



THE PRIME MINISTER'S CHALLENGE ON DEMENTIA

Delivering major improvements in dementia care and research by 2015: A report on progress



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Foreword

Dear Prime Minister

Dementia is now the greatest health concern for people over 55¹ and the economic cost of dementia is more than cancer, heart disease or stroke.

In March at Alzheimer's Society Dementia 2012 conference you launched the Prime Minister's Challenge on Dementia. In tasking the six of us as Co-chairs to lead your Champion Groups, you said:

In less than ten years, as we all live longer lives, the number of people with dementia will reach a million.² So my argument today is that we've got to treat this like the national crisis it is. We need an all-out fight-back against this disease; one that cuts across society.

Since you launched your Challenge on Dementia on 26 March 2012, we have marshalled some of the key minds in dementia research, the leaders of business and civic society and those that drive our health and social care system. Here we present our first report on initial progress made over the past seven months.

People with dementia and their carers are at the heart of our champion group discussions. Our focus is to improve treatments for people with the disease from diagnosis until the end of life, and where possible prevent it from occurring or from progressing beyond a very early phase. Our success would fundamentally change the course of dementia. In this country, we have world leading strength in neuroscience and some of the best specialist research facilities in the world. We want to build on these strengths.

At the same time we have also heard how much can – and must – be done to provide better support to people with dementia today. We must tackle unacceptably low diagnosis rates; poor

access to services; prolonged hospital stays; too early admission to nursing homes; poor care, isolation, neglect and despair, and inadequate information, advice and support for carers must all be tackled. Over the past seven months we have seen many examples of good practice across our health and care systems as well as examples of the unacceptable. We must act to encourage the poor performers to reach the standards of the best.

As a result of the long-standing challenges in the social care system, people with dementia and their carers often report that they cannot access good quality care at the right time. Many also face high costs for care. We therefore welcome the commitment that you and the government have made to find a solution to the question of how we pay for care.

Finally, we have been told how people with dementia are excluded from the society they live in, putting untold pressures on family carers and enormous reliance on charities that can reach some but by no means all. The Dementia Friendly Communities Champion Group is showing how this can change in the future. From banks to faith groups; utilities to the fire service, from shopkeepers to schools, we are already seeing new commitments to people with dementia. We already see a growing movement of parish, town and city councils that are committing to address the question 'how can we ensure that our residents find this a dementia-friendly place to live well to the very end of their life'. And with this report we announce our ambition to create 1 million 'dementia friends' across the country – an army of people who will understand better the challenge of dementia and how it is possible to help.

¹ YouGov poll 'What the world thinks', 15 August 2011

² Dementia UK 2007, Alzheimer's Society, 2007

Your Challenge on Dementia has already helped to make dementia a globally recognised issue and place the UK at the forefront of developments in improving care in the community, outcomes and experience in health and care settings and in dementia research. Whilst seven months is a too short a time to redress the balance, we have started to identify what needs to happen and have

raised awareness of the key issues. We look to your continued leadership across government and beyond as we develop the full plan and ensuing actions up to and beyond 2015. There is much to do and we are determined to work together across the three Champion Groups to make a real and lasting difference for people with dementia, their families and carers.



Jeremy Hughes



Dame Sally Davies



Mark Walport



Sarah Pickup



Sir Ian Carruthers



Angela Rippon



Creating dementia-friendly communities that understand how to help

The challenge

The challenges people with dementia have to deal with go far beyond a diagnosis and getting support from the health and care system.

People living with dementia often find everyday things we all take for granted, like spending time with friends and families, enjoying hobbies, going shopping or getting money from the bank, much more difficult.³

A recent report from Alzheimer's Society found as many as 67% of people with dementia often do not feel part of their community.⁴

People living with dementia said they commonly experience loneliness, isolation, anxiety and depression and three quarters of people said they feel society is not geared up to deal with people with dementia.

Trevor Jarvis, who has dementia, told us about the difficulties he has experienced accessing his savings from a bank. He explained he finds it hard to remember his bank passwords and PIN numbers. A lack of understanding of dementia within the financial sector often makes it difficult for people with dementia to use banking services and manage their money.

Even using public transport, something most of us take for granted, can prevent people who have dementia from being active in their community, leading to feelings of isolation. Difficulties in issues around communicating with the bus driver, getting off at the right bus stop and processing information can make it very hard to use buses.

What we want to be different

We want to create dementia-friendly communities across the country. In these communities: people will be aware of and understand more about dementia; people with dementia and their carers will be encouraged to seek help and support; and people with dementia will feel included in their community, be more independent and have more choice and control over their lives.

By 2015, our vision is to more than double our initial ambition of at least 20 cities, towns and villages working towards becoming dementia friendly.

This means creating local Dementia Action Alliances to bring together community leaders alongside people with dementia and their carers to identify the changes and action needed to make their community dementia friendly.

It is about businesses, organisations and services understanding and responding to the needs of people with dementia.

Simple things, like changing the layout of a shop, improving or using different signage and training staff so they are more aware of dementia can make a difference. Even products can be designed and adapted to become dementia friendly.

Our ambition is to support wider society to make the change to enable people who have dementia to be able to confidently go about their daily lives safely and free from stigma.

³ *Dementia 2012: A national challenge, Alzheimer's Society, 2012*

⁴ *Dementia 2012: A national challenge, Alzheimer's Society, 2012*

What has been achieved so far

Increasing dementia awareness and understanding in specific sectors: Since the launch of the Prime Minister's Challenge, creating dementia-friendly organisations has been gaining momentum. The Champion Group has identified an initial group of sectors that play a part in the everyday lives of people who have dementia and action has started towards them becoming dementia friendly.

Much of the increased learning has been shared in reports produced by, amongst others, the Housing and Learning Improvement Network, Local Government Association, Liverpool Hope University and Joseph Rowntree Foundation working with Alzheimer's Society, Innovations in Dementia and local Dementia Action Alliances.⁵

Financial Institutions: Financial institutions are working together to create a 'dementia-friendly protocol'. This will be a set of commonly agreed principles for consistent customer experience that is structured around the concepts of "Recognise, Understand, Respond". This is something that any financial institution can implement so it can provide better support to customers with dementia and make it easier for

them and their carers to be in control of their finances. An event, hosted by Lloyds Banking Group, Nationwide, Aviva and Alzheimer's Society – and attended by representatives from 24 financial service organisations and industry bodies – initiated this work, with the ambition of developing the protocol by spring 2013. The work to develop the protocol will consider issues such as staff training and supporting people with dementia to access their money, without compromising on security.

