Commissioning Brief (11/1014)
Call for proposals for rapid synthesis of evidence on delivering effective self-management support
Closing date: 1.00pm on 17 March 2011

1. Introduction

In the UK, it is estimated that almost one in three people live with a longterm condition. There is growing support for self-management, where patients play an active role in looking after their own health, to improve outcomes and quality of life as well as reducing avoidable demands on emergency and planned care. Interventions have been developed, ranging from group patient education to telephone 'coaching' for people with complex needs. But it is difficult for health service managers to know which interventions work, at what cost and the impact on the wider health system.

This is a complex field and it is difficult to make sense of current state of knowledge; a brief sketch is given in Section 2. A number of reviews have been carried out on different aspects of self-management. But these do not always answer the pressing questions for commissioners – which approaches will help to reduce demands on hospitals while improving health outcomes for this population? This brief calls for a single authoritative narrative review to summarise existing evidence in key areas, set out in Section 3. The completed synthesis could inform a future major trial of a 'package' of self-management support for a whole population, based on best available evidence of what works.

Section 4 of this call for proposals offers general guidance to applicants on what makes for a successful application to the SDO programme, while section 5 sets out our expectations in relation to research outputs and knowledge mobilisation, and section 6 explains how applications are assessed and selected. Please note that sections 4 and 5 of this call for proposals providing the SDO programme's general guidance on research applications and knowledge mobilisation have been extensively revised and researchers are advised to note the changes.

The NIHR Service Delivery and Organisation programme is funded by the NIHR, with contributions from NISCHR in Wales. Researchers from Scotland and Northern Ireland should contact NETSCC to discuss their eligibility to apply.

The NIHR SDO programme improves health outcomes for people by:

- Commissioning research which evaluates models of service organisation and delivery and interventions which have the potential to improve service effectiveness, efficiency and productivity

- Building capacity and capability in NHS organisations to understand and implement the findings from health research in ways that improve service delivery and performance

The primary audience for SDO commissioned research is decision makers in the NHS in England and Wales – particularly managers and leaders in NHS organisations. We focus our research commissioning on topics and areas where we think research evidence can make a significant contribution to improving decision making, and so to improving the organisation and delivery of healthcare to patients.

Further information on the NIHR SDO programme, including a list of past, current and recently commissioned projects, can be found on the SDO website: www.sdo.nihr.ac.uk

2. Background to this call

The concept of supported self-management has been actively promoted in the last fifteen years. Pioneer work by Kate Lorig in the US (Lorig) in developing structured support for people with arthritis suggested potential benefits for patients and cost savings. In this country, a number of interesting local developments have emerged ‘bottom-up’. An example includes work at Hull to develop bundles of supported self-care for patients with heart failure, diabetes and dermatology. This involves a number of players ranging from general practice (including enhanced services) and community nursing; hospital and specialist outreach services, such as cardiology teams; local authorities; voluntary sector and patient support groups. There have also been important national initiatives. Perhaps the best known is the generic Expert Patient Programme launched in 2001 and aims to enrol 100,000 patients by 2012 [Phillips 2010]. Given the scale of planned participation, the challenge is moving from innovative service pilots to what some commentators have called “industrialising self-care” (Wilson 2005).

Note that in this brief, the term self-management is used to cover a range of activities to support people with longterm disease. This extends across the pyramid of tiered care, from low-level self-care and monitoring to more intensive support (case management) for frail older people with complex needs. Although these needs and activities are very different, the perspective of commissioning services for a given population makes it important to keep the scope broad. The focus of this brief is on self-management support for people with longterm disease (as opposed to other areas such as maternity services where self-care may also be important), given existing levels of demand and potential to make more effective use of resources.

2.2 State of research

A preliminary compendium of evidence on self-care support (DH 2007) describes a huge range of activities, from self-care plans to support networks. It is difficult though to identify key headline messages on what works. Some findings emerge from a review of patient-focused interventions on self-health (Coulter and Ellins 2006), suggesting limited effectiveness of information-only patient education. Reviewing different kinds of self-care support, including combined packages of care, there were a few general observations. Although no consistent pattern was found between intervention characteristics and strength of outcomes, the following factors were associated with larger effect sizes; longer intervention (twelve weeks or more) and higher intensity programmes; regular review by health professionals; focus on condition-specific topics; participative rather than didactic teaching methods; and involvement of family and carers.

