

David Cameron
Prime Minister
10 Downing Street
London
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7 May 2014

Dear Prime Minister,

Progress on the Prime Minister's Challenge on Dementia: Year Two

It is now two years since you set us the challenge to deliver major improvements in dementia care, support and research. We are pleased to report that significant progress has been made.

Your continued leadership and personal commitment and that of the Secretary of State for Health and Minister of State for Care and Support have been instrumental in our progress. In particular, your decision to hold a Dementia Summit during the UK Presidency of the G8 in 2013 was a landmark in national and international terms in the fight against the condition.

It remains our ambition for England to become amongst the best countries in the world for dementia care and support and for people with dementia, their families and carers to live.

Your challenge has enabled us to move further and faster to deliver improvements to dementia care and support and to boost research. Throughout our work we have built on your original ambition. We have identified new priority areas for focus and been more challenging in others.

Some of our key achievements since you launched the Dementia Challenge in 2012 include:

- **Diagnosis rates increased by 6% since March 2012 with an ambition to ensure that two-thirds of the estimated number of people with dementia receive a diagnosis by March 2015 with an expansion of post-diagnosis support.** Just under half of the people diagnosed with dementia over the past 12 months have been in the early stages of the condition.
- **Over 50 communities across England signed up to the national Dementia Friendly Communities recognition process** within six months, with an increased ambition to reach 75 by March 2015.
- **Research spending on dementia has increased by nearly 50% since 2010/11,** with an ambition to further double spending over the decade following the end of the present Parliament.

The work of the Champion Groups has grown from strength to strength over the last twelve months and we are well placed to deliver on the key commitments set out in the Dementia Challenge in its final year.

Since the launch of the Challenge, there has been significant change to the structure of the health and social care landscape. Your Champion Groups have been instrumental in ensuring leadership and focus on dementia across national partner organisations and local government and social care. Our summary below reflects achievements led directly by

national partner organisations, local government and social care as well as those which we have championed through our Groups.

Key successes during year two

We have continued to build on the foundations set in the first year of the Dementia Challenge. In this second year, across the Champion Groups, we have increasingly been working together to ensure impact and integrated delivery throughout all our work. Full details of our work are set out in the Annex to this letter.

Creating dementia-friendly communities that understand how to help

Co-chairs: Jeremy Hughes and Angela Rippon OBE

The work of the Dementia Friendly Communities Champion Group has continued at a pace, with an increasing number of private, public and voluntary organisations now involved in its work and has become more ambitious. This has resulted in the establishment of six Task and Finish Groups aimed at significantly enhancing the work towards becoming dementia friendly in specific areas or sectors. For example, a retail task and finish group, another looking at power of attorney and data protection, as well as one focusing on dementia friendliness in rural communities.

Some of the key successes for the work of the Dementia Friendly Communities Champion Group include:

- **Launch of the national recognition process for communities wanting to become dementia friendly:** There are now over 50 communities from across England that have formally signed up to this process.
- **Launch of the Dementia Friends Campaign,** a major new campaign led by Alzheimer's Society and Public Health England to mobilise the whole country to tackle one of the biggest health issues of our time. The campaign will raise awareness of dementia, improve attitudes towards the condition and create a more dementia friendly society by encouraging one million people to become Dementia Friends.
- **Over 280,000 new Dementia Friends** including, with support from Public Health England, Dementia Friends from private businesses. Argos, Homebase, Lloyds Banking Group, Marks and Spencer and Lloyds Pharmacy have all committed to recruit Dementia Friends throughout their workforce. The Dementia Friends Campaign launched today will make further announcements on the numbers of Dementia Friends committed by private businesses.
- **Launch of the Dementia Friendly Financial Services Charter:** The Charter, published in October 2013, developed by over 20 financial organisations and institutions, sets out ways in which financial services organisations can work to become more dementia friendly.
- **Dementia Resource Suite for schools:** This resource, published in October 2013, is being used by an increasing number of schools to raise awareness and understanding of dementia. There are over 140 schools that now have similar programmes in place.
- **Publication of evidence about dementia friendly communities:** In September 2013, Alzheimer's Society held the first ever national conference on dementia friendly communities, including publication of a report providing evidence about the factors and priorities that people with dementia say helps makes a dementia friendly community.

