, S., Grimshaw, J., Davey, P., Grant, J. and Ruta, D. (2004) Implementation strategies for a Scottish National Epilepsy Guideline in Primary Care: results of the Tayside Implementation of Guidelines in Epilepsy Randomized (TIGER) Trial, *Epilepsia*, 45, 28-34.

Edmonds, D.P. (2005 - March) *Proposal for a Flagship Neurology and Specialist Palliative Care Service for People Severely Affected by Multiple Sclerosis in South London: Post-Service Exploratory Study.*

Edmonds, D.P. (2006 - April) *Proposal to Create a Flagship Neurology and Specialist Palliative Care Service for Patients with Severe Multiple Sclerosis in South London: Service Design Study.*

Freeman, G.K. and Richards, S.C. (1994) Personal continuity and the care of patients with epilepsy in general practice, *British Journal of General Practice*, 44, 395-399.

Freeman, J.A., Langdon, D.W., Hobart, J.C. and Thompson, A.J. (1999) Inpatient rehabilitation in multiple sclerosis: do the benefits carry over into the community? *Neurology*, 52, 50-56.

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, 232-238.

Goldstein, L.H., Minchin, L., Stubbs, P. and Fenwick, P.B. (1997) Are what people know about their epilepsy and what they want from an epilepsy service related? *Seizure*, 6, 435-442.

Goldstein, L.H., Pender, N., Parshall, A.M. and Fenwick, P.B. (1997) Patients' and referring doctors' perceptions of treatment on an in-patient neuropsychiatry/epilepsy unit: a study of three cohorts, *Seizure*, 6, 13-20.

Goodwin, M., Wade, D., Luke, B. and Davies, P. (2002) A survey of a novel epilepsy clinic, *Seizure*, 11, 519-522.

Gunter, M.J., Brixner, D., Von Worley, A., Carter, S. and Gregory, C. (2004) Impact of a seizure disorder disease management program on patient-reported quality of life, *Disease Management*, 7, 333-347.

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Appendix 7 Reported measures of disability and/or impairment

Table A7.1 Disability or impairment measures reported

<i>First author and year</i>	<i>Model of care</i>	<i>How measured</i>	<i>When measured</i>	<i>Results for controls/before</i>	<i>Results for subjects/after</i>	<i>Statistical significance</i>
Epilepsy						
Davis 2004	Supported implementation of national care guidelines	Mean (95% CI) ESI-55 cognitive function test	Baseline	21.0 (19.9 to 22.0)	Intermediate: 21.3 (20.6 to 22.0) Intensive: 20.7 (19.9 to 21.4)	
			12m	21.1 (20.2 to 22.0)	Intermediate: 20.9 (20.1 to 21.7) Intensive: 20.3 (19.6 to 21.1)	Paired t-tests value not reported. Said to be ns.
Multiple sclerosis						
Rossiter 1998 and 1999	Integrated care pathway	Mean Barthel Index score	Admission and discharge	Cohort 1: 12 Cohort 2: 12 Cohort 3: 12	Cohort 1: 15 Cohort 2: 15 Cohort 3: 14	Not reported. Said to be no sig, diff between each cohort.
		Mean Handicap Assessment Scale ¹ score	As above	Cohort 1: 16 Cohort 2: 17 Cohort 3: 15	Cohort 1: 17 Cohort 2: 15 Cohort 3: 13	As above. Said to be ns.
		Mean FIM – motor score	As above	Cohort 1: 60 Cohort 2: 61 Cohort 3: 60	Cohort 1: 69 Cohort 2: 69 Cohort 3: 67	As above. Said to be ns.
		Mean FIM – cognitive score	As above	Cohort 1: 29 Cohort 2: 30 Cohort 3: 29	Cohort 1: 29 Cohort 2: 30 Cohort 3: 29	As above. Said to be ns.
Makepeace 2001	Multi-disciplinary community team	Means Kurtzke Expanded Disability Status Scale score	Baseline and 6m	4.78	4.93	Wicoxon test. Not reported directly, $p < .05$ ²

<i>First author and year</i>	<i>Model of care</i>	<i>How measured</i>	<i>When measured</i>	<i>Results for controls/before</i>	<i>Results for subjects/after</i>	<i>Statistical significance</i>
		Mean FIM motor score	As above	71.9	69.7	As above, $p < .05$ ²
		Mean FIM cognitive score	As above	31.2	29.7	T-test. Not reported directly. $p < .05$ ²
		Mean Newcastle Independence Assessment Form	As above	26.5	28.0	Wicoxon test. Not reported directly, said to be ns
Craig 2003	Multi-disciplinary team management of relapse, combined with IV steroid treatment	Mean (SD) GNDS score	Baseline	21.5 (7.2)	21.1 (7.1)	
			3m	19.7 (10.6)	13.2 (8.9)	Univariate ANOVA on change from baseline to 3m. Result not reported, said to be significant.
		Mean (SD) AMCA	As above	48.0 (13.8)	56.1 (15.4)	
				54.3 (18.0)	69.1 (6.9)	Mann-Whitney U on change from baseline to 3m. Said to be significant
		Mean (SD) Barthel Index	As above	14.7 (2.2)	14.8 (2.7)	
				15.2 (4.1)	17.4 (2.3)	As above. Said to be significant
		Mean (SD) Human Activity Profile (Maximum Score)	As above	58.3 (16.2)	54.4 (20.2)	
				54.5 (25.1)	69.9 (14.2)	As above. Said to be significant.

