## **ANNEX**

## DRIVING IMPROVEMENTS IN HEALTH AND CARE

| Key commitments                                                     | Status                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                               |  |
|---------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--|
| Increased                                                           | Work completed to date:                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                              |  |
| diagnosis rates<br>through regular<br>health checks<br>for over-65s | Since April 2013 Local Authorities have had a statutory responsibility to give everyone aged 65-74 who is having an NHS Health Check information at the time to raise awareness of dementia and the availability of memory services. Training tools and an information leaflet, available in 15 languages as well as large print, have been produced to support this. Since April 2013 over 400,000 leaflets have been provided for local use. Between April and December 2013 of the 15.3 million people eligible 13.2% (2,022,063 people) were offered an NHS Health Check. Of those, 48.1% (973,093 people) took up the offer. This compares to 11.7% and 48.5% respectively over the same period in 2012. To raise awareness of dementia more generally, Public Health England are planning to undertake an evaluation of the Dementia Friends Campaign launched on 7 May 2014, which will include tracking data and prevention message testing. |  |
| Ambition for diagnosis rates across the country                     | The ambition that, by 2015, two thirds of the estimated number of people with dementia should have a diagnosis, with appropriate post diagnostic support has been agreed with NHS England. A programme of work is underway to support and monitor this. NHS England are working with those areas with the longest waits, with the aim of ensuring that anyone with suspected dementia will not have an excessive wait for a timely assessment.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                       |  |
|                                                                     | The Alzheimer's Society, working with NHS England, has commissioned the London School of Economics to undertake a review into the accuracy of dementia prevalence data. The updated data is expected to be published in Autumn 2014.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                 |  |
| Dementia                                                            | Work completed to date:                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                              |  |
| Commissioning<br>for Quality and<br>Innovation<br>(CQUIN)           | The revised national dementia CQUIN for 2013/14 was published in February 2013, incorporating new elements on leadership and support for carers. Hospitals must confirm that they have a named lead clinician for dementia and an appropriate staff training programme. They must also undertake a monthly audit of carers of people with dementia, including how supported carers feel. The findings must be reported to the Trust Board at least twice per year.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                   |  |
|                                                                     | The CQUIN has led to over 4,000 referrals a month, which will contribute to improving diagnosis rates for dementia. For quarter 3 2013/14, 83% of admitted patients were initially assessed for potential dementia. Of those assessed and found as potentially having dementia, 89% were further assessed. And of those diagnosed as potentially having dementia, 86% were referred on to specialist services.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                       |  |

| Key<br>commitments            | Status                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                      |
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| Innovation                    | Work completed to date:                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                     |
| Challenge Prize of £1 million | The £1m Breakthrough Challenge for Dementia was launched by the Secretary of State for Health on 25 June 2012. The aim of the challenge is to achieve a dramatic reduction in the proportion of people who have undiagnosed dementia, with evidence of a step change in the diagnosis rate and a strong service response.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                   |
|                               | The NHS Innovation Challenge Prize for Dementia in collaboration with Janssen Healthcare Innovation was announced in May 2013. £150,000 was awarded for solutions that provide an integrated care pathway for people dementia. The winners of the Challenge Prize were announced on the 26 November 2013. The judges awarded a share of the £150,000 prize to 3 schemes from across the country. The £80,000 top prize was awarded to Memory First, a new integrated dementia service, run by a consortium of 162 GPs across 41 practices in Staffordshire. Its pioneering joined-up approach to care has cut diagnosis times from 3 years to 4 weeks and led to major improvements in patient experience.                                                                                                                                                                                                                                                                                  |
|                               | The other 2 winning schemes, awarded prizes of £35,000 each, are the Greenwich Advanced Dementia Service, which is helping people in the borough remain in their own homes for longer; and the Early Intervention Dementia Service in Worcestershire, which has already helped 2,000 people in the county get a more timely diagnosis.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                      |
| Dementia Care                 | Work completed to date:                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                     |
| and Support<br>Compact        | From 10 signatories in March 2012, to date, there are now 173 organisations representing nearly 3,000 care services committed to delivering high quality, personalised care to people with dementia and their carers. On 28 February 2013 the Secretary of State for Health wrote to the Chairman of the Local Government Association to request support in engaging councils in this work, and to encourage them to work with the social care providers in their area to ensure that they sign up. Care England is discussing with the Care Quality Commission (CQC) how to use the regulatory system to encourage care services to sign the Care Compact and to enshrine the objectives of the Compact in how they deliver care. In the coming year CQC will be developing a quality scheme and discussions are underway as to how the Dementia Care and Support Compact can be incorporated as evidence of a commitment to delivering high quality care to people living with Dementias. |

| Key commitments                                                                    | Status                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                   |  |  |
|------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--|--|
| Dementia Care and Support Compact (continued)                                      | In November 2012, The Secretary of State for Health announced a £50 million dementia-friendly environments capital investment fund to support the NHS and social care to create dementia-friendly environments. Approximately £25 million has subsequently been allocated to local authorities working in partnership with social care providers and £25 million to NHS providers for these national pilot projects. This investment is intended to deliver physical improvements and knowledge-based evidence in NHS and social care environments that provide care for people with dementia. 42 NHS and 74 Social Care National pilot schemes were approved in June 2013 as national pilots. Most of the projects have now been completed, and they will be evaluated by a team of researchers at Loughborough University over the coming months. The evaluation will provide knowledge and evidence about those aspects of the physical care environment which can be used to provide improved care provision for people with dementia, their families and carers. On the basis of this evidence, the Department of Health intends to issue best practice guidance emerging from the pilots at the end of March 2015. |  |  |
|                                                                                    | Recognising that care and support spans wider than care homes the Health and Care Champion Group has initiated work in a number of Task of Finish groups. This includes end of life care; dementia care at home; engaging with social care providers; and in collaboration with the Dementia Friendly Communities Champion Group, looking at how best to support dementia friendly workplaces and use of assistive technology for people with dementia.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                  |  |  |
| NHS information                                                                    | Completed                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                |  |  |
| offer                                                                              | The DementiaChoices website (www.nhs.uk/dementiachoices) was launched at the 2013 Healthcare Innovation EXPO event. Since then, all of the regional sites have been launched.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                            |  |  |
| Work with the                                                                      | Work completed to date:                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                  |  |  |
| profession to<br>identify how<br>best to improve<br>early diagnosis<br>of dementia | To support GPs and other primary care staff, a Dementia Roadmap web-based tool has been commissioned by the Department of Health from the Royal College of General Practitioners. The roadmap will be launched on 22 May and will provide a framework that local areas can use to provide local information about dementia from health, social care and the third sector to assist primary care staff to more effectively support patients, families and carers at the time of diagnosis and throughout the dementia journey.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                            |  |  |
|                                                                                    | In April 2014 NHS England published a new Dementia Directed Enhanced Service (DES) for take up by GPs to reward practices for facilitating timely diagnosis and support for people with dementia. Patients who have a diagnosis of dementia will be offered an extended appointment to develop a care plan. The care planning discussion will focus on their physical and mental health and social needs, which will include referral and signposting to local support services.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                         |  |  |