The Champion Group has an ambitious programme of work during year three of the Challenge, reflecting both our own work and that of partners, and this will include:

- **Fulfilling the ambition of the Dementia Friends Campaign** led by Alzheimer's Society and Public Health England to have achieved 1 million dementia friends by March 2015, including further work with businesses, local authorities and government departments across Whitehall.
- **An increased ambition to have 75 communities signed up to the recognition process by March 2015**, exceeding the original ambition of 20 communities committed to work to become dementia friendly.
- **Publishing a code of practice on dementia friendly communities:** Alzheimer's Society has commissioned the British Standards Institution to develop this code of practice with the ambition for 15 communities to be signed up by March 2015.
- **Dementia Friendly Awards:** Later this month Alzheimer's Society will host the first annual Dementia Friendly Awards to recognise the pioneering work that is going on in our communities to become more dementia friendly.
- **Launch of a criteria for businesses and organisations for how they can work towards becoming dementia-friendly** to be launched in Summer 2014, with the ambition of 10 businesses or organisations signing up to this process by March 2015.
- **Dementia friendly sectors or industries:** We will learn from the success of the Financial Services Dementia Charter and work with industry leaders to develop similar resources for sectors and industries to become more dementia friendly, such as the launch of a Dementia Technology Charter.
- **Building on the success of the 2013 G8 Dementia Summit:** We will engage with civil society across key countries involved in the Summit to enhance the work of the Champion Group and exchange ideas and best practice. This will be done as part of the global work with Alzheimer's Disease International, Non Government Organisations (NGOs) and non-health related organisations such as the Samaritans.

Driving improvements in health and care

Co-chairs: Sir Ian Carruthers and Sarah Pickup

The Health and Care Champion Group's work continues to highlight that alongside the NHS, social care and wider local government has a central role to play in improving care and support for people with dementia, particularly after they have been diagnosed. Considerable work has been in progress over the last year to support the ambition that by March 2015, two-thirds of the estimated number of people with dementia should receive a diagnosis and appropriate post diagnosis support. Some of the key successes for the work of the Health and Care Champion Group, through national delivery partners, include:

- **Timely dementia assessments:** We know that in around three quarters of the country, people with suspected dementia are referred to and assessed by a memory clinic within an average of six weeks. To ensure that this is a reality across the country, NHS England are working with those areas with the longest waits, with the aim of ensuring that anyone with suspected dementia will not have an excessive wait for a timely assessment.
- **Provision of new incentives for GPs and hospitals to better identify and support people with dementia and their carers:** In April 2014 NHS England published a new Dementia Directed Enhanced Service (DES) for take up by GPs to reward practices

for facilitating timely diagnosis and support for people with dementia. Patients who have a diagnosis of dementia will be offered an extended appointment to develop a care plan focusing on their physical, mental health and social needs, including referral and signposting to local support services. In the hospital setting, through the Dementia Commissioning for Quality and Innovation (CQUIN) reward, with around 4,000 referrals a month, it is clear that we are also better at identifying and assessing people with dementia in hospitals since the launch of Challenge in 2012.

- **Better support for people with dementia and their carers following diagnosis:** Working with the Department of Health's Post Diagnosis Working Group, we have supported work to survey local areas to identify 'what good looks like' in terms of post-diagnosis support and to improve our understanding of the level of care currently available. This will include developing a measure of the effectiveness of post-diagnosis care and support. To support GPs and other primary care staff, a Dementia Roadmap web-based tool has been commissioned by the Department of Health from the Royal College of General Practitioners. The roadmap will be launched later this month and will provide a framework that local areas can use to provide local information about dementia to assist primary care staff to more effectively support people with dementia and their carers. People diagnosed with dementia and their carers are now able to sign up to a new email service on the NHS Choices website to get essential help and advice in the early stages of their condition.
- **Exceeding the ambition for 100,000 NHS staff to have received foundation level training in dementia by March 2014:** By October 2013 108,000 staff had received foundation level (Tier 1) training, exceeding the original aim of 100,000 staff trained by March 2014. This means more staff will be able to spot the early symptoms of dementia, know how to interact with those with dementia and ensure that patients receive the most appropriate care. The Government's refreshed Mandate to Health Education England (HEE), published on 1 May 2014, builds on this by setting an ambition for a further 250,000 NHS staff to receive Tier 1 training in dementia by March 2015, with the tools and training opportunities being made available to all staff by the end of 2018.
- **Supporting a new programme of work led by Public Health England on the prevention of dementia:** At a meeting of leading public health practitioners, policy makers, researchers and others, convened by Public Health England and the UK Health Forum in early 2014, consensus was reached on the preventability of dementia and the need for action on prevention and risk reduction. A consensus statement will be published shortly. In response, Public Health England has initiated a programme of work to promote public and professional awareness and action. This includes developing a ground-breaking 'brain ageing' risk assessment tool for use by individuals and clinicians, integrating dementia prevention as a key outcome in health improvement programmes such as NHS Health Checks, and running a consumer research programme to test the effectiveness of different marketing approaches in stimulating positive change on lifestyle risk factors.