Schools: 21 schools have formed a "Pioneer Group" to develop dementia awareness sessions for children and young people across England. This is in recognition that the effects of dementia are not only on the individual, but also on their families, and young people are often forgotten in this. The aim is that the sessions will educate children and young people about dementia, remove stigma and provide the opportunity for interaction with people with dementia. We hope that schools and youth projects nationwide will take part from autumn 2013.

5 http://www.local.gov.uk/c/document_library/get_file?uuid=0a7a291b-d6a3-4df6-9352-e2f3232db943&groupId=10171
http://www.innovationsindementia.org.uk/projects_communities.htm
<http://www.housinglin.org.uk/Topics/browse/HousingandDementia/Design/?parent=5091&child=8525>,
http://www.housinglin.org.uk/_library/Resources/Housing/Support_materials/Other_reports_and_guidance/Neighbourhoods_for_Life_Checklist.pdf
http://dementiacentre.com/files/downloads/Final_Report_HopePSS_Campaign_Week_Final_v2.pdf
http://www.phine.org.uk/uploads/doc/vid_16756_Dementia_Friendly_Communities_Report_Final.pdf
<http://www.jrf.org.uk/publications/creating-dementia-friendly-york>

Helping children and young people to be dementia aware

Swanshurst School is a secondary school with 300 pupils in each year group. Birmingham is a multi-cultural city so Swanshurst has many different nationalities represented. They have developed three lessons on dementia for Year 9 pupils, which aim to:

- raise awareness of dementia;
- develop knowledge and understanding about the types of dementia and its causes; and
- understand how the chances of getting dementia can be lessened.

Douglas Smith, the teacher leading the project said:

"This is an incredibly important initiative because so many people are and will be affected by dementia and we are proud to be in the pilot scheme. It is so important that young people see that dementia is not an inevitable part of growing old and also that early detection will greatly help in slowing down the illness. There is also the very important lifestyle message that living a healthy lifestyle will lessen their chances of getting dementia later. I cannot think of a better way of getting the 'don't smoke, don't take drugs, don't drink to excess, and eat sensibly' message across than this."

Emergency Services: The Fire and Rescue Service have indicated that half of people who die in accidental house fires are over 65 years old. Two-thirds of people who have dementia live in the community.⁶ Recognising this, the Fire and Rescue Service have made a Pledge on Dementia.

The pledge commits Fire and Rescue services to take action to increase the safety of people with dementia, and increase awareness amongst their staff. Already 28 Fire and Rescue services have signed up and a Dementia Awareness App is being developed to support fire service staff.

Improving home safety for people with dementia

The Kent Fire and Rescue Service fitted socket locks in a house belonging to a couple in their eighties. The husband, who has dementia, had taken to putting his pyjamas into the microwave to warm them up. His wife was so worried about this that she was carrying the microwave upstairs to the bedroom with her every night. The fire service provided a lockable cover so all she needs to do is take the key with her when she is not around. They used the cover for the toaster too, just in case he thought to use that to warm his pyjamas.

His daughter told us: "The help provided by Kent Fire and Rescue Service was invaluable. I don't think Mum and I could have coped over the last year without it. Dad has now had to go into residential care, but I have no doubt that the help they gave us meant he was able to stay at home much longer. And just as important it gave Mum real peace of mind and she was able to sleep soundly – which meant she could cope better with his day to day care. The lady who came to see us was absolutely lovely and made a real effort to communicate with Mum, who is profoundly deaf. Advice on things like escape plans and safety might not seem much, but they save lives just the same."

⁶ Dementia UK 2007, Alzheimer's Society 2007

The Association of Chief Police Officers (ACPO) are committed to this challenge and are able to strategically oversee and offer guidance to all police forces in England and Wales, including British Transport Police. People with dementia can often find themselves in situations where they become lost or disorientated, which may lead to them becoming vulnerable, due to their situation or circumstances. Some forces have developed an 'Emergency' ('E card') or 'Keep Safe' card for people with dementia to carry with them. Greater Manchester Police have circulated 36,000 'E Cards' within their area. Several forces have developed specialist teams who work closely with other agencies to ensure that the police and partners are responding in the most appropriate way to people living with dementia, which includes family and carers. ACPO is working with Forces and the College of Policing to identify and share good practice.

Energy providers: People with dementia can have problems keeping their houses energy efficient and warm, as well as remembering to submit meter readings for utility usage and contacting their utility suppliers if they have a problem.

E.ON has committed to creating dementia champions within their specialist customer service teams, as a point of contact for other advisors who may need advice on how to help customers with dementia. They are also working with Alzheimer's Society to increase awareness of dementia, its symptoms and the extra support required by those with the condition, among their customer service advisors. This will help ensure that their customer services staff have the knowledge and understanding to better help people with dementia and their carers.

E.ON is also trialling local Energy Health Check events for carers of people with dementia, covering energy efficiency measures and advice, tariff checks and advice on claiming benefits and additional support including the Warm Home Discount. This will significantly improve the service provided to people with dementia and help ensure accurate energy bills.

Telecommunications: BT and Alzheimer's Society have committed to produce a fact sheet on dementia for customer facing employees to help them to become more aware and deliver a better service to those living with dementia.

The Direct Marketing Association, a membership body of 800 organisations, has developed a best practice guide for call centres for vulnerable customers to include specific reference to people with dementia. This guide will help those working in call centres respond to people with dementia in a supportive way and will give call centre staff a level of confidence when speaking to customers.

Leisure: The Bingo Association is promoting Alzheimer's Society resources about dementia to its member companies to help them become more dementia aware. This will give bingo clubs the understanding to help people with dementia and enable people with dementia to make the most of bingo as a leisure activity.

The British Museum hosted an event to explore how museums and galleries could become age friendly. As a result of this they will prioritise how they can meet the needs of people with dementia. Alzheimer's Society and others are working with other organisations in the museums and galleries sector so best practice can be shared.

House of Memories – National Museums Liverpool

The House of Memories is centred on the fantastic objects, archives and stories at the Museum of Liverpool and is delivered in partnership with a training provider, AFTA Thought. The programme provides social care staff, in home settings and residential settings, with the skills and resources they need to inform their practice and support people living with dementia. They can help unlock the memory that is waiting to be shared, and provide a stimulating and rewarding experience for the person living with dementia.

Carol Rogers, Executive Director, Education, Communities and Visitors said:

“The House of Memories uniquely demonstrates the power of National Museums Liverpool to positively change people's lives. We have truly valued the opportunity to develop a very special training programme for the health and social care workforce in our region. We have witnessed a real passion and willingness from participants to positively engage with new ideas that have refreshed their knowledge and raised awareness of untapped cultural resources that can support people to live well with dementia. We want to see a House of Memories in every town and city and support the development of dementia-friendly communities. Our ambition is fuelled by a strong desire to continue to support the exceptional workforce that cares for the growing number of people living with dementia in the UK.”