The literature on self-management is dispersed and varies for different conditions. For instance, there is reasonable evidence of effect of condition-specific education programmes on improved disease control of diabetes and asthma but less for other conditions such as arthritis (DH 2007). This may reflect the complexities of strategies to deal with symptoms of pain and consequences of disability in a disease like arthritis, as opposed to those such as diabetes with clear interventions to improve blood glucose control (Newman). This can make it difficult to generalise from one disease area to another. Some patient groups are relatively overlooked in the evidence base, such as those with heart failure and chronic kidney disease.

In the UK, interest in self-care has focused on the expert patient programme. This is a structured programme to increase patients self-care skills, focused on a six week generic course delivered by trained patients. A national evaluation of this work, including a randomised trial of 629 patients does not seem to support early assertions that such interventions lead to marked improvements in health status and/or efficiency savings (Kennedy 2007). A review of this evaluation and three other well powered randomized trials in the UK confirmed the modest results (Griffiths 2007). It concluded that although lay led programmes increase patients' confidence to manage their disease, they are unlikely to reduce either hospital admissions or the use of other healthcare resources in the NHS.

The issue of resource use is key. Pioneer work in the US by Lorig and others led to inflated claims of reduced demands on services, including claims of 40% reduction in physician visits as well as improved outcome for patients (Lorig 1993). The recent Cochrane review concluded that lay led programmes found no significant change in healthcare use (Foster 2007). A more focused Cochrane review of web-based and telephone-based self-management interventions for people with chronic conditions concluded that they may serve as useful adjuncts (rather than substitutes for) traditional therapies (Glueckauf 2009). Commentators (Greenhalgh 2009) have noted that greater engagement by patients in managing their disease may actually lead to increase demand for formal care. Others reflect on changes in resource use in different parts of the system – for instance (Griffiths 2007), increases in scheduled care may be offset by reduced demand in unscheduled (emergency) care.

Management of longterm diseases is complex and support covers a diverse number of providers, from secondary to primary care, generic and specialist, and including voluntary sector and social enterprise. One interesting feature of the review of expert patients programmes was a process evaluation which concluded that this support did not easily fit with current services which are condition-specific and accessed via specialist health professional and either focused on primary or secondary care provision. The complexity of current health care provision was confirmed by a recently completed SDO funded project by Challis on self-care and case management in longterm conditions (Berzins 2009). This showed considerable variation (and confusion) in arrangements for self-care and nurse-led case management (for high resource-use patients), which was more complex than suggested by some US models.

2.3 Summary

Self-management spans a number of different interventions, from patient education to self-monitoring. Reviewing the state of current evidence is difficult, given the scatter of relevant studies and the lack of a common definition of self-management. There is a reasonable body of evidence on self-management education for people with chronic diseases which suggest modest, short-term improvement in patients' confidence to manage conditions but little evidence of improvement in symptoms or health-related outcomes or, importantly, in reduced healthcare. Many interventions are not well described. In addition, reviews confirm the limitations of much of the present research in terms of long term outcomes or comparative effectiveness and cost-effectiveness of different self-management strategies. There is considerable variation in what is provided to whom and it is difficult for decision-makers to identify 'headline findings' on what works.

2.4 Commissioned research – underway and just completed

NIHR SDO Programme –

The SDO programme issued a call in 2006 on self-care support. This resulted in £1.5 million funding in five projects, three of which have completed. This included a study on self-care and case management arrangements (Challis - a literature review and national survey plus multiple case studies); understanding barriers and facilitators of self-care support in mental health trusts (Gillard - mixed method cohort study in three contrasting self-care pilots in mental health trusts); self-management support among older adults (Parsons – case studies plus survey and audit of practice on choice and use of services by older people).

