



Department
of Health

Prime Minister's Challenge on Dementia 2020

Implementation Plan



March 2016

You may re-use the text of this document (not including logos) free of charge in any format or medium, under the terms of the Open Government Licence. To view this licence, visit www.nationalarchives.gov.uk/doc/open-government-licence/

© Crown copyright

Published to gov.uk, in PDF format only.

www.gov.uk/dh

Prime Minister's Challenge on Dementia 2020

Implementation Plan

Prepared by the Dementia Policy Team

Contents

1. Foreword	3
2. Executive Summary	5
3. Introduction	8
Implementing the Prime Minister’s Challenge on Dementia 2020	8
Reviewing our progress	9
How we engaged on this plan	9
Engaging with people with dementia and carers	9
4. Measuring our progress	11
Metrics and Measurement	11
Public Health England Dementia Intelligence Network	11
NHS England CCG Improvement and Assessment Framework	12
Governance	13
Where we want to be by 2020	13
5. Delivery priorities by theme	16
a) Continuing the UK’s Global Leadership role	17
WHO Global Dementia Observatory	18
World Dementia Council (WDC)	18
New UK Dementia Envoy	18
A global Dementia Friendly Communities movement	18
Dementia Research Institute	19
International Dementia Research	19
Dementia Discovery Fund	19
Integrated development	20
European Union Joint Action on Dementia	20
International benchmarking on prevention, diagnosis, care and support	21
How will we know that we have made a difference?	21

b) Risk Reduction	22
Progress since March 2015	23
Key Priorities	24
Raising Awareness	24
Enhancing the data and evidence	26
Reducing dementia inequalities	26
How will we know that we have made a difference?	28
c) Health and Care	29
Progress since March 2015	29
Key Priorities	30
d) Dementia Awareness and Social Action (including Dementia Friends and Dementia-Friendly Communities)	53
Progress since March 2015	54
Key Priorities	54
Dementia Friends	55
Dementia Friendly Communities	55
Dementia friendly businesses	56
National and local government	57
Evaluation	57
How will we know that we have made a difference?	58
e) Research	62
Progress since March 2015	62
Engaging with the research community and people with dementia	62
Key Priorities	63
Delivering increases in research funding	63
Increasing dementia research capacity	65
Delivering better treatments, faster	66
Improving the lives of people with dementia	68
How will we know that we have made a difference?	71
Annex 1:18 Key commitments from the Prime Minister's Challenge on Dementia 2020	78

1. Foreword



Jane Ellison MP, Parliamentary Under Secretary of State for Public Health

The Prime Minister's Challenge on Dementia 2020 was clear and unequivocal. Building on the vital progress that resulted from the first Challenge issued in 2012, the new Challenge aims to make England, by 2020, the best country in the world for dementia care, support, research and awareness. By 2020, England should be the best place for people with dementia, their carers and families to live and the best place in the world to undertake research into dementia and other neurodegenerative diseases.

However, while the challenge was issued by the Prime Minister, it is clear that this goal is shared by many more. It is something to which organisations across the country are determined to contribute. It is something that millions of individuals, who know at first hand the impact of dementia, are determined to embrace.

Already, we are seeing the fruits of that determination.

As this document shows, across the country, there are pioneering initiatives and potentially life-changing partnerships in research and in frontline care. From local programmes to national or international ones, there is a clear sense of enormous momentum in response to the Challenge. Our goal in this Implementation Plan is to build on this momentum, harness it and use it in a co-ordinated way, so accelerating progress to our shared goal.

This Implementation Plan sets out the actions we and our partners will take to ensure the commitments set out in the Prime Minister's Challenge are delivered.

Working with key partners, we will publish a number of short, tailored guides to bring this Implementation Plan to life for organisations and individuals.

It provides a detailed plan for the priorities and actions up to 2018 – many of which are already underway. It then summarises the further actions from 2018 to 2020. These will be considered further when we formally review progress and refresh the plan in 2018.

The immediate actions will be kept under ongoing scrutiny – not least by a panel of people affected by dementia (the creation of which is a priority action in itself), who will be well placed to advise on whether our actions are making a real difference.

I want to thank everyone involved in the development of this plan for their time, energy and commitment. More importantly still, I want to thank everyone in every part of the country that is working towards our bigger goal:

- the over one million Dementia Friends (and counting), the carers, service providers, health and care workers, researchers and others who are ensuring that local initiatives flourish.

The Prime Minister's 2020 Challenge is crucial; globally, for our country and for the many people and their families affected by dementia. This plan shows how, together, we intend to rise to it.

A handwritten signature in black ink that reads "Jane Ellison". The signature is written in a cursive style with a horizontal line underlining the name.