<i>First author and year</i>	<i>Model of care</i>	<i>How measured</i>	<i>When measured</i>	<i>Results for controls/before</i>	<i>Results for subjects/after</i>	<i>Statistical significance</i>
		Mean (SD) Human Activity Profile (Adjusted Score)		33.2 (15.4)	35.1 (19.0)	
				36.7 (23.7)	53.2 (20.7)	As above. Said to be significant.
Pozzilli 2002	Multi-disciplinary home care	EDSS	Baseline and 12m	Not reported	Not reported	Results not reported. Said to be no sig. diff in change between subjects and controls
		MMSE	As above	As above	As above	As above
		FIM	As above	As above	As above	As above
		Fatigue Severity Scale	As above	As above	As above	As above
Chataway 2006	Home-based IV steroid administration	Mean (SD) MSWS-12 walking score	As above	73.7 (23.4)	67.7 (31.1)	
				54.9 (31.7)	46.1 (28.2)	Repeated measures ANOVA of difference (95%CI) in mean score change. 2.6 (-5.8 to 11.1), p=.536
		Mean (SD) EDSS score	As above	5.2 (1.3)	5.1 (1.5)	
				4.4 (1.9)	4.1 (2.0)	As above. 0.2 (-0.2 to 0.6), p=.321
Oeseburg 2004	Transmural care (same as Jansen?)	Mean (range) EDSS score	Baseline and 15m	4.7 (0 to 8.5)	Not reported	Not reported. Said to be no sig. change over time
		Mean (range) ISS score	As above	19.9 (3 to 44)	Not reported	As above
		Mean (range) Environmental Health Scale score	As above	14.2 (1 to 28)	Not reported	As above
O'Hara 2002	Consumer focussed,	Median (range) Barthel	Baseline	17 (0-20)	17 (0-20)	

<i>First author and year</i>	<i>Model of care</i>	<i>How measured</i>	<i>When measured</i>	<i>Results for controls/before</i>	<i>Results for subjects/after</i>	<i>Statistical significance</i>
	professional advice about self-care	Index score				
			6m	17 (0-20)	17 (0-20)	Wilcoxon test of difference from baseline to follow-up. Subjects $z=0.49$, $p=.62$. Subjects $z = -3.41$, $p=.001$
		Mean (SD) score on De Souza MS mobility scale	Baseline	5.8 (3.4)	5.8 (3.7)	
			6m	5.6 (3.3)	5.8 (3.6)	ANOVA. $F=0.01$, $p=.91$
		Mean (SD) score on SDDR: SDDRO subscale	Baseline	6.6 (7.0)	5.5 (6.3)	
			6m	7.4 (7.4)	6.0 (6.6)	ANOVA $F= 0.26$, $p=.61$
		SDDRE subscale	Baseline	5.2 (4.2)	5.0 (4.3)	
				5.8 (4.3)	4.8 (3.8)	ANOVA $F=4.17$, $p=.04$
Parkinson's disease						
Trend 2002 and associated papers	Multi-disciplinary rehabilitation with group educational support	Mean (SD) PD Disability Questionnaire	Baseline	50.3 (18.0)	48.9 (14.4)	
			24 weeks	55.3 (19.5)	53.4 (17.4)	GLIM analysis of difference in change scores controlling for baseline differences. Not reported directly. $p=.558$
		Mean (SD) stand-walk-sit time (seconds)	As above	21.5 (8.0)	20.1 (8.7)	

<i>First author and year</i>	<i>Model of care</i>	<i>How measured</i>	<i>When measured</i>	<i>Results for controls/before</i>	<i>Results for subjects/after</i>	<i>Statistical significance</i>
				23.1 (10.3)	19.4 (6.9)	As above. p=.093.
		Mean (SD) nine-hole peg test (seconds)	As above	20.2 (8.1)	23.9 (31.2)	
				20.0 (8.1)	20.4 (14.8)	As above, p=.273
		Mean (SD) UPDRS score, speech	As above	1.68 (0.97)	1.40 (0.97)	
				1.61 (0.97)	1.60 (0.97)	As above, p=.129
		Mean (SD) UPDRS score, salivation	As above	1.24 (1.04)	1.13 (1.11)	
				1.34 (1.17)	1.21 (1.03)	As above, p=.922
		Mean (SD) UPDRS score, swallowing	As above	0.85 (1.09)	0.89 (1.05)	
				1.10 (1.07)	1.15 (1.10)	As above, p=.923
		Mean (SD) UPDRS score, writing	As above	2.27 (1.16)	2.17 (1.14)	
				2.46 (1.05)	2.30 (1.15)	As above, p=.747