Other relevant work in the SDO portfolio include commissioned studies on e-health, with four studies completed and four at an advanced stage of progress. In addition, the NHS Evaluations panel have recommended for shortlisting a number of proposals relating to e-consultations and telehealth.

NIHR – other programmes

The Department of Health has funded substantive programmes related to self-care. An evaluation of expert carer (as opposed to patient) programme underway – Sue Yeardle, University of Leeds. In addition, substantial work currently funded to evaluate the pilots for personalised health budgets. Further work of relevance in this area is underway on care planning in long term conditions.

An ambitious programme of Whole Systems Demonstrators is also being funded by the Department of Health, centred on three sites (Cornwall, Kent, Newham), It is using tracers of chronic heart failure, COPD and diabetes to conduct a clustered randomized controlled trial (involving over 6000 patients) of telehealth and telecare in integrated health and social care settings. The evaluation is multi-faceted, with different components undertaken by different units, but the overall programme is led by Stan Newman (UCL) and due to conclude in 2011.

DH has also funded a cluster of projects on technology support for self-care including four completed studies on the role of networked technology for dementia care; self-management (social network and other activities) of obesity; modelling the impact of service innovation in chronic disease management; and integrating telecare for chronic disease management in the community.

Further substantial trials are funded through the Programme Grants for Applied Research, ranging from self-management of chronic pain to stepped care for depression, but many are not due to conclude for a few years.

Other national work (selective)

Other relevant condition-specific work has been funded by programmes such as Diabetes UK (for instance, a range of studies on patient-education programmes such as DESMOND and an important joint funded project on care planning, called Diabetes Year of Care), as well as the alliance of self care research which has commissioned a number of related studies at http://www.ascr.ac.uk/ResearchGrants2.htm.

The Health Foundation has invested £5 million in its Co-Creating Health programme, extended until 2012. This is a large-scale demonstration project in 8 sites to embed self-management support within mainstream health services (including a programme of clinician training). Evaluation findings are expected in 2012 [www.health.co.uk].

The National Primary Care R&D Centre in Manchester is undertaking a number of relevant studies. It has also developed the Whole Systems Informing Self-management Engagement

(WISE) approach, which includes changes to the system (open access rather than fixed outpatient appointments for patients) as well as other interventions directed at the patient (information/ education) and professional (training to support self-care). [www.npcrdc.ac.uk]

3. Remit of this call: main topic areas identified

The focus of this call is a **single evidence synthesis** on key findings on self-management. In particular, this will focus on the information needs of commissioners at a population level to identify effective strategies to support people with longterm conditions. It will consider evidence of effectiveness of validated self-management interventions at an organisational level to reduce hospitalisation rates and costs, without compromising patient outcomes. This synthesis is needed to inform decision-making by commissioners. A robust overview of the effectiveness and cost-effectiveness of different components in this complex field could also help to identify a likely package of care at a population level which could be tested by a major trial in the future. It is likely that the duration of the proposed project will be in the region of 12 months.

A narrative synthesis is needed, which would cover:

Models of care – who for?

Different models have been used to support self-management. These range from 'universal' models, such as the WISE approach, where practices are trained to deliver care and all patients normally attending clinics take part; to 'opt-in' models, such as expert patient programme, where patients elect to join patient education/support groups; to targeted model, such as Wennberg, where predictive models are used to target resources at high-need patients. Evidence on stepped care approaches in areas such as chronic depression, will also be useful. What are the trade-offs in these different approaches? How do different approaches compare in delivering support for 'hard to reach' groups? At a population level, what models work best? What is the impact on service use, including unscheduled (emergency admissions and ambulance) and planned care (including general practice consultations, as well as hospital outpatient appointments and inpatient stays).

Skillmix – who by?

An important area for the evidence synthesis is also the comparative effectiveness of professional versus peer-led education initiatives. Within the area of professional support, there are a number of questions about the cost-effectiveness of different kinds of team to support self-management. These include comparisons of primary care, secondary care and integrated teams. This would also include questions such as community matron role in intensive case management and impact of condition-specific specialist nursing support and other skillmix questions. Evidence on the role of generalists, such as the general practitioner or district nurse, in care planning would also be important to assess.

Intervention – what?