| Key<br>commitments                                                                                                                                           | Status                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                   |
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| NICE to                                                                                                                                                      | Completed                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                |
| consider ways<br>of improving the<br>dementia<br>indicators in the<br>QoF                                                                                    | The consultation on potential new indicators for consideration for the 2014/15 QOF closed on Monday 4 February 2013. There were no new dementia indicators included in the 2014/15 Quality Outcomes Framework (QoF). The Directed Enhanced Services (DES), published in April 2014 for GPs includes a new financial incentive to reward practices for having a pro-active approach to assessing patients who may be showing the early signs of dementia.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                 |
| Call on the                                                                                                                                                  | Work completed to date:                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                  |
| Royal Colleges to respond to the challenge of dementia by bringing forward plans to ensure that all their members are capable and competent in dementia care | Health Education England (HEE) national returns show that, by October 2013, 108,000 NHS staff had received foundation level (Tier 1) training in dementia. This exceeded the original aim of 100,000 staff trained by March 2014, as set out in the Government's Mandate to Health Education England published on 28 May 2013. The training will enable staff to spot the early symptoms of dementia; know how to interact with those with dementia; and ensure that patients receive the most appropriate care.                                                                                                                                                                                                                                                                                                                                                                                                                                                         |
|                                                                                                                                                              | The Government's refreshed Mandate to HEE, published on 1 May 2014, builds on this by setting an ambition for a further 250,000 NHS staff to receive Tier 1 training in dementia by March 2015, with the tools and training opportunities being made available to all staff by the end of 2018. This will be backed up with more in-depth training of expert leaders and staff working with people with dementia. HEE will also work with bodies that set curricula to ensure that by September 2015 all undergraduate courses will include training in dementia, and will work with higher education providers and regulators to ensure that newly qualified staff who look after patients with dementia receive Tier 1 dementia training. In addition, HEE will work with the Royal College of General Practitioners to continue to take forward the objective to include compulsory work-based training modules in mental health, including dementia, in GP training. |
|                                                                                                                                                              | The Department of Health is commissioning research to inform and evaluate HEE's investment in dementia education and training, to ensure that this is based on sound evidence.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                           |
|                                                                                                                                                              | As part of its commitment to improve professional education in dementia care, Higher Education for Dementia Network (HEDN) has developed a Curriculum for Dementia Education (CfDE). The curriculum is designed to guide Higher Education providers on the key areas for inclusion in courses related to dementia care, at both pre-registration and post-qualifying levels.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                             |
|                                                                                                                                                              | The Royal College of Nursing Foundation has published 'Carers Included: A Guide to Best Practice for Dementia Care.'                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                     |

| Key commitments                                                                                                                                                                      | Status                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                              |
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| Call on the Royal Colleges to respond to the challenge of dementia by bringing forward plans to ensure that all their members are capable and competent in dementia care (continued) | The size of the adult social care workforce is 1.5 million people (figures from the National Minimum Data Set – Social Care), and the vast majority of these people are employed by independent care providers. Previous research in 2010 has indicated that over 40% of this workforce is involved in supporting people with dementia. Over the past 12 months, Skills for Care estimate that over 100,000 social care workers have received some form of dementia awareness training through workforce development funding from local authorities and care providers. In this time, Skills for Care has also been supporting this workforce in a variety of different ways. Pilot sites have been set up across England to consider the social care workforce's role in supporting dementia friendly communities and these sites will report in Autumn 2014. In addition, Skills for Care has developed resources to support people working with people in the advanced stages of dementia, and are currently producing resources to support the homecare workforce. Over the past year, with funding from the Department of Health, Skills for Care has supported over 7000 learners to undertake some form of dementia workforce development, including accredited Qualification and Credit Framework units and qualifications. |
| Ensure that memory clinics are established in all parts of the country and drive up the proportion of memory services that are accredited                                            | Work completed to date:  There are now in the region of 56 services accredited with the Royal College of Psychiatrists Memory Services National Accreditation programme out of 94 members who are currently part of the programme. The Department of Health commissioned the Royal College of Psychiatrists to undertake a survey of memory clinics and this reported in November 2013. The audit reported that the number of people being assessed by memory clinics has risen four-fold since 2010/11, with just under half of the people diagnosed with dementia over the last 12 months being in the early stages of the condition. This is encouraging. However, in some parts of the country people are waiting too long before being seen by memory services. As a result of the audit findings, NHS England are working with local areas with the aim of bringing the average wait for a diagnostic assessment for dementia down to 6 weeks from GP referral in each area of England.  NHS England and the Department of Health are working with the Royal College of Psychiatrists to encourage more Memory Services to become accredited.                                                                                                                                                                                 |

