



#### PROGRAMME OF RESEARCH ON MODELS OF SERVICE DELIVERY

# RESEARCH ON THE ORGANISATION, MANAGEMENT AND DELIVERY OF SPECIALIST NEUROLOGICAL REHABILITATION (REF: NR249)

#### 1 Introduction

The National Institute for Health Research Service Delivery and Organisation Programme (NIHR SDO) wishes to commission research on the organisation, management and delivery of specialist neurological rehabilitation. The intention is to add to the evidence base that is relevant to:

 the commissioning, development, implementation and management of rehabilitation services for neurological conditions in the NHS and wider health and social care system

This call seeks proposals from researchers that address a number of key questions identified by an SDO commissioned scoping report on specialist neurological rehabilitation (Gladman et al 2007: SDO/132/2006). This brief sets out the context for this topic area and indicates issues that might fruitfully be investigated.

For those interested in making an application the Full Proposal Application form and associated guidance notes are available from the SDO website (<a href="www.sdo.lshtm.ac.uk/ecashome.html">www.sdo.lshtm.ac.uk/ecashome.html</a>) and should be read in conjunction with this Research Brief.

## 2 The SDO Programme

The Service Delivery and Organisation Research and Development Programme (SDO) is one of the national research programmes of the NHS in England and is a constituent programme of the National Institute for Health Research (NIHR). The NIHR SDO Programme improves health outcomes for people by:

 Commissioning research and producing research evidence that improves practice in relation to the organisation and delivery of health care, and  Building capacity to carry out research amongst those who manage, organise and deliver services and improve their understanding of research literature and how to use research evidence.

Further information on the Programme, including a list of past, current and recently commissioned projects, can be found on the SDO website (www.sdo.lshtm.ac.uk).

# 3 Background

The National Service Framework for Long Term Neurological Conditions (DH 2005) defines a long-term neurological condition as one that results from disease of, injury or damage to the body's nervous system (the brain, spinal cord and/or their peripheral nerves) which will affect the individuals and their family in one way or another for the rest of their lives. This definition includes sudden onset conditions such as traumatic head injury, intermittent conditions such as epilepsy, progressive conditions such as Parkinsons disease and stable neurological conditions but with changing needs due to development or ageing. Neurological disorders are the commonest cause of long-term dependence and account for the largest single use of resources within the NHS It is estimated that around 350, 000 people in the UK need help with activities of daily living due to a long term neurological condition.

Rehabilitation aims to maximise social participation while minimising the somatic and emotional distress of both the patient and any family. It depends upon full diagnosis (assessment) of the situation followed by goal setting and multi-focal interventions co-ordinated between different professions and agencies and spread over time. Rehabilitation is not a specific treatment or group of treatments and therapies. It is a way of thinking, a method used to resolve as far as possible problems experienced by the patient (Wade and de Jong, 2000). Good quality rehabilitation generally requires not only a specialist team of people but also budgetary and management arrangements that facilitate cooperation and avoid blocking any of the actions needed.

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

In 2006, the SDO Programme commissioned a scoping study to review the national and international literature around the organisation and delivery of specialist neurological rehabilitation services and to map the current

provision of services in the United Kingdom (SDO/132/2006: a copy of which from SDO be obtained the website: www.sdo.lshtm.ac.uk/files/project/132-final-report.pdf). The review concluded that much investment into evaluating rehabilitation services is still required (Gladman et al 2007). Apart from the acute management of stroke, there is an absence of evidence in favour of any model of specialist neurological rehabilitation. However findings were consistent with a beneficial effect of rehabilitation and re-state the view that services should be patientcentred, long-term, joined-up and participation orientated but identified no evidence of how these could be achieved. In particular little is known about models of specialist neurological community rehabilitation or the best way to meet longer term needs.

The review found several examples of well organised specialist neurological rehabilitation services in cities, particularly those with academic centres of expertise. Service users were less well served living at a distance from specialist hubs or in rural areas. Services were better developed for certain conditions (e.g. the acute management of stroke) than for others (e.g. traumatic brain injury and hidden disabilities such as cognitive impairment or psychological problems). Innovative ways of organising and delivering services were reported but many of these resulted from good-will rather than cross commissioning with for example the voluntary and independent sectors.

The deficiency in the available evidence meant that the scoping study was not able to identify clearly dominant models of health service delivery or provide much evidence in the way of comparative outcome or cost-data concerning most forms of in-patient or out patient services. It has however identified several key research questions relating to the delivery and organisation of specialist rehabilitation services that require additional empirical research in order to inform service development and improve care for individuals with neurological conditions.

# 4 Current call for proposals

The SDO programme is inviting research proposals to conduct empirical research on the topic of specialist rehabilitation services for neurological conditions that can contribute to high quality services in the future.