Transport: First Group plc are providing 17,000 of their bus drivers with dementia awareness training in order to improve understanding of dementia and some of the challenges people with dementia face in using public transport. They are developing a new training module component on

dementia for their Driver Certificate of Professional Competence. They are also developing their safe journey cards for passengers with dementia. This means that First Group staff will be aware of people with dementia using their buses and can ensure that they can use the bus service safely and get to their destination.

Transport for London has also launched the Travel Support Card aimed to make travel easier for people with hidden disabilities. It is particularly useful for those with communication, learning or cognitive disabilities, who may find it difficult speaking with staff or asking for assistance.

Retail: When shopping in unfamiliar areas or larger supermarkets, some people with dementia said they sometimes lacked confidence or felt pressurised. This is because staff are unlikely to be aware that they have dementia and that they may need more time to count change or understand instructions. In response to this Tesco are committed to looking at ways to increase dementia awareness and understanding with their staff. They have worked with Alzheimer's Society to produce a DVD which will be piloted with Tesco staff to help raise awareness of dementia and help staff to better support customers with dementia.

For retailers, as for other employers, we are also looking at improving their understanding of dementia and ways of supporting people caring for family members with dementia.

Communities committed to becoming dementia friendly: What we see as a dementia-friendly community is one that shows a high level of public awareness and understanding so that people with dementia and their carers are encouraged to seek help and are supported by their community. Such communities are more inclusive of people with

dementia, and improve their ability to remain independent and have choice and control over their lives.

It will take time for communities to become truly dementia friendly, but we've made a great start and interest around the country is growing by the day. Already we know of groups in over 20 areas, including Leeds, Sheffield, Bradford, Liverpool, Wakefield, Plymouth, Wolverhampton, Northamptonshire, York, Wokingham, Torbay, Salford, Falmouth, Hampshire, Tavistock, Thurrock, Crawley, Bracknell Forest, Oxfordshire, Leicestershire, Nottingham and Lincoln that have now committed to working towards becoming dementia-friendly villages, towns and cities. As we develop a process and criteria for developing dementia-friendly communities we expect this number to grow.

Dementia-friendly parishes around the Yealm

It is not just cities and towns that are seeking to become dementia friendly. For example, five parishes around the River Yealm in South Devon have come together and committed to improve and change the lives of people with dementia and their carers.

To help deliver this innovative two year project a co-ordinator has been employed in the Parishes of Brixton, Yealmpton, Wembury, Newton and Noss and Holbeton to develop dementia-friendly parishes. Some of the key aims of dementia-friendly parishes around the Yealm are to promote individual and community based activities for people with dementia and their carers, contribute to the development of sustainable inclusive social activities and services and ensure people with dementia and their families have a voice and are able to maintain, and where necessary, increase their social contacts within their local community.

Thirty new members have signed up to the Dementia Action Alliance (DAA), taking the number of bodies and organisations to nearly 140. Each organisation has produced an action plan on what they will do to become more dementia friendly. The DAA is a membership body committed to transforming the quality of life of people living with dementia in the UK and the millions of people who care for them.

Dementia Awareness campaign: On World Alzheimer's Day 2012, the Department of Health, in partnership with Alzheimer's Society, launched the latest phase of its early diagnosis awareness advertising campaign. The campaign runs until January 2013, and encourages people to visit their doctor if they are worried about dementia.

What we're going to do next

We know that the journey towards becoming dementia friendly will differ depending on the type and size of an organisation and the make-up of a community. The aims of the Champion Group are to increase awareness, understanding and action within communities. We will instigate, expand and support the necessary change for communities to become dementia friendly and undertake a number of actions.

Raising awareness and understanding across society: On 8 November 2012, we launched a new programme to educate 1 million people to become 'dementia friends' by 2015. Through this programme, we will increase awareness and understanding of dementia across society, in boardrooms and workplaces, community halls, churches and schools. Awareness training is just the first step. Over time we hope that dementia friends will go on to learn more or participate in ways to help support people with dementia, through volunteering.

Launching a dementia-friendly communities

symbol: To recognise those who are dementia aware, and in association with the dementia friends programme, we have created a dementia-friendly symbol – the forget-me-not. Beyond the dementia friends programme, we will use the symbol to recognise dementia-friendly communities, companies and other organisations.

Encouraging more communities to commit to being more dementia friendly:

By 2015, our vision is to more than double our initial ambition of at least 20 cities, towns and villages working towards becoming dementia friendly. In practice, this will mean the establishment of local Dementia Action Alliances and other forums bringing together key stakeholders within a community alongside people with dementia and their carers to identify the key changes required to make their community dementia friendly and the action that needs to be taken.

Working with faith groups: Early discussions have taken place about the role of faith communities in delivering dementia-friendly communities. In January 2013, an inter-faith meeting will discuss how to progress work within faith communities on dementia.

Harnessing technology: There are many ways technology can transform everyday life for people affected by dementia, including assistive technology, social networks and smarter information provision. We will be holding discussion groups with key technology inventors and providers to better focus and harness their talent.

Encouraging more companies to commit to being dementia friendly:

To make a community friendly, businesses, organisations and services need to understand and respond to the needs of people with dementia. This may be about changes to signage, the layout of a shop or ensuring customer facing staff have undertaken dementia awareness training. As well, it is about examining

the design of products and adapting them to become dementia friendly. We will work with representatives of industry to identify what it means to be dementia friendly and to help them work towards this. As well as the representatives already identified, we will expand our reach to include other sectors that have a big impact on the lives of people with dementia, for example plumbers, electricians, beauticians and hairdressers.

The work of the Champion Group has helped to identify some of the key products and services that people with dementia and their carers rely on in order to live well in their community. It has also pointed to some priority areas of action that the Champion Group should focus on over the next six months. These include:

- identifying what it means to be dementia friendly;
- increasing awareness and understanding;
- development of effective training and learning materials for organisations; and
- identifying the support that organisations and communities need to become dementia friendly.

As a shared priority, the group will focus on widening engagement across the public, private and voluntary sector so that action and support to create dementia-friendly communities continues to gain momentum.

Driving improvements in health and care

The challenge

The health and care system has a central role to play in improving support for people with dementia. But it alone cannot tackle the challenge. A wide range of organisations and services, for example, housing, transport, leisure and welfare have a key role to play in ensuring that people with dementia, their families and carers can be active citizens with the potential to live well with dementia at every stage of the condition. Health and wellbeing boards will provide a new and substantial opportunity to bring these together through agreeing joint health and social care outcomes, local monitoring and championing quality and an improved experience.

Across the system, health and social care and wider local government working with the independent sector collectively can make a difference and overcome a number of challenges to improve care and support for people with dementia and their families and carers.