Jane Ellison MP
March 2016

2. Executive Summary

- 2.1 Together, we are making measurable, tangible progress in our vital work to make England the best place in the world to live well with dementia.
- 2.2 Since 2012, we have increased diagnosis in England by almost 50 per cent so that people with dementia receive more appropriate care, sooner. We are raising awareness of the many ways dementia affects lives, and crucially awareness of the factors that can increase the risks of dementia. We are building a society that is more equipped to support those with dementia, through transforming health and social care, training thousands of staff, and through community programmes like Dementia Friends – a success of which we can all be proud.
- 2.3 UK leadership continues to galvanise global action to improve the lives of people with dementia, and during the UK presidency of the G8 in 2014, we hosted the first ever Summit on Dementia. And through a wealth of pioneering, inter-connected research, we are leading the way in developing new disease-altering and life-altering therapies, and investing more than ever in our search for a cure.
- 2.4 Over the next four years, we will accelerate our progress in all of these areas. This document – the Implementation Plan for the **Prime Minister's Challenge on Dementia 2020** (referred to throughout as the 2020 Challenge) – explains how.
- 2.5 Building on the vital progress made under the previous challenge launched in 2012, the 2020 Challenge set out more than 50 specific commitments, across four core themes of risk reduction, health and care, awareness and social action, and research, that together will make England the world-leader in dementia care, research and awareness by 2020. Eighteen of these were identified as the crucial enablers – those that need to be started first, because they are so important we cannot wait, or completed first, because they underpin further changes. This Implementation Plan, which has been developed in partnership with a range of organisations – named throughout – and influenced by the views of people with dementia and carers across England, sets out clearly the actions we will take by 2018 to address each of these.

- 2.6 We will transform our approach to **risk reduction**, using the NHS Health Check programme to educate more people earlier about the risks of developing dementia – and the steps they could take to reduce those risks. In a pilot scheme delivered in partnership with voluntary organisations like the Alzheimer's Society and Alzheimer's Research UK, this will now be extended to those aged 40 or older – down from 65 currently. We will also launch a new campaign, 'One You', and a Brain Age tool, to promote public understanding of healthy brain ageing and advice on preventive action.
- 2.7 In **health and care**, we will build on the outstanding work that has seen the dementia diagnosis rate reach above two-thirds nationally. We will take steps to reduce local variation in this. Building on the **national post diagnosis support declaration**, we expect to see joined-up plans for health and care support in every area and personalised care plans for every person with dementia.
- 2.8 We are also renewing our focus on creating **dementia-friendly health and care settings**. By 2020, we want every person with dementia to get the safest, best care in hospital, when they receive care at home and in every care setting. We will continue our focus on staff training. And we will make sure that people can make meaningful comparisons about the quality of care in their area, by publishing a new improvement and assessment framework, which will include clear assessments and ratings for dementia care.
- 2.9 **Awareness and social action** has already been a phenomenal success with over 1.4 million people becoming Dementia Friends and 142 communities to date across England signed up to be Dementia Friendly Communities. By 2018, we aim to increase the total number of Dementia Friends to at least 2.5 million, on track towards a goal of 4 million by 2020, and establish at least 100 more Dementia Friendly Communities.
- 2.10 Between 2012 and 2015, Government funding for dementia **research** doubled, to over £60m a year. Crucially, this commitment was backed by a wider group of potential investors: the Dementia Discovery Fund has been established and backed by worldwide investors, and the total funding for dementia research from the commercial sector, NIHR, Research Councils and charity partners is continuing to rise. This is vital in our goal to accelerate progress towards disease modifying therapy, and ultimately a cure by 2025.
- 2.11 We will establish a new **Dementia Research Institute** that puts the UK at the forefront of this global effort. A director will be appointed, and the hub and regional spoke sites selected. And we will offer more opportunities to participate in research, so that by 2018, 12% of people newly diagnosed with dementia each year will be registered on **Join Dementia Research**.
- 2.12 That is just one of the ways we are putting the views and lived experience of people with dementia and carers at the heart of our delivery strategy. We will, as a priority action, **establish a new Dementia 2020 Citizens' Panel**, that will build on wider engagement and will provide first-hand reports to Ministers and senior management to determine if our actions are making the difference we all want to see.

- 2.13 It is also important to underline that the Plan fits with other key strategic plans, including the NHS Mandate,¹ NHS Five-Year Forward View² and the Government's Shared Delivery Plan for health and social care.³
- 2.14 Just as we are joined up in our action at home, the UK also continues to play a pivotal role internationally. This has already resulted in a clear Call for Action on Dementia by over 90 countries. The plan sets out how we will continue our partnership with the World Health Organization (WHO) and the Organisation for Economic Co-operation and Development (OECD), to lay the foundations for a global framework.
- 2.15 By 2020 we want to be able to say with pride, that England is the leading country in the world for dementia care and support, for undertaking research into dementia and other neurodegenerative diseases and for people with dementia, their carers and families to live. This Implementation Plan and a commitment to the actions within it, provide a clear pathway to that goal.