The Champion Group, working with delivery partners, intends to focus on the following key areas in year three of the Challenge:

- **Supporting the national ambition that two-thirds of the estimated number of people with dementia receive a diagnosis by March 2015:** While the diagnosis rate has increased and is increasing, more needs to be done and we will support NHS England in its work with local areas to drive up diagnosis rates and to ensure timely diagnosis.

- **Sharing best practice about high quality post-diagnosis support:** We will, working with the Department of Health's Post Diagnosis Working Group, spread best practice of what high quality, personalised dementia care and support should look like for people with dementia, their family and carers.
- **Challenging and supporting commissioners and providers to deliver high quality care at home:** The Champion Group's subgroup on Dementia and Homecare will deliver and disseminate a report setting out what good practice and innovation with regard to care at home looks like.
- **Improving End of Life care to reduce avoidable acute hospital admissions and to improve experience for people with dementia and their carers:** Working with the National Council for Palliative Care and other partners, the Champion Group will consider what further actions can be taken to support people with dementia to have more choice and control over their care and to provide better quality and experience of care.
- **Engaging with social care providers to improve dementia diagnosis, care and support:** We will work with Care England, the UK Home Care Association, the Care Quality Commission, Local Authorities and other partners to identify how best to support social care providers to identify and better support people with dementia and their carers, building on initiatives such as the Dementia Care and Support Compact.
- **Supporting the provision of integrated care:** Health and Wellbeing Boards continue to have a key role to play in driving change and supporting more integrated care. We will support them through highlighting best practice and learning about what works.

Research Champion Group

Co-chairs: Professor Patrick Maxwell and Dame Sally Davies

During the second year of the Prime Minister's Challenge, research funders have implemented and enhanced initiatives to generate the research evidence needed to make a step change in prevention, treatment and care. This work has been broad based, building on the strong research base that already exists in the country, focusing on research infrastructure and capacity, as well as the research projects themselves. Our approach has been characterised by a broad view encompassing all types of dementia, and taking as a starting point the promotion of cognitive (brain) health.

The most significant research event during the second year of the Challenge, was the highly successful 2013 G8 Dementia Summit, about which further details are provided later in this letter.

Some of the Research Champion Group's key achievements since May 2013, include:

- **Continuing progress towards achieving the doubling of public sector research funding** during the lifetime of this government. Funding has already increased by 50% since 2010/11.
- **£20m for research on living well with dementia:** Public sector funders (the National Institute for Health Research, NIHR, and the Economic and Social Research Council, ESRC) awarding jointly-funded research grants focused on improving quality of life for people with dementia and their carers. The funding exceeded the original target of £13m and now represents the world's largest social science research programme on dementia and care.

- **Further progress towards recruiting 10% of patients into clinical studies:** The number of people with dementia involved in studies in 2012/13 was 11,859 (3.7%); the forecast figure for 2013/14 is 13,400 (4.4%), more than ever before. 2013/14 was a record year in terms of the number of dementia-related studies coming onto and open to recruitment on the NIHR Clinical Research Network DeNDRoN Portfolio (79 and 181 studies respectively), the number of NHS Trusts involved in dementia research (200) and the performance of dementia studies, with over 85% completing on time to target. Over 670 care homes are now participating in an 'ENRICH' (Enabling Research in Care Homes) Network, support that provides straightforward advice for researchers, care home staff, and others which will help to increase the volume of dementia research in care homes.
- **Further progress on international initiatives in neurodegenerative disease research.** A £3m Medical Research Council (MRC) investment included Centres of Excellence in Neurodegenerative disease (CoEN) pathfinder grants to support 'high risk, high pay-off' approaches to identify and validate new drugs and develop innovative therapeutic approaches; and in international projects funded through the EU Joint Programme in Neurodegenerative Disease (JPND) identifying new genetic and environmental risk and protective factors.
- **NIHR has appointed Professor Martin Rossor** (Clinical Neurology, University College London) **as the NIHR National Director for Dementia Research.** Professor Rossor will contribute towards the leadership needed to facilitate and support the Department of Health's response to the research commitments within the Dementia Challenge and the 2013 G8 Dementia Summit, including working with the World Dementia Envoy, Dr Dennis Gillings.