A rigorous mapping of interventions and their effects in reducing avoidable hospitalisation and improving outcomes are needed. These will range from patient education programmes of different kinds (generic versus condition-specific); group support versus individual; professional-led versus peer-led. It will also include a range of technologies to support patients at home and in self-monitoring. A key strand of work relates to ehealth and telehealth initiatives – replacing standard consultations with telephone, email or other technology. Initial findings should emerge during 2011, especially from the Whole System

Demonstrators project and other centrally-funded work, which should inform this review. However, other key studies on telehealth will take more time to conclude.

Delivery of care – how?

A key question is access to interventions (see models above) and how these are delivered. For instance, a structured patient education programme for diabetes could be delivered through general practice or by voluntary groups in the community. Some of these questions will inevitably overlap with the description of the intervention itself. However, there may be some generaliseable findings about what features are associated with greatest impact. This includes a body of knowledge about interventions to motivate professionals – at a team and individual level - to best support effective self-management.

Research gaps?

The evidence synthesis would also identify research gaps and need for further primary research. Initial overview suggests possible gaps in existing knowledge base include:

- generic stage-based interventions (contrasting needs of newly diagnosed with patients at maintenance stage of disease) versus a 'one size fits all' package;
- self-management interventions tailored for hard to reach groups, such as cognitively impaired and minority ethnic groups;
- interventions relating to neglected conditions (such as chronic kidney disease and heart failure);
- structured approaches to engage and motivate clinicians (GPs, nurses and others) to support self-management.

The completed synthesis should describe the key components of what appears to be effective and cost-effective programmes to support self-management for people with longterm conditions. This could be used as the basis for developing and testing a population-based package of care to improve outcomes and reduce avoidable hospitalisation.

4. General guidance for applicants

NB: This is general guidance and not all the sections will apply to the specific call

Our main concern is to commission research which is well designed; will be effectively carried out by the research team; will provide findings which meet the needs of the NIHR SDO programme and the NHS management and leadership community it serves; and will be used to improve health services. With these aims in mind, we offer the following general guidance to applicants. We do not prescribe or prohibit particular approaches to research, but we encourage applicants to take account of this guidance in their project proposals, and point out that the SDO Panels and Commissioning Board will take account of this guidance when they assess and select proposals.

Research team makeup and expertise

Our key concern is that projects should have a research team with the right skills to undertake the research. It is important that the team has the necessary expertise, but is not so large that project management will be difficult. Projects are likely to use a team with significant input from diverse disciplines appropriate to the content and methods of the project. All applicants need to show that they will commit appropriate time and effort to the project, and the use of large teams of applicants with little or no apparent time commitment to the project is discouraged. Full proposals should make it clear what responsibilities and roles will be fulfilled within the project by each team member.

The chief investigator or principal applicant should generally be the person who has contributed most to the intellectual and practical development of the proposal, and who will take lead responsibility for its implementation. This is not necessarily the most senior investigator in the research team. Where the principal applicant has a limited past track record in holding grants, we will look for evidence that they will be supported and mentored by more experienced co-applicants.

NHS management engagement

Our key concern is that NHS managers should be directly engaged or involved with SDO research projects because this will produce research that is more closely grounded in and reflective of their concerns and makes the subsequent uptake and application of research findings more likely.

We particularly welcome project proposals in which an NHS manager is formally part of the project team as a co-applicant, and in which they (and/or other NHS managers) play a significant part in the project. Their contribution may be to facilitate or enable research access to organisations, to be directly involved in research fieldwork, to comment on and contribute to emerging findings, and to be involved in knowledge mobilisation (see below). We think that direct NHS management involvement in proposals of this kind shows commitment to and support for the research from the NHS organisations involved. The time of NHS manager(s) as co-applicants can be costed into the proposal, as part of the NHS Support Costs.

There are other ways in which NHS management support for the proposed research can be demonstrated, such as co-opting managers to project advisory or steering groups, the inclusion with full proposals of a letter or statement of support from senior leaders in relevant NHS organisations.