All proposals should identify and address questions regarding:

- the clinical effectiveness of services
- the extent to which services meet the different needs of and produce different outcomes for service users, families, professionals and services over the short and longer term
- economic effectiveness

This call focuses on services other than the acute management of stroke for which there is existing evidence.

Applicants should be guided by the findings of the scoping review but pay particular attention to the following priority areas for the SDO:

- how effective are different models of care delivery for specialist neurological rehabilitation? How do they contrast and compare particularly for those conditions for which evidence is more patchy such as traumatic brain injury?
- how do services which provide generic models of care delivery for neurological rehabilitation compare to those focusing on specific conditions in specialist units? What are the key contributors to success? How do specialist practitioner roles contribute within these services?
- how effective are models/organisation of rehabilitation services in different settings for example home-based, community settings and in-patient settings?
- how effective are innovative ways of organising services for example; hub and spoke models, novel web-based support services, vocational rehabilitation and use of trained volunteers?
- how is continuity maintained within rehabilitation services?; how do professionals work together in particular across transitions, between services, service providers (including the voluntary and independent sectors) and rehabilitation phases?

## References

Department of Health (2005) The National Service Framework for Long-Term Conditions London: DH

SDO 132/2006: Gladman J. Radford k. Edmans J. Sach T et al (2007) Specialist Rehabilitation for Neurological Conditions: Literature Review and Mapping Study SD Final Report found at:

www.sdo.lshtm.ac.uk/files/project/132-final-report.pdf

Wade DT, de Jong B (2000) 'Recent advances in rehabilitation' *British Medical Journal*: **320**: 1385-1358

## **5** Call for Proposals

The SDO Programme is seeking applications for innovative research that addresses the key priorities identified in the scoping report and which builds on previous SDO work and that is linked to the delivery and organisation of

rehabilitation for neurological conditions. Projects of up to three years duration may be funded to a maximum of £450,000 per project for empirical projects. Applicants should note that these are upper limits and that SDO anticipates funding some projects of shorter duration and lower cost. Value for money will be an important consideration in decision making and all costs must be justified.

The application process will be in one stage, and a maximum of £1.2 million over three years is available for research in this area. It is anticipated that up to three empirical research projects will be commissioned.

Because of the emphasis on empirical investigation it is important that proposals have adequately addressed issues of access and organisational support. For this call, joint proposals between NHS organisations and researchers or from researchers embedded in NHS organizations are most likely to be successful.

SDO funds research that is primarily of relevance to the NHS in England. However, there is no restriction on where researchers are based, or as to where empirical studies are undertaken. For this topic, studies located in the other countries of the UK may be particularly informative, as may comparative studies within the UK or between the UK and other national settings.

In developing new projects, proposal applicants are invited to take into consideration the following important points of guidance.

## 6 Appropriate areas of investigation

- Proposed projects should be clearly linked to the research priorities identified in the scoping report (SDO/132/2006).
- Projects should develop work clearly located within one or more of the key topic areas identified above.
- Applicants should familiarise themselves with relevant earlier work by the SDO Programme, including previous Research Funding Briefs, Scoping Papers, Research Reviews and completed and ongoing empirical research projects. Work that builds on, extends and deepens the ideas explored in the current SDO portfolio will be welcomed (www.sdo.LSHTM.ac.uk).
- Proposed projects should be fully cognisant of current policy priorities, managerial concerns and practice-level preoccupations. They should draw on and clearly relate to, for example, National Service Frameworks (NSFs), national implementation programmes, pressing and emergent policy issues, and the research priorities as articulated by other important national bodies (including key charitable organisations).

 Although there is no restriction on where in the UK funded work can take place, all work proposed should have clear and demonstrable relevance to the English health care system.

#### 7 Involvement of stakeholders

- SDO research is largely stakeholder-driven. Applicants should demonstrate involvement of all relevant stakeholders in the design, execution and communication of the research. In addition to health care practitioners and managers, 'stakeholders' also include service users, carers and lay people, local communities and minority ethnic communities.
- A core issue is the practical application, communication and uptake of research findings. Applicants are invited to consider the nature of expected research outputs and how these might be better communicated to important policy, managerial and practice audiences in ways that are likely to enhance impact.
- Given the core research concerns of the SDO Programme, and the need to build robust bodies of knowledge, successful projects are most likely to involve partnership working between experienced academic teams and those more closely involved in the design and delivery of services.
- It is a core concern of the SDO Programme that all commissioned projects should pay full attention to the needs and experiences of services users and their carers. Thus proposed projects should be explicit in communicating how the proposed work has potential implications for service delivery that could lead to enhanced public and community engagement.