¹ <https://www.gov.uk/government/publications/nhs-mandate-2016-to-2017>

² <https://www.england.nhs.uk/ourwork/futurenhs/>

³ <https://www.gov.uk/government/publications/department-of-health-shared-delivery-plan-2015-to-2020>

3. Introduction

Implementing the Prime Minister's Challenge on Dementia 2020

- 3.1 The Prime Minister's Challenge on Dementia 2020 contains over 50 commitments that together aspire to make England the best country in the world for dementia care and support, for people with dementia to live; and to conduct dementia research.
- 3.2 The 50 commitments are split across four themes: risk reduction, health and care, awareness and social action, and research. Many of them can only be met through the joint efforts of multiple organisations, from government departments and arms-length bodies, to the NHS and local authorities, research institutions, and the charity and voluntary sector. Though the underlying aims are shared, clearly implementing a programme of such size and scope will be complex. Some actions lay the foundations for others; some can and will need to be completed relatively swiftly, others will be ongoing for years.
- 3.3 The Secretary of State for Health therefore decided at the outset that it was essential to develop a full Implementation Plan for the 2020 Challenge, and that the plan would be informed by the views of a wide range of stakeholders.

Two clear phases

- 3.4 The 2020 Challenge spans five years. It is crucial that we do not constrain ourselves unnecessarily with concrete plans for the full five years that cannot be adjusted to meet future needs. Therefore, we have built this plan around two clear phases:
 1. **Up to 2018** – this covers the immediate actions both Government and delivery partners will take over the next 12-18 months to improve dementia care and support, awareness and research. Funding for these is already set, and the Implementation Plan describes in more detail how these actions will be achieved.
 2. **2018-2020** this covers longer term actions that will deliver all of the 2020 Challenge commitments. The actions included in this phase are indicative and in less detail. They may need to be altered or amended in future years to take into account funding allocations, emerging and planned research into science and medicine, and best practice in both clinical and social care.

Reviewing our progress

- 3.5 The delivery of the 2020 Challenge is overseen by a Dementia Programme Board, chaired by Jane Ellison MP, Parliamentary Under Secretary of State for Public Health, and comprising senior leaders from many of the partner organisations involved in the 2020 Challenge.
- 3.6 Progress in both phases will be monitored by the Dementia Programme Board, who will use this document to hold delivery partners to account. In addition, the Government, working with key delivery partners, will establish a **Citizens' Panel** of people with dementia and carers to regularly review the progress we have made against the plan. The Citizens' Panel will report to the Programme Board.
- 3.7 **A full formal review** of this Implementation Plan will take place **in 2018**. Using the findings of the Citizens' Panel, wider engagement and range of data and measures, the review will assess whether we have achieved the actions included in this plan. It will also look ahead to the actions up to 2020 and develop more detailed delivery plans for them.
- 3.8 This will provide the necessary governance and transparency to ensure that the actions in this plan – and later updates – make a real and lasting difference to people with dementia, their families and their carers, our most important stakeholders.

How we engaged on this plan

- 3.9 To ensure stakeholders' views on implementation were taken into account, the Programme Board led a comprehensive engagement programme, in which Board members hosted roundtable sessions or workshops with key stakeholders. Attendees were asked to consider the theme commitments and the respective work underway. Comments were then sought using standardised engagement questions as well as online surveys and questionnaires. Responses from the engagement sessions were then collated and fed into the theme chapters.
- 3.10 This Implementation Plan has been agreed by each delivery partner, and signed off by the Dementia Programme Board and Ministers.

Engaging with people with dementia and carers

- 3.11 However, engagement with delivery partners was only part of the process. There was also extensive engagement, with people with dementia and carers, in partnership with Dementia UK, Alzheimer's Society and the DEEP⁴ and Tide⁵ networks. These sessions took a different format, building on the 'I' statements developed by the Dementia

⁴ <http://dementiavoices.org.uk>

⁵ <http://www.lifestorynetwork.org.uk/tide/>

Action Alliance in its National Dementia Declaration⁶ which were designed to summarise what people with dementia say they need most.⁷

3.12 The engagement sessions were focused on what people with dementia and carers felt were the key priorities in the 2020 Challenge that will make the biggest difference to them. The Programme Board was clear that engagement should be inclusive (for example ensuring we heard views from black and minority ethnic groups and people with early onset dementia). The people we engaged with identified the following priorities:

- better support for people with dementia and their carers following diagnosis.
- people with dementia being able to live in their own home independently for longer.
- improved waiting times for diagnosis, applied consistently and country-wide.
- GPs ensuring continuity of care.
- all people with dementia being given the opportunity to plan ahead at the right time through advanced care planning.