| Key<br>commitments                                                            | Status                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                     |
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| Guarantee a written integrated personalised care plan to people with dementia | Work completed to date:                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                    |
|                                                                               | Under the revised dementia Directed Enhanced Service (DES) published in April 2014, people who have a diagnosis of dementia are offered an extended appointment to develop a care plan. The care planning discussion will focus on their physical and mental health and social needs which will include referral and signposting to local support services.                                                                                                                                                                                                                                                                                                                                |
|                                                                               | On 28 February 2014 the Secretary for State of Health announced his ambition for improving dementia care and support for people with dementia, their family and carers. This signalled the importance of a tailored plan of care as part of a package of high quality, personalised dementia care and support. The ambition also highlighted the importance of:                                                                                                                                                                                                                                                                                                                            |
|                                                                               | a timely assessment of their condition and diagnosis                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                       |
|                                                                               | someone who can help and advise, such as a dementia adviser                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                |
|                                                                               | support to remain as independent as possible                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                               |
|                                                                               | access to high-quality personalised information to help understand<br>and manage their condition                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                           |
|                                                                               | access to support services such as reminiscence and counselling                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                            |
|                                                                               | co-ordinated care towards the end of life                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                  |
|                                                                               | timely access to support for carers                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                        |
|                                                                               | seamless care with health and social care professionals working together to provide the best care and support.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                             |
|                                                                               | A Department of Health working group focusing on post diagnosis support has been established with representatives from Public Health England, NHS England, the Association of Directors of Adult Social Services, the Local Government Association, NHS improving Quality, Dementia Action Alliance, Alzheimer's Society and other partners to support areas to improve post-diagnosis support. This work aims to make clear 'what good looks like' in terms of post-diagnosis care and improve our understanding of the level of care currently available. It will also seek to understand the support local commissioners need, and enable clearer expectations for patients and carers. |
|                                                                               | As part of the NHS Outcomes Framework, NHS England are developing an indicator to measure the effectiveness of post-diagnosis care in sustaining independence and improving quality of life.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                               |

| Key<br>commitments           | Status                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                |
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| There will be                | Work completed to date:                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                               |
| better support<br>for carers | Provision within the care and support Bill includes a new duty on local authorities to meet carers' eligible needs for support. This is supported by a Department of Health commitment to make an extra £175 million available to councils to meet additional costs of improving both assessment and support for carers.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                              |
|                              | The Personal Social Services Survey of Adult Carers in England is a biennial survey, undertaken by councils, which took place in its current format for the first time in 2012-13. 57,860 people out of a sample of 126,755 carers of social care users, including carers of people with dementia, responded to the survey, a response rate of 46 percent. The survey found that carers of people with dementia are most likely to have had some sort of interaction with support, services and information resources, and that carers were more able to take a break from caring at short notice or in an emergency, where the person they cares for had dementia, a learning disability or difficulty, or a terminal illness. The average scope for carer related quality of life was 8.1 out of a maximum possible score of 12. The equivalent score for a carer of a person with dementia is 7.8. |
|                              | The Dementia Action Alliance launched a 'Carers Call to Action' on 20 November 2013 setting out goals to bring about real change for carers. It calls for a society where carers of people with dementia:                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                             |
|                              | have recognition of the unique experience of caring for someone with dementia;                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                        |
|                              | are recognised as essential partners in care – valuing their knowledge<br>and the support they provide to enable the person with dementia to<br>live well;                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                            |
|                              | have access to expertise in dementia care and support for<br>personalised information, advice, support and co-ordination of care<br>for the person with dementia;                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                     |
|                              | have assessments and support to identify the on-going and changing<br>needs to maintain their own health and wellbeing; and                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                           |
|                              | have confidence that they are able to access good quality care, support and respite services that are flexible, culturally appropriate, timely and provided by skilled staff for both the carers and the person for whom they care.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                   |
|                              | NHS England have extended the Dementia Commissioning for Quality and Innovation (CQUIN) initiative to include measures to identify carers and provide them with relevant information and advice, as well as asking hospitals to undertake a monthly audit of carers of patients with dementia to see if they feel supported.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                          |

| Key commitments                                                                                                                                                                                      | Status                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                          |
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| There will be better support for carers (continued)                                                                                                                                                  | The Department of Health contributed to the funding of the Alzheimer's Society's 'Dementia Guide', designed to help guide people with dementia and their carers through their journey with dementia. The Guide provides useful information for carers, following a diagnosis of dementia, and includes advice to help people understand a diagnosis of dementia to enable them to live well with the condition.                                                                                                                                                                                                                                                                                                                 |
|                                                                                                                                                                                                      | The government's mandate to NHS England made it clear that by 2015, carers looking after friends and family members should routinely have access to information and advice about support available, including respite care. Support for carers is integral to the work NHS England is leading to improve the quality of life of people with long term conditions. NHS England has developed an action plan NHS England's Commitment to Carers, which includes a series of commitments around 8 priorities, among which are raising the profile of carers, person-centred, well-coordinated care, commissioning support and partnership links. It is being launched at the Carers UK's State of Caring 2014 Conference on 7 May. |
| The NHS                                                                                                                                                                                              | Work completed to date:                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                         |
| should also<br>ensure that a<br>range of<br>psychological<br>therapies are<br>commissioned<br>and made<br>available to<br>carers of people<br>with dementia in<br>line with NICE/<br>SCIE guidelines | The NHS Outcomes Framework for 2013/14 includes a new measure relating to psychological therapies. Since last year there has been significant progress in developing Domain 3 (Helping people to recover from episodes of ill health or following injury). This includes developing an indicator (3.1.v) regarding the Improving Access to Psychological Therapy programme, in line with the objective in the Mandate to ensure parity of esteem between people with mental health conditions and the population as a whole. Development of the remaining indicators is expected to be complete before autumn 2014.                                                                                                             |
| By September                                                                                                                                                                                         | Completed                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                       |
| 2012 we will<br>launch pilots of<br>dementia<br>clinical networks<br>aimed at<br>spreading<br>clinical expertise                                                                                     | A national strategic clinical network (SCN) for mental health, dementia and neurological conditions has launched. SCNs are bringing together groups of health professionals to support commissioners to improve services for a particular condition in order to improve the quality of care and outcomes for patients.                                                                                                                                                                                                                                                                                                                                                                                                          |

| Key commitments                                                                                                                                                                                                         | Status                                                                                                                                                                                                                                                                                                                                                                                                                                |
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| Welcome the Nursing and Care Quality Forum's forthcoming views on what should be done to address the needs of people with dementia as part of its work to spread best practice in nursing and care in all care settings | Completed  The Nursing and Care Quality Forum has collected and published examples of best practice in nursing and care in all health and care settings. These can be found on the 6Cs Live! Website as a range of case studies – 18 of which are relevant to care of people with dementia. The website address is:  http://www.6cs.england.nhs.uk/pg/cv_content/76110?searchFileKey=dementia&sort_priority=&ETSortAttrs=&filter_type |

