

**THE PRIME
MINISTER'S
CHALLENGE
ON DEMENTIA**
Delivering major improvements
in dementia care and research
by 2015: Annual report of
progress



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Introduction

The challenge

Prime Minister,

In March 2012 you set us a challenge to deliver major improvements in dementia care and research by 2015. You identified dementia as one of the biggest challenges society faces today, a challenge that we cannot afford to ignore any longer and one that can only be tackled through approaches that draw on all parts of society.

We are now over one year into our three-year programme of work to address this challenge. This report celebrates our initial successes, identifies shared themes across the work of the three Champion Groups and reflects on what we have learnt so far.

We also set out what the combined forces of the Champion Groups will work on next to sustain and accelerate progress and to tackle the remaining barriers to improving the quality of life for people with dementia, their families and carers.

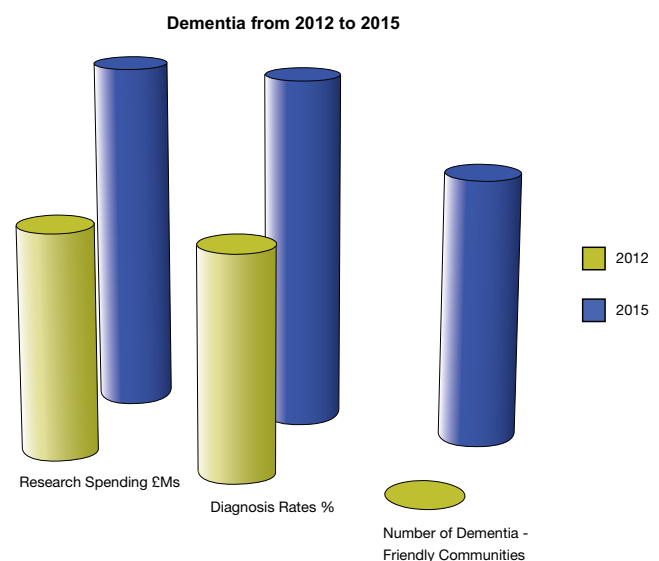
Our shared ambition

Our shared ambition is to make a real and positive difference to the lives of people affected by dementia. We want to ensure that people with dementia and their carers receive high quality, compassionate care whether they are at home, in hospital or in a care home. We want the person with dementia, and their family and carer, to be at the heart of everything we do. We also want their wellbeing and quality of life to be first and foremost in the minds of those commissioning and providing services for them.

Building on the National Dementia Strategy¹, we want England to be amongst the best in the world in dementia care and research. A society where people with dementia can say:

- I was diagnosed in a timely way.
- I know what I can do to help myself and who else can help me.
- Those around me and looking after me are well supported.
- I get the treatment and support, which are best for my dementia, and for my life.
- I feel included as part of society.
- I understand so I am able to make decisions.
- I am treated with dignity and respect.
- I am confident my end of life wishes will be respected. I can expect a good death.
- I know how to participate in research.

By 2015, we want to see significant increases in research funding, diagnosis rates and the number of dementia-friendly communities.



¹ Living Well With Dementia: A National Dementia Strategy, Department of Health, 2009

Where we've come from

When we began our work in March 2012, we identified the key issues affecting the lives of people with dementia where we needed to take urgent action. Under diagnosis of dementia was the norm, with only 42 percent of people in England having a formal diagnosis². The provision of information and advice and the quality of support for people following diagnosis, in their own homes and communities, was variable.

Under a third of GPs believed they had received sufficient training to diagnose and manage dementia³, and more generally, we identified that much more needed to be done to increase the capability and skills of the health and care workforce.

A quarter of all hospital beds were occupied by someone with dementia⁴, with many hospitals struggling to provide the high quality care needed to meet the needs of people with dementia. While many care homes and home care services offered excellent support for people with dementia and their carers, some were not doing enough. Too many people with dementia were not being supported to have early discussions about their wishes and make plans for their end of life care. Inappropriate prescribing of anti-psychotic medication was a major concern.

Despite the rising numbers of people living with dementia, public understanding of the condition was limited, with people not understanding dementia or how to support those affected by it to live well with the condition. The Alzheimer's Society report *Dementia 2012: A national*

*Challenge*⁵, published in March 2012 found that 55 percent of people with dementia are living well with the condition, which suggests what can be achieved. However, the report also reveals a different story. *Dementia 2012* showed that the number of people who felt anxious or depressed was substantial, 77 percent of people surveyed said they felt anxious or depressed and 61 percent of people with dementia feel lonely. This can have a significant impact on the quality of life for people living with dementia. Factors contributing to increased loneliness among people with dementia include difficulties maintaining social relationships and reduced mobility. Put simply, our society is not geared up to ensure people with dementia can live well in the community.

While the UK was considered one of the top countries for dementia research, we identified major challenges including developing a wider programme of research coordination and engagement, spanning basic research through to living well with dementia and significantly increasing capacity and capability across the entire national research system.

Over the past year we have prioritised our work, focusing on delivery of the original key commitments and actions in your challenge, but also initiating some new actions to go further and faster in a number of areas, with the aim of beginning to deliver the change we all want to see. That is:

- the need for people to receive a timely diagnosis;
- for better quality care;
- reducing stigma by increasing understanding and awareness across society and;
- building national capacity and capability in dementia research.

² Mapping the Dementia Gap 2011: Alzheimer's Society, 2012

³ Living Well With Dementia: A National Dementia Strategy, Department of Health, 2009

⁴ Counting the Cost: Alzheimer's Society 2009

⁵ Dementia 2012: A National Challenge, Alzheimer's Society, 2012

More widely, the initial Government response to the Report of the Mid Staffordshire NHS Public Inquiry⁶ highlighted the importance of making the quality of care as important as the quality of treatment. We know the majority of patients in hospital at any given time will be over 65, many of whom will be living with dementia. However, the messages in the report apply to the way people are cared for across health and care settings. The key issues raised such as staff training, care planning, ensuring a positive patient environment and communication with patients, their families and carers are all relevant to the care of people with dementia. The work that has started in response to Robert Francis's report will be crucial to improving the standard of care for people with dementia in all care settings.

Where we've got to

A focused approach to delivering improvements

One thing is clear: the Prime Minister's Challenge on Dementia has created a new momentum in health and social care, research and across society as a whole to do more to help and support people with dementia, their carers and families. Some of our key successes, just over a year in to the challenge, are:

Driving improvements in health and care

- NHS England has set the first ever national ambition to improve dementia diagnosis rates. **By 2015, our aim is that two-thirds of people should have a diagnosis, with appropriate post diagnosis support.** Achieving this ambition will mean that over 160,000 more people with dementia will be diagnosed in 2015

than in 2011/12 and will receive appropriate support following their diagnosis. This will need support across health and wellbeing boards and clinical commissioning groups. NHS England has established a programme of work to support and monitor progress against this ambition. As part of this, plans from local clinical commissioning groups will be made available publicly.

- There is a **new Enhanced Service for take up by GPs as part of the GP contract for 2013/14 to reward practices for having a pro-active, case finding approach to the assessment of patients** who may be showing the early signs of dementia.
- The **Government's response to Dilnot and the reforms to the social care system** will begin to make a difference once implemented in 2016. The commitments on the system of charging for care, including the creation of a cap on care costs, which people will pay, expending the means test threshold for financial assistance and ensuring people do not have to sell their home in their lifetime to pay for residential care, will help to protect people with dementia from the high costs of care. However, it is also essential that the social care system is properly funded.
- **Public Health England has named dementia as one of its seven high level priorities** for 2013/14, in recognition of the key role public health can play in the delivery of better dementia care and support.
- The launch of a **'Dementia Care and Support Compact'** with major care providers to improve care and support for people with dementia living at home and in care homes. From 10 signatories a year ago, there are now, to date, over 148 signatories representing nearly 3,000 care services.

⁶ Patients First and Foremost: The Initial Government Response to the Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry, The Department of Health, March 2013

- Establishing and beginning to embed the **Commissioning for Quality and Innovation (CQUIN) reward for hospitals** offering dementia risk-assessments to all over-75s admitted to hospital as an emergency. This has led to over 4,000 people a month being referred for further investigation, for example to a memory service. **From April 2013, the CQUIN reward has been extended to the quality of dementia care delivered and support for carers of people with dementia.** Trusts have also been asked to appoint a senior clinical lead for dementia who will be responsible for ensuring that staff are trained in dementia care.
- **Dementia friendly hospitals:** Since we reported in November 2012, 118 acute trusts and 22 non-acute trusts have committed to becoming dementia friendly, working in partnership with their local Dementia Action Alliance.

Creating dementia-friendly communities that understand how to help

- The **Dementia Friends programme run by Alzheimer's Society** and co-funded by the Department of Health and Cabinet Office aims to increase awareness and understanding of dementia by educating 1 million people to become 'Dementia Friends' by 2015. Since the formal launch of Dementia Friends in February 2013, over 2247 people have signed up to train as volunteer Dementia Friends Champions, with **over 500 people already trained**. Those signed up for Dementia Friends Champion training have the potential to reach **over 100,000 members of the public through dementia awareness sessions**. In government, the Department of Health has committed to rolling out the Dementia Friends initiative to its staff with the aim of having 500 friends by August 2013. Within NHS England,

Sir David Nicholson has committed to become a Dementia Friend and to support all staff to become Dementia Friends. We are working with government departments to roll out the programme across Whitehall.

- **Over 50 cities, towns and villages are already taking local action to become dementia friendly**, more than doubling our original ambition of 20 cities, towns and villages signed up to be dementia friendly by 2015. **Fifteen of these communities are now part of a pilot phase for the recognition process** for dementia friendly communities. The purpose of the recognition process is to show that the community in question has committed to action to become dementia friendly.

The communities that are part of the pilot are those that can demonstrate tangible progress in becoming dementia friendly based on the values and standards identified by people affected by dementia. Some examples include raising awareness of dementia in the local community or working with local stakeholders to set up a local dementia action alliance.

The pilot was developed based on the outcomes of a consultation carried out in September 2012 on what the key elements of a recognition process should be. The pilot will ensure that when the national process is launched in September 2013 it is robust, rigorous and determined by what is important to the lives of people affected by dementia. It will also inform the development of ways to recognise excellence, best practice and innovation being undertaken by dementia friendly communities.

- Alzheimer's Society is working in partnership with the Dementia Action Alliance to establish local dementia action alliances across the country. **Over 20 Local Dementia Action Alliances have been established** bringing together organisations to take responsibility

for improving the lives of people with dementia and carers in their area. Membership of the local alliances ranges from local authorities to acute trusts, corner shops to solicitors. Local Dementia Action Alliances have now signed up to the National Dementia Declaration⁷ and committed to hundreds of actions to support people with dementia and their carers. Local Dementia Action Alliances are a key way of supporting and sustaining communities that are working to become dementia friendly.