3.13 These priorities underline that, while tangible progress has been made in dementia care and support, there is still more that needs to be done to improve the personal experience of people with dementia and their carers, and reduce regional variation. Therefore, one of the first actions of the newly formed Citizens' Panel will be to **contribute towards a review of the National Dementia Declaration**, recognising the progress made since the "I" Statements were published in 2009.

⁶ <http://www.dementiaaction.org.uk/nationaldementiadeclaration>

⁷ I have personal choice and control or influence over decisions about me, I know that services are designed around me and my needs, I have support that helps me live my life, I have the knowledge and know-how to get what I need, I live in an enabling and supportive environment where I feel valued and understood, I have a sense of belonging and of being a valued part of family, community and civic life, I know there is research going on which delivers a better life for me now and hope for the future.

4. Measuring our progress

Metrics and Measurement

- 4.1 It is vital that we are able to assess whether the actions in this plan are making a demonstrable difference to dementia care and support. Previously, data and measurement on dementia has been ad-hoc and fragmented, making it difficult to monitor progress both locally and nationally across the full dementia care pathway. **Robust health and care system data and metrics** will allow system leaders to assess and drive performance through benchmarking local health and care systems, improving accountability and transparency.
- 4.2 Two distinct data mechanisms are described below that will provide this data. We will use these and the views of the newly created **Citizens' Panel** to assess progress to 2020 and beyond.

Public Health England Dementia Intelligence Network

- 4.3 The ambition of Public Health England's Dementia Intelligence Network (DIN) is to work across all organisations involved in the care and support of people who have dementia, providing data and intelligence that complements the NICE dementia pathway and supports improved outcomes for people with dementia and their carers.
- 4.4 The dementia profile,⁸ developed by the DIN and launched on 12 January 2016, collects new and existing data on dementia at both CCG and local authority level. The data covers six key domains across the entire dementia pathway:
- prevalence
 - preventing well
 - diagnosing well
 - living well
 - supporting well
 - dying well.

⁸ <http://fingertips.phe.org.uk/profile-group/mental-health/profile/dementia>

- 4.5 The profile gives commissioners, local decision makers and health professionals access to local data and intelligence to enable local teams to compare themselves against other areas in England, or those with similar demographics. This will assist the local planning of services and support areas to make sustainable improvements from an easily accessible online platform.
- 4.6 In addition to the profile, the DIN has created the first dementia data catalogue to identify and categorise all dementia related data. The data catalogue is the first step in ensuring all gaps in dementia data are filled, and aims to stimulate conversation across organisations and promote joint working to make more data available for potential inclusion within the dementia profile.
- 4.7 Current areas of focus include the data held by Alzheimer's Society on its Dementia Friends and Champion initiatives and work is beginning to scope the availability of information held by CQC and the emergency services. We anticipate that the new Mental Health Services Data Set will also provide key information about the dementia pathway.

NHS England CCG Improvement and Assessment Framework

- 4.8 In addition to the Dementia Profile tool, a CCG Improvement and Assessment Framework (CCGIAF) is being developed and will replace NHS England's CCG assurance framework. Currently only quality ratings for individual providers are available, but for long term conditions such as dementia, care is provided by a range of different providers. The aim of the CCGIAF is to drive continuous improvement of CCGs and to provide a good sense about the quality of healthcare being provided in their area. Its relevance reaches beyond CCGs, because it is about how local health and care systems and communities can assess their own progress. The CCGIAF will be aligned to the *Five Year Forward View*. The new process and metrics will apply from 2016/17 and serve as the core means of driving implementation of the NHS sustainability and transformation agendas.
- 4.9 Each Clinical Commissioning Group's (CCG) commissioning performance will be rated as either 'Outstanding', 'Good', 'Requires improvement' or 'Inadequate' for its performance as a commissioner. Each CCG will also receive a similar rating for the quality of the services it commissions in each of the following clinical areas:
- cancer
 - **dementia**
 - diabetes
 - mental health
 - learning disabilities
 - maternity.

