Health Services and Delivery Research Programme



Commissioning Brief 14/154 - New research on organisation of dementia services Closing date: 11 Sep 2014 (two stage – outline to full)

1. Remit of this call: main topic areas identified

Large numbers of people are now living with dementia. This poses specific challenges for health and care services, where people with dementia make up about a quarter of hospital inpatients and more than two thirds of care home residents. The majority of people with dementia though live at home and a key issue is how best to support them and their families and carers. National strategies and local service improvements have changed some ways in which care is delivered. But in many areas there is a lack of robust evidence on the most effective and cost-effective service models.

Following an NIHR themed call, six new health service research projects on dementia were funded in 2012. However, these addressed only a few of the pressing service problems in and around dementia care. Since 2012, stakeholders have continued to identify dementia as a priority area at annual workshops for the HS&DR programme. In addition, the James Lind Alliance and Alzheimer's Society held a priority setting partnership between patients, carers, researchers and clinicians in 2013 which identified key priorities for future research on dementia¹. This was broad and included all aspects of patient experience and care. The ten priorities and the longer list of 146 questions identified through widespread consultation highlighted a number of important service uncertainties where there is no reliable evidence. This has informed the present call, which focuses on research around delivery of services and organisation of care. Other important areas relating to diagnosis/screening, therapeutic interventions or health promotion fall within the remit of other NIHR programmes.

Four particular areas have been identified, where new health services research would help service leaders and managers to make decisions about commissioning and delivering care for people with dementia. Studies are likely to use mixed methods, given complexity of interventions and context. Care should be given to identifying a range of appropriate outcomes including different aspects of patient and carer experience, including quality of life, independence, management of behaviour and progression of disease.

- (1) Memory clinics and allied services what is the best way of organising post-diagnosis treatment and coordination of care for people with dementia and how are they best configured and staffed?
- (2) Integrated community and intermediate care what are the most cost-effective ways of providing integrated 24/7 health and care support for people with dementia and their carers at home?
- (3) Care homes understanding differences in care home settings and impact on costs, quality and outcomes for people with dementia?
- (4) Hospitals which models of acute care and staffing lead to better quality care and shorter length of stay for people with dementia?
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Over two hundred memory services in England have been set up in the last few years, following recommendations in the national dementia strategy in 2009 and similar in other parts of the UK. These are loosely defined, but are designed to provide early assessment and treatment by

¹ http://www.lindalliance.org/DementiaPSP.asp

multidisciplinary teams. These might be led by specialist nurses, old age psychiatrists, neurologists, geriatricians or general practitioners with a special interest. Many are run as part of community mental health teams for older people. Following early evaluation of pilot schemes, services have emerged in different forms according to local configurations, funding and interest. The most recent national audit² provides information about current provision – for instance, a third are stand-alone clinics and not all provide psychological therapies. More research is needed to assess the impact of different models on patients, resources and systems. Not enough is known about the best way to organise post-diagnosis. General cognitive and neurology clinics which provide services similar to memory clinics for patients with dementia should be included in these studies. There are also gaps in existing descriptive data – for instance, little is known about staffing configurations, including input from allied health professionals. Memory clinics are an important node for a web of other services and imaginative approaches will be needed to track use of services across agencies and settings. We know less about access and appropriateness of these services for people living on their own, on low incomes or from minority ethnic groups. Research should also examine aspects of organisational form and culture, leadership, staffing mix and context as well as impact on patients and service use.

(2) Integrated community support and intermediate care – what are the most cost-effective ways of providing integrated 24/7 health and care support for people with dementia and their carers at home?

The vast majority of people with dementia live at home looked after by family or informal carers. Different support from many agencies is provided, often poorly coordinated. These range from specialist or general home care support, to day centres, to care provided by community mental health teams and other practitioners. Research is needed to understand the most cost-effective ways of providing integrated health and social care support, including out of hours and seven-day arrangements for community nursing and other teams. These include respite care and a range of intermediate care activities, from admission avoidance to supported early discharge after a hospital stay. There is also scope for work examining the impact and cost-effectiveness of case managers, specialist nurses (including Admiral Nurses) and other staffing roles for community-dwelling people with dementia and their carers. This includes single point of access for these multiple services and continuity of care as the needs of people with dementia change over time. There are useful examples in the HS&DR portfolio of mixed method evaluations of complex interventions, from virtual wards to hospital at home schemes. An HS&DR call was recently issued on reablement services, which is outside the scope of this call.

(3) Care homes – understanding differences in care home settings and impact on costs, quality and outcomes for people with dementia?