Gains for the service

Not all research will individually result in potential savings or direct gains for the service. However it may lead to a better understanding of organisations, systems or services and contribute to that body of knowledge. Where it is appropriate, studies should include a cost-effectiveness component with a view to helping managers and service providers make decisions and identify potential for savings. As a publicly funded programme in a time of restraint, researchers should look to demonstrate potential savings and gains for the service, where appropriate. This includes setting out in broad terms the likely impact and implications of this work for the wider service at outline stage.

Research methods

Our key concern is that the research proposed is well designed, will be well conducted, and will add to knowledge in the area. It is not our intention here to specify particular research methods, but to highlight areas where we have found common weaknesses in the past.

Proposals need to make proper use of relevant theory and of the findings in the existing literature to frame their research questions. Although at outline stage, comprehensive referencing is not required, illustrative sources and indication of the grounding in a body of literature should be given. Theoretical, descriptive evaluations, proposals which appear not to be informed by the existing literature and projects which appear to replicate rather than add to existing research are unlikely to be funded. Research questions need to be very clearly stated and framed – in terms which are sufficiently detailed and specific. This includes a clear description of the intervention which is being assessed (where relevant) and articulating the objectives and aims of the research.

The research methods proposed must be appropriate to the nature of the research questions and to the theoretical framework for the project. It is important that the proposal makes a clear link between the research questions and the intended empirical approach and fieldwork, showing what data will be gathered and how it will be used. The approach to data analysis must be clearly explained. The proposal needs to show that the research team has considered and addressed the logistics and practical realities of undertaking the research – gaining ethical and research governance approval, securing access, recruitment, data collection and management, etc. Studies should be realistically costed to take account of these activities. Where trial methodology is proposed, researchers would be advised to have got input from local trial taken advice from their local clinical trials unit or officer.

Researchers should be mindful of the need for generalisability of results and the relevance of the outputs for the service as a whole. This may affect the study design – for instance, single case studies are only likely to be supported only exceptionally.

The plan of investigation should set out clearly and in some detail the proposed methodology. It should include a Gantt chart or project timetable showing clearly the planned dates of different project phases and of project outputs.

Public involvement

It is a core concern of the SDO programme that all commissioned projects should pay appropriate attention to the needs and experiences of all relevant stakeholders (including local communities, lay people, service users, carers and minority ethnic communities as well as healthcare practitioners and managers) during the design, execution and communication of the research. Proposed projects should be explicit in describing their arrangements for public and patient involvement and in communicating how the proposed work has potential implications for service delivery that could lead to enhanced public and community engagement. The application includes a section for the non-expert and care should be given to `pitching' the proposal at a lay audience, avoiding jargon and explaining clearly the expected benefits of the research.

Research governance

Applicants should show that they understand and that their proposal complies with the Research Governance Framework for the NHS. Successful applicants will be required to provide proof of research ethics committee approval for their project, if it is required, before funding commences. The project plan should take realistic account of the time required to secure ethics and governance approval.

Costs and value for money

Project costs will be carefully scrutinised and must always be well justified and demonstrate value for money. NIHR programmes currently fund Higher Education Institutions (HEI) at a maximum of 80% of Full Economic Cost (except for equipment over £50,000 – 100%). For non-HEI institutions, NIHR may fund 100% of costs. However, the NIHR SDO programme reserves the right to award a grant for less than this maximum and for less than the amount sought by applicants.

5. Research outputs and knowledge mobilisation

Our key concern is to ensure that projects funded by the SDO programme are designed from the outset to produce useful, timely and relevant research findings which are then used. Experience suggests that this is most likely if researchers collaborate with NHS managers throughout the life of a project, and aim to produce a variety of research outputs – not just a final report and one or more papers for academic peer reviewed journals.

All full proposals submitted to the SDO programme must include a detailed section on research outputs and knowledge mobilisation in the full plan of investigation which is attached to the proposal when it is submitted. We would expect to see that section and the project plan detailing the outputs and knowledge mobilisation activities which are planned across the life of the project, and the resources section of the proposal showing that sufficient resources have been allocated within the project budget to undertake these knowledge mobilisation activities. In general terms, all projects which are longer than 12 months are expected to produce some interim outputs during the life of the project as well as those at the end of the project.