- 4.10 An annual assessment of these six areas will be moderated by an independent panel of experts for each area. A first simple assessment of all CCGs in these six areas will be published in summer 2016. The formal annual summative assessment of all CCGs for 2016/17 will take place at the end of that financial year and ratings will be published in summer 2017.
- 4.11 In addition to data collection on outcomes and process measures, it is important not to lose sight of experiential data from people with dementia and their carers directly. Research underway by the London School of Hygiene and Tropical Medicine, due to conclude during 2016, will establish the feasibility of using patient reported outcome measures (PROMs) routinely with people with dementia and of using trained proxies to obtain health related quality of life information from people with dementia in residential care where family carers are not available. This important study into the methodology for obtaining data and information from people with dementia and their carers will lay the foundations for future work in this area to measure the effectiveness of post-diagnosis care in sustaining independence and improving quality of life, as part of the NHS Outcomes Framework.⁹

Governance

- 4.12 These new systems of metrics will enable greater monitoring of improvements in dementia care and support. The national Dementia Programme Board will hold delivery partners to account for delivering the actions in this Implementation Plan. The Board will be supported by wider engagement and by the new Citizens' Panel that will report to the Board with insight on how dementia care and support is being delivered. In addition, an internal Progress Review Group will continually monitor key performance indicators against the commitments within the 2020 Challenge and report to the Programme Board on progress.

Where we want to be by 2020

- 4.13 The following case study provides one example of how we would want dementia care and support to look in the future. We acknowledge there is no 'one size fits all' solution, but hope this will provide a useful framing point for other areas to develop high quality, fully integrated dementia health and care services that are aligned with the commitments in the 2020 Challenge. Work like this is leading the way to make England the best place in the world for dementia care and support.

⁹ https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/257032/nhs_of_technical_append.pdf

Case Study: Greater Manchester 'Dementia United' – What will 'good' look like?

City devolution deals across England have the potential to provide an unprecedented opportunity to raise the quality of life for people living with dementia – and in Greater Manchester (GM) the scale of ambition is unparalleled. Dementia has been set as a key devolution priority with the launch of www.dementiaunited.net. The programme is being led by Sir David Dalton, Chief Executive of Salford Royal Foundation Trust and Pat Jones-Greenhalgh, Executive Director Adult Social Care at Bury Council on behalf of the thirty seven GM partner organisations.

The ambition is clear: to make Greater Manchester the best place for people with dementia and their carers to live. Over the next five years the programme will achieve this through improving the lived experience of people with dementia, and reducing dependence on the health and social care system. People with dementia and their carers will be at the heart of this transformation programme.

Dementia United is central to the GM programme of reform for mental health services and will engage health and social care commissioners, providers, wider public services, businesses, voluntary sector groups and most importantly people with dementia and carers themselves, working together to improve health and care systems. Our partnerships with the GM Academic Health Science Network, the strategic clinical networks and Alzheimer's Society have been, and will continue to be, invaluable in securing deep engagement with providers and citizens.

Where do we want to be by 2021?

The dementia challenge in Greater Manchester is one of standardisation, care pathway re-design, new care models and implementation. To deliver this we need to do things in a highly reliable and standardised way:

Identify patients early: supporting them to live well and to manage their health

Prevent deterioration and social isolation: through regular monitoring and support to avoid unplanned admission to hospital and long-term residential care

Provide high quality healthcare in the community: to prevent hospital admission

Provide high quality hospital care: to prevent unnecessary increases in length of stay

The operational delivery of this work relies on coordinated programme support and the active participation of Greater Manchester's 10 local authorities and 12 Clinical Commissioning Groups. Nominated locality leads are working in cross-GM partnership to co-design this work and ensure it is integrated into locality plans.

What are we going to do?

The programme covers five broad areas, reflected in Dementia United's pledges:

1. **Improve the lived experience:** develop a regular measure of insight into 'what it is like to live with dementia 'round here'? We will use this information to re-design services and inform our improvement efforts
2. **Reduce variance:** commit to building a GM commissioning framework to support local commissioning and agree core deliverables and outcomes
3. **Co-production and redesign:** agree to connecting providers in locality improvement collaboratives to re-design care pathways, removing waste and improving experience
4. **Key worker pilot:** testing whether supporting every newly diagnosed person and their care support system with a named individual (key worker) who can help families build a resilient infrastructure for post diagnostic support and 'living well' with dementia
5. **Technology adoption:** testing how digital technologies can support individuals and carers to monitor health, reduce social isolation and connect people

Dementia United's role in reducing dependence on health and care services will contribute to the aim of the Greater Manchester devolution programme to increase the financial sustainability of the region's health and social care system. Initial cost-benefit analysis of Dementia United has identified potential savings from delayed entry into residential care, reduced emergency hospital admissions and length of stay, with an estimated gross fiscal benefit to local authorities and the NHS of £49m over five years if successfully implemented.

Dementia United's work with local commissioners will test new payment models for dementia care. For example, a shift in contracting from activity based to outcomes based commissioning will be tested as part of the programme. This shift will enable conversations with social financiers who will be approached to invest in dementia services in GM, bringing in social investment alongside public money to 'ignite' the transformation work and deliver improved outcomes.