- A **dementia education pioneer programme was launched with 21 schools across the country** who are testing different approaches to educating children and young people about dementia. The findings from this pioneer group are being written up to be made available to all schools who wish to participate from the forthcoming autumn term.
- **Delivered a nationwide campaign to raise awareness of dementia and to encourage people to visit their doctor if they are worried about dementia.** The campaign which ran at the end of 2012, reached out to over 37 million people. The evaluation findings show that three quarters of people agreed the campaign would help people with dementia and their families. In addition, the findings show that 86 percent agreed that some people with dementia can still take part in everyday activities and 83 percent agreed that they would encourage a relative or friend to visit a GP if they thought they had symptoms of dementia.

Better research

- Major expansion of the neuroscience programmes at the world-leading Medical Research Council (MRC) **Laboratory of Molecular Biology (LMB)**. Resources have been increased by 50 percent with a **major part dedicated to research on dementia** and neurodegeneration.
- Through the National Institute for Health Research (NIHR), provision of over **£22 million of additional funding into twenty-one pioneering research projects.**
- **Created the NIHR Translational Research Collaboration**, which brings together the country's leading dementia research facilities to collaborate in translating discoveries from basic scientific research in dementia into benefits for patients.
- Jointly with the Economic and Social Research Council (ESRC) and the Department of Health, launched a call in July 2012 to **fund up to £13 million social science research proposals in preventing dementia.** Final decisions on which proposals to fund will be made in July this year.
- **Major investment in brain scanning: £9.6million is being provided by the MRC** for a pilot study involving 8,000 volunteers as the first phase of a brain imaging programme that will ultimately scan the brains of 100,000 Biobank participants.
- On 10 October 2012, we **brought together the UK's research system to showcase this country's dementia research and resources.** The event proved an important step in developing industry's interest in an area where there are no easy 'quick wins'. Eight different companies are involved in collaborations as a result of the event across a range of different dementia research questions. In parallel, MRC has engaged with pharmaceutical companies towards the establishment of a new public-

⁷ http://www.dementiaaction.org.uk/who_are_we/national_dementia_declaration

private partnership focussed on target validation and experimental medicine in dementia research. Nine companies are currently engaged in discussions with a budget of up to £12 million identified to deliver this initiative.

■ **Developed two facilities that will help to increase the proportion of people with dementia** having the opportunity to participate in research through:

- ENRICH, a toolkit for care home research providing simple, practical advice for researchers, care home staff and others; and
- Creation of 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 research, and have their permission recorded for their data to be used so that they can be contacted about appropriate research.

Shared themes and challenges

Increased public and professional awareness and understanding

The challenge and benefits of raising awareness and understanding of dementia is a theme cutting across the work of all three Champion Groups. We will continue to push hard on this over the next two years.

Dementia is coming out the shadows. The success of the nationwide awareness raising campaign in November 2012 encouraging people to seek advice from their GP, alongside action across the health and care sector, particularly in hospitals and care homes, has put in place a framework to embed dementia awareness and training across the system. Examples include the support tools developed by the Department of Health and NHS England for GPs, nurses and clinical commissioning groups, and guidance for

health and care staff on implementing the new dementia component of the NHS Health Check.

We will continue to focus on educating the health and care workforce and supporting family carers to care effectively, to look after their own health and well-being and to have a life of their own alongside caring. Embedding tailored high quality dementia training and development across health and social care, working closely with Health Education England, is essential to deliver the transformational culture change needed to improve care and support for people with dementia, their carers and families.

The launch of the Dementia Friends programme in February 2013 will see one million people educated about dementia by 2015 so they can better understand how to help someone with dementia in their community. In doing so, this programme will act as a real driver to creating more dementia friendly communities and organisations. Through Dementia Friends, we have the potential to transform awareness and understanding of dementia across society and to engage with sectors, organisations and communities beyond health and social care.

In March 2013, approximately 6,000 people including members of the public, health and social care professionals, researchers and others visited the first ever model dementia friendly village at the National Healthcare Innovation Exposition (EXPO). The Dementia Village was a collaborative effort across the three Champion Groups and showcased innovation and achievements right across the challenge, as well as a wide range of practical approaches to supporting people to live well with dementia.

A drive towards making integrated care and support the norm

We know the dementia journey differs for everyone. Our work has highlighted that all too often care, support and our efforts on improving

research can be fragmented, delayed or duplicated. Individual parts of the local, national and international system do not always work effectively together to meet the holistic needs of people with dementia and their carers. Not only does this risk poorer quality of care, but also inefficient use of public resources. We need joined up care, centred on the individual and their family and spanning across health and care, which recognises the important role of a wider range of services, for example housing, transport, leisure and welfare, for supporting people with dementia to live well with the condition.

We must do more to accelerate learning across the system on making integrated care and support a reality and to ensure that this learning is widely disseminated. We would like to see greater action to promote and incentivise integration to become the norm and see this as an important step to delivering the necessary improvements to health and care for people with dementia and their carers. We would like to use our learning to support the integration agenda.

Where we are going

Greater collaboration

We need to make a real and lasting difference to the lives of people with dementia, their families and carers. Looking ahead to the next two years of our work, we must acknowledge the changed landscape in which we now need to work following the health and care reforms and the establishment of new international, national and local delivery partners.

We will work collaboratively across our three Champion Groups and with these new organisations to embed the early successes and initiatives of the Challenge into widespread practice across health, care and wider society. It is clear we are now in a position to transform dementia care and research as never before. With

our key partners, we will continue to build momentum, but will also look at how we ensure that the changes we make are sustained over the longer term.

Reaching out further

Some people with dementia and their carers remain isolated and afraid. Some local authorities have reduced spending on adult social care, meaning that fewer people with dementia and their carers are able to access the care and support that they need. For example, some people are unable to access planned, funded respite care, putting additional pressure on already exhausted family carers. The Government has taken important steps forward on the Dilnot proposals on charging for care. This needs to be supported by the provision of sufficient funding to meet the needs of people with dementia and their families.

There are a number of areas where, working with our key delivery partners, we need to penetrate more effectively to ensure sustainable change. For example:

- working closely with Public Health England on the next awareness raising campaign and looking at how we can encourage the public to make lifestyle changes that will help to reduce the risk of vascular dementia and support the creation of dementia friendly communities and;
- working with Health Education England to look at how we can embed and support high quality education and training and culture change right across the health and care workforce, recognising the important role that staff in a wide range of professions play in supporting people with dementia and their carers;
- encouraging other and more diverse sections of the community to play a role in the drive towards dementia friendly communities and;
- supporting more young researchers to make their career choice dementia.

Influencing the wider system

At national level we will be working closely with a range of partners including NHS England, Public Health England, Health Education England and the Care Quality Commission to influence and support their work programmes. We will also be looking more widely across Whitehall to establish what further actions can be taken by other government departments to support the Prime Minister’s Challenge on Dementia.

At local level, we recognise the important role of health and wellbeing boards as central to driving integrated care and support for people with dementia and their carers, with representation from the NHS, public health, local authorities and others.

In years two and three of our work programme, through the Society of Local Authority Chief Executives (SOLACE) we will explore the opportunity to work with a number of exemplar health and wellbeing boards to implement the Challenge and disseminate learning at national level. We will also work more closely with the Department for Communities and Local Government, the Local Government Association, London Councils, Greater London Authority and the Homes and Communities Agency.

We would like to take this opportunity to thank you for your continued leadership and support and your welcome determination to make life better for people with dementia, their families and carers. Working across government and wider society, we remain committed to making a real and lasting difference.

Jeremy Hughes

Dame Sally Davies

Sarah Pickup

Sir Ian Carruthers

Angela Rippon



Our progress

The work of the Champion Groups is starting to deliver the required step change to boost dementia care and research. The annexes to this report summarise our progress against the original key commitments and actions in the Prime Minister's Challenge on Dementia.

Driving improvements in health and care

Achievements

Timely diagnosis

Since we last reported in November 2012, dementia has been prioritised by both the Department of Health through the Mandate to NHS England and NHS England's subsequent planning guidance⁸ and business plan.

The number of people diagnosed with dementia has increased by 27,000 between 2010/11 and 2011/12, an increase of 10 percent. This has had the effect of raising the diagnosis rate from 42 percent in 2010/11 to around 45 percent in 2011/12⁹. However, it is unacceptable that less than half of people with dementia in England receive a formal diagnosis and that the diagnosis rate in Primary Care Trusts varied from 31 percent in the worst performing areas to 75 percent in the best¹⁰. The Secretary of State for Health and Minister for Care and Support wrote to every MP, Peer and local authority Chief Executive in January 2013 to draw their attention to the current diagnosis rate nationally and in their local area, encouraging them to engage with their local clinical commissioning groups and health and wellbeing boards to prioritise improvements.

NHS England have set the first ever national ambition to improve dementia diagnosis rates. By 2015, our aim is that two-thirds of people should have a diagnosis, with appropriate post-diagnosis support. Achieving this ambition will mean that over 160,000 more people with dementia will be diagnosed in 2015 than in 2011/12 and will receive appropriate support following their diagnosis.

The newly formed clinical commissioning groups will lead on planning and commissioning to deliver their local ambition. They are ideally placed as partners in health and wellbeing boards to champion the wider support, which will be needed from a range of partners. NHS England has provided clinical commissioning groups with tools and guidance to help them set a local ambition to improve their dementia diagnosis rate, to commission sufficient memory services, and to track and demonstrate their progress.

8 Everyone Counts: Planning for Patients 2013/14, NHS England, April 2013 (<http://www.england.nhs.uk/everyonecounts/>)

9 Final figure to be published in the NHS Outcomes Framework in June.

10 Mapping the Dementia Gap 2012, Alzheimer's Society 2013

Integrated dementia care in Dudley

Dudley Council, working in partnership with NHS Dudley, has developed an innovative, integrated approach to the diagnosis, care and support offered to people with dementia, their carers and families. They have developed three dementia gateways located across the borough, which provide care and support for those affected by dementia throughout all stages of the condition.

If dementia is suspected by a GP in Dudley, they will refer the person to the borough's dementia pathway. The pathway will ensure that a formal diagnosis is made by a dementia specialist and care and support is then offered by a dementia nurse or dementia advisor – this will be a lifetime contact. The advisors and nurses are based in the dementia gateways and work closely with people, families and carers on an ongoing basis developing a plan of support, help and advice – unique to each person.

Through attention to the individual needs and wishes of the person, the gateways ensure tailored care, as well as providing extensive support and advice for families and carers. The gateways aim to ensure those affected by dementia enjoy life to the full, and they offer a wide range of sessions and therapies, from crafts and memory exercises to gardening. There are also day sessions available to provide a break for family and carers.

