The Programme

This research programme, funded by the National Institute for Health Research (NIHR) Programme Grants for Applied Research, has now reached the end of its second year. This newsletter highlights work so far. The Programme, of nine distinct but interlinked projects, has generated evidence relating to routine home support in dementia care. Figure 1 shows the work so far. Below we describe work on one of the projects, describing patterns of provision in dementia care in England.

A National Survey of ‘Patterns of Provision’ in Dementia Home Support

Data collection for Project 2 - a national survey of approaches to home support in England - was completed in 2015. We are grateful to all respondents for their contribution to this dataset and for the support of the Association of Directors of Adult Social Services, NHS England and Clinical Commissioning Groups.

The aim was to build a national picture of the home support services available across England provided by the local authorities and NHS Trusts. Recruitment was undertaken in two stages: first we contacted local authorities and second we supplemented this with data from the corresponding NHS Trusts. Table 1 shows the response rate by region demonstrating the representativeness of the national survey.

Table 1: Response rate from national survey

<table>
<thead>
<tr>
<th>Region</th>
<th>LA responses</th>
<th>NHS responses</th>
<th>Matched dataset</th>
</tr>
</thead>
<tbody>
<tr>
<td>North West (23)</td>
<td>22 (96%)</td>
<td>23 (100%)</td>
<td>22 (96%)</td>
</tr>
<tr>
<td>East Midlands (9)</td>
<td>7 (78%)</td>
<td>9 (100%)</td>
<td>7 (78%)</td>
</tr>
<tr>
<td>Yorkshire &amp; The Humber (15)</td>
<td>12 (80%)</td>
<td>14 (93%)</td>
<td>11 (73%)</td>
</tr>
<tr>
<td>North East (12)</td>
<td>12 (100%)</td>
<td>12 (100%)</td>
<td>12 (100%)</td>
</tr>
<tr>
<td>South East (19)</td>
<td>16 (84%)</td>
<td>14 (74%)</td>
<td>11 (58%)</td>
</tr>
<tr>
<td>East of England (11)</td>
<td>8 (73%)</td>
<td>7 (64%)</td>
<td>5 (46%)</td>
</tr>
<tr>
<td>West Midlands (14)</td>
<td>9 (64%)</td>
<td>13 (93%)</td>
<td>8 (57%)</td>
</tr>
<tr>
<td>South West (15)</td>
<td>13 (87%)</td>
<td>11 (73%)</td>
<td>11 (73%)</td>
</tr>
<tr>
<td>London (33)</td>
<td>24 (73%)</td>
<td>13 (39%)</td>
<td>9 (27%)</td>
</tr>
<tr>
<td><strong>TOTAL (N=151)</strong></td>
<td><strong>123 (82%)</strong></td>
<td><strong>116 (77%)</strong></td>
<td><strong>96 (64%)</strong></td>
</tr>
</tbody>
</table>

From this a matched dataset by local authority area of 64% was created for the purpose of further analysis. The term ‘matched dataset’ referred to areas where we had received a completed questionnaire response from both the local authority and the NHS Trust provider. Data collected will also inform site selection for Project 5, an observational study of different home support approaches in later stage dementia. Detailed findings from the project will be reported in a variety of formats.

The Study Partners

The University of Manchester; The University of East Anglia; Swansea University; Edge Hill University; University of Nottingham; Pennine Care NHS Foundation Trust; North East London NHS Foundation Trust; and Prof Narinder Kapur.
Figure 1: Nine interlinked projects – work so far

1. Evidence Synthesis of Home Support Interventions
   A synthesis of the evidence, from an overview of reviews of psychosocial treatments combined with that from a systematic review of home support interventions, has been collated. This is to be reported and used to inform other aspects of the programme.

2. National Survey of Approaches to Home Support
   A national survey identifying different approaches from local authority commissioners and NHS Trust managers has been completed (see page 1). This will inform the selection of sites for project 5.

3. Developing an Economic Model of Approaches to Home Support
   A systematic literature review of the economic evidence for home support interventions in dementia has been completed. Data from this, and other sources, have been used to develop an economic model. This tracks virtual participants (people with dementia and their carers), through care pathways. This model will be added to and modified, based on the results of other projects on the programme.

4. Trial of Memory Aids through Dementia Support Practitioners in Early Stage Dementia
   The planning and ethical agreement for this pragmatic trial in two English Trusts is nearing completion. It is aimed to begin the trial recruitment in 2016.

5. Observational Study of Different Home Support Approaches in Later Stage Dementia
   This study, exploring the relative effects of different approaches to home support, relying on different components, has received all formal ethical approvals. Recruitment will take place in different geographical areas of England in 2016.

6. Field Testing a Dementia Toolkit to Improve Management and Commissioning
   Development of the dementia home support toolkit will begin in late 2016, synthesising the evidence for home support and providing guidance to managers and commissioners in the NHS and partner agencies. This will be undertaken in two participating Trusts and partner agencies.

7. Analysis of Costs to People with Dementia and their Carers and their Relationship to Formal Care
   Diverse groups of informal carers of people with dementia and formal care staff have been recruited. Analysis of data concerning how costs may be shared between carers and formal (NHS/social care) home support is now taking place.

8. Discrete Choice Experiments establishing preferences for components of support by People with Dementia and their Carers
   User and carer preferences for different components of support have been systematically elicited and analysed through Discrete Choice Surveys for early and later stage dementia. This project is now being reported and disseminated.

9. Economic Modelling of the Impact of Different Home Support Approaches for Dementia
   Evidence from all projects will be brought together to identify potential home support approaches, combining cost-effective components into coherent and feasible packages. This will begin late 2017.

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