Many of the commitments within the Dementia Challenge have now been delivered and the Research Champion Group is considering the next steps needed to move further and faster. A recent meeting in January 2014 identified the need for further action in the following areas during the third year of the Challenge:

- **Developing 'readiness' cohorts of patients** consenting to be approached about research. The NIHR, Alzheimer's Society and Alzheimer's Research UK will launch *Join Dementia Research*, a new nationally consistent service to improve recruitment to dementia studies, in the summer of 2014.
- **Better data sharing**, including a governance framework that could facilitate data sharing linked to work by the Organisation for Economic Co-operation and Development (OECD) and JPND to map global research activity.
- **Identifying and validating therapeutic targets** (for both basic science and applied clinical research) with a clear trajectory into patient care.
- **Maintaining a broad focus on cognitive health and impairment**, while also retaining a stratification (and sub-stratification) of disease classification, which will be of potential value to industry partners.
- **Development of innovative trials and innovative funding models:** Discussions are underway about what is needed to successfully set up clinical trials in individuals before symptoms of memory loss have emerged. The Champion Group will feed into discussions led by the World Dementia Envoy on innovative funding models for research.
- **Creating 'self-sustaining' capacity development:** Research funders have been supporting research training in relevant disciplines. Focussed funding calls are

bringing a wider spectrum of the UK's research community into the dementia field. Consideration will be given to what more needs to be done to reach a point where the field of dementia research grows under its own momentum. This will include the launch of a scheme for care research training in dementia, through the NIHR Collaborations in Leadership on Health Research and Care.

- **Contributing to the development of an international action plan for research**, which will account for the current state of science and promote global efforts to maintain brain health and find therapies for dementia.
- **Living well with dementia:** Facilitating research to support living well with dementia initiatives and identifying effective interventions, in the clinic, in the nursing home, and in everyday life.

Shared themes and challenges

Global action on dementia

In December 2013, the highly successful G8 Dementia Summit was held, which brought together Ministers, and key opinion formers in the field of dementia research, from different countries. The Declaration and Communiqué set out an international commitment to closer collaboration, in particular:

- Announcing an ambition to identify a cure or disease modifying therapy by 2025, and to increase collectively and significantly the funding for dementia research to reach that goal.
- Work together, share information about the research we fund, and identify strategic priority areas, including sharing initiatives for big data, for collaboration and cooperation.
- Development of a co-ordinated international research action plan, which accounts for the current state of science, identifies gaps and opportunities, and lays out a plan for working together to address them.
- Significantly increasing the number of people involved in clinical studies.
- Appointing a global Dementia Innovation Envoy to draw together international expertise to stimulate innovation and co-ordinate international efforts to attract new sources of funding.
- Promoting the sharing of information and data from research studies.

Since the Summit, on 28 February 2014, you appointed Dr Dennis Gillings as a World Dementia Envoy to lead a World Dementia Council, which already has 14 members with more to follow. The Council met for the first time on 30th April 2014. At the inaugural meeting, the Council considered how it could unlock the brainpower and financial muscle required to meet the objective from the 2013 G8 Dementia Summit to identify a cure or disease modifying therapy by 2025. The Council will work over the next year to identify the barriers to innovation and improve the conditions around investment. To continue the momentum of the Summit and focus on specific key issues, several countries (at the Summit and since) have committed to host legacy events including the UK, Canada (a joint event with France), Japan and USA. The first of these events will be hosted by the UK in London on 19th June 2014 and will focus on financial and social impact investment in Dementia. It will drive the development of a timeline and plan towards a global private and philanthropic fund to:

- stimulate greater investment and innovation in dementia research,
- improve the prevention and treatment of dementia, and
- improve quality of life for people with dementia and their carers through innovation in local care and technologies.

This is an area of work that is incredibly exciting and fast paced. We have the opportunity to influence change across the world and to use the successes of the UK dementia programme as a model from which others can learn.