The aim of the Dementia United programme is not only to transform the lived experience for people with dementia for today, but to be at the vanguard of how health and care services are funded, commissioned, designed, delivered, experienced and evaluated in the future.

5. Delivery priorities by theme

- 5.1 This chapter highlights the priority areas and corresponding actions that were heard and developed through the engagement process. This is not an exhaustive list of everything underway or planned to be incorporated. The full **roadmaps** for delivery by theme are available at **Annex 2**.
- 5.2 Due to the size and scope of the 2020 Challenge, the commitments were broken into four distinct themes:
- Risk Reduction
 - Health and Care Delivery (including Workforce training and development)
 - Dementia Awareness (and social action)
 - Research
- 5.3 For the purpose of this Implementation Plan, a further theme has been added: “Continuing the UK’s global leadership role” to reflect the UK government’s commitment to further work to fight dementia together with our international partners. Every aspect of this plan has an international dimension, where collaboration across nations will allow the UK to benefit from the momentum created by global effort, as well as providing opportunities to learn from and share good practice initiatives.
- 5.4 The 2020 Challenge contained over 50 separate commitments across the themes, but it specifically highlighted 18 individual commitments that were considered **key priorities (see annex 1)**. These 18 key priorities, and a summary of the main actions derived from the engagement process for each one, are outlined in tables at the end of each theme under the heading ‘how will we know we have made a difference?’. These tables also provide a link back to the National Dementia Declaration ‘I’ Statements to reflect the impact upon people with dementia and carers.

a) Continuing the UK's Global Leadership role

A sustainable continuation of the UK Government's global leadership role on dementia

- 5.5 Enormous progress in the global fightback against dementia has taken place since the UK Government's G8 Dementia Summit in December 2013 and the Declaration¹⁰ agreed at that event.
- 5.6 The UK's leadership in galvanising global action led to:
- the appointment of the first World Dementia Envoy, Dr Dennis Gillings, and the establishment of the World Dementia Council;
 - the number of dementia strategies increasing from 13 at the time of the Summit to 23 today, with others in the pipeline;
 - the first regional dementia plan adopted by the Pan-American Health Organisation region of the World Health Organization (WHO);
 - the raising of a \$100m Dementia Discovery Fund to spearhead pre-clinical development of dementia drugs led by the UK;
 - a transatlantic clinical trial project to reduce the time, cost and risk of clinical research;
 - work with national medicines regulators on the challenges faced when developing treatments for dementia (known as Integrated Development), led by the UK;
 - Switzerland formally proposing a WHO Resolution on dementia, and calling for a side event on dementia at the World Health Assembly this year, which the UK will co-sponsor;
 - Luxembourg and the Netherlands prioritising dementia as part of their EU Presidencies; and
 - the establishment of the Global Dementia Action Alliance.
- 5.7 The first global Ministerial Conference on dementia in Geneva in March 2015, co-sponsored by the UK Government, WHO and the Organisation for Economic Co-operation and Development (OECD), resulted in the adoption of a Call for Action by over 90 countries and a broad consensus that the momentum achieved should continue. The continuity model developed since then has clear roles for WHO and its Member States consolidated around a WHO Global Dementia Observatory, and for a reformed, independent and more globally inclusive World Dementia Council to drive forward global actions to tackle this condition.

¹⁰ https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/265869/2901668_G8_DementiaSummitDeclaration_acc.pdf

- 5.8 The UK's leadership has been recognised across the world. However, with no effective drug yet on (or near) the market, and many people still facing stigma and inadequate care, there is no cause for complacency. The UK will continue to be a major player on the international stage, across a range of areas.

WHO Global Dementia Observatory

- 5.9 WHO made a commitment in March 2015 to develop a **Global Dementia Observatory**. This will allow all WHO countries easy access to comparable epidemiological, policy, research and resource data at a country-level through an interactive repository that will be continuously updated. WHO is working with a number of countries, including England, to pilot the Observatory. Following this pilot phase, the Observatory will be rolled out to a larger pool of countries, including middle and low income countries. It is expected that the platform, based on information from some countries, will be operational by the end of 2017.

World Dementia Council (WDC)

- 5.10 The WDC has, at its seventh meeting in February 2016, been re-formed, with a new Chair and Vice Chair, a refreshed membership and terms of reference and a new more action-focused operating model. It is now independent of government. Members of the re-formed Council have been drawn from all the key constituencies and sectors and from all regions of the world. They will provide advocacy and challenge to governments and other stakeholders that can help to bring about the changes that are necessary to improve dementia prevention, diagnosis, care and support, raise awareness, reduce stigma and bring disease-modification and ultimately a cure closer. As well as having associate membership status on the Council, the UK government will also be one of a number of funders of the external independent Executive Team that now provides the WDC with strategic communications and engagement, and secretariat support.