Dudley Council and NHS Dudley

As part of the GP contract for 2013/14 a new enhanced service has been introduced to reward practices for having a pro-active, case finding approach to the assessment of patients who may be showing the early signs of dementia. This will be undertaken through an initial enquiry followed by a memory test, as necessary. To support GPs, a guide on cognitive assessment, including

memory, has been jointly published by the Department of Health and Alzheimer's Society.

From 1 April 2013, as part of the NHS Health Check programme, people aged 65 to 74 have been given information at the time of the risk assessment to raise their awareness of dementia and the availability of memory services. This will help to support more people in getting a timely diagnosis.

NHS Health Checks in Southwark

Southwark integrated dementia awareness into NHS Health Checks in March 2013 and is now rolling this out to all GP practices and pharmacies. The outreach nurses completed both face to face and online training and commented "The training was great. Doing both was very helpful, I didn't know very much about dementia so it gave me the confidence to be able to talk about it with my clients."

A patient commented: "I was really scared when the nurse mentioned dementia. The information was very helpful, I had no idea this was something I could influence."

High quality, compassionate care in hospitals

Dementia Commissioning for Quality and Innovation (CQUIN):

From April 2012, the Dementia Commissioning for Quality and Innovation (CQUIN) rewarded hospitals for offering dementia risk-assessments to all over-75s admitted to hospital as an emergency. From April 2013, this has been extended to the quality of dementia care delivered and support for carers of people with dementia as set out in guidance published by NHS England in February 2013¹¹. This has led to over 4,000 referrals a

11 Commissioning for quality and innovation (CQUIN): 2013/14 guidance, NHS England, February 2013

month, which will contribute to improving diagnosis rates for dementia.

From April 2013, trusts are being asked to appoint a senior clinical lead for dementia who will be responsible for ensuring that staff are trained in dementia care. Trusts can utilise the dementia e-learning sessions published by e-learning for healthcare in June 2012 as a means of ensuring that staff are capable and competent in dementia care. Trusts will have to report twice a year to their board the results of audits of carer experience.

Dementia Friendly Hospitals: In March 2013, the Care Quality Commission (CQC) published the results of a thematic review¹² which showed that in most NHS acute trusts people with dementia stayed in hospital significantly longer than those without the condition when admitted as an emergency (in 96 percent of trusts) or as an elective (76 percent of trusts) and were more likely to be readmitted (70 percent of trusts) and die in hospital (85 percent of trusts). The review, which was published as part of CQC's care update, will be repeated this autumn.

Since we reported in November 2012, 118 NHS acute trusts (over 70 percent of acute trusts), and 22 non-acute trusts, have now committed to becoming dementia friendly, working in partnership with their local Dementia Action Alliance. We are working to encourage the remaining trusts to sign up.

The Prime Minister announced in 2012 a new patient-led assessment scheme in hospitals. This includes a new focus on how the ward environments have been designed to support the needs of patients with dementia. The new assessments were launched in April 2013.¹³

12 The state of health care and adult social care in England: an overview of key themes in care in 2011/12, Care Quality Commission, March 2013

13 <http://www.england.nhs.uk/ourwork/qual-clin-lead/place/>

Dementia Friendly Hospitals in Bradford

Bradford Teaching Hospitals NHS Foundation Trust has made a public commitment to become a Dementia friendly hospital by signing up to the National Call to Action. "We have achieved considerable success in improving the quality of care and the nature of the experience that patients with dementia and their carers receive. This has been done by working in collaboration with patients and carers and by recognising and valuing their experience and feedback. We have also worked in partnership with our regional and local action alliance groups which has allowed us to share our knowledge and experience with other organisations as we have progressed towards becoming an exemplar trust.

Our success in getting through to the second stage of the bid process for the 'Improving the environment of care for people with dementia capital fund' will enable us to be pioneers in meeting the challenge of improving public spaces with regard to way finding and orientation and in the development of outside environments."

Bryan Millar, Chief Executive, Bradford Teaching Hospitals NHS Foundation Trust

High quality, compassionate care in the community

Dementia Care and Support Compact: From 10 signatories a year ago, there are now, to date, 148 signatories to the Dementia Care and Support Compact representing nearly 3,000 care services committed to delivering high quality, personalised care to people with dementia and their carers¹⁴. Every registered care provider is now able to

14 <http://www.dementiaaction.org.uk/dementiacompact>

show the public how they meet the Dementia Care and Support Compact using their on-line quality profile, which is available on the NHS Choices website.¹⁵

On 25 June, the English Community Care Association is holding the first ever 'National Care Home Open Day' to raise awareness about the important contribution that care homes make to local communities. Thousands of care homes across the country will be putting on events and activities for members of the public to connect care homes to their local communities and to change perceptions. This provides a positive opportunity to encourage volunteering, improve community relations and develop a purpose for



communities to engage with some of the residents in their local care homes.

Anchor Trust and the Dementia Care and Support Compact

Anchor Trust is working towards improving the lives of their residents living with dementia using the Dementia Care and Support Compact. Staff are supported by a dedicated team of dementia specialists to understand dementia and develop skills which promote a philosophy of enjoyment and engagement, so residents can live full and interesting lives in environments adapted to encourage independence and choice. Based on a philosophy of relationship centred care, Anchor encourages family and friends to be involved in care and with the communities in which residents live. By understanding the individual needs of people with dementia, staff are able to tailor care and activity which is of interest and is meaningful for each person.

Joan is a younger resident in the care home who was very reserved and avoided group situations. Through conversations, and the development of a life story, it became apparent that Joan had had a very active social life involving many friends. The care home staff arranged for Joan, with a care worker, to visit a local Italian restaurant for elevenses, coffee and a cake every week. Joan looks forward to these visits, the time she spends with others in a situation that is similar to her life before moving into the care home and she is now much happier.

Housing: The National Housing Federation, in partnership with the Housing Learning and Improvement Network, Foundations (the national umbrella body for home improvement agencies) and the Dementia Services Development Centre have published a report on how housing can impact positively on the lives of people with

dementia. This report includes examples of dementia friendly housing design, where the delivery of timely interventions at home has delayed more intensive forms of care, including preventing admissions and readmission to hospital.

Provision of information: The information offered pioneered by NHS South West is now available across the whole of the country, enabling access to comprehensive information about local dementia services. It is hosted on the Dementia Choices website (www.nhs.uk/dementiachoices), which was launched at this year's Healthcare Innovation EXPO event.

Care at home and home care services: UK Home Care Association (UKHCA) has work underway to support homecare providers in helping people to live well with dementia by providing high quality dementia care services and a well-trained, competent workforce. This includes dementia awareness, education, information and resources; developing dementia-friendly communities; development and delivery of quality homecare services; and raising the profile and role of homecare providers in dementia.

UKHCA have launched a specific dementia helpline to respond to homecare providers on a range of dementia issues. This has been well received and the advice and support provided has directly helped people who are living with dementia and their families. In *Homecarer*¹⁶, UKHCA regularly publish articles on dementia and provides practical advice for care workers and managers of homecare services.

Looking ahead, UKHCA is establishing a number of dementia focus groups, which will play an important role in building dementia friendly communities. The groups will help providers to share experiences, challenges and opportunities when providing a quality service for people with

dementia. A dementia lead has been appointed, who will oversee the development of the groups. Homecare providers will also be encouraged to comment on key dementia issues through social media such as LinkedIn and Twitter.

Developing the groups will enable UKHCA to map out a picture of innovative dementia developments and challenges across the country and will provide a vital new platform for information, knowledge and experience to be collated and disseminated.

An innovative approach to communication with a person with dementia

A homecare manager was asked to provide care and support for a woman with dementia, Mrs G, who was experiencing problems with her memory and communication.

As part of the assessment, the homecare manager discovered that Mrs G was a dog lover, but had been without a dog for some time as she was unable to look after one. Mrs G's homecare workers were dog lovers and it was suggested, and agreed with her daughter, that the care workers should visit with their dogs. The effect it had on Mrs G was monitored.

Mrs G enjoyed stroking the dogs and seemed more relaxed as the care workers carried out the care. She started to talk about her dogs, recalling their names and telling funny stories about times when they had been naughty. As time went on, she reminisced about her own life and her communication abilities improved. Mrs G's daughter, other members of her family and the homecare provider were amazed at the results and enjoyed reminiscing with their mother and seeing how much more relaxed she appeared to be, and agreed the dogs were helping.

¹⁶ <http://www.ukhca.co.uk/homecarer.aspx>

End of Life Care: The Prime Minister's Challenge on Dementia has enabled the National Council for Palliative Care (NCPC) to learn from partners about the kind of resources they need in supporting people affected by dementia. The Alzheimer's Society report *My life until the end: Dying well with dementia*¹⁷ provides new evidence on the needs of people with dementia at the end of life and makes recommendations for change and improvements.

Through working closely with people with personal experience of dementia, on 4 December 2012, the NCPC published guidance on managing pain and distress for people with dementia approaching the end of life¹⁸. The guidance is aimed at all those who care for people with dementia in all settings, for health and care support staff, GPs and clinicians, as well as family carers and friends. The NCPC will be evaluating this guidance so they can see the difference it is making to people with dementia and their carers.

The NCPC has also published a training DVD for GPs called *'Time to Talk, Doc?'*. This is supporting GPs to initiate and continue conversations about end of life care with people affected by dementia.

Looking ahead, we know that dementia friendly communities must also ensure that people with dementia and their carers can get access to good end of life care in all settings. NCPC are committed to working with other partners engaged in the Prime Minister's Challenge on Dementia to be able to create a brighter future for those affected by dementia to the very end of their lives.

Commissioning effective, high quality care

National Institute for Health and Care Excellence (NICE) quality standard on Dementia:

On 3 April 2013, the quality standard for supporting people to live well with dementia was issued by the National Institute for Health and Care Excellence¹⁹. The quality standard covers the care and support of people with dementia and it applies to all social care settings and services working with and caring for people with dementia.

National Institute for Health and Care Excellence (NICE) commissioning guide:

NICE has also issued a guide to support the commissioning of high-quality, evidence-based care for people with dementia²⁰. This provides practical advice for commissioners to improve the integration of health and social care services. This will help to ensure that more people with dementia receive a timely diagnosis and can access the care and support that they, and their carers, need to live well and independently with dementia for as long as possible. The support for commissioning will help commissioners achieve the outcomes set out in the clinical commissioning group outcomes indicator set and other national health and social care outcomes frameworks.