Timely diagnosis: Dementia affects a large number of people, one in three people over 65 will develop dementia⁷ but currently only 42% of people with dementia in England have a formal diagnosis and too often, diagnosis comes too late.⁸

In the report of the National Audit of Memory Services published in September 2011 94% of all PCTs that responded to the audit reported having a memory service in place.⁹ It is not clear, however what capacity these memory services have to diagnose people with dementia in a timely way. The services available and the way they are organised, vary from area to area.

High-quality, compassionate care in hospital:

A quarter of all hospital beds are occupied by someone with dementia and people with dementia stay longer in hospital, but we know that some hospitals struggle to provide the high-quality care that meets the needs of people with dementia.¹⁰

High-quality, compassionate care in the community:

An estimated two-thirds of people with dementia live at home.¹¹ There are problems in some areas with the quality of domiciliary social care for people with dementia, including care staff who are not sufficiently trained in providing person-centred support. There can also be a lack of staff continuity, which can be confusing for a person with dementia and cause distress.¹²

⁷ *Dementia 2012 report*, Alzheimer's Society, 2012

⁸ *Quality and Outcomes Framework QOF Results 2010/11*, NHS Information Centre, 2011

⁹ *Establishment of Memory Services- Results of a survey of PCTS, final figures 2011*, NHS Information Centre, 2011

¹⁰ *Counting the Cost: caring for people with dementia*, Alzheimer's Society, 2009

¹¹ *Living well with dementia: A National Dementia Strategy*, Department of Health, 2009

¹² *Improving domiciliary care for people with dementia: a provider perspective*, South West Dementia Partnership and the UK Home Care Association, 2009

People living with dementia sometimes do not have the same access to social care services, including re-ablement services, and health intermediate care services after a stay in hospital or to prevent admission in the first place.

High quality, compassionate care in care homes:

While many care homes offer excellent support, some are not doing enough to provide high quality, personalised care for people with dementia that help individuals to lead as fulfilling a life as possible.

“Often, when people go into a care home, the care homes are registered and they say that they can provide the care that the person needs and they clearly can't. You're dealing with a situation where people are being moved on all the time, not through any fault of theirs but because the care homes haven't got the qualified staff to deal with the issues that come up with dementia.” *(quote from a carer that responded to the consultation exercise on the National Dementia Strategy)*

Information and support to make decisions and to plan care:

Evidence suggests that for up to 50% of people with dementia there may be a 'vascular' component to their condition and we know the effects of vascular dementia can be minimised or prevented altogether through healthy lifestyle.¹³ Helping people to understand the impact on lifestyle through better information could help people make informed lifestyle choices.

The quality of advice and information that people receive is variable. In all too many areas, it is extremely difficult for people who have dementia to find out what support is available and to what they are entitled.¹⁴ There is also a lack of

personalised support for people with dementia after they have been diagnosed, which is vital to the approach of “no decision about me, without me”.

“They didn't give me enough information. I came away thinking, “What do we do now, where do we go from here?” I have a prescription in one hand and a note for blood tests in the other and nobody has said what the CAT scan showed...nobody has given me that information. I am the person who is going to deal with (my husband).” *(quote from a carer that responded to the consultation exercise on the National Dementia Strategy)*

We know that too many people with dementia are not supported to have early discussions and make plans for their end of life care.¹⁵ This means that difficult, emotional decisions are often made in crisis and the person with dementia's wishes, including for example where they want to die, cannot be taken into account.

Support for carers: Research shows that carers of people with dementia experience greater strain and distress than carers of other people.¹⁶ Most family carers want to be able to provide support to help the person with dementia stay at home, but they sometimes need more assistance in terms of information and advice on caring for someone with dementia and support in looking after their own health.

Supporting health and care professionals:

We know health and care professionals and others involved in the care of people who may have dementia need more support to ensure they have the right skills and knowledge to provide the best quality care. For example, only 31% of GPs believe they have received sufficient training to

¹³ *Living well with dementia: A National Dementia Strategy*, Department of Health, 2009

¹⁴ *Prime Minister's challenge on dementia: Delivering major improvements in dementia care and research by 2015*, Department of Health, 2012

¹⁵ *Difficult Conversations*, National Council for Palliative Care and the Dying Matters Coalition, 2011

¹⁶ Alzheimer's Society 2011

diagnose and manage dementia.¹⁷ We also know that more needs to be done to increase the capability and skills of the workforce in the care sector.¹⁸

The right treatment: Anti-psychotic drugs should only be prescribed to people with dementia in exceptional circumstances and if prescribed, the person should be reviewed on a regular basis. The place of pharmacological treatment in dementia is described in the joint NICE/SCIE guideline.¹⁹ There has been a reduction in the prescribing of antipsychotic drugs nationally, but over prescribing is still a problem with wide regional variation.²⁰

What we want to be different

Our ambition is to create a society where everyone diagnosed with dementia, their families and carers receive high quality and timely care and support regardless of the care setting. For example:

- more people to have an early diagnosis, with our diagnosis rates among the best in Europe;
- high quality care in hospitals, at home and in care homes;
- helpful information given to people at the right time and effective signposting to local and national services; and
- access for carers to support networks, information and respite care.

17 *Improving Services and support for people with dementia*, NAO, 2007

18 *Scoping Study Report*, Department of Health/Skills for Care/Skills for Health, September 2010
Mapping Existed Accredited Education/Training and Gap Analysis Report, Department of Health/Skills for Care/Skills for Health, September 2010

19 *NICE clinical guideline on Dementia: publications.nice.org.uk/dementia-cg42*

20 *National Dementia & Antipsychotic Prescribing Audit, 2012*, NHS Information Centre, 2012

What has been achieved so far

Improving the quality of care in hospitals:

Building on an objective within the National Dementia Strategy to improve the quality of care for people with dementia in general hospitals, including identifying a clinical leader for dementia in every hospital, the NHS Institute has set out a call to action for every hospital in England to commit to being dementia friendly by 31 March 2013. This means hospitals responding to the specific needs of people with dementia and their carers. The call to action involves people with dementia and their carers, and uses partnership working between the NHS, social care and the voluntary sector to share best practice to improve the quality of hospital care for people with dementia.

Since the introduction of the Commissioning for Quality and Innovation (CQUIN) payment to hospitals offering risk assessments to all over 75s,²¹ over 2800 people have been referred to a memory service. In total, approximately £54 million is available to hospitals through these CQUIN payments. As more people in hospital are having their risk of dementia assessed, they will be better able to manage the condition and its symptoms and should receive better care in hospital.