New UK Dementia Envoy

- 5.11 The Prime Minister has appointed David Mayhew as the new **Dementia Envoy** for the UK, building on the excellent work of Dr. Dennis Gillings. As the new envoy, David will promote and support delivery of the 2020 Challenge for the UK, whilst ensuring that our expertise is shared and used to influence global change. He will work with other countries and leaders from around the world to realise the benefits of taking action together to promote innovation and support people with dementia and their carers.

A global Dementia Friendly Communities movement

- 5.12 The UK and Japan have a shared ambition to support countries around the world to become dementia friendly. The successful programmes in both countries, to promote Dementia Friendly Communities and Dementia Friends, have already been adopted in around 11 other countries and people with dementia in communities, large and small, are benefitting from the values and opportunities offered by these initiatives. We will work with Japan to learn from our respective programmes and to identify ways in which we can support more communities, including in low and middle income

countries, to introduce programmes of their own. The World Health Organization will provide technical assistance for this work. We will continue to work with international NGOs who are raising awareness and understanding through the Global Alzheimer's and Dementia Action Alliance. In addition, Japan is considering addressing healthy ageing in its G7 Presidency in 2016.

Dementia Research Institute

- 5.13 The Prime Minister announced in late 2015 that the first national **Dementia Research Institute (DRI)** in the UK is to be established. The DRI, which will bring together world leading expertise in discovery science in the fight against dementia, is set to receive up to £150m in Government funding and be fully functional by 2020. It will place the UK at the centre of a global effort to tackle the disease, accelerating the pace of research and developing much needed new treatments.

International Dementia Research

- 5.14 The UK is a key player in international dementia research, with the Medical Research Council (MRC) being a founder member of both the **Joint Programme in Neurodegenerative Disease (JPND)**, (encompassing 27 EU countries, Canada and Australia), and the **international Centres of Excellence in Neurodegeneration (COEN)** initiative. MRC led the development of the JPND's research strategy and will continue to promote and fund the involvement of the UK research community with these activities.
- 5.15 MRC has been working closely with OECD and other global players to develop a coordinated international approach to promote the use of big data in dementia research, as reported to the G7/WHO dementia summit in Geneva in March 2015. The **Dementias Platform UK (DPUK)** will continue to play a leading role in developing this activity further, building on the Memorandum of Understanding signed with the Canadian CCNA in 2015. Once functional, the new DRI will also have close connectivity to the big data agenda in relation to its mechanistic and target discovery work.

Dementia Discovery Fund

- 5.16 **The Dementia Discovery Fund (DDF)** is a ground breaking venture capital fund for dementia research. It aims to boost investment in dementia by bringing together investors from public, private and philanthropic sectors to identify, invest, and advance early stage (pre-clinical) drug development projects.
- 5.17 The Fund was publically announced in March 2015 at the WHO First Ministerial Conference on Global Action Against Dementia, with initial investors from some of the world's leading pharmaceutical companies, including Biogen, GSK, Johnson & Johnson, Lilly, Pfizer and Takeda, along with the UK government (with a £15 million commitment), and Alzheimer's Research UK (ARUK). In the first close, over \$100m was committed to the Fund.

- 5.18 On 21 October 2015, the Fund celebrated the formal launch with the global dementia community and announced the appointment of the fund manager SV Life Sciences.
- 5.19 SV Life Sciences has already funded the first asset through the DDF in the antibody discovery company "Alector LLC". Alector is an innovative pre-clinical company developing an immune-neurology approach to several dementia targets, including frontotemporal dementia, Parkinson's disease and ALS. The DDF is participating in a series of funding to allow progression of Alector's pre-clinical candidates towards (and ultimately into) clinical trials.
- 5.20 Further investment opportunities are being researched and negotiated by SV Life Sciences and it is anticipated that the DDF will fund two of these proposals in the first two quarters of 2016. Ultimately the DDF seeks a final close of £132m (\$200m) in the later stages of 2016.

Integrated development

- 5.21 The Department of Health considered recommendations made by Raj Long in her 2015 report on Integrated Development¹¹ and these are now being taken forward by Alzheimer's Research UK. Eleven regulators remain engaged in the ambition to achieve greater alignment of drug development within current regulatory pathways. Contact has been made with SV Life Sciences to explore the possibility of using the Dementia Discovery Fund to identify potential compounds for a more streamlined and co-ordinated process. There is also a good relationship with the Accelerated Access Review which has considered dementia as an exemplar during its work on how to speed up access for patients to new technologies and create a more attractive environment for investment in life sciences.