Improving health and care environments for people with dementia and their carers: On 25 October 2012, the Secretary of State for Health announced that £50 million capital funding was being made available in 2013-14 for the NHS and local authorities to work with providers to create care environments to help people with dementia live well with the condition. The findings and evidence from the pilot projects will be used to

17 *My life until the end: Dying well with dementia*, Alzheimer's Society, 2012

18 *How to help someone with dementia who is in pain or distress*, The National Council for Palliative Care, 2012

19 *Quality standard for supporting people to live well with dementia*, National Institute for Health and Care Excellence, April 2013

20 *Support for commissioning dementia care*, National Institute for Health and Care Excellence, April 2013

develop future guidance in this area. The initiative was heavily oversubscribed and following a robust evaluation process, 42 NHS schemes and 74 social care schemes were approved at stage one and announced at the end of February 2013. Final decisions on the funding will be made in June 2013 following consideration of more detailed bids from the successful stage one applicants.

Support for carers: Carers are central to the Government's proposals for care and support. For the first time, provision for assessing and supporting carers is in the mainstream of government legislation, including a simplified process of assessments and a new duty on councils to meet carers' eligible needs for support. This will be underpinned by a Department of Health commitment to provide new resources starting in 2015 and rising to £175 million per annum by 2020.

The NHS is well placed to identify carers or potential carers when a diagnosis of dementia is made and to signpost them to information, advice and support that will enable them to care effectively, to look after their own health and to have a life of their own alongside caring. Funding of over £800,000 has been provided in 2012/13 to the Royal College of General Practitioners (RCGP), Carers UK and the Carers Trust, the Queens Nursing Institute (QNI) and the Royal

College of Nursing (RCN), to develop initiatives to increase awareness of carers' needs among healthcare professionals and to improve outcomes for carers including those caring for people with dementia.

Supporting carers in Surrey

Carers Support Waverley in Surrey have developed 'Our Plan', a plan to help carers and family members to support someone living with dementia. The plan helps them by explaining what might happen to the person with dementia, including how their needs will change as the condition progresses, and gives advice on how they can help them live well with the condition. It also provides practical advice on care and support, advocacy, care plans and end of life care.

In addition, the local NHS in Surrey has provided over £1 million to provide breaks for carers with over 200 carers benefitting from this support in the last year. The Royal Surrey County Hospital are piloting a carer passport, which provides advice and support.

A Task and Finish Group, jointly chaired by the Department of Health and Employers for Carers has been looking at how carers can be better supported to remain in employment and exploring



how different ways of supporting carers help them to remain in employment alongside caring. It will report to Department of Health Ministers in summer 2013.

Supporting health and care professionals

Nursing: On 4 January 2013, the Prime Minister announced a recommendation from the Chief Nursing Officer and the Department of Health/ Public Health England Director of Nursing that:

- all nurses have an understanding of dementia to enable them to give informed advice, to signpost those with concerns to the right support, to promote dementia awareness in communities and to encourage nurses to become Dementia Friends;
- those who care for older people at home, in care homes and hospitals have dementia training, with a link nurse in every ward or care setting; and
- each organisation has a dementia nursing expert to lead and promote improvements.

The Prime Minister also announced the roll-out of a dementia package that would see 100,000 nurses and health care assistants receiving dementia training via e-learning by 2015. These new e-learning resources are being published today and are available to health and social care staff through the Health Education England e-learning for Healthcare portal²¹.

Nursing vision and strategy: In March 2013, the Department of Health launched a new nursing vision and strategy for dementia care making clear that every nurse can make a difference to the care of people with dementia²². This new vision supports the Prime Minister's Challenge

on Dementia by raising the profile of the wider nursing contribution to dementia care and describing what is expected of all nurses to meet the level and quality of care expected in all care settings.

Education and training for nurses

“The Dementia Leadership Education Programme provided by University of Worcester, enabled me to gain an understanding of person centred approaches in caring for people with dementia and how this can be implemented within the acute hospital environment. The inclusion of people with dementia and carers in the programme, in particular, enabled me to gain insight into the needs of both the patient and the families/ carers and to fully understand the importance of a partnership approach to care. I have been seconded to the post of Dementia Specialist Nurse for Hampshire Hospitals NHS Foundation trust and I have been able to use the knowledge and skills I learnt on the programme to teach others about individual needs and perspectives of someone with dementia. I am also developing a dementia training programme for trust employees to ensure that all staff have the knowledge and confidence to care and work with people with dementia, their families and carers. I feel privileged to have been given the opportunity to be part of this work. The educational programme I attended has given me the knowledge to be able to fulfill my new role and to successfully make a positive change to dementia care within my trust.”

Rachel Hayden, Dementia Specialist Nurse, Hampshire Hospitals Foundation trust

21 <http://www.e-lfh.org.uk/projects/dementia>

22 Making a Difference to Dementia: Nursing Vision and Strategy, Department of Health 2013

Dementia Pledge: The Dementia Pledge was launched on 13 February 2013 under the leadership of the English Community Care Association, with funding from the Department of Health. The Pledge builds on the Dementia Care and Support Compact and supports social care employers to implement workforce excellence. Over 900 care providers have signed up to the Pledge, demonstrating a commitment to developing their workforce's understanding of dementia and adapting their services to meet the needs of people living with dementia.

The right treatment

Reducing inappropriate prescribing of antipsychotic medication: In July 2012, the National Dementia and Antipsychotic Prescribing Audit reported a 52 percent reduction in the prescribing of antipsychotics for people with dementia²³. The Department of Health has now commissioned a further audit from the Health and Social Care Information Centre, and the results are expected to be published by the end of the year. A risk assessment for anti-psychotic prescribing for people with dementia has been developed by members of the Antipsychotic Working Group, chaired by Professor Alistair Burns, and it will be published shortly.

Next steps

Timely diagnosis: We will work with NHS England and the Department of Health to consider how we can best support clinical commissioning groups and local health and wellbeing boards to deliver the ambition that by 2015, two-thirds of people with dementia should have a diagnosis, with appropriate post diagnosis support. This will include holding a roundtable discussion in June with the Chair of the BMA's General Practitioners Committee and others from the GP profession to

discuss what further support GPs need with respect to dementia, what the profession will be doing to support the aim of timely diagnosis and how we can work together.

Detecting vascular dementia: In November 2012, we reported that evidence suggests that for up to 50 percent of people with dementia there may be a 'vascular' component to their condition²⁴. We know the effects of vascular dementia can be minimised or prevented altogether through healthy lifestyle. The Department of Health and Alzheimer's Society together have commissioned Kings College look into the evidence on the prevention of vascular dementia and to undertake a review of this evidence. The review will be published shortly and will inform our future work with Public Health England.

The Public Health agenda: We will work with Public Health England and other partners across the NHS, local government and the voluntary and community sector to develop a co-ordinated national approach to preventing dementia, maximising the contribution of NHS Health Checks, and we will focus on reducing the burden and stigma of dementia families by supporting dementia friendly communities.

Working with Health Education England: The Department of Health and NHS England will work closely with Health Education England (HEE) to put in place a forward work programme for the delivery of the work on dementia to be set out in the Government's forthcoming Mandate to HEE. This will build on the work already taken forward by the National Dementia Strategy Workforce Advisory Group and will take forward the priorities of the government for education and training on dementia across the health and social care workforce. The forward work programme will be discussed in detail by the Workforce Advisory Group at its next meeting in June 2013.

²³ National Dementia and Antipsychotic Prescribing Audit, NHS Information Centre, 2012

²⁴ Living Well with Dementia: A National Dementia Strategy, Department of Health, 2009

Post diagnosis support: The Department of Health funded a pilot programme of dementia advisor and peer support network services to look at the value of these services for people with dementia and their carers. As part of the programme, the Department commissioned an independent evaluation. The evaluation report will be published this summer. The Department of Health will disseminate the key findings and learning from the pilot programme to inform local commissioning processes.

Development of the Dementia Care and Support Compact: The Department of Health and NHS England are working with the care provider sector to develop the reach of the compact, including potential work with the Care Quality Commission (CQC) to look at how the principles of the compact can be reflected in CQC's future regulatory model.

Integrated care: National Voices, a coalition of health and social care charities, has identified the lack of joined-up care as a source of huge frustration for patients and carers and that "achieving integrated care would be the biggest contribution that health and social care services could make to improving quality and safety". National Voices has reported that "people want to experience seamless care, where it comes from is secondary." Navigating complex care systems can be particularly difficult and confusing for people with dementia, and therefore integrated care, across health and social care, would be particularly beneficial in assisting people with dementia and their carers to live well with the condition.

The NHS Innovation Challenge Prize for Dementia in collaboration with Janssen Healthcare Innovation will be awarding up to £150,000 for solutions, which demonstrate delivery of a comprehensive integrated service across health, care and support for people with dementia. This Challenge Prize will be launched in spring 2013 and remain open for a period of four months.

Creating dementia friendly communities that understand how to help

Achievements

Alzheimer's Society has been working with the Prime Minister's Champion Group on Dementia Friendly Communities and the Dementia Action Alliance to help create dementia friendly communities. There are four key parts to the programme of work:

1. Getting evidence from people with dementia and carers about what would make it possible for them to enjoy a better quality of life in their community. The evidence will then be used to develop information and tools for organisations to help them meet the needs and aspirations of people with dementia;
2. Creating a system of recognition so that places and organisations wanting to become dementia friendly can use a symbol to show they are working to become dementia friendly;
3. Creating local Dementia Action Alliances across the country to bring together people and organisations who can change things for the better;
4. Educating the public so that more people understand dementia and start to think about how they can make things better. The Dementia Friends Programme is a central part of this.

Raising awareness and understanding across society

The Prime Minister's Champion Group on Dementia Friendly Communities has worked with partners across the community to look at what can be done to improve the ways that communities understand and act on dementia.

Dementia friendly in action

Trevor says: "It was fantastic and a pleasure to be involved with planning the garden for the dementia village at the Healthcare Innovation Expo and I felt that people were genuinely interested in my views and opinions."

He says "dementia is not just a problem with your head but has a much wider impact on your everyday life including hobbies" and in his case this affected his ability to maintain his garden. He realised that, for financial and safety reasons, he would need to make changes if he was going to continue enjoying his own garden.

At NHS Expo, Trevor used his knowledge and experience of redesigning his own garden to help visitors to the dementia village to think about the potential hazards in the garden for all older people, including those with dementia. He pointed out the dangers with using chemicals, power tools, electric lights and pumps and helped people to think about alternatives such as solar powered lighting and pumps for ponds. He says: "Take this away if you have a neighbour with dementia. You could suggest changes they could make to their own garden to make it safer. It's not being a nosey neighbour but a dementia-friendly neighbour."

Trevor has used his own experience to help people with dementia within his own community to make changes to their own gardens to ensure they are safe for them to enjoy.

"It's out there now for people to think about and see what changes they could make that would help to make a difference for someone with dementia."

Trevor Jarvis, person with dementia

The dementia awareness campaign, run by the Department of Health in partnership with Alzheimer's Society at the end of 2012, reached out to 37 million people. The campaign encouraged people to visit their doctor if they were worried about dementia. The evaluation findings show that:

- three quarters of people agreed the campaign would help people with dementia and their families;
- 86 percent agreed some people with dementia can still take part in everyday activities;
- 83 percent agreed they would encourage a relative or friend to visit a GP if they thought they had symptoms of dementia.