Improving the quality of care in care homes and care at home:

More care homes and providers are taking action to improve the quality of dementia care, so that more people will get personalised care and support to enable them to live well. From the initial 10 organisations that signed up to be part of the Dementia Care and

21 *Prime Minister's Challenge on dementia: Delivering major improvements in dementia care and research by 2015*, Department of Health, 2012

Support Compact there are now 42 signatories representing over 1,800 care services – this will mean improved care for over 200,000 people.²²

We are working with local authorities, housing associations, care homes and domiciliary care associations to encourage their members to sign up to the Compact and to take specific action to develop innovative fit-for-purpose solutions to help people stay at home with the right level of personalised support.

Improving housing choices: There is a need for a clearer understanding of the role good housing plays in helping people with dementia to live independently for longer and improving the quality of care and support on offer. The Department of Health, working with the Homes and Communities Agency and the Greater London Authority (for London based schemes), has committed up to £300 million over five years to encourage local authorities to build effective partnerships with housing associations and private house-builders to develop innovative housing solutions for people with long term conditions, including dementia.²³

Improving dementia diagnosis rates: We have developed an analytical model toolkit to support the NHS to achieve a significant increase in diagnosis rates from the current 42%. It will support clinical commissioning groups to set a local ambition to improve their dementia diagnosis rate, commission sufficient memory services to deliver their ambition, and to track and demonstrate their progress.

We are working with the Royal College of Psychiatrists Memory Services National Accreditation Programme (MSNAP)²⁴ to assure and improve the quality of memory services for people with memory problems and dementia. MSNAP engages staff in a comprehensive process of review, through which good practice and high quality care are recognised, and services are supported to identify and address areas for improvement. There are currently only 34 accredited memory services. We have written to the NHS to encourage memory services to sign up to MSNAP²⁵ and to also sign up to the National Memory Services Register. This will enable us to develop a complete map of services across England.

We will use the NHS Outcomes Framework 2013/14 to measure progress on diagnosis rates. Early diagnosis will help people with dementia have more control and to be better able to manage the condition, cope with the symptoms, plan and make informed choices about how they would like to be cared for.

22 The full list of signatories can be found at:
<http://www.ecca.org.uk/article/prime-ministers-challenge-on-dementia-list-of-signatories/>

23 <http://www.homesandcommunities.co.uk/ourwork/care-and-support-specialised-housing-fund>

24 www.rcpsych.ac.uk/quality/qualityandaccreditation/memoryservices/memoryservicesaccreditation.aspx

25 <http://www.rcpsych.ac.uk/quality/qualityandaccreditation/memoryservices/memoryservicesaccreditation/memoryservicesregister/registeredservices.aspx>

How early diagnosis helps

“My mother Pauline was diagnosed with Alzheimer’s disease in 2006. Her practicality and creative spirit helped her deal with this traumatic news. Afterwards, Mum told other people about it, so sharing this information was clearly important. We were advised to establish Power of Attorney and arrange Mum’s will and legal affairs while she still had capacity to make decisions.

Since her partner’s death four years ago, Mum has remained at home with live-in carers. Her speech has changed, words slip, and she confuses people, places and time easily. The carers provide the physical care and support Mum needs, while helping her maintain her independence where possible. A family friend keeps an eye on things, and I visit regularly. She has a weekly timetable of events to provide stimulation and activity, including an Alzheimer’s Society art group and a choir, organised by Dementia Compass.

Early diagnosis helped my mum to make the right legal arrangements and to establish a system of care, which gradually evolved along with her needs. The care package has enabled her to stay in her own home. Her GP has provided great support throughout. Did early diagnosis help us access services earlier? Yes. Financial arrangements to provide care for someone in their home are complicated and it takes perseverance to understand what is needed, and what is available.”

(James Murray-White, a carer)

Improving education and training for GPs on dementia:

We will shortly be putting out a tender for the development of a toolkit to support GPs to understand, diagnose and support people with dementia, as well as help their families and carers. The toolkit will be available next year and will complement the analytical model.

Improving end of life care: Working with the National Council for Palliative Care (NCPC) and others, we are working to raise awareness with health and care professionals of the possible alternatives to hospitalisation so that people with dementia have more choice and control over their care. To support ‘planning ahead’ discussions and to ensure that peoples’ needs and wishes are respected, the NCPC has developed a leaflet to help GPs have these important conversations in a sensitive way with patients and carers. Practical guidance for all professionals and carers will be launched in 2013.

Encouraging innovation in dementia care: Three prize funds have been established as follows:

- The Innovation Challenge Prize for Dementia, announced by the Prime Minister in March, was formally launched by the Secretary of State for Health on 25 June.²⁶ The Challenge is making £1 million available to the NHS for projects that demonstrate innovative ways of achieving 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. To date 28 expressions of interest have been received. The prize winners will be announced in 2014.
- Nationally, a new partnership between the Department of Health and Janssen Healthcare Innovation (JHI) has been established to create a Challenge Prize for those who support people with dementia. The prize, of up to

²⁶ www.challengeprizes.institute.nhs.uk/the-challenges/breakthrough-challenges/dementia-challenge/

£150,000, is being provided by JHI for evidence of meeting the challenge in a sustained way that can be spread across the NHS and social care.²⁷

- NHS South of England have announced a regional Dementia Challenge Fund of £10 million to support the adoption and spread of proven innovations in dementia care. Awards will be made this month.

Supporting the workforce through networks and training:

The NHS Commissioning Board Authority has created a Strategic Clinical Network for Mental Health, Dementia and Neurological conditions. The network will help NHS commissioners to reduce unwarranted variations in services and to encourage innovation.

Via Skills for Care, the Department of Health has a fund of £2.4 million for social care employers and providers who support people with dementia, including those who employ their own support staff, to build the skills of their employees by completing relevant accredited qualifications.

On 8 June 2012, e-learning for Healthcare published an e-learning package, funded by the Department of Health, to train health and social care staff in recognising, assessing and managing dementia and providing high quality dementia care. There are ten sessions covering a wide range of issues relevant to dementia, such as diagnosis of dementia and managing symptoms. The first session, on general dementia awareness, is also available to the public and to anyone working in the public environment such as shops, transport and banks.

Improving information provision: The government's information strategy for health and social care in England '*The power of information*' published in May 2012 aims to harness

information and new technologies to achieve higher quality care and improve outcomes for patients, families and the public.

The Our Health website²⁸ is the first of its kind in England. It aims to transform the way patients, their carers and health professionals access and share the latest information on a range of key local health and care services across the South West. The website now offers the most comprehensive local service directory in the region. Our Health publishes the local performance of health and care services for people with dementia through 25 indicators covering the whole spectrum of dementia services. This enables comparison between localities that can support patients and carers in making choices about their care and support and demanding improvements in local services. As part of the PM's Dementia Challenge, Our Health is being rolled out across the South of England by the end of December 2012 and similar services will be available across England by the end of March 2013.