## DEMENTIA FRIENDLY COMMUNITIES CHAMPION GROUP

| Key commitments               | Status                                                                                                                                                                                                                                                                                                                                                     |                                        |                                  |
|-------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------|----------------------------------|
| Dementia Friendly Communities | Work completed to date:                                                                                                                                                                                                                                                                                                                                    |                                        |                                  |
|                               | Recognition process for Dementia Friendly Communities                                                                                                                                                                                                                                                                                                      |                                        |                                  |
| across the country            | There are now over 70 places across England committed to become dementia friendly.                                                                                                                                                                                                                                                                         |                                        |                                  |
|                               | In September 2013, Alzheimer's Society formally launched the Dementia Friendly Communities recognition process. To date, over 50 communities have formally signed up to this recognition process and using the nationally recognised symbol. There is now an increased ambition to have 75 communities signed up to the recognition process by March 2015. |                                        |                                  |
|                               | Communities signed-Recognition Process:                                                                                                                                                                                                                                                                                                                    | up to the Dementia Frie                | ndly Communities                 |
|                               | York                                                                                                                                                                                                                                                                                                                                                       | Peterborough                           | Windsor and                      |
|                               | Crawley                                                                                                                                                                                                                                                                                                                                                    | Salford                                | Maidenhead                       |
|                               | Bradford                                                                                                                                                                                                                                                                                                                                                   | Yorkshire                              | Kent                             |
|                               | Debenham                                                                                                                                                                                                                                                                                                                                                   | Tring                                  | Wimborne                         |
|                               | Camelford                                                                                                                                                                                                                                                                                                                                                  | Manchester                             | Malpas                           |
|                               | Plymouth                                                                                                                                                                                                                                                                                                                                                   | Stockon                                | Bexhill                          |
|                               | Doncaster                                                                                                                                                                                                                                                                                                                                                  | Gedling                                | Luton                            |
|                               | Thurrock                                                                                                                                                                                                                                                                                                                                                   | Liverpool                              | Deal                             |
|                               | Tavistock                                                                                                                                                                                                                                                                                                                                                  | Wakefield                              | North and Northeast Lincolnshire |
|                               | Falmouth                                                                                                                                                                                                                                                                                                                                                   | Bracknell Forest                       | Wolverhampton                    |
|                               | Hampshire                                                                                                                                                                                                                                                                                                                                                  | The Parishes of                        | Bourne                           |
|                               | Sheffield                                                                                                                                                                                                                                                                                                                                                  | Wembury, Brixton,<br>Yealmpton, Newton | Newbury                          |
|                               | Surrey                                                                                                                                                                                                                                                                                                                                                     | and Noss and                           | Lancaster,                       |
|                               | Leeds                                                                                                                                                                                                                                                                                                                                                      | Holbeton                               | Morecambe and                    |
|                               | Warwickshire                                                                                                                                                                                                                                                                                                                                               | Bury                                   | district                         |
|                               | Coventry                                                                                                                                                                                                                                                                                                                                                   | Corbridge                              | Wokingham                        |
|                               | Harlow                                                                                                                                                                                                                                                                                                                                                     | Portsmouth                             | Worthing                         |
|                               | London Borough of                                                                                                                                                                                                                                                                                                                                          | Marple (Stockport)                     | Sandwell                         |
|                               | Richmond                                                                                                                                                                                                                                                                                                                                                   | Poole                                  | Barnsley                         |

| Key commitments                                              | Status                                                                                                                                                                                                                                                                                                     |  |
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| Dementia Friendly Communities across the country (continued) | Development of a code of practice on dementia friendly communities                                                                                                                                                                                                                                         |  |
|                                                              | Building on the foundation stage of the recognition process, the Alzheimer's Society has commissioned British Standards Institution (BSI) to develop a code of practice for dementia friendly communities. The ambition is to have 15 communities signed up to the BSI code of practice by March 2015.     |  |
|                                                              | Dementia friendly awards                                                                                                                                                                                                                                                                                   |  |
|                                                              | In order to celebrate the progress that is being made across England, the Alzheimer's Society is holding the first annual Dementia Friendly Awards at the end of May 2014. The awards will recognize communities, organisations and individuals who have helped to make their area more dementia friendly. |  |

| Key commitments                 | Status                                                                                                                                                                                                                                                                                                                                                                                   |
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| Support from leading businesses | Ongoing                                                                                                                                                                                                                                                                                                                                                                                  |
|                                 | Sector based Task and Finish Groups                                                                                                                                                                                                                                                                                                                                                      |
|                                 | Through the Champion Group, the Alzheimer's Society has been working directly with a number of leading businesses to develop dementia friendly practices with the financial services industry. We are now looking at extending this model into different sectors, including transport and telecommunications.                                                                            |
|                                 | The Champion Group has established six task and finish groups which are engaging businesses. They include:                                                                                                                                                                                                                                                                               |
|                                 | a group of organisations including Sainsbury's and Home Retail     Group that is developing guidance on how the retail sector can work to become more dementia friendly;                                                                                                                                                                                                                 |
|                                 | an employers group that is developing guidance on what steps businesses need to take to become a dementia friendly employer;                                                                                                                                                                                                                                                             |
|                                 | a group that is focusing on the issues of Power of Attorney and data protection developing consumer focused leaflets (reflecting the two types of power of attorney) containing dementia friendly messaging, sign-posting to expert information, and myth-busting barriers to data sharing guidance for people affected dementia when dealing with companies and organisations;          |
|                                 | a group focusing on the role of civil society and the voluntary sector; developing a framework of key characteristics to assess and promote innovative practices and projects in mainstream communities to enable the participation of people with dementia and their carers as citizens;                                                                                                |
|                                 | a group that is focusing on the needs of people living with dementia<br>and carers living in rural communities has identified some key issues<br>and outcomes that people with dementia and their carers rely on in<br>order to live well in their community. It has also pointed to some<br>priority areas of action that the group should focus on over the next<br>twelve months; and |
|                                 | a group focusing on developing a dementia friendly technology charter to help people with dementia and carers get access and navigate assistive technology options.                                                                                                                                                                                                                      |
|                                 | A further three Task and Finish Groups on transport, leisure and personal services will begin work this month.                                                                                                                                                                                                                                                                           |