<i>First author and year</i>	<i>Model of care</i>	<i>How measured</i>	<i>When measured</i>	<i>Results for controls/before</i>	<i>Results for subjects/after</i>	<i>Statistical significance</i>
Carne 2005	Multi-disciplinary assessment and management	Mean (SD) UPDRS Part III Motor Examination Score	Baseline and follow-up (around 12m)	28.72 (13.16)	30/43 said to have improved with mean improvement of -11.28. 11/43 said to have deteriorated with mean deterioration of +9.72 Mean improvement of -5.38 ³	None reported
Montgomery 1994	Patient education and health promotion programme	Mean (SE) UPDRS summary score	Baseline	29.2 (1.1)	28.8 (1.3)	
			6m	31.9 (1.2)	28.9 (1.3)	Paired difference t-test on mean change score. Not reported directly, p said to be =.007 ⁴
Jahanshahi 1994	Nurse practitioner	Mean (SD) Functional Disability Questionnaire score. PD patients	Baseline	49.7 (14.2)	53.1 (19.7)	
			6m	54.2 (19.4)	54.2 (19.4)	Not reported. Appears to be within group analysis. Reported as ns
		Mean (SD) Functional Disability Questionnaire score. Dystonia patients	As above	56.8 (10.3)	55.7 (21.2)	
				56.4 (18.5)	56.6 (19.2)	As above.

<i>First author and year</i>	<i>Model of care</i>	<i>How measured</i>	<i>When measured</i>	<i>Results for controls/before</i>	<i>Results for subjects/after</i>	<i>Statistical significance</i>
Reynolds 2000	Nurse specialist	Functional Disability Scale. Social disability	Baseline and possibly 12m	Not reported	Not reported	Kruskall-Wallis test on change in score. H=3.91, df=3, ns
		Physical activity				H=3.18, df=3, ns
		Self-care				H=7.12, df=3, ns
		Leisure				H=2.67, df=3, ns
Hurwitz 2004	Nurse specialist	Mean (SD) Dot-in-square test score	Baseline	45.0 (21.8) N=808	45.6 (21.7) N=1028	
			2 years	46.0 (21.1) N=558	45.3 (21.2) N=696	OR (95% CI) -0.70 (-3.25 to 1.84), p=.59
		% able to rise from sitting position	Baseline	42.6% no problems 19.2% without holding on 37% unable or had to hold on N= 798	46% no problems 18.2% without holding on 34.3% unable or had to hold on N=993	
			2 years	39.6% no problems 14.7% without holding on 44.2% unable or had to hold on N = 550	35.6% no problems 16.4% without holding on 47.3% unable or had to hold on N = 691	Single OR (95% CI) is reported (not clear for which part of results this was calculated) 1.15 (0.93 to 1.42, p=.19)

<i>First author and year</i>	<i>Model of care</i>	<i>How measured</i>	<i>When measured</i>	<i>Results for controls/before</i>	<i>Results for subjects/after</i>	<i>Statistical significance</i>
Mixed neurological						
Haig 1994	Multi-disciplinary team assessment	Reported change of overall function from telephone follow-up questionnaire	12m after evaluation	-	16/40 rated no change 13/40 rated better 8/40 rated worse 3 nk	Chi-squared test of goodness of fit. $X^2 = 2.89$, ns.
Sitzia 1998	Multi-disciplinary rehab with post-discharge follow-up	Median NHP (part 1) – physical mobility. PD patients	Baseline and one month after discharge	56.6	54.5	Wilcoxon $Z=2.1$, $p<.05$ ⁵
		As above, MS patients	As above	66.1	55.5	Wilcoxon $Z=2.1$, $p<.05$ ⁵
Ward 2004	Individualised patient education	Mean (SD) NEADL score	Baseline	6.15 (5.58)	7.83 (6.33)	
			12m	6.65 (6.07)	9.45 (7.13)	Paired difference t-test (within group) not reported directly. Controls ns, subjects $p=.002$. Mean difference for subjects (95% CI) 1.62 (0.69 to 2.55), $p=.001$

AMCA Amended Motor Club Assessment
 EDSS Kurtzke's Expanded Disability Status Scale
 FIM Functional Independence Measure
 GNDS Guys Neurological Disability Scale
 IMPACT measure of impact of epilepsy on individuals' lives
 ISS Incapacity Status Scale
 MMSE Mini-Mental State Examination
 MSIS
 MSWS
 NEADL Nottingham Extended Activities of Daily Living Scale
 NHP Nottingham Health Profile

SDDR: Standard Day Dependency Record

SDDRO: subscale of SDDR – measure of number of times people have been helped on range of 'life domains' in past 24 hours

SDDRE: subscale of SDDR – indication of how essential help given is in each life domain.

UPDRS Unified Parkinson's Disease Rating Scale

1. Decrease in score indicates improvement
2. Performance declined over time.
3. Calculated by us.
4. The mean change for the control group is reported to be 29.7. This is very different from the apparent mean change reported in other tables in the paper – i.e. from 29.9 to 31.9 is a mean change of 2.0. It is not clear on which of these figures the apparently statistically significant change is based.
5. Reported values were identical for both groups. This is not explained in the paper.

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