Launching the pilot recognition process and the symbol

Alzheimer's Society is now piloting a recognition process for dementia friendly communities. The purpose of the recognition process is to show the community in question has committed to action to become dementia friendly. The pilot is based on values and standards that people with dementia and carers have identified as important to them.

A symbol to show that communities are working to become dementia friendly has been developed for use by communities participating in the pilot, as illustrated below. These communities will be able to display this symbol once they have registered with the recognition process and demonstrated they meet the criteria for working to become dementia friendly.



The pilot phase will ensure that, when the national recognition process is launched in September 2013, it is robust and rigorous and determined by what is important to people with dementia. The pilot phase will also inform the development of ways to recognise best practice and innovation in dementia friendly communities.

Crawley Dementia Action Alliance

The Crawley Dementia Alliance is reaching out to new networks to make Crawley a dementia friendly community. Bringing together a range of players across government, health, business and community, the Alliance is working to make Crawley "a town where the people living with dementia and their families are able to live well and are supported across the town to get the help they need to ensure everyday life and pursuit of leisure and cultural activities are made easy."

The Alliance has taken a proactive attitude towards new projects and ideas for becoming dementia friendly. It has launched a range of training opportunities, events and neighbourhood programmes and also started the Forward Thinking group which brings together people with dementia to find out their experiences and aspirations for the community.

One of the neighbourhood programmes is focusing on breaking down the stigma of dementia often faced in Asian communities. The neighbourhood involved in the programme has the highest density BAME population in the local area. The local GP surgery is leading the work and encouraging their partners and staff to be a part of the social movement to become dementia friendly. The programme aims to build awareness throughout local businesses around the neighbourhood centre.

Crawley Dementia Action Alliance

Evidence on social isolation from people with dementia

Alzheimer's Society's second annual report *Dementia 2013*²⁵ was published in April 2013. It provides a snapshot of how well people are living with dementia and explores the progress made in the last year. The report provides new evidence about quality of life and dementia, specifically loneliness, which will inform the Dementia Friendly Communities programme, along with Dementia Friends and other programmes. The report found that 62 percent of people with dementia living alone are lonely and that people with dementia find it hard to access services, which may help them overcome this isolation.

Encouraging more communities to commit to being more dementia-friendly

To ensure support and sustain the social movement to create a dementia friendly society, the national Dementia Action Alliance is working in partnership with Alzheimer's Society to drive forward the development of Local Dementia Action Alliances across the country. There are now 20 local alliances, with several having launched recently in Manchester, Yorkshire and Humber, Bolton and many other places. Overall, more than 50 places across England have committed to becoming dementia friendly.

Working with faith groups

Faith leaders and groups have a crucial role in community engagement and in offering knowledge and support, and so have an important role to play in working within communities that are becoming dementia friendly. Work has already begun to engage local faith groups across England in increasing awareness of dementia and supporting people to live well with dementia.

The Church of England is currently developing a booklet on dementia friendly churches which will be provided to local parishes.

Working with schools

Schools and colleges have a key role in creating a dementia friendly generation for the future through the education of children and young people. More young people are coming into contact with people living with dementia within their own families and the families of their friends.

The vision for the work with schools and colleges is three-fold:

- to remove the stigma of dementia in society and achieve better community support and engagement both now and in the future, by educating children and young people about the condition;
- to provide children and young people with confidence and insight into a widespread issue affecting their lives and communities; and
- to provide interaction and enrichment between people with dementia and children and young people.

Since September 2012, twenty one pioneer group schools from across the country, including both primary and secondary schools, have been developing innovative ways of focusing on dementia within their curriculum. The creativity and enthusiasm shown by students and teachers has been inspirational and will act as a stimulus to other schools across the country, highlighting the benefits for the students themselves, for schools and for communities.

Teachers, students and representatives of local statutory and non statutory agencies have created a wide range of ideas, approaches and activities about dementia for use within schools. These include lesson plans covering dementia awareness, memory, assistive technology, drama,

²⁵ Dementia 2013: The hidden voice of loneliness, Alzheimer's Society, 2013

Dementia awareness in Northfleet School for Girls, Kent

Led by Amanda Martin, Acting Health and Society Domain Leader, dementia awareness was included in Health and Social Care Studies (AS/A2 level) and in PHSE lessons. Consequently, it impacted on nearly 300 students aged 12-16.

As part of the project a number of activities were undertaken including:

- talking about dementia and raising awareness (whole school activity). Pupils were asked to write any thoughts or fears about dementia on luggage labels, then hang them on a Christmas tree to share with other pupils;



- appreciating some of the problems experienced by people with dementia:
 - **The star game.** Pupils draw around the outline of a star by looking at an image reflected in a mirror. As the image is backwards, the pupils get a better understanding and appreciation of the confusion, difficulty and/or frustration experienced by people with dementia when they undertake what is essentially quite a simple activity.
 - **Distraction.** Pupils read a book whilst wearing goggles, gloves and headphones playing loud music. The different distractions affect concentration and again help pupils to appreciate how difficult everyday activities can become for someone with dementia.
 - **Meeting people with dementia.** Pupils paired up and went to visit people with dementia in their own homes (accompanied by a care support worker – arranged by Alzheimer's Dementia Support Service). Over the course of three half-hour sessions, the pupils came to know more about the people with dementia and their life histories. By taking copies of old photographs and finding relevant photos on the internet, the pupils compiled photo books recording the life stories of people with dementia. The school then held a tea party for the people with dementia and their carers to present them with copies of the life story books.

dance and music activities, intergenerational projects such as life story books for local people with dementia, school choir visits to care homes, debates, assemblies and many more.

We are looking at how to make the wide range of resource materials and case studies developed to date available to other schools. In this way, a large number of children and young people will learn about dementia within their school's programme of study, as well as the practical ways of contributing to a dementia friendly generation. The impact on student knowledge, attitudes and behaviours is also being academically evaluated and a full report will be produced at the end of August 2013.

Launch of Dementia Friends

The Dementia Friends project was launched in February 2013. To date this has made significant progress and we now have **2247** people signed up to train as volunteer Dementia Friends Champions, with over **500** already trained. Those signed up for training could reach over **100,000** Dementia Friends, as we expect Champions to create an average of 150 Dementia Friends each by running information sessions within their own networks and communities.



Dementia Friends

Champions are planning to run information sessions in all kinds of imaginative ways. One has involved the landlord of her local pub and told us:

- "People living with dementia often retain a tremendous enjoyment of music and can usually sing entire songs from earlier in their lives, without the words! So I am running a sing-along on a Friday afternoon, when the pub is closed. I will promote it in the post office, local notice boards and our local free paper, where the editor is making encouraging noises about Dementia Friends."

Each Dementia Friend is encouraged to take action, and here are some of the actions logged on the Dementia Friends website:

- "I'm going to spread the word about Dementia Friends amongst work colleagues, family and friends. Will probably register as a Dementia Champion in the future."
- "Be more aware and allow more time for talking with members of my audiences at concerts who need more time to think through what they want to say."
- "I currently assist with the care of a 92 year old aunt who has dementia and I have also volunteered to help at my local Dementia Cafe."

Comments taken from Dementia Friends website

Working with football and sports clubs

In March 2013, Minister of State for Care and Support Norman Lamb MP hosted a meeting with Alzheimer's Society and a range of sporting organisations, including the Football League, Everton Football Club, Telford United Football Club and Sporting Memories Network, to discuss creating dementia-friendly sports clubs.

Alzheimer's Society is now moving this project forward and, working with the above organisations and people living with dementia, aims to create a guide for sports club to assist them in becoming dementia-friendly. An action plan will be developed over the next few months.

Working with the emergency services

Alzheimer's Society has been working with the emergency services to look at how they can become dementia friendly. The Fire and Rescue Services have launched a pledge on dementia that 44 services have now signed up to. To support this, they have also produced online training resources through the Chief Fire Officers Association. In addition a number of police services across the country have been developing guidelines on how to help people with dementia.



British Transport Police – Northeast Region

The British Transport Police, as members of the Yorkshire and Humber Dementia Action Alliance, have committed to a number of actions to make their force dementia friendly, including:

- making dementia a standing agenda item on the Area Diversity Awareness Group;
- identifying where dementia may cause a barrier to police being able to deliver a quality service;
- displaying dementia awareness literature in public facing areas at all police stations;
- providing training to all staff to ensure basic dementia understanding;
- aiming to work with our partners in the railway industry to assist them in making the railway environment more accessible to people living with dementia;
- creating an internal network of champions to ensure we remain committed to promoting dementia awareness amongst our staff and partners;
- coordinating railway familiarisation days, working in partnership with the train operating companies and Alzheimer's Society.

Harnessing technology

Alzheimer's Society convened a group of leading experts and stakeholders from the dementia and technology community to a roundtable seminar to discuss the opportunities for harnessing technology. The group recognised the need for practical steps to be taken by businesses and organisations to deliver dementia-friendly products and services and have identified a

number of steps in a report which will be considered by the Champion Group. Some of the key insights from the report included:

- **Blanket approach.** There is no one size fits all model and technology must be tailored to an individual's needs if it is going to be effective. It is challenging getting the right balance between enabling someone's independence and keeping them safe;
- **Co-morbidities.** People with dementia are likely to have other health and care issues which will need to be managed. So technological solutions must, therefore, be adaptable and appropriate to support the needs of these individuals too;
- **Lack of awareness of service quality.** People with dementia and families currently find it difficult to access information about the quality of care homes in caring for people with dementia;
- **Variation in workforce awareness,** Insufficient investment or attention was being placed on ensuring the workforce is adequately trained in utilising dementia friendly technology;
- **Capital investment.** A number of attendees noted the rollout of dementia friendly technology can be hindered by the prohibitive cost of investing in these services;
- **Awareness of evidence.** It is important to ensure dementia-friendly technology is evaluated to ensure it meets the needs of people with dementia;
- **Lack of incentives.** Despite the significant number of people affected by dementia, there remains a poor level of incentive for industry to develop technological solutions;
- **Incompatible systems:** Fragmented and incompatible systems were identified as significant barriers for the roll-out of dementia friendly technologies.

Encouraging more companies to commit to being dementia-friendly

We have made an excellent start on encouraging companies to commit to being more dementia friendly. The financial services industry has taken a lead in this area. The industry is working on a charter for dementia friendly financial services to be published in late summer 2013. Building on this approach, we have begun to explore how this model will work in other sectors, such as transport and telecommunications. We will be working with the organisations in the Champion Group to look at the benefits for organisations in becoming dementia friendly, particularly in improving business processes and human resources policies.