| Key commitments                             | Status                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                              |
|---------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Support from leading businesses (continued) | Recognising dementia friendly businesses and organisations                                                                                                                                                                                                                                                                                                                                                                                                                                                          |
|                                             | The Alzheimer's Society will launch criteria for businesses and organisations that want to work towards becoming dementia friendly, with 10 businesses committed by March 2015.                                                                                                                                                                                                                                                                                                                                     |
|                                             | The Alzheimer's Society is committed to engaging three sectors or industries to lead the way to becoming dementia friendly, for example through the establishment of a sector charter, by March 2015.                                                                                                                                                                                                                                                                                                               |
|                                             | Engaging businesses in Dementia Friends                                                                                                                                                                                                                                                                                                                                                                                                                                                                             |
|                                             | In December 2013 the Secretary of State, together with the Alzheimer's Society, hosted a business breakfast to engage key business leaders to commit to creating Dementia Friends within their companies. Since then the Dementia Friends programme has received a huge boost, with a commitment from major British businesses. Argos, Homebase, Marks and Spencer, Lloyds Banking Group and Lloyds Pharmacy, have committed to create over 190,000 Dementia Friends in shops and banks across the UK.              |
|                                             | Dementia Friendly Financial Services Charter                                                                                                                                                                                                                                                                                                                                                                                                                                                                        |
|                                             | The 'Dementia-friendly financial services charter' which was launched in October 2013 has been designed to help financial services organisations recognise, understand and respond to the needs of customers living with dementia and their carers.                                                                                                                                                                                                                                                                 |
|                                             | Together, Lloyds Banking Group and Alzheimer's Society worked with 24 other financial organisations to develop the charter. The charter lays out a number of ways financial services organisations can work towards becoming more dementia-friendly, such as appointing a 'Champion' to drive forward the initiative in each branch. Customers with dementia will also be given more choice, including the option to flag up to the bank that they have dementia so customer service can be tailored appropriately. |

| Key commitments                   | Status                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                        |
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| Awareness-<br>raising<br>campaign | Work completed to date:                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                       |
|                                   | The campaign delivered at the end of 2012 reached out to over 37 million people. The evaluation findings show that:                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                           |
|                                   | three quarters of people agreed that the campaign would help people with dementia and their families.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                         |
|                                   | 86 percent agreed that some people with dementia can still take part in everyday activities.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                  |
|                                   | 83 percent agreed that they would encourage a relative or friend to visit a GP if they thought they had symptoms of dementia.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                 |
|                                   | Dementia Friends Campaign                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                     |
|                                   | Work is now underway on a further campaign for 2014. Dementia Friends is gaining real momentum across England. We are increasingly raising awareness and understanding of dementia within local communities. Today there are over 61,000 Dementia Friends, with a commitment from key businesses to recruit Dementia Friends within their organisations.                                                                                                                                                                                                                                                                                      |
|                                   | Public Health England has worked together with the Alzheimer's Society to launch on 7 May 2014 a major new national multi-media campaign, the Dementia Friends Campaign, which aims to inspire and support a movement of friendship in which everyone plays a part. It aims to up-skill society so more people develop an understanding of how to engage with people with dementia by recruiting people into the Dementia Friends programme. The campaign will raise awareness of dementia, improve attitudes towards the condition and create a more dementia friendly society by encouraging one million people to become Dementia Friends. |
|                                   | Schools project                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                               |
|                                   | The work across the pioneer group of 22 schools raising awareness and understanding of dementia was evaluated by the University of Worcester in 2013. Building on the success and learning of this pioneer group, a Dementia Resource Suite for Schools was developed and launched on 16 October 2013 at the National Children and Adult's Conference. The Suite has been developed to support teachers to devise and deliver their own dementia awareness lessons and activities.                                                                                                                                                            |
|                                   | It is hoped schools across England will start to deliver lessons and activities on dementia, leading to the creation of a dementia friendly generation.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                       |
|                                   | The Dementia Friendly Communities Champion Group are asking the pioneer schools to make contact with other schools in their area and to support schools with the development of dementia awareness activities and lessons. They are also hoping to work strategically with local councils to pursue opportunities in a whole area.                                                                                                                                                                                                                                                                                                            |

| Key<br>commitments                                                                           | Status                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                             |
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| Awareness-raising campaign (continued)                                                       | Working with faith groups                                                                                                                                                                                                                                                                                                                                                                                                                                                                                          |
|                                                                                              | Faith leaders and groups have a crucial role in working within communities that are becoming dementia friendly because of their community engagement, knowledge and the support that they provide to people. Work has already begun to engage local faith groups across England in their role in increasing awareness of dementia and how they can support people to live well with dementia. The Alzheimer's Society is working with the charity Liviability to develop a dementia friendly churches sermon pack. |
|                                                                                              | Raising Awareness across Black and Minority Ethnic (BME) communities                                                                                                                                                                                                                                                                                                                                                                                                                                               |
|                                                                                              | In July, Irish in Britain is hosting a one-day conference titled: Responding to Dementia: Inclusion for All. The aims of this event are to highlight the needs of vulnerable BME communities, the meaning of culturally and dementia friendly services for different BME groups and to showcase good practice.                                                                                                                                                                                                     |
|                                                                                              | The conference will bring together professionals in mainstream and third sector organisations and commissioners (or those who influence them) and will include people with memory loss and their carers.                                                                                                                                                                                                                                                                                                           |
| Major summer                                                                                 | Completed                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                          |
| event bringing<br>together leaders<br>from industry,<br>academia and<br>the public<br>sector | In September 2013 the Alzheimer's Society hosted a major conference to present the evidence on dementia friendly communities, along with resources for local communities and organisations to help them become dementia friendly. The conference launched the foundation stage recognition process for dementia friendly communities.                                                                                                                                                                              |
|                                                                                              | The Alzheimer's Society has also taken part in international conferences in Malta, Washington and Madrid showcasing the Dementia Friendly Communities Programme.                                                                                                                                                                                                                                                                                                                                                   |
|                                                                                              | Throughout the year the Alzheimer's Society will be raising the profile of dementia friendly communities at key conferences and industry sector events. They are partnering with Hawker publications and the Joseph Rowntree Foundation on a two day conference on dementia friendly communities that will take place in June.                                                                                                                                                                                     |