More generally, we are making links to the proposals for improving the provision of information as set out in the White Paper '*Caring for our Future: Reforming Care and Support*'. This includes every registered residential or home care provider having a provider quality profile on the NHS and social care information website.²⁹ By April 2013, the Department of Health will also publish clear and accessible information on staff training as part of the provider quality profiles, so that people can understand the skill mix of staff at different care providers. We are working to ensure that services and support for people with dementia and their families is a key consideration in the implementation of the White Paper.

²⁷ <http://www.challengeprizes.institute.nhs.uk/the-challenges/partnership-challenges/>

²⁸ www.ourhealth.southwest.nhs.uk

²⁹ www.nhs.uk

“For me, the chance to give feedback on services and share my experiences on the online forum is a really important part of the website and one that will help to shape and improve services in future.”

Norms McNamara was diagnosed with early onset Alzheimer’s disease in September 2008, aged 50

“Publishing meaningful data about services will help to drive improvements in those services, as well as help patients and their families to make informed decisions about their care. Planning for the future is particularly helpful for people with dementia, their families and carers, and knowing what is available locally can help this immensely.”

Dr Nick Cartmell, a GP and Dementia Lead in Devon

Better support for carers: Dementia cafes – like those set up in Dartford, Gravesend and Swanley – are helping to reduce social isolation and providing tools to enable carers and the person with dementia to live well with dementia.

Mrs D’s daughter says: “Mum and I really enjoy the cafés, especially the variety of talks and entertainment that we have. Everyone joins in and is friendly. It’s a pleasant way to spend the afternoon. It is a huge benefit. Every talk has been helpful, for instance we got Mum a GPS watch after one talk. The entertainment such as the singing, dancing and exercises has been good. Mixing with other people has helped us to see that we are not on our own.”

Another carer wrote about her experience at the dementia café:

“It was a lifeline to find the Dementia Café and enjoy the tea and biscuits and to be able to talk to other carers and staff about day to day problems and happenings with my husband John. I particularly look forward to the interesting guest speakers and have benefitted from their knowledge and learnt what is available to carers, especially Kent Carers Emergency Service and the Advocacy Services. The staff work hard to provide a varied programme, including entertainment which makes a very happy and relaxing atmosphere which we both look forward to.”

“I have seen a couple in my surgery this evening, who have just been awarded a break. The husband’s mum has dementia. The stress has been one of the causes of the wife having a significant episode of depression this year. Only when I tried to delve into possible stresses she had, did I find they were supporting her husband’s mother. They did not even consider themselves as carers. They are overwhelmed with the carers break and the husband said he felt humbled that they should have it. The wife is already starting to get better!”

Dr. Yvonne Collins, North West Surrey Dementia CCG lead

What we're going to do next

Our ambition for the coming year is to support people with dementia to live well with dementia in all care settings. We want to galvanise engagement and support for this important agenda working with the other Champion Groups.

Having listened to the views from the public via the Dementia Challenge website, we have developed an action plan setting out 15 priority work areas. The plan widens the challenge to encompass social care and integration issues including, for example, extending the scope of the work to include end of life care, rehabilitation, reablement and housing. The priorities for the next phase of the Champion Group's work include the following:

Commissioning effective, high-quality care:

We will build understanding and capacity about commissioning services for people with dementia, working with health and wellbeing boards, clinical commissioning groups, with Healthwatch and Public Health England to raise their awareness of the Dementia Challenge and support them to promote and deliver integrated, quality dementia care.

We will spread best practice about high quality dementia care and disseminate learning about the effectiveness of personal budgets for people with dementia. We will also share training materials for staff within health, social care and housing, and for carers of people with dementia, with the aim of providing better support to carers.

Working closely with the Dementia Friendly Communities Champion Group, we will support the full range of health and care services in different settings to become "dementia friendly". This includes supporting the Department of Health's work programme on improving health and care environments for people with dementia

and their carers. On 25 October the Secretary of State for Health announced that £50 million capital funding is 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 develop future guidance in this area.

Timely diagnosis: We will step up work with GPs and other health and care professionals to drive significant improvements in the diagnosis of dementia. We will work with the NHS Health Check programme, so that from April 2013 people aged 65 to 74 will be 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 ensure that people with dementia are diagnosed at an earlier stage.

We will support an increase in the coverage and accreditation of memory services and roll-out the information offer pioneered by the South West across England.

To measure progress on the coverage and capacity of memory services the Department of Health will re-run the National Audit of Memory Services, which reported its first results in September 2011.

High quality, compassionate care in hospitals:

From April 2013, we will extend the Dementia Commissioning for Quality and Innovation (CQUIN) to include measures of the quality of dementia care in hospital and support for carers of people with dementia.

High quality, compassionate care in the community:

We will encourage local authorities, housing associations, care homes and domiciliary care associations to sign up to the Dementia Care and Support Compact and take action to develop innovative fit-for-purpose solutions to help people stay at home with the right level of personalised

support. The provider quality profile on the NHS and social care information website will highlight if providers have signed up to the Compact. We will work with health and wellbeing boards to ensure that people with dementia get equal access to intermediate care or re-ablement services including telecare and home adaptations.

We will also continue to work with the National Council for Palliative Care and other key organisations to support access to high quality personalised end of life care for people with dementia. The NCPC is launching in December 2012 a dementia specific communications training programme to support staff in different care settings to be skilled in end of life conversations. To support health and care professionals a practical guide for the recognition, assessment and management of pain in people with dementia, including an assessment of hydration and malnutrition, is also being developed and will be available in December 2012.

Supporting health and care professionals:

To better support staff, we will continue to take action to improve the whole health and social care workforce (in the statutory, third and independent sectors) to be positive, have the right level of expertise for their role, deliver excellent standards of care and have the confidence to involve people and families in designing care and support.

The right treatment: Finally, we will work with the NHS Institute and other stakeholders to understand reasons for regional variations in the prescribing of antipsychotic medication and how this can be addressed. The Department of Health will re-run the national audit into the prescribing of these drugs to monitor the level of prescribing and regional variation.

There is much to do, but we are determined to make a difference and look forward to making progress in the next phase of our work.

Better research

The challenge

The ageing population will result in more and more people developing dementia. They and their families will need appropriate and effective diagnosis, assessment, treatment, management and care.

Some of the most critical discoveries in Alzheimer's disease were made in the UK, and we remain at the forefront of advanced diagnostic investigative techniques. Our companies and researchers already punch above their weight in taking technology from clinical trials into clinical practice.