Next steps

A national recognition process for dementia friendly communities

Building on the progress in year one, we want to see even more communities and organisations becoming dementia friendly. The purpose of the recognition process is to show the community in question has committed to becoming dementia friendly. To achieve this goal, a national recognition process for dementia friendly communities will be launched in September 2013 with tools and resources for the public and communities to help them become dementia friendly. All the communities that are part of the recognition process will display the 'working to become dementia friendly' symbol once they have registered with the process and demonstrated they meet the criteria for working to become dementia-friendly.

Alongside the development of the recognition process, it is essential that using the symbol has real purpose and is a showcase of excellence and good practice. We will look for ways to incentivise communities committed to becoming dementia friendly to strive to deliver best practice and innovation. This could involve a national event each year that recognises excellence and celebrates the progress being made and encourage others to work towards becoming a dementia friendly community. We will also recognise those that have already become dementia friendly.

Publishing evidence on what it means to be dementia friendly

Later in 2013, Alzheimer's Society will launch a report drawing together evidence on dementia friendly communities in England, Wales and Northern Ireland. The report will consider how people are currently living in their communities and present the priority factors to address for communities becoming dementia friendly.



The report will cover:

- how well people are currently living in their area (how active they are, what do they do in their local area, what have they stopped doing?);
- what would people with dementia like to do and contribute in their local area (for example what new activities would they like to try; what skills and experience could they share?);
- what are the barriers to people living well in their community and what would support them to live better (priority areas for action)?;
- examples of organisations and communities becoming dementia friendly.

Publish evidence from people with dementia from BAME communities

Alzheimer's Society is supporting the All-Party Parliamentary Group on Dementia (APPG), which is running an inquiry exploring the current provision of support for people living with dementia in minority ethnic groups in the UK. The inquiry will investigate the current problems people with dementia from BAME groups face, whilst exploring the dementia support available to them. The APPG on Dementia will make recommendations for action to ensure individuals and families from BAME communities are well supported. It will also identify and share examples of services that are providing effective and high quality support. This evidence will support work to ensure the work being progressed by the Champion Groups is relevant and reflects the needs of BAME communities.

Reaching out to different sectors

Based on the evidence about what the building blocks for a dementia friendly community are, in years two and three we will begin establishing what role different sectors of the community might play in creating dementia friendly communities. Diverse groups and organisations,

such as dentists, opticians, pharmacists, local hairdressers, faith groups, social care employers and trades people, can play an important role. Working with Alzheimer's Society, we will identify the key sectors of the community considered important when supporting those with dementia to live well in their communities.

Reaching out to more schools

Once the evaluation of the pioneer schools programme comes through, we need to see the resources developed and made available to all schools across the country so that dementia becomes an established feature of education for all children and young people. The second phase of the work will aim to focus, not only on the curriculum base and the activities and resource materials for use within schools, but also the wider context of the schools and colleges themselves being a vital part of the development of dementia friendly communities.

Reaching further

Throughout our activities, we have recognised the important role government departments can play to contribute and support the creation of dementia friendly communities. Engaging with Whitehall and agreeing action plans will be a key task over the next year.

Our challenge is to build a framework that is accessible, but adequately resourced and sustainable, for communities and organisations to respond successfully to the needs of people with dementia and their carers.

Better research

Achievements

New Government funding opportunities for applied health research on dementia

We have seen significant developments in dementia research since the Route Map for Dementia Research, published by the Ministerial Advisory Group on Dementia Research (MAGDR) in June 2011.

The Route Map for Dementia recognised the greater role research should play in improving treatment and care. More effort was needed to develop effective collaborations and make best use of existing resources. At the time, DeNDRoN (the NIHR Dementia and Neurodegeneration Disease Research Network) began work to develop new ways to get patients involved in research and to support research in the non-NHS sector.

We also faced the challenge of building national capacity and capability in dementia research. Government funding was lower than we would have wanted due to the low volume and quality of applications for dementia research funding at the time. We needed to develop a wider programme of research coordination and engagement from basic research and living well with dementia, through to increasing capacity and capability across the entire research system. A key outcome from MAGDR was the launch of significant new Government funding opportunities for applied health research on dementia. This secured over £22 million of research, helping to increase Government spending in dementia research.

The support and funding of world-class health research in the best possible facilities by NIHR, Medical Research Council (MRC), the Economic and Social Research Council (ESRC) and the

Research Charities is vital to the development of new and better treatments, diagnostics and care. Our diverse partnerships across the life sciences and social science disciplines were already capable of making UK dementia research globally competitive – we just needed to make it happen.

Since the launch of the Prime Minister's Challenge on Dementia, the Government has implemented a range of plans that have presented new funding opportunities and strengthened underpinning systems, resources and partnerships.

NIHR Dementia Translational Research Collaboration

The Government established the NIHR Dementia Translational Research Collaboration involving four newly funded NIHR Dementia Biomedical Research Units and six NIHR Biomedical Research Centres to focus on dementia research. These are internationally leading research centres based in the UK and are pulling exciting developments from basic science into clinical research and benefits for patients. In total, the NIHR is providing £36 million for this collaboration.

Given the recent failures of dementia drugs and the scientific challenges faced by industry in carrying out dementia research, there was a need for better engagement with industry around dementia research and to showcase the country's excellent research system. In October 2012, we held an industry showcase event for pharmaceutical and biotechnology companies that demonstrated the benefits for industry in conducting dementia research in partnership with the UK, and the work taking place to remove any barriers.

Harness UK Expertise

Through a joint funding initiative between the NIHR and the Economic and Social research Council (ESRC), we continue to invest in outstanding and comprehensive social science research expertise including prevention and behaviour change, interventions for symptom management, alleviation and inhibiting progression and addressing the major challenges for service delivery across a range of settings. Alzheimer's Society is also partnering and directly funding a significant amount of research in this area.

The UK's research system encourages innovation as well as supporting the basic and translational research needed to develop and test new preventive approaches, diagnostics and treatments, but also bringing together our social research and healthcare communities, to ensure we address issues right now around what works to deliver high levels of care.

We will continue to take an interdisciplinary and inclusive approach that brings benefits to patients. We will ensure the basic and experimental science funded by the MRC, the Wellcome Trust, Alzheimer's Research UK and Alzheimer's Society, and the translational research supported through the MRC and our NIHR Biomedical Research Units and Centres focuses on patients.

Our charities also made an important contribution to the collective research efforts. Alzheimer's Research UK recently announced an increase in current research funding to over £20m and an innovative new strategy to help academic and pharmaceutical research to join up more effectively and speed up the development of effective treatments. Alzheimer's Society also announced an increase in research funding to over £11m within its unique programme which supports research into cause, cure, care and prevention of dementia. Alzheimer's Society and

Alzheimer's Research UK jointly invested a further £3.3m into the internationally renowned Brains for Dementia Research brain bank programme to fund its operation for the next five years. This programme is supported by the MRC and DeNDRoN.

We want to involve more patients in research. Around 4 percent of UK patients with diagnosed dementias are currently involved in clinical research, but the NHS wants to increase to 10 percent within the next 4 years. This will require all funders, including industry, to fund more dementia studies in which patients can be involved.



Next steps

We want to deliver effective therapies that will improve the course of dementia.

To do this we must develop our research community by attracting and training more postgraduate students in dementia research, and by fully exploiting the UK's key strengths and infrastructure in dementia research. This will concentrate on the five dimensions highlighted below.

We will disseminate best practice to enable the UK to become the leading data integration health system and place to go for industry and academia wishing to collaborate on patient-facing research leading to better health outcomes.

We also want to extend our reach and, by working through the Organisation for Economic Co-operation and Development (OECD), become a driving force for global collaboration in research. We will use our Presidency of the G8 to help shape an effective international response.

Patients and their data: innovating the way we link, analyse and use data to support research and support implementation for patients living well with dementia.

The NHS routinely collects data on patients as they receive care, which is a rich source of information about how disease and treatments work. The information collected includes data on biomarkers, diagnosis, treatment and clinical outcomes. This information is vital to understanding how the NHS and Social Care system can improve outcomes for patients, yet it remains a relatively untapped resource.

We will take advantage of existing UK strengths in health informatics and advances in safe and secure data sharing technologies to make effective use of electronic records. Where a **patient agrees**, this data can become a standard to assess symptoms and the impact of treatment. To drive this forward the MRC, in partnership with a consortium of 10 Government and charity funders, invested £19 million to establish four e-health research centres of excellence to link the electronic health records available through the jointly funded NIHR and the Medicines and Healthcare products Regulatory Agency Clinical Practice Research Datalink with other forms of clinical, social and research data, which we

anticipate will be exploited by dementia research in the coming years.

By mid 2014 we will have:

- seen the roll out of a system, which will enable the joining up of patient medical records in five mental health NHS trusts to support research. This is already in place at the Maudsley Hospital to improve research and care of people with dementia. This will provide a powerful platform with further potential.

By the end of 2014 we will

- establish a nation-wide consent-for-approach list of people with dementia who agree to participate in research

By 2025 we will

- support patients and carers to play a more active and empowered role in their healthcare. We will do this by enabling the use of personal health records so patients and carers can enter data themselves that is linked to medical records. This will improve the quality of data needed by both clinical services and researchers

Discovery science: to harness UK expertise and the resource and skills in UK centres and clusters of excellence to understand the development and progression of the dementias and generate discoveries

The UK has internationally leading expertise in the science of neurodegenerative diseases including genetics, epidemiology and public health, cognitive neuroscience, neuroimaging, neural network biology, animal modelling and the application of stem cell biology, which together have created new insights into the molecular basis of dementia.

The molecular basis of dementia

In the past year, an international team led by UK researchers at UCL identified a new genetic risk factor for Alzheimer's diseases, which showed the inflammation process plays a part in the development of disease. NIHR and MRC funded researchers at UCL also led one of twelve centres that have contributed to the US-led DIAN study (Dominantly Inherited Alzheimer Network Study), which showed that for genetically at risk individuals, unusual changes in a number of biomarker appear up to 25 years before the expected age of the start of the programme. Both studies may help to support prevention research programmes in this area. Looking ahead, a new £2.2 million strategic award from the Wellcome Trust to the London Down's Syndrome Consortium aims to examine the link between Alzheimer's disease and Down's syndrome to try to better understand and predict as early as in infancy which individuals are most at risk of Alzheimer's disease in adulthood.

We will continue to invest through the MRC, the Wellcome Trust, the ESRC, Alzheimer's Research UK and Alzheimer's Society to support universities to pursue the most important research questions as well as provide complementary strategic funding to build capacity and drive collaborative working. International initiatives such as through the EU Joint Programme in Neurodegenerative Disease (JPND) and Network of Centres of Excellence in Neurodegeneration research (COEN), co-developed by MRC, will continue to enhance UK capability in this area. UK experts can draw on the world-leading research platforms already in place around longitudinal population cohorts for clinical and genetic analysis, and stem cell resources as a basis for disease-modelling at the cellular and molecular level. We will continue to help drug development through the work of the

UK brain banks network leading to better understanding of the molecular basis of disease, and through the national phenomics centre carrying out detailed biochemical analysis. Our e-health platforms will integrate and exploit the data available from lab and clinical-based studies and NHS records.