Two thirds of residents in care homes have dementia and provision is spread across general care homes and those with specialist registration. Given the numbers of residents with dementia, most care homes would claim expertise in dementia care and the distinction between specialist and general care homes is now less clear. The vast majority of care homes (three quarters) are now provided in the commercial sector. Care homes can range hugely from hospital-like environments to family homes. Not enough is known about the differences between care homes in terms of staffing (including input from registered mental health and other nursing staff, role of care home manager), costs, size and organisational features and their impact on experience and outcomes for residents with dementia. Studies should consider differences in organisational culture and environment – an early study suggested that general care homes had a more community-linked social model of service compared with a more clinical approach in specialist care homes. More research is needed on the effect of these differences and could include work to develop and test tailored staffing or care interventions (such as person-centred care) to particular care home environments as well as studies comparing impact of different models. Study design will need to adjust for differences in resident profile and funding sources, ownership, skillmix, culture and focus. Research should aim to provide useful learning for commissioners on good practice and value for money in different settings. For researchers interested in studying care homes, NIHR network and resources are available at http://www.enrich.dendron.nihr.ac.uk.

http://www.rcpsych.ac.uk/workinpsychiatry/qualityimprovement/nationalclinicalaudits/memoryservicesaudit.aspx

(4) Hospitals – which models of acute care and staffing lead to better quality care and shorter length of stay for people with dementia?

Around a quarter of acute inpatients have dementia and some hospitals have planned services differently for these patients. Instead of coming through general medical assessment units before admission to general or older care wards, some places now have specialist units for patients with dementia and/or delirium. The cost-effectiveness of these dedicated wards and units is uncertain. A large recent study found no difference in service use and outcome for specialist units, but this trial was based in one hospital only. Ambitious multi-centre studies are needed to compare models of admission and treatment for people with dementia who have acute care needs. These may combine experimental or quasi-experimental methods with substantive process evaluation given the complexity of intervention and context. Studies are needed to examine costs, casemix, skillmix, activity and impact on quality and outcomes for patients. Staffing models are important – a recent review found only one empirical study evaluating the hospital specialist dementia nurse role. A key factor would be study of coordinated and patient-centred care, given complexity of many patients and range of physical and mental health care needs. Note that a recent HS&DR call was issued on general all-age hospital liaison psychiatry services, but particular studies assessing the cost-effectiveness of old age mental health liaison teams in hospitals could also be considered as part of this call.

2. Purpose of call

The topic organisational research on dementia care was identified as a continuing priority for the HS&DR programme in consecutive years by clinicians, patients, service leaders and managers. This also addresses particular service uncertainties identified through a James Lind Alliance priority service partnership on dementia in 2013. The five areas identified in this call focus on organisational research, building on existing work and gaps in the current portfolio after the NIHR themed call on dementia.

3. Notes to Applicants

The NIHR Health Services and Delivery Research (HS&DR) programme aims to produce rigorous and relevant evidence on the quality, access and organisation of health services, including costs and outcomes in order to improve health and health services. It is focused on research to support decisions by frontline managers and clinical leaders on the appropriateness, quality and cost-effectiveness of care.

The NIHR HS&DR programme is funded by the NIHR, with contributions from NISCHR in Wales, the HSC R&D Division, Public Health Agency in Northern Ireland, and case by case contributions from the CSO in Scotland.

The programme operates two funding streams; researcher-led and commissioned. Researchers in England, Wales and Northern Ireland are eligible to apply for funding from either workstream under this programme. Researchers in Scotland may apply to the researcher-led workstream but are not eligible to respond to the commissioned workstream and should contact the CSO to discuss funding opportunities for healthcare delivery-type research

4. Application process and timetable

This call for proposals should be read alongside further supporting information and general guidance from the HS&DR programme on applications.

Should you have any questions or require any further clarification please refer to the NETSCC FAQs at <u>HS&DR programme - FAQs</u>, if the answer to your question cannot be found please email your query to <u>hsdrinfo@soton.ac.uk</u> with the 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.**

The process of commissioning will be in **two stages** and applicants should submit **outline proposals** via the HS&DR website by **1pm** on **11 September 2014**. All proposals will initially be checked for remit and competitiveness³. No late proposals will be considered. No paper-based only submissions will be considered.

³ 'Non-Competitive' means that a proposal is not of a *sufficiently high* standard to be taken forward for further assessment in comparison with other proposals received and funded by the HS&DR programme because it has little or no realistic prospect of funding. This may be because of scientific quality, cost, scale/duration, or the makeup of the project team

Applicants will be notified of the outcome of their outline application in Nov 2014.

Shortlisted applicants will be invited to submit a full proposal via the HS&DR website (a link will be sent to shortlisted applicants). Applicants will be notified of the outcome of their full proposal application in Apr 2015. Please note that these dates may be subject to change.

5. Transparency agenda

In line with the government's transparency agenda, any contract resulting from this tender may be published in its entirety to the general public. Further information on the transparency agenda is at: http://transparency.number10.gov.uk/