| Key actions                                                                                                                                                     | Status                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                     |
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| We will work with the Alzheimer's Society to develop local Dementia Action Alliances to bring together people with dementia, their carers and key organisations | Work completed to date:                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                    |
|                                                                                                                                                                 | One of the ways that communities are working to become dementia friendly is through local Dementia Action Alliances. These are a way of bringing together organisations and individuals committed to taking action to support people with dementia and their carers. Their membership ranges from local authorities to acute trusts, from corner shops to solicitors. There are now over 83 local Dementia Action Alliances across the country. During the third year of the Prime Minister's Challenge the ambition is to:                                                                                |
|                                                                                                                                                                 | <ul> <li>maintain and increase the network of Local Dementia Action Alliance<br/>Co-ordinators, widening the spread across England to establish and<br/>engage with key local stakeholders, with the ambition of 100%<br/>coverage by March 2015;</li> </ul>                                                                                                                                                                                                                                                                                                                                               |
|                                                                                                                                                                 | • increase the number of local authority members of Dementia Action Alliances from 32 to 76, which will include 50% of Upper Tier local authorities by March 2015.                                                                                                                                                                                                                                                                                                                                                                                                                                         |
| We will make                                                                                                                                                    | Completed                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                  |
| sure that people with dementia and carers on diagnosis have an information pack about dementia produced in conjunction with the Alzheimer's Society             | A new resource has been developed by the Alzheimer's Society for people who are given a diagnosis of dementia. <i>The dementia guide: Living well after diagnosis</i> was made available in print in June in 2013. In Autumn 2013 a film was made available on DVD and online. The booklet and videos were offered in a range of accessible formats. Research was undertaken with people with dementia and carers as well as professionals to determine the content and appropriate level of detail. They have also reviewed the content and contributed towards the development of the design and layout. |
|                                                                                                                                                                 | The resource is available through Alzheimer's Society and the Department of Health, who contributed towards cost of development of the guide. It has been is endorsed by the Royal Colleges of Psychiatrists and General Practitioners as well as the Association of Directors of Adult Social Services. Over 90,000 copies have been issued to date.                                                                                                                                                                                                                                                      |

| Key actions                                                                                                                                                           | Status                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                |
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| The Dementia- friendly Communities Programme working in partnership with the Dementia Action Alliance will develop evidence on what a dementia- friendly community is | Completed                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                             |
|                                                                                                                                                                       | Building Dementia Friendly Communities: A priority for everyone                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                       |
|                                                                                                                                                                       | In order for dementia friendly communities to succeed, the views and opinions of people with dementia and their carers must be at the heart of any considerations or decisions. <i>Building dementia-friendly communities: A priority for everyone</i> was published by the Alzheimer's Society in September 2013 and provides evidence of dementia friendly communities from the perspective of people affected by dementia. It explores the barriers that people face in their community, how they would like to be engaged in their local area and the support they need to empower them to do so. |
|                                                                                                                                                                       | Overall, the report aims to provide guidance to areas that are looking to become dementia friendly and to provide extra evidence for those already committed to becoming dementia friendly. New and existing evidence from people with dementia and their carers is collated alongside examples of projects that are making a difference for people with dementia.                                                                                                                                                                                                                                    |
|                                                                                                                                                                       | Dementia Friendly Yorkshire - The First Steps                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                         |
|                                                                                                                                                                       | This collection produced by the Joseph Rowntree Foundation contains 20 examples of inspiring grassroots dementia friendly projects transforming communities across Yorkshire. The collection can be accessed at: http://www.jrf.org.uk/publications/dementia-friendly-yorkshire                                                                                                                                                                                                                                                                                                                       |

## **RESEARCH**

| Key                                                               | Status                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                            |
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| commitments                                                       |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                   |
| More than doubling dementia research funding by 2015              | On track  The target is to double public sector research funding to £66 million by 2015.                                                                                                                                                                                                                                                                                                                                                                                                                          |
| Major                                                             | Completed                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                         |
| investment in<br>brain scanning<br>(MRC Biobank<br>proposal)      | £9.6 million is being provided for a pilot study involving 8000 volunteers as the first phase of a brain imaging programme that will ultimately scan the brains of 100,000 Biobank participants.                                                                                                                                                                                                                                                                                                                  |
|                                                                   | To further enhance the impact of this work, the Medical Research Council (MRC) and Department of Health have jointly awarded £20 million to enable all 500,000 Biobank participants to be genotyped, with a particular focus on the identifying the genetic signature associated with risk of developing of dementia.                                                                                                                                                                                             |
|                                                                   | These investments provide a key foundation for the development by MRC of the new UK Dementias Research Platform (see below). This has UK Biobank at the core of some 20 cohorts which will be integrated and exploited to open up new avenues of research in dementias. They will span stratified and experimental medicine and enabling researchers to take account of the interplay between the onset of neurodegeneration and accompanying cardiovascular, metabolic or other body changes that affect health. |
| £13 million<br>NIHR/ESRC<br>social science<br>research<br>funding | Completed                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                         |
|                                                                   | The National Institute for Health Research (NIHR) and the Economic and Social Research Council (ESRC) jointly ran a competition for projects focussing particularly on how we can improve quality of life for people with dementia and their carers. Funding was increased to £20 million due to the quality of bids received, with 6 large projects awarded, commencing in 2014 (Q1). This now represents the world's largest social science research programme on dementia and care.                            |