We are developing the next generation of research leaders. The MRC and Wellcome Trust have recently funded two new senior clinical fellows to investigate the molecular mechanisms causing neurodegeneration.

By 2015 we want:

- improved animal and cellular models of these diseases, including models based upon human stem cells and research using animals that will be of use in preclinical studies of novel diagnostic markers and novel therapies, as well as providing new tools for drug discovery for novel molecular targets;

By 2015 we want:

- novel biological, imaging and cognitive markers. These tools will have many uses in population studies and experimental medicine trials, and once fully validated will be used to improve clinical care. They will be used to help detect the presence of disease before clinical symptoms emerge, to determine the stage and progression of disease, and to monitor response to therapies. They will also be used to assemble stratified, homogeneous cohorts of participants with similar underlying disease processes for experimental medicine studies.

By 2015 we want:

- improved understanding of the mechanism and temporal sequence by which co-morbid conditions such as diabetes and vascular disease contribute to accelerating the onset and progression of dementia. This will lead to clues about how effective care and treatment of these co-morbid conditions can help manage symptoms, slow disease progression and reduce disease burden.

By 2015 we want:

- novel therapeutic targets for the discovery of both: i) new symptomatic therapies designed to treat abnormalities in neural circuits affected by these diseases; and ii) new disease-modifying therapies directed at the molecular pathways underlying these diseases.

By 2025 we want:

- novel symptomatic and disease-modifying therapies to be tested in well designed clinical trials whose outputs will, we hope, impact on these disorders and further shape and refine the questions discovery scientists will ask.

Translational research: to drive the translation of discoveries into treatments

A number of key resources and initiatives have been developed and will support dementia translational research.

We have established four NIHR Biomedical Research Units specifically for dementia and six NIHR Biomedical Research Centres together with a major dementia focus within internationally leading research centres in the UK. We have also brought these NIHR Units and Centres together and established the NIHR Translational Research Collaboration in Dementia (TRC-D), to improve translational research by working collaboratively, and to encourage more funding for dementia

research, including increasing research partnerships with industry.

A number of new programmes have been established, including the investment of £4.5 million in three new therapeutic programmes seeking to evaluate the use of existing drugs for the treatment of Alzheimer's disease.

Two new clinical trials have been awarded by the MRC/NIRH Efficacy and Mechanism Evaluation programme to look at the use of either an antibiotic or a blood-pressure controlling drug in patients with Alzheimer's disease. A new study funded under the landmark MRC-AstraZeneca compound collaboration is investigating the possible application of a novel AstraZeneca compound that has already passed clinical tests for use in other diseases.

In addition, a £2.8 million investment is being made through the MRC/TSB Biomedical Catalyst programme. £2.2m has been committed towards a £3.4 million project led by Ixico Ltd, to interpret UK imaging and cognitive testing technology into a digital healthcare platform for early dementia diagnosis. This builds on other UK work – called the CANTAB assessment – developed and validated by researchers over the last decade at the MRC/Wellcome Trust Centre for the **Behavioural and Clinical Neuroscience Institute** Centre in Cambridge. A further £600k has been awarded for the development of novel drugs for Alzheimer's disease and a new device for the treatment of Parkinson's disease.

By end 2013 we will have:

- fully established the infrastructure and processes for the TRC-D to deliver a single point of contact and negotiation with industry.
- initiated a major research programme to develop biomarkers using brain imaging, spinal fluid and blood tests to enable better and earlier diagnosis.

- initiated through our TRC-D at least one large re-purposing trial using a drug developed in another area of medicine, such as metabolic disorders, inflammation or oncology.

By 2014:

- TRC-D will work together to pool resources, expertise and by sharing protocols used in neuroimaging, improve MRI and PET imaging research in the UK.

By 2014:

- MRC will deliver a major new stratified medicine initiative partnership as well as a linked collaborative activity with pharmaceutical companies to build on unique UK strengths in population cohorts to deliver an integrated and coherent dementia research platform for target validation and experimental medicine.

By 2025 we will:

- facilitate public-private consortia to undertake research in dementia with multiple companies working collaboratively with multiple NIHR Biomedical Research Units and Centres



- develop a shared bioresource containing samples ranging from induced pluripotent stem cells to blood and CSF for collaborative research and link this to our electronic medical-records network to take advantage of the unique benefits of the NHS.

Implementing clinical research: to develop our understanding of all the stages of dementia as well as raise awareness of dementia and the role that research can play in rising to the challenge of dementia

A wealth of data relevant to dementia is collected daily throughout the NHS from clinical and cognitive assessments, to brain images and biological samples. At the same time, clinical therapeutic trials acquire a tremendous amount of valuable information, images and samples that could be used to address important research questions beyond those of trial itself. There is growing interest from companies that have sponsored the trials to make this data available.

There is a real opportunity to engage companies in making available the data they collect to speed up recruitment to clinical therapeutic trials and natural history studies, which will improve the quality of research conducted around diagnosis and diagnostic methods.

By 2015 we want to;

- encourage the sharing of data from existing research results to inform current and future research that will build greater understanding of disease development
- improve recruitment of NHS patients into therapeutic trials, building upon the NHS pledge – as set out in the NHS Constitution – to inform patients about clinical trials in which they would be eligible to participate. In addition, the work being undertaken to establish a nation-wide consent-to-approach

list will provide better access for patient into clinical trials.

- determine the cost-effectiveness and added-value of current diagnostic approaches and tests; the potential for improvements such as automated image analysis or computerised cognitive testing and effective implementation strategies
- assess novel biomarkers (see discovery science) and their implementation in clinical practice such as imaging, blood or cerebrospinal fluid markers
- have developed appropriate frameworks for consent and use of data that allow diagnostic data, investigations and samples to be used for research. This will make the NHS a world-leading resource for clinical research.

By 2025 we want to:

- show the benefits of improved and timely diagnosis from patient and carer quality of life through to health economics and demonstrate that such improvement in diagnosis can be effectively implemented.

Living well with dementia: to help people with dementia lead healthy, independent lives for longer.

The UK is a leader in dementia care research and is a key collaborator in the European INTERDEM research collaboration. The recent increases in research funding in the social sciences will enable the UK to strengthen its research efforts to bring about non-drug interventions that make a real difference to people's lives and improve quality of life for those with dementia.

We want to use research to enable people to maintain their dignity and independence for longer, reducing disability and better integration of care for frailty and sensory problems such as visual and hearing loss. Dementia care and psychosocial research needs to focus on key

outcomes such as improved quality of life, improved cognition, avoidance of hospital admissions and better mental health for carers.

By 2015 we want to:

- identify effective psychosocial interventions likely to benefit people with dementia and their carers that represent good value for money.
- promote the widespread implementation of useful interventions through national quality networks such as the Memory Services National Accreditation Programme (MSNAP). Increasing the number of memory services participating in MSNAP will lead to faster diagnosis and higher quality services.
- increase the number of people with dementia and their carers recruited into research studies.

By 2025 we want to have:

- created a new generation of research leaders able to continue to expand the UK's capability for applied dementia care underpinned by excellent research.
- improved the relevance and quality of research through having effectively involved people with dementia and their family carers.

Annexes

Driving improvements in Health and Care

Key commitments	Status
<p>Increased diagnosis rates through existing health checks for over-65s</p> <p>Ambition for diagnosis rates across the country</p>	<p>On track</p> <p>Local Authorities now have a statutory responsibility to give everyone aged 65-74 having an NHS Health Check information at the time to raise awareness of dementia and the availability of memory services, which offer advice and assistance to people who may be experiencing memory difficulties, including making a diagnosis of dementia. Training tools and an information leaflet have been produced to support this.</p> <p>The ambition that, by 2015, two thirds of people with dementia should have a diagnosis, with appropriate post diagnostic support has been agreed with NHS England and a programme to support and monitor this, to include use of the Dementia Prevalence Calculator, an Expert Reference Group and commissioning support tools and well as the recently published NICE guidance.</p>
<p>Dementia Commissioning for Quality and Innovation (CQUIN)</p>	<p>Completed</p> <p>The revised national dementia CQUIN for 2013/14 was published in February 2013, incorporating new elements on leadership and support for carers.</p> <p>The current CQUIN has led to over 4,000 referrals a month which will contribute to improving diagnosis rates for dementia</p>

Key commitments	Status
<p>Innovation Challenge Prize of £1 million</p>	<p>On track</p> <p>The £1 million Breakthrough Challenge for Dementia was launched by the Secretary of State for Health on 25 June 2012.</p> <p>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.</p> <p>The NHS Innovation Challenge Prize for Dementia in collaboration with Janssen Healthcare Innovation will also award up to £150,000 for solutions that provide an integrated care pathway for people with dementia. The challenge was defined based on suggestions submitted from people involved with dementia care as healthcare providers, carers, patients and patient groups, which were reviewed by a team of dementia and innovation experts.</p> <p>The challenge will be launched shortly and will remain open to applications from across the Health and Social care sector for a period of four months. It will be assessed by a panel of experts from the NHS, social care industry and academia as well as individuals living and working with people with dementia.</p>
<p>Care and Support Compact</p>	<p>Ongoing</p> <p>From 10 signatories a year ago, to date, there are now 148 signatories representing nearly 3,000 care services committed to delivering high quality, personalised care to people with dementia and their carers.</p>
<p>NHS information offer</p>	<p>Completed</p> <p>The DementiaChoices website (www.nhs.uk/dementiachoice) was launched at this year's Healthcare Innovation EXPO event.</p> <ul style="list-style-type: none"> ■ All of the regional sites have been launched: NHS London launched the myhealthlondon dementia website in November 2012. ■ The Our Health website launched in the South of England on 3 January 2013. So far, there has been an average of 10,000 visitors per month. ■ The Live Well dementia website launched in the North of England on 7 March 2013. ■ The Our Health website in Midlands and East went live in April 2013.

