Progress on the Dementia Research Challenge 2014/15

NIHR Clinical Research Network

- 21,499 people took part in dementia research supported by the NIHR, an increase of 58 per cent from last year
- 81 new dementia studies were adopted onto the NIHR portfolio and were supported by the Clinical Research Network (CRN), a total of 202 studies being open for recruitment (up from 182 in 2013/14)
- 78 per cent of studies achieved their recruitment targets within agreed timescales
- 202 studies were open to recruitment, an 11 per cent increase from 2013/14
- 3,171 participants were recruited during to studies 2014/15

Join Dementia Research

During 2014/15 the NIHR developed, tested and launched a major new service to make it easier for people from across the UK to participate in dementia studies. ‘Join Dementia Research’ is an online and telephone service through which people can register their interest in dementia research, and be contacted about potentially suitable studies. Following a successful pilot in London, the service was rolled out nationally in February 2015. The service is run in a partnership between the NIHR, Alzheimer’s Society, Alzheimer’s Research UK and Alzheimer Scotland.

Over 12,059 people have now registered, 1,730 of whom have been enrolled in one of the 44 studies currently supported by the service.

ENRICH

The Enabling Research in Care Homes (ENRICH) Programme continues to support researchers, care homes and residents. Later this year an updated ENRICH toolkit website will be launched to ensure access to the latest guidance and advice to support delivery of dementia research outside the usual NHS settings. To date around 1,000 research ready care homes are involved in the network.

Capacity Building

NIHR has invested in expanding the dementia research workforce, via the NIHR Integrated Academic Training for medical researchers, and via a new scheme led by the NIHR Collaborations for Leadership in Applied Health and Care (CLAHRCs), which is training nurses, social care and allied health professionals to become dementia researchers. A dementia BRU trainees workshop was hosted by UCL in September.

Portfolio Development

NIHR and medical research charity partners have agreed to fund portfolio development activities previously supported by the NIHR Dementias and Neurodegenerative Diseases Research Network (DeNDRoN), following the success of the support provided for the NIHR Dementia Themed Call (DTC) and ESRC/NIHR Living Well with Dementia call.

Dementias Platform UK

The Dementias Platform UK (DPUK) is now well established (academic partners Cambridge, Cardiff, Edinburgh, Imperial College, Newcastle, Oxford, Swansea and UCL; with industry

The DPUK comprises approximately two million participants aged 50 and over, from 22 existing cohorts within the UK that include participants from the general population, those known to be at-risk of developing dementia (familial cohorts), and people diagnosed with early-stage dementia.

The DPUK includes imaging, stem cell, and informatics networks. A workshop at UCL explored opportunities for facilitating interactions between the various dementia infrastructures supported in the UK and a diagram illustrating the landscape is attached.

**Prime Minister’s Challenge of Dementia 2020**

The Prime Minister’s dementia 2020 vision document includes a number of research ambitions:

- Expansion of the dementia research workforce
- Greater participation of people with dementia in research
- Increased research in care homes

The stretch targets of 25% of newly diagnosed patients registered on ‘Join Dementia Research’ and ‘10% of patients engaged in research are on track.

**Advisory Group on Dementia Research (AGDR)**

An Advisory Group on Dementia Research is being convened and chaired by the CMO and Professor Patrick Maxwell to advise on research priorities and related to the 2020 Dementia Challenge.

**International Global Action Against Dementia (GAAD)**

Five post-G7 [Dementia Summit (December 2013)] legacy events have been held: in 2014/2015 to discuss Social Impact Investment (June 2014, UK), Harnessing the Power of Discoveries and Maximizing Academia-Industry Synergies (September 2014, Canada), New Care and Prevention Models (November 2014, Japan), and Alzheimer’s Disease Research (February 2015, USA). These meetings culminated in the first WHO Ministerial Conference on Global Action Against Dementia (March 2015, Geneva).

The OECD has been leading the commitments on sharing and use of big data and published “[Addressing Dementia: The OECD Response](#)” (March 2015) at the Geneva event. An advisory group on access to health data held its first meeting last week and will report in 2016. The WHO has led on developing an international action plan and held a series of workshops using the [Child Health and Nutrition Research Initiative (CHNRI)] methodology. The CHNRI approach ensures inclusion of all stakeholders and low and middle income countries in the prioritisation exercise. The prioritisation working group has drafted a paper for publication this year.
Dementia Research Infrastructure

CLAHRCs
CRN
ENRICH

Basic Science
I  II  III  IV  V  VI
Capacity: new talent, repurposing, incentivisation, citizen science, data science

EPAD
DPUK
TRC-D

High risk  Pre-symptomatic  Early symptomatic  MCI  Mild  Moderate  Severe

Trend to researching earlier populations