#### 8 Nature of the investigations

- The research proposed can be secondary analysis of existing data, or new primary empirical research. Combinations of these and projects with multiple strands of work are also welcomed.
- In addressing issues in a way likely to lead to the wide applicability of findings, firm theoretical and conceptual underpinnings in tandem with substantial empirical work are likely to be important features. Approaches that utilise and take forward wider social science theories are encouraged.
- Empirical projects are likely to use a wide diversity of methods, including both qualitative and quantitative approaches, carefully matched to study questions and with clear understandings as to how findings from different empirical approaches will be integrated.
- Substantial empirical projects are likely to utilise broad teams with significant input from diverse disciplines and a commitment to developing robust inter-disciplinary approaches. It is frequently

- necessary to involve researchers with skills in organisational issues, although skills in human resource planning, health economics, sociology, psychology or other disciplines may also be required depending on the proposed study.
- Empirical work will need to address complex issues of service design, delivery and management, paying attention to inputs (including costs), processes, outputs and outcomes. Processes and outcomes should be addressed from varying perspectives including, importantly, those of front-line staff and those of patients and carers.

## 9 Outputs from the proposed work

- In outlining their research plans, the applicants should make clear how findings will be communicated effectively to a wide variety of academic, policy and service audiences.
- At a minimum, researchers will be expected to deliver the following written outputs from any proposed research: an executive summary with clearly identified policy, managerial and practice implications; a full report detailing all the work undertaken; supporting technical appendices.
- In addition, on completion of projects, successful applicants should be prepared to work with the SDO to develop summaries of their work for wider audiences (for example, see the *Research Briefs* already developed from many completed SDO projects; www.sdo.LSHTM.ac.uk).
- Applicants should outline plans for conference, seminar and other forms of dissemination to go alongside written communications.
- Where appropriate, the proposed work should be designed and delivered in a way that is likely to lead to significant high-quality peerreviewed publications.
- Projects lasting more than one year may be expected to deliver interim reports on progress and provisional findings (approximately annually).

## 10 Application process and schedule

- The process of commissioning the study will be in one stage and applicants should submit full proposals via the SDO electronic Commissioning and Appraisal System (eCAS).
- Applicants must submit proposals online via the SDO website: www.sdo.lshtm.ac.uk/ecashome.html
- Further guidance regarding online submission is available on the eCAS website using the help guidance on each page. If you are a first time applicant you will need to register with eCAS. All applicants are

- advised to familiarise themselves with eCAS before the deadline for proposals.
- To ensure the efficient and equitable answering of additional queries, all questions about this research call should be sent by e-mail only to Donna.Cox@LSHTM.ac.uk with the words 'Neurological Rehabilitation NR249 Query' in the subject/header. Questions received by 10 April 2008 will have generic answers posted on the SDO website (www.sdo.LSHTM.ac.uk) by 17 April 2008. No other correspondence about this research call can be entered into.
- Full proposals should be submitted by 1pm on 1 May 2008. No late proposals will be considered. No paper-based submissions will be considered.
- Following submission of proposals successful applicants will be notified no later than end of June 2008. The project should start in September 2008 at the latest. Please note that these dates are approximate and may be subject to change.
- Projects of up to three years' duration may be funded up to a maximum of £450,000 per project. Proposed costs of the project should not exceed the limits stated. NHS R&D Programmes are currently funding Higher Education Institutions (HEI) at a maximum of 80% of Full Economic Cost (except for equipment over £50,000 100%). For non-HEI institutions, NHS R&D may fund 100% of costs. However, the SDO Programme reserves the right to award a grant for less than this maximum where appropriate.
- The SDO Programme will look favourably on proposals that include an element of research capacity building.
- Applicants should indicate how they will work with the SDO Programme and relevant stakeholders to build in an active program for disseminating their research findings in policy, practice and research contexts.
- Applicants should ensure that their proposal complies with the Research Governance Framework. Successful applicants will be required to provide proof of research ethics committee approval for their project, if this is required. Further guidance on requirements can be found on the SDO website http://www.sdo.lshtm.ac.uk/proposalresources.html
- Successful applicants will be expected to attend at least one meeting with the SDO Programme at their central London offices during the project lifetime and, as such, should ensure that travel costs are appropriately costed within the proposal budget. We anticipate that

there will be informal discussions with NCCSDO throughout the duration of the project regarding the final report.

- The successful applicant's final report will consist of three components. NCCSDO will provide templates and guidance notes for:
  - a 500-word executive summary
  - a 5000-word summary (content for a publishable SDO research summary)
  - a main report (plus appendices) which should not exceed 80,000 words.

#### Addendum

This document was published by the National Coordinating Centre for the Service Delivery and Organisation (NCCSDO) research programme, managed by the London School of Hygiene & Tropical Medicine.

The management of the Service Delivery and Organisation (SDO) programme has now transferred to the National Institute for Health Research Evaluations, Trials and Studies Coordinating Centre (NETSCC) based at the University of Southampton. Prior to April 2009, NETSCC had no involvement in the commissioning or production of this document and therefore we may not be able to comment on the background or technical detail of this document. Should you have any queries please contact sdo@southampton.ac.uk.