According to the Association of the British Pharmaceutical Industry, globally there is a pipeline of over 200 medicines for dementia in

various stages of development.³⁰ Many of these medicines are likely to work best if treatment starts before significant damage to the brain has occurred. To help develop effective medicines, the UK is working to identify and work with patients at an earlier stage.

Our focus is to improve treatments for people with dementia and if possible, prevent it from occurring in the first place or at least slowing it from progressing beyond a very early phase. Without intense research, we can make only limited progress in our understanding of dementia.

We want to build on our strengths and end up with better outcomes for people with dementia. If we are successful, we will fundamentally change the course of dementia.



In this country, we have world leading specialist facilities and strengths in neuroscience.

1. The NHS is unique in the world as a resource for patients and data.
2. UK researchers welcome collaboration with the UK and global life-science industry.
3. The UK has the unique capability to combine world-leading research in genetics, cognitive neuroscience and neuroimaging with very large population and patient cohorts.
4. Different types of clinical and non-clinical research studies are underway that aim to advance treatment and care.
5. There is a new legal requirement on the Secretary of State for Health, the NHS Commissioning Board, clinical commissioning groups and Monitor to promote research and the use of research evidence.

³⁰ Personal Communication. Stephen Whitehead, CEO, The Association of the British Pharmaceutical Industry

What is dementia?

Dementia is a syndrome and refers to the impairment of cognitive brain functions of memory, language, perception and thought.

There are many diseases that cause dementia such as Alzheimer's disease, dementia with Lewy bodies and Parkinson's Disease-associated dementia. The majority are degenerative but not all, for example, vascular dementia. Dementia is not a single disease.

We do not yet fully understand the balance of genetics and environmental causes that lead to the diseases associated with dementia. We do know, however, that there are only a very small number of dementia diseases where single genetic defects are largely responsible. At the moment, there are very few disease-modifying treatments available for dementia.

Why is it so difficult to find treatments that slow or stop dementia?

Today important trials for the treatment of dementias often focus on patients at a relatively late stage of disease. For these patients, some of the damage to the brain may be largely irreversible and may explain some of the lack of success.

Many scientists now believe that trials will need to happen much earlier in the course of the disease and run over a longer period. More research could be done if research cost less to carry out. We also need a new approach to some of the research we do, to detect and assess the benefit of therapies more effectively.

We need new breakthroughs to improve our understanding of the mechanisms underlying the development and progression of dementia, with a focus to identify new targets for intervention.



We must develop drug and non-drug interventions that manage the symptoms of dementia, as well as slowing progression, helping people who have more than one illness and maintaining independence. This is particularly difficult because some patients are reluctant to enrol in research studies. Changing that is essential.

Why is it important to involve patients in clinical research?

To discover which treatments work for which patients, researchers need to access well-characterised patients in whom we can measure disease progression. We also need to understand disease sub groups and follow the impact of the treatment they receive over time.

In response to this:

- The Government has put in place new initiatives to enable more patients to find out about and volunteer for research. This will help to make it easier to identify and work in partnership with groups of patients with many different types of dementia and other neurodegenerative diseases.
- NIHR Dementias and Neurodegenerative Disease Research Network (NIHR DeNDRoN) and the UK Clinical Trials Gateway are making it easier for the public to get information about and participate in, clinical trials. For companies, NIHR DeNDRoN supports the delivery of world-class research in the NHS. It also provides a single point of access to the entire NHS clinical research infrastructure.

What have we achieved already?

Patients and their data: Since the launch of the Prime Minister's Challenge, the NIHR and the Medicines and Healthcare Products Regulatory Agency have launched the Clinical Practice Research Datalink (CPRD) service to allow better access to anonymised NHS patient data. The CPRD service, jointly funded by the NIHR and the Medicines and Healthcare Products Regulatory Agency, is designed to maximise the way anonymised NHS clinical data can be used. It will facilitate studies of epidemiology, diagnosis, care pathways, drug effects and side effects and outcomes research. CPRD will make clinical trials more efficient.

£9.6 million has been provided by the MRC to expand the UK Biobank. This is the first phase of funding with the aim to undertake further studies such as scanning the brains of up to 100,000 Biobank volunteers. The UK Biobank, a unique national epidemiological resource of 500,000 individuals aged 40-69 years, will provide a platform for future dementia research. This offers a unique dataset that will allow further prospective studies linked to clinical histories, cognitive assessments and associated DNA, blood, urine and saliva samples. The information will help scientists discover how some people develop dementia and others do not.

NIHR DeNDRoN is enabling more people to sign up for research. It has established a system to help people find and join research studies. This will help increase public participation in research from the current low level of approximately 4% of people known to have dementia. It is creating a large disease register of patients with dementia.

Discovery science: The UK is investing in the very latest technology to model disease and better target drugs specifically to an individual patient using the patient's own genetic information.

The MRC has provided 50% more money for neuroscience research, with an expansion of its programmes investigating neurodegenerative disease, at the internationally renowned MRC Laboratory of Molecular Biology, Cambridge that has increased its capacity to undertake research. This means a commitment of £29 million over the next three years, with a further indicative budget of £10 million for each of 2015/16 and 2016/17.

UK involvement through the MRC in the international Centres of Excellence in Neurodegeneration (COEN) initiative, with seven other national funding partners, is linking national centres of excellence so these can share the best knowledge.

The MRC and the NIHR have invested £10 million in a new national Phenome Centre, the first of its kind in the world, to enable researchers to explore the characteristics of diseases in order to develop new drugs and treatments for patients. Researchers at the Centre will investigate the phenome patterns of patients and volunteers by analysing samples – usually blood or urine – very rapidly and on an unprecedented scale. This will help them to discover new 'biomarkers' to explain why one individual or population may be more susceptible to a disease than another. This knowledge will aid scientists in finding new, safer and more targeted treatments.

Imanova, a new state-of-the-art imaging centre established through a public-private partnership co-owned by MRC and Kings College, University College and Imperial College, London, was opened in May 2012 and aims to become an internationally renowned imaging centre and partner of choice for industry and academia. Its capability in PET and MRI brain scanning will offer significant capability for studies of dementia,

and will both enhance translational research and offer the potential to significantly shorten drug development times.

Translating research: To help reduce the costs of trials involved, the Government provided £36 million for a new National Institute for Health Research (NIHR) Translational Research Collaboration in dementia. These centres of excellence in dementia will work on commercial and non-commercial research to answer questions about early diagnosis, patient stratification and novel therapeutics. This work should lead to new proof of concept trials and discoveries, as we explore new approaches and validate existing ones.