Increasing public awareness and understanding

Challenging the unacceptable stigma and low awareness that surrounds dementia has been one of our key priorities. Across the health and social care systems we are raising expectations about the level and understanding of dementia within all professions. Health Education England has reported that over 108,000 staff have received foundation level training as defined by the government's Mandate to Health Education England, but we know this is just a start and appropriate dementia training in health and social care needs is a necessity to delivering quality care and support. Over the past 12 months, Skills for Care estimate that over 100,000 social care workers have received some form of dementia awareness training through workforce development funding from local authorities and care providers. Skills for Care has also been supporting the workforce in a variety of different ways, including the establishment of pilot sites to consider the social care workforce's role in supporting dementia friendly communities, the development of resources to support people in the advanced stages of dementia and the production of resources to support the home care workforce. Other initiatives, such as the Dementia Guide and the forthcoming GP Guide are also providing greater awareness of dementia.

Across wider society there are a number of key initiatives underway to raise awareness and understanding. The flagship Dementia Friends programme is now underway and there is a real momentum to recruit Dementia Friends across the country including the Local Government Association recruitment campaign. This will be further boosted by the Dementia Friends Campaign launched today by Alzheimer's Society and Public Health England. Financial services, other industries and sectors are also raising awareness and so too are schools.

Integrated care and support

We support the positive steps taken to better join-up health and social care – particularly the launch of the Better Care Fund and Integration Pioneers. However, too many people with dementia are confronted with an uphill struggle to access a timely and seamless package of care and support.

Joined-up, or integrated, services are still the exception, rather than the norm. Dementia care and support is still too focused around structures and systems, rather than the individual needs of the person and their carer. Our interest in better joined-up and co-ordinated care and support stems beyond health and social care to housing, transport and other services essential for a person with dementia to live well in their community.

Going forward we recognise the importance of spreading best practice of integrated dementia care and support, as well as being a continuing priority across health, social care and wider local government. With regard to the role of national government, in articulating your priority on dementia across Whitehall, we would like to see all government departments

taking work forward to improve the lives of people with dementia, for example, participation in the Dementia Friends programme. Within the Department of Health over 500 members of staff have been trained as Dementia Friends.

Provision of timely and accessible care and support for people with dementia at all stages of the condition is essential for independent living and keeping families together. In order to achieve this and to successfully integrate services it is important that available resources, both locally and nationally, are considered. In our first annual report of progress, we supported many of the Dilnot reforms that are now part of the Care Bill and we look forward to their implementation. We also said the reforms needed to be supported by the provision of sufficient funding to meet the needs of people with dementia and their carers. Looking ahead, this will help to ensure that the changes we make are sustained over the longer term.

The final year and beyond

We are fully focused on delivery during the final year of the challenge. The key priority areas for action are continuing to support improvements to the number of people with dementia being diagnosed and receiving high quality post-diagnosis support; increasing the number of communities and sectors that are working towards becoming dementia-friendly and focusing on those activities where action can make a real difference to progressing research in the fight against dementia, for example collaboration on an international plan for research, better international coordination on data sharing, as well as specific national activities. We are confident that the changes we make will have made a positive difference to the lives of people with dementia.

Evaluating and learning about what has been achieved to date is essential. We are pleased that the Department of Health is conducting an independent assessment of improvements in dementia care and support since 2009. During the final year of our work we will look at how we can initiate development of work to measure improved outcomes for people affected by dementia.

We are clear that dementia will still remain the biggest health challenge facing the country today and in the future – with still much more to do. It is our view that the timescale and parameters set out in the Prime Minister’s Challenge document have driven a step-change in responding to dementia, not a completed transformation. A continued national focus and drive will still be necessary beyond the life time of the Prime Minister’s Challenge on Dementia. Some people with dementia and their carers are still facing a journey through their condition without access to the care and support they need and that is why the Secretary of State’s ambition that everyone diagnosed with dementia should receive high quality post-diagnosis support, for example someone who can help and advise like a dementia adviser, access to high quality personalised information to help them understand and manage their condition and access to support services such as reminiscence and counselling, is so important.

We support the development of a successor to the Prime Minister’s Challenge on Dementia and would be willing to work with your officials to inform this work. This will ensure the impact made by your challenge to us grows and continues – as we all strive to deliver on our ambition for England to be a world leader in dementia care and support.

On behalf of all those who are involved in your challenge on dementia we would like to take this opportunity to thank you for your continued leadership and determination to improve the lives of people with dementia and their carers.

Yours sincerely,



Sir Ian Carruthers



Sarah Pickup



Angela Rippon OBE



Jeremy Hughes



Professor Patrick Maxwell DPhil FRCP FMedSci



Dame Sally Davies

Copied to:

The Rt Hon Jeremy Hunt – Secretary of State for Health
Norman Lamb MP – Minister of State for Care and Support