| Key commitments                                                                              | Status                                                                                                                                                                                                                                                                                                                                                                                                                                                                  |
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| £36 million funding for NIHR dementia translational research collaboration                   | Completed                                                                                                                                                                                                                                                                                                                                                                                                                                                               |
|                                                                                              | The collaboration was established in 2012 bringing together four new NIHR Biomedical Research Units in dementia and NIHR Biomedical Research Centres with dementia-related themes. Collaborations are already underway with a number of companies across industry addressing a range of challenges in imaging, biomarkers and presymptomatic research. The collaboration is a member of the transnational Centres of Excellence in Neurodegeneration initiative (CoEN). |
|                                                                                              | NIHR is establishing a governance and technical solution to enable access to electronic medical records for research in dementia across the NIHR Dementia Translational Research Centre                                                                                                                                                                                                                                                                                 |
|                                                                                              | The Dementia Case Records Interactive Search system with a governance model led by service users is fully on track to be completed during Q2 2014. Approximately 1 million pseudonymised mental health records, including those of people with dementia, will be enabled for research in a safe and secure environment by NIHR researchers, and to improve monitoring of health services. Funding has been provided to pump-prime dementia research on this system.     |
|                                                                                              | NIHR committed £0.6M co-funding for TRC-D towards the feasibility phase of a planned jointly funded deep and frequent phenotyping study with MRC as part of the development of the UK Dementias Research Platform.                                                                                                                                                                                                                                                      |
| Offering the                                                                                 | On track                                                                                                                                                                                                                                                                                                                                                                                                                                                                |
| chance to participate in dementia research to be a condition of memory service accreditation | New standards relating to research have been included in the accreditation criteria. The new <i>Join Dementia Research</i> national service will be available for use by the Memory Services National Accreditation Programme (MSNAP) clinics during 2014 to enable them to meet the criteria.                                                                                                                                                                          |

| Key actions                                                   | Status                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                            |
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| The MRC will                                                  | Work completed to date:                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                           |
| spend over £3 million in supporting the UK brain bank network | MRC provides approximately £1 million per annum as core support to four banks, and funds coordination within the UK network of 10 brain banks. During 2012, an additional £0.5 million was provided to support the process for the donation of brain tissue, by funding the retrieval and banking of brain tissue following death, and the costs associated with providing a diagnosis for families and their clinicians. In conjunction with publicity regarding donation, in 2013 MRC has renewed this commitment. This has led to an increase of 18 percent in the number of brains collected by the Network. Alongside this, a new on-line database, launched by the MRC in March 2013, will speed up access to more than 7,000 donated human brains. This initiative involves collaboration with five leading charities. It will help scientists from academia and industry to investigate the underlying causes of major brain diseases including dementia. |
| A major event                                                 | Completed                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                         |
| will be staged<br>for<br>pharmaceutical<br>and biotech        | On 10 October 2012, partners in the research system came together to showcase dementia research and resources. As a result, eight different companies are involved in collaborations across a range of different dementia research questions.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                     |
| companies                                                     | Additional activity                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                               |
|                                                               | In a parallel process MRC has engaged with pharmaceutical companies and SMEs towards the establishment of a new public-private partnership focussed on target validation and experimental medicine in dementia research. First stage funding for the MRC UK Dementias Research Platform (UKDP) was announced in December with second stage funding recently approved leading to an overall MRC investment in the UKDP of £12 million. This will be added to by anticipated investment from industry partners, with 8 companies currently engaged in advance discussion towards the full launch of the UKDP by summer 2014. Alzheimer's Society is partnering on the deep and frequent phenotyping of this important initiative.                                                                                                                                                                                                                                   |
|                                                               | MRC also hosted a one-day international workshop with industry on 29 November 2013 to showcase research funded under the Centres of Excellence in neurodegenerative disease research (COEN) initiative and to raise awareness of the potential for COEN to facilitate partnership with biopharma. The workshop involved researchers drawn from the COEN Centres of Excellence in the 8 partner countries, and senior industry representatives. Outputs will inform the future development of the COEN strategy in a way that is complementary to the needs of industry.                                                                                                                                                                                                                                                                                                                                                                                           |
|                                                               | There are several collaborative initiatives being developed between industry and the charity sector, including the Dementia Consortium. This £3 million project will expedite the development of new drugs for dementia, combining Alzheimer's Research UK with life science technology transfer experts MRC Technology and the pharmaceutical companies Eisai and Lilly.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                         |

| Key actions                                                                                                                                             | Status                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                               |
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| We will work<br>towards<br>recruiting 10<br>percent of<br>patients into<br>clinical trials                                                              | Work completed to date:                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                              |
|                                                                                                                                                         | NIHR has developed 'ENRICH': a Toolkit for Care Home Research. This provides straightforward advice for researchers, care home staff, and others which will help increase the volume of dementia research in care homes. Over 170 care homes are already participating in an ENRICH Network.                                                                                                                                                                                                                                                                                                                                                                                                                                         |
|                                                                                                                                                         | A barrier to patient participation is the lack of a nationally consistent system to help people to find and join studies. DeNDRoN is working in partnership with Alzheimer's Society, Alzheimer's Research UK, the Royal College of Psychiatry, people affected by dementia, researchers and the NHS, to address this through developing a consent-for-approach list through which people with dementia and their carers will be offered the opportunity to register their interest in being contacted about appropriate research. The new system will be called 'Join Dementia Research' and will be launched in spring 2014 in the University College London Partners region before being rolled out nationally later in the year. |
|                                                                                                                                                         | The number of people with dementia involved in studies is increasing based on studies already funded. The 2012/13 figure was 11,859 (3.7%); forecast 13/14 figure 13,400 (4.4%).                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                     |
| Up to £9 million of Department of Health funding will be made available for research into 'living well with dementia' and the delivery of dementia care | On track  This work was awaiting the outcome of the NIHR/ESRC dementia research initiative to see where gaps and opportunities exist. Discussions are now underway with the Economic & Social Research Council (ESRC).                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                               |
| The Department                                                                                                                                          | On track                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                             |
| of Health will increase its support for capacity-building in dementia research, focusing on nurses as well as doctors                                   | Dementia nursing research was highlighted in the latest competition for NIHR clinical academic training awards for nurses (funded by HEE and managed by NIHR). Discussions are continuing between DeNDRoN, NIHR, Alzheimer's Society and Royal College of Nursing on how best to build significant capacity in dementia nursing research.                                                                                                                                                                                                                                                                                                                                                                                            |
|                                                                                                                                                         | NIHR Collaborations in Leadership on Heath Research and Care are developing the details of a scheme to fund care research training in dementia. NIHR continues to build the community of clinical academics active in dementia research, through specifically targeting some of its research training posts for trainee doctors, towards relevant clinical specialties and centres of excellence in dementia research.                                                                                                                                                                                                                                                                                                               |
|                                                                                                                                                         | Focussed funding calls are bringing a wider spectrum of the UK's research community into the dementia field.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                         |