This collaboration provides unrivalled access to:

- NHS patients and their data with appropriate ethical and confidentiality safeguards.
- A developing portfolio of research including markers for the amyloid protein, neuroinflammation, blood flow and metabolism. Using the latest clinical and research scanners, the study of disease models together with leading edge research developing biomarkers in blood and cerebrospinal fluid is possible.
- Well-characterised dementia-related tissue samples through links to the MRC supported UK Brain Banks Network and supportive disease-cohorts, which can also provide specimens of plasma, serum, urine, DNA and RNA.

Since the launch of the Prime Minister's Challenge, a £2.1 million investment is being made through the UK's Biomedical Catalyst Programme³¹ towards a £3.3 million project to translate UK imaging and cognitive testing technology, widely used in clinical trials, into a digital health care platform for early dementia diagnosis. This will ultimately help to define strategies for treatment and the prevention of dementia. This collaborative project is led by UK SME's involving academic researchers, the NHS and Alzheimer's Society.

A new £0.5 million study has been funded through the landmark MRC-AstraZeneca compound collaboration, which provides academic researchers unprecedented access to 22 chemical compounds to extend their possible application into new disease areas. This study will investigate the potential use of one such compound in controlling cerebral blood flow in Alzheimer's disease with a view to identifying a new route for treatment.

On 10 October 2012, the Government brought together representatives from across the UK's research system to showcase this country's specialist dementia research and resources at a major industry event. This event showed what is on offer in the UK and how a more coordinated approach from basic science, translational research and clinical research in dementia can provide an environment that gives the life sciences industry important additional opportunities to work in the UK to develop new approaches to dementia.

Implementing clinical research: The NIHR has invested £1 million to evaluate how quality of life can be improved through the impact of different memory assessment services and the withdrawal of prescribed anti-psychotic medication. We will then be able to investigate the possibility of using patient reported outcome measure (PROMs) more frequently in dementia care.

The NIHR is also creating the right incentives to increase the numbers of patients participating in clinical research. NIHR DeNDRoN is implementing new ways to integrate existing capabilities of local NHS systems. Jointly with the NIHR School for Social Care Research, NIHR DeNDRoN is also promoting research in care homes, helping to increase recruitment to dementia studies.

Living well with dementia: to help people with dementia lead healthy, independent lives for longer: The Economic and Social Research Council and the NIHR launched a call up to £13 million for social science research on dementia on the 9 July to fund national or international social science research in dementia that can make a significant contribution to scientific, economic and social impact.

What next

We expect funding for dementia research provided by NIHR and the MRC to double over the lifetime of this Government.

This means funding will increase from £26.6 million per annum in 2009/10 to an estimated £66.3 million per annum in 2014/15, including funding over £20 million of proposals under the recent NIHR Themed Call on Dementia.

The MRC spend on dementia and neurodegeneration research is currently around £34 million per annum and will increase by 10% to £37.5 million per annum by 2014/15 including:

31 The Biomedical Catalyst is a £180 million programme of public funding designed to deliver growth to the UK life sciences sector, delivered jointly by the MRC and the Technology Strategy Board

- The MRC is providing £1 million towards a new £5 million COEN funding call for high-risk/high pay-off research to provide new mechanistic insights in neurodegenerative disease, to be launched this month. The NIHR Translational Research Collaboration in dementia is also being incorporated into this initiative to provide further impact.
- The MRC is also involved in the EU Joint Programme on Neurodegenerative Diseases (JPND) initiative, for which it led the development of an EU-wide research strategy published earlier this year. The MRC is contributing £2 million to support UK groups in the forthcoming JPND call for research into the risk factors that contribute to dementias and other neurodegenerative disorders, to be launched at the end of 2012.
- The MRC will continue to support the UK Brain Banks Network and four MRC brain banks that collect, archive and supply brain tissue to enable the study of disease mechanisms and the development of potential drug treatments.

2012 – A pivotal year in drug development?

Alzheimer's disease and dementia are different. We now know a great deal more about what causes Alzheimer's disease and how we might treat it than dementia.

However, most clinical trials of drug treatments against Alzheimer's disease are giving us important clues even though they have been studied when the disease is well-established and its effects on the brain are difficult to reverse.

Significant research continues across all stages of the disease, but this year has brought forward some potentially interesting developments in treating early stage dementia in Alzheimer's disease in particular.

Global trials of the Solanezumab drug by Lilly failed to show benefit for all dementia sufferers, but appear to show some improvements in those with mild dementia, suggesting treatments could be developed to help slow or prevent the disorder if caught early enough.

Whilst the Janssen studies of the Bapineuzumab drug did not show any clear clinical benefits for patients, the drugs did appear to affect the underlying biology of the disease by halting growth in harmful amyloid protein deposits, providing insights to support development of future treatments. Further phase III trials will report in April 2013.

Drug companies continue to invest in further research, reflected in Roche's decision to expand testing of their Gantenerumab drug on more patients with pre-dementia. This will further build the body of evidence.

Lilly and Merck are starting global trials on therapies that block the betasecretase enzyme – involved in the build-up of the abnormal amyloid protein deposits – which may help prevent dementia arising in patients with mild memory problems.

UK scientists in industry and universities have made significant contributions to the understanding of the disease process that has led to these studies, and in the analysis of the results from these studies, provide some optimism for the future.

Recent Government action in The Plan for Growth³² is also playing a key part by requiring NIHR contracts to providers of NHS services to include a benchmark of 70 days from receipt of a valid application to the recruitment of the first patients to clinical research study. From 2013, performance against this benchmark will have implications for future research funding.

Our ultimate goal is to improve the prevention, diagnosis, treatment and care of patients with dementia. If we are going to achieve this, we must make sure that research remains at the forefront of our efforts – and communicate this effectively to researchers, industry and the public.

In December 2012, we will publish our collective vision for what we would like to achieve in the coming years and over the next decade, as well as the collaborative approach we need to take to reach it. Our ambitions will be stretching yet measurable, relying on collaboration nationally from key funders, charities and the research community and internationally. We will focus on five key areas:

- Patients and their data: to safely unlock the potential of data sources (including NHS patient data) to enable ground-breaking research.
- Discovery science and experimental medicine: to identify new targets for therapeutic development taking potentially successful compounds forward to late stage trials.
- Translational research: to encourage the life sciences industry to harness the UK's extensive dementia research capacity across all stages of drug discovery.
- Implementing clinical research: to increase public participation in 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.

- Living well with dementia: to help people with dementia lead healthy, independent lives for longer, devising, and evaluating non-drug interventions.

³² The Plan for Growth, March 2011 http://www.hm-treasury.gov.uk/ukecon_growth_index.htm

An annex summarising the progress made by the three Champion Groups on the key commitments and actions included in the Prime Minister's Challenge on Dementia document is available at the Department of Health's Dementia Challenge website at: www.dementiachallenge.dh.gov.uk

Photography supplied courtesy of Alzheimer's Society