Key commitments	Status
<p>Work with the profession to identify how best to improve early diagnosis of dementia</p>	<p>On track</p> <p>We are investigating how we can work more proactively with primary care to support timely diagnosis of dementia, exploring areas around awareness, training and the use of technology, including memory tests and tests that look at executive function, which are affected by vascular dementia.</p> <p>Work is underway with the Royal College of General Practitioners to develop a toolkit to support GPs to understand dementia, as well as help their families and carers. The toolkit will be published in early 2014.</p> <p>NHS Improving Quality is establishing a programme of work to support improvement in diagnosis and management.</p>
<p>NICE to consider ways of improving the dementia indicators in the QOF</p>	<p>On track.</p> <p>The consultation on potential new indicators for consideration for the 2014/15 QOF closed on Monday 4 February 2013.</p> <p>The results of the consultation will be considered by the Independent Primary Care QOF Indicator Advisory Committee in June 2013 along with the results of the piloting across a representative sample of general practices. The Committee will then recommend which of these indicators should be included on the NICE menu for consideration for the 2014/15 QOF.</p>
<p>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</p>	<p>On track</p> <p>The Royal College of Nursing have developed a published a resource supporting the further implementation of its five principles for improving the quality of care for people with dementia. This works complements the Department of Health's Nursing vision.</p> <p>NHS England and the Department of Health are working with Health Education England who have adopted dementia as one of their priorities.</p>
<p>Ensure that memory clinics are established in all parts of the country and drive up the proportion of memory services that are accredited</p>	<p>On track.</p> <p>There are now 69 services registered with the Royal College of Psychiatrists Memory Services National Accreditation programme, double the number registered last year.</p> <p>The Royal College of Psychiatrists has been commissioned to conduct a survey of memory services and this will report later this year.</p>

Key commitments	Status
Guarantee a written integrated personalised care plan to people with dementia	<p>On track</p> <p>NHS England has put personalised care and care planning central to enhancing the quality of life for all people with long term conditions, including dementia.</p> <p>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.</p>
There will be better support for carers	<p>On track.</p> <p>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 DH commitment to make an extra £175 million available to councils to meet additional costs of improving both assessment and support for carers.</p>
The NHS should also ensure that a range of psychological therapies are commissioned and made available to carers of people with dementia in line with NICE/SCIE guidelines	<p>On track</p> <p>The NHS Outcomes Framework for 2013/14 includes a new measure relating to psychological therapies.</p>
By September 2012 we will launch pilots of dementia clinical networks aimed at spreading clinical expertise	<p>Complete</p> <p>A national strategic clinical network (SCN) for mental health, dementia and neurological conditions has launched. SCNs will bring 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.</p> <p>SCNs will be supported and funded through network support teams covering 12 defined geographical areas. The support teams will be hosted by NHS England. A meeting of the leads of the 12 networks is planned for June 2013.</p>

Key commitments	Status
<p>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.</p>	<p>Ongoing</p> <p>The Nursing and Care Quality Forum has been active in highlighting the issues, which need to be addressed in improving care. As part of its work the Forum has collected, and is due to publish soon, examples of best practice in nursing and care in all health and care settings. A number of these examples focus specifically on dementia patients, addressing issues such as mapping and personalising services for them and effective ways of seeking feedback from patients to help service improvement in many different settings.</p>

Dementia Friendly Communities Champion Group

Key commitments	Status
Dementia Friendly Communities across the country	<p>Ongoing</p> <p>There are now over 50 places across England that have committed their intention to become dementia friendly. A number of these areas are part of a group of early adopters working with Alzheimer's Society helping us to pilot the recognition process for dementia friendly communities.</p>
Support from leading businesses	<p>Ongoing</p> <p>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.</p>
Awareness-raising campaign	<p>Ongoing</p> <p>The campaign delivered at the end of 2012 reached out to over 37 million people. The evaluation findings show that:</p> <ul style="list-style-type: none"> ■ 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. <p>Work is now underway to develop a further campaign for 2013.</p>
Major summer event bringing together leaders from industry, academia and the public sector	<p>Ongoing</p> <p>There will be a major conference in September to launch a report, which will present the evidence on dementia friendly communities, along with resources for local communities and organisations, to help them become dementia friendly.</p>

Key actions	Status
<p>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</p>	<p>Ongoing</p> <p>The Alzheimer's Society is working with the DAA by establishing local Dementia Action Alliances in communities throughout England. Over 400 organisations from local authorities to acute trusts, corner shops to solicitors have now signed up to the National Dementia Declaration and committed to hundreds of actions to support dementia friendly communities. Over 20 Local Dementia Action Alliances had been established across the country, bringing organisations together to take responsibility for improving the lives of people with dementia in their area.</p> <p>Local Dementia Action Alliances established by Alzheimer's Society</p> <ul style="list-style-type: none"> ■ Coventry Dementia Action Alliance ■ Derbyshire Dementia Action Alliance ■ East Midlands Regional Board ■ Leicestershire Dementia Action Alliance ■ Lincoln Dementia Action Alliance ■ Northamptonshire Dementia Action Alliance ■ Nottinghamshire Dementia Action Alliance ■ South Lincolnshire Dementia Action Alliance ■ Staffordshire Dementia Action Alliance ■ Warwickshire Dementia Action Alliance ■ West Midlands Dementia Action Alliance ■ Wolverhampton Dementia Action Alliance ■ Yorkshire & Humber Dementia Action Alliance <p>Affiliated with action plan on DAA website</p> <ul style="list-style-type: none"> ■ Bolton Dementia Action Alliance ■ Falmouth Dementia Action Alliance ■ Norfolk and Suffolk Dementia Alliance ■ Plymouth Dementia Action Alliance ■ Tavistock Dementia Action Alliance <p>Affiliated without action plan on DAA website</p> <ul style="list-style-type: none"> ■ Torbay Dementia Action Alliance

Key actions	Status
	<p>Individual actions already completed by member organisations include:</p> <ul style="list-style-type: none"> ■ Northamptonshire Dementia Action ■ Northamptonshire Fire and Rescue – Installation of portable water mist system <p>A portable mist system will be most effective where vulnerable persons live alone and are confined to one room for the majority of the time and particularly where the occupant is confined to one location within the room, such as the bed or chair.</p> <ul style="list-style-type: none"> ■ We will invite a group of people with dementia and their carers to assess our venue, and feed back their experiences, allowing us to identify and make what changes are deemed necessary. ■ We will set up a steering group made up of external groups including the Alzheimer’s Society, other local care organisations, people with dementia and their carers. This group will work together to shape the future of the Courtyard becoming a more dementia friendly venue.
<p>We will make sure that people with dementia and carers on diagnosis have an information pack about dementia produced in conjunction with the Alzheimer’s Society.</p>	<p>On track</p> <p>Work is underway to develop a new resource for people are given a diagnosis of dementia. The new resource – called ‘The dementia guide: Living well after diagnosis’ will be available in print in June in 2013. A film will follow in Autumn 2013 that will be available on DVD and online. The booklet and videos will be 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.</p> <p>The new resource will be available through Alzheimer’s Society and the Department of Health, which has contributed towards costs of development. The dementia guide is endorsed by the Royal Colleges of Psychiatrists and General Practitioners as well as the Association of Directors of Adult Social Services.</p>

Key actions	Status
<p>The Dementia-friendly Communities Programme, working in partnership with the Dementia Action Alliance, will develop evidence on what a dementia-friendly community is.</p>	<p>On track</p> <p>On 3 September 2013, the Society will launch a report that draws together evidence on dementia friendly communities in England, Wales and Northern Ireland.</p> <p>The report will put a spotlight on how people are currently living in their communities and present the priority factors to address for communities becoming dementia friendly. It is based on a range of evidence including:</p> <ul style="list-style-type: none"> ■ Survey responses from over 500 people with dementia ■ Focus groups and interviews with seldom heard groups ■ Case studies from areas committed to becoming dementia friendly. ■ Evidence from the Dementia Action Alliance ■ A YouGov poll of UK adults <p>The report will cover:</p> <ul style="list-style-type: none"> ■ How well people are currently living in their area (how active are people, what do they do in their local area, what have people stopped doing) ■ What would people with dementia like to do and contribute in their local area (for example what new activities would they like to try; what skills and experience could they share) ■ What are the barriers to people living well in their community and what would support them to live well (priority areas for action) ■ Examples of organisations and communities becoming dementia friendly.

Better Research

Key commitment	Status
More than doubling dementia research funding by 2015	On track Target is to double public sector research funding to £66 million by 2015.
Major investment in brain scanning (MRC Biobank proposal)	Completed. £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, MRC and DH have jointly awarded £20M 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.
£13 million NIHR/ESRC social science research funding	On track. Final funding decisions will be made in July.
£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 with a number of companies across industry addressing a range of challenges in imaging, biomarkers and pre-symptomatic research.
Offering the chance to participate in dementia research to be a condition of memory service accreditation	On track.

Key action	Status
<p>The MRC will spend over £3 million in supporting the UK brain bank network</p>	<p>On track.</p> <p>MRC provides approx. £1 million per annum as core support to four Banks and coordination activity 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, 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, 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 investigate the underlying causes of major brain diseases including dementia.</p>
<p>A major event will be staged for pharmaceutical and biotech companies</p>	<p>Completed</p> <p>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.</p> <p>In a parallel process MRC has engaged with pharmaceutical companies towards the establishment of a new PPP focussed on target validation and experimental medicine in dementia research. Nine companies are currently engaged in advance discussion, with a budget of up to £12 million identified to deliver this initiative.</p>
<p>We will work towards recruiting 10 percent of patients into clinical trials.</p>	<p>Ongoing</p> <ul style="list-style-type: none"> ■ 'ENRICH' a Toolkit for Care Home Research developed by NIHR, provides simple, practical advice for researchers, care home staff, and others. This will help increase the volume of dementia research in care homes. Over 50 care homes are already participating in an ENRICH Network. ■ One of the barriers 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 research, and have their permission recorded for their data to be used to contact them about appropriate research.

Key action	Status
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 hold Awaiting the outcome of the NIHR/ESRC dementia research initiative to see where gaps and opportunities exist.
The Department of Health will increase its support for capacity-building in dementia research, focusing on nurses as well as doctors.	On track. Dementia nursing research was highlighted in the latest competition for clinical academic training awards for nurses. One award has been made. Discussions are continuing on how best to build significant capacity in dementia nursing research.
The MRC is a leading partner in two international initiatives in the area of neurodegeneration research.	The latest phases of the Network of Centres of Excellence in Neurodegeneration 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 to be announced in July 2013. This involves <ul style="list-style-type: none"> ■ £1 million towards a new £5m call under COEN initiative, for high-risk/high pay-off research to provide new mechanistic insights and drug targets in neurodegenerative disease ■ £2 million towards a new £10 million call under the JPND initiative for research into the risk factors that contribute to dementias and other neurodegenerative disorders ■ The ESRC is contributing €1 million to a new call under the JPND initiative for research into the evaluation of health care policies, strategies and interventions
Major expansion of neuroscience programmes at the world-leading MRC Laboratory of Molecular Biology (LMB)	Completed. The 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. Alongside this, LMB has now moved into a new £200 million building providing state of the art facilities in support of this research agenda

Key action	Status
The NIHR has also just completed a first-ever themed call for proposals in dementia research	Completed. NIHR has provided over £22 million of additional funding into twenty-one pioneering research projects.

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