| Key actions                                                                                                                     | Status                                                                                                                                                                                                                                                                                                                                                                                                                                                                         |
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| The MRC is a leading partner in two international initiatives in the area of neuro-degeneration research                        | Work completed to date:                                                                                                                                                                                                                                                                                                                                                                                                                                                        |
|                                                                                                                                 | The latest phases of the Network of Centres of Excellence in Neurodegenerative disease research (COEN) and the EU Joint Programme in Neurodegenerative Disease (JPND) were launched in 2012.                                                                                                                                                                                                                                                                                   |
|                                                                                                                                 | MRC is providing £3 million to fund the participation of UK groups in collaborative cross-border programmes, with awards announced in July 2013. This resulted in:                                                                                                                                                                                                                                                                                                             |
|                                                                                                                                 | • £0.4 million investment to support UK involvement in 2 CoEN 'pathfinder' grants, as part of a package of 5 awards made in summer 2013 which overall provided €3 million to support 'high risk, high pay-off' approaches to identify and validate new potential drugs and develop innovative therapeutic approaches for neurodegenerative disorders; and                                                                                                                      |
|                                                                                                                                 | • MRC investment of £2.7 million in support of UK-based research in four of the five successful international projects funded under the most recent JPND call. UK researchers are also involved as collaborators in the fifth. The aim of the call was to find innovative and ambitious approaches that would add value to existing research by identifying new genetic, epigenetic and environmental risk and protective factors associated with neurodegenerative disorders. |
|                                                                                                                                 | ESRC contributed a total of €1.7 million across 5 of the 6 applications which were successful under the JPND Transnational call 2012: "European research projects for the evaluation of health care policies, strategies and interventions for Neurodegenerative Diseases". The Projects will all have commenced by April 2014.                                                                                                                                                |
|                                                                                                                                 | In April 2014 JPND launched a rapid action call for working groups to progress dementias research based on longitudinal cohort studies. Each working group will receive €50 thousand funding to develop enabling strategies to maximise the potential of longitudinal cohort studies for neurodegenerative diseases research.                                                                                                                                                  |
| Major expansion<br>of neuroscience<br>programmes at<br>the world-<br>leading MRC<br>Laboratory of<br>Molecular<br>Biology (LMB) | Completed                                                                                                                                                                                                                                                                                                                                                                                                                                                                      |
|                                                                                                                                 | The Laboratory of Molecular Biology (LMB) Neuroscience Division has been provided with an expanded budget of £49 million over the next 5 years, an increase of 50 percent, with a major part dedicated to research on dementia and neurodegeneration, involving a recruitment drive. Alongside this, LMB has moved into a new £200 million building providing state of the art facilities in support of this research agenda.                                                  |

| Key actions                                                                                  | Status                                                                                                                                                                                                                                                                                                                                                                                                                                                                       |
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| The NIHR has also just completed a first-ever themed call for proposals in dementia research | Completed                                                                                                                                                                                                                                                                                                                                                                                                                                                                    |
|                                                                                              | NIHR has provided over £20 million of additional funding into twenty-one pioneering research projects.                                                                                                                                                                                                                                                                                                                                                                       |
| Other funding                                                                                | Work completed to date:                                                                                                                                                                                                                                                                                                                                                                                                                                                      |
| initiatives                                                                                  | The National Centre for the Replacement, Refinement and Reduction of Animals in Research (NC3Rs) and Alzheimer's Research UK have invested over £1 million to challenge the best minds to devise an innovative non-animal approach to understand dementia. They want researchers to use human stem cells to model tau behaviour. The ultimate aim of the challenge is to use this technique to screen compounds that could be developed into new treatments for Alzheimer's. |
|                                                                                              | Alzheimer's Research UK and the Alborada Trust are also about to announce a £2 million Stem Cell Research Centre, which will use stem cell models to identify new potential drug treatments for Alzheimer's and other dementias.                                                                                                                                                                                                                                             |
|                                                                                              | The Alzheimer's Society continues to increase its investment in research into the cause, cure, care and prevention of dementia. It has recently doubled investment to £5 million per year in new research, will re-double to £10 million by 2016, and has made a long term commitment to spend at least £100 million on research over the next decade. In addition, Alzheimer's Society is also partnering on two of the NIHR/ESRC funded proposals.                         |
|                                                                                              | In response to the 2013 G8 summit on dementia, the Alzheimer's Society, working through Alzheimer's Disease International, has established a global taskforce on dementia research.                                                                                                                                                                                                                                                                                          |
|                                                                                              | The Alzheimer's Society has stepped up its commitment to increase the UK's dementia research capacity through offering significant funding to establish Doctoral Training Centres across the UK (funding to be announced Autumn 2014)                                                                                                                                                                                                                                        |
|                                                                                              | Alzheimer's Society's Drug Discovery Programme funded two major 'repurposing' trials in 2013: one trialling a type 2 diabetes drug for Alzheimer's (Liraglutide) and another trialling an anti-hypertensive drug for vascular dementia (Amlodipine). A \$3 million joint call for proposals has also been launched in collaboration with Alzheimer's Drug Discovery Foundation in the US.                                                                                    |
|                                                                                              | Alzheimer's Research UK has launched its Drug Discovery Institute, which is the first of its kind in Europe and aims to fast-track the translation of promising academic research findings into patient benefits.                                                                                                                                                                                                                                                            |