The outputs and knowledge mobilisation activities shown in the project proposal are likely to include some or all of the following:

- A final and full research report detailing all the work undertaken and supporting technical appendices (up to a maximum 50,000 words), an abstract and an executive summary (up to 2000 words). This is a required output. The executive summary must be focused on results/findings and suitable for use separately from the report as a briefing for NHS managers. Care should be given to using appropriate language and tone, so that results are compelling and clear. The report must use the layout template provided. Following scientific peer review and editing/revision, the report will be made available on the SDO programme website. This is a required output from all projects.

- A set of PowerPoint slides (up to 10 maximum) which present the main findings from the research and are designed for use by the research team or others in disseminating the research findings to the NHS. The slides must use the template provided. They will be made available alongside the report on the SDO programme website. This is a required output from all projects.

- Journal papers for appropriate academic peer reviewed journals, designed to ensure the research forms part of the scientific literature and is available to other researchers.

- Articles for professional journals which are read by the NHS management community and which will be helpful in raising wider awareness of the research findings.

- Seminars, workshops, conferences or other interactive events at which the research team will present and discuss the research and its findings with NHS managers

- Guidelines, toolkits, measurement instruments or other practical methods or systems designed to enable NHS managers to use the research findings in practice. We are looking for practical, innovative ideas – such as questions arising from the research that non-executive directors could raise at Board meetings or similar.

This list is illustrative rather than comprehensive, and we will welcome project proposals which include other forms of output and knowledge mobilisation activities. All projects are encouraged to collaborate in knowledge mobilisation with the SDO Network, which is hosted by the NHS Confederation and exists to enable managers to improve and develop the services they manage by facilitating their access to and use of the latest health services research. (http://www.nhsconfed.org/networks/sdonet/Pages/SDONetwork.aspx).

6. Process for proposal selection

The NIHR Service Delivery and Organisation programme is funded by the NIHR, with contributions from NISCHR in Wales. Researchers from Scotland and Northern Ireland should contact NETSCC to discuss their eligibility to apply.

Whilst we have not set a maximum duration or cost for projects, value for money will be scrutinised and all costs must be justified. It is very important that costs are realistic as the SDO programme does not normally accept requests for variations to contracts for additional time or funding once projects have been contracted.

7. Application process and timetable

The process of commissioning will be in **one stage** and applicants should submit **full proposals** via the SDO website by **1pm** on **17 March 2011.** No late proposals will be considered. No paper-based submissions will be considered.

Applicants will be notified of the outcome of their full proposal application in July 2011. Please note that these dates may be subject to change.

The board's primary concern is the **quality of the proposed research**. It uses two main criteria to make this judgement:

- Scientific rigour and quality of the proposed research, and the expertise and track record of the research team.
- Value for money of the proposed research, taking into account the overall cost and the scale, scope and duration of the work involved.

Should you have any questions or require any further clarification please refer to the NETSCC FAQs at http:\\www.sdo.nihr.ac.uk/faqsnetscc.html, if the answer to your question cannot be found please email your query to sdofund@southampton.ac.uk with the reference number (11/1014) and title for the call for proposals as the email header. Applicants should be aware that while every effort will be made to respond to enquiries in a timely fashion, **these should be received at least two weeks before the call closing date.**

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SDO funded projects

08/1715/165 Understanding the barriers and facilitators of effective implementation of self care in mental health trusts Complete. Available at http://www.sdo.nihr.ac.uk/projdetails.php?ref=08-1715-165

08/1715/161 Self-management support among older adults: the availability, impact and potential of locally based services and resources Complete Available at http://www.sdo.nihr.ac.uk/projdetails.php?ref=08-1715-161

08/1715/201 Self care and case management in long term conditions: the effective management of critical interfaces Complete
Available at http://www.sdo.nihr.ac.uk/projdetails.php?ref=08-1715-201

08/1718/145 Health, medicines and self-care choices made by children, young people and their families: information to support decision making. In progress Available at http://www.sdo.nihr.ac.uk/projdetails.php?ref=08-1718-145