Research Infrastructure Service Developments to Support Increased Dementia Research in the UK

Gary Nestor¹, John O’Brien², Ian McKeith¹, Piers Kotting³

¹. Newcastle University, Newcastle, UK
². University of Cambridge, Cambridge, UK
³. UCL Institute of Neurology, London, UK

OBJECTIVE

To describe a set of United Kingdom (UK) research infrastructure service improvements and the impact that these have had on the growth of dementia research in the UK following the Prime Minister’s Challenge on Dementia in 2012.

BACKGROUND

In the UK the National Institute of Health Research (NIHR) Clinical Research Network’s (CRN) remit is to support the delivery of high-quality clinical research within the UK National Health Service (NHS). It is considered as the research arm of the NHS. Its purpose is to provide efficient and effective support for the initiation and delivery of funded research in the NHS. Fifteen local CRNs (LCRNs) form the national CRN covering the whole of England.

Studies funded by the NIHR and recognised organisations that support research through competitive funding streams with rigorous peer review processes are eligible for adoption to the NIHR portfolio and thus CRN support. LCRNs fund research staff to deliver studies in as many units across the country as needed to expedite results, ensuring good socio-economic inclusion, that rare diseases are not neglected and that there is equity of access to enable patients to be able to participate in research.

Following the Prime Minister’s Challenge on Dementia there were two dementia themed calls and a number of research infrastructure service developments were introduced to support the enablement of the research commitments made. These improvement initiatives are described in the panel opposite.

RESULTS

In 2012/13 the NIHR CRN Dementia portfolio was less than 100 open studies being supported, recruiting less than 5,000 participants during the year. With the advent of the PM’s Challenge on Dementia and the themed funding calls and service developments, study numbers increased by over 10% each year and participant numbers over 48% each year. The numerical analysis is presented below, which shows a continual increase in both the number of studies and research participants within the data analysis period up to 31st March 2016. This four year period culminated with 159 supported studies (71% total period increase) and over 24,000 participants (395% total period increase) within the NIHR CRN Dementia portfolio.

<table>
<thead>
<tr>
<th>£/€ Year</th>
<th>Study No.s</th>
<th>% Increase</th>
<th>Participants</th>
<th>% Increase</th>
</tr>
</thead>
<tbody>
<tr>
<td>12/13</td>
<td>93</td>
<td>10%</td>
<td>4,877</td>
<td>48%</td>
</tr>
<tr>
<td>13/14</td>
<td>102</td>
<td>17%</td>
<td>7,234</td>
<td>63%</td>
</tr>
<tr>
<td>14/15</td>
<td>119</td>
<td>34%</td>
<td>11,815</td>
<td>104%</td>
</tr>
<tr>
<td>15/16</td>
<td>159</td>
<td></td>
<td>24,133</td>
<td></td>
</tr>
</tbody>
</table>

CONCLUSIONS

Overall the results demonstrate the success of the combination of the two dementia themed funding calls (2011 & 2012) and the NIHR CRN research infrastructure service developments that better enabled the initiation and delivery of more research into Dementia.

It follows that:

1. Dementia research is thriving in the UK, thanks to major investment in infrastructure and networks
2. NIHR fully supports researchers by funding their work (funders) and then helping them initiate and deliver their studies (Clinical Research Network)
3. The UK is an excellent place to undertake new studies, both commercial and non-commercial

RESEARCH INFRASTRUCTURE SERVICE DEVELOPMENTS

NIHR CRN National Rater Programme

A sustainable training and skills maintenance programme was developed and introduced into the CRN research support workforce, which is still successfully in operation supporting both commercial and non-commercial studies on the NIHR CRN Dementia portfolio.

Join Dementia Research

A national register was established to enable research interested individuals to register their details & interest and potentially match them to suitable research studies. This is now running as an on-going national service in partnership with our Alzheimer’s charities.

Costing Support

Costing and attribution (research, support, treatment or excess treatment costs) support was provided during the dementia themed funding calls. This improved both call uptake, submission success and final deliverability of the studies funded.

ENRICH

Resources were created to provide advice, guidance and support for researchers, research staff, and local research networks on how to prepare and carry out studies in care homes.

METHODS

A retrospective analysis of research study and participant numbers in the NIHR CRN Dementia research portfolio was performed, particularly focusing on studies coming onto the portfolio following the 2012 announcement of the Prime Minister’s Challenge on Dementia.