European Union Joint Action on Dementia

- 5.22 **The UK will lead a work package on Dementia Friendly Communities as part of the EU Joint Action on Dementia** that commenced in March 2016. The Scottish Government will lead the overarching Joint Action which is focused on improving post-diagnosis care and support for people with dementia throughout EU28. This will provide all EU Member States with clear, evidence-based and tested information and recommendations on how to effect change and improve support for people with dementia to live at home through the development of dementia friendly communities by March 2019.

¹¹ https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/451874/DH_DementiaReport_acc.pdf

International benchmarking on prevention, diagnosis, care and support

5.23 The Department of Health is providing a financial contribution to support the OECD's activities to map dementia policies and current national data collections related to prevention, diagnosis, care and support across OECD countries.

This will build towards the development of a common set of indicators which will allow OECD countries to benchmark their performance against that of their peers in future years, either quantitatively or qualitatively. Anticipated outputs include:

- an OECD publication comparing dementia care in OECD countries and setting out a roadmap for indicator development, with a final published version by the end of 2017; and
- the inclusion of indicators of the quality and outcomes of dementia care in future editions of the OECD's *Health at A Glance* publication, subject to a sufficient number of countries being able to collect comparable data.

How will we know that we have made a difference?

Commitment 1: An international dementia institute established in England.

Lead Organisation (and partners)	Action	Start date	What will success look like?
Medical Research Council (MRC) BIS (DH)	Up to £150m has been announced by Government to fund a national UK wide Dementia Research Institute. Development will be led by the MRC and will function on a hub and spoke model integrating sites across the UK. Research charities and other stakeholders will be involved in the development.	March 2016	The national Dementia Research Institute operational by 2020.

b) Risk Reduction

Dementia isn't an inevitable part of ageing

- 5.24 There is a growing body of evidence to suggest that it is possible to reduce an individual's risk of dementia, and that doing so would have great benefits to individuals and wider society. The **Blackfriars Consensus** (2014)¹² makes the case for concerted action to reduce people's risk of dementia by supporting them to live healthier lives and manage pre-existing conditions that increase their risk of dementia. The evidence suggests that smoking, excessive drinking, high blood pressure, lack of physical activity and diabetes all contribute to a higher risk of an individual getting dementia later in life.
- 5.25 Around a third of Alzheimer's disease cases worldwide might be attributable to potentially modifiable risk factors.¹³
- 5.26 People are more likely to live well in their older years if they live more healthily in earlier life, particularly during mid-life (40-65 years), though it is also never too late to benefit from changing unhealthy behaviours. The recently published **NICE guidance on mid-life approaches to delay or prevent the onset of dementia, disability and frailty in later life**¹⁴ sets out the case for promoting a healthy lifestyle to reduce the risk of or delay the onset of dementia. The guidelines also highlight that there is emerging evidence on the importance of psychosocial risk factors throughout life such as loneliness, isolation and depression. The recommendations within the guidelines make it clear that risk reduction is everyone's business.
- 5.27 As we work towards a cure for dementia, risk reduction to prevent the onset and the progression of dementia is crucial. Achieving these aims requires concerted action from a wide variety of organisations, collaboration and cooperation from the public, private and third sector and a national, regional and local level focus. It means incorporating dementia risk reduction and brain health promotion messages within other policy work streams for pre-disposing conditions, such as cardiovascular disease and diabetes. The benefits of such approaches and activities will be broad and wider than dementia, including helping to prevent cognitive decline in later life.
- 5.28 To further develop our understanding of dementia risk factors and to track the effectiveness of public health efforts, **national public health observatories** will be set up by public health agencies in England, Scotland, Wales and Northern Ireland to monitor and manage data on the prevalence, diagnosis and demography of the diseases that cause dementia.

¹² <https://www.gov.uk/government/news/call-for-new-policy-focus-on-brain-health-to-reduce-the-risk-of-dementia>

¹³ Norton, S., Matthews, F., Barnes, D., Yaffe, K., Brayne, C. Potential for primary prevention of Alzheimer's disease: an analysis of population-based data. *The Lancet: Neurology*. 2014,13:788-94

¹⁴ <https://www.nice.org.uk/guidance/ng16>

Progress since March 2015

5.29 In recognition of the importance and potential of dementia risk reduction, Public Health England (PHE) has identified dementia as one of its seven priority areas since 2014 with the ambition to reduce the incidence and prevalence of dementia amongst 65-74 year olds. Over the last 18 months there has been a considerable shift towards acceptance of the need to promote risk reduction amongst key partners in the system and PHE will continue to build on this momentum over the next few years, to further embed risk reduction approaches.

5.30 Over the last year, PHE and partners have made a number of achievements in relation to developing and implementing the risk reduction agenda:

- The UK was recognised for its leadership in driving the global risk reduction agenda at the March 2015 ministerial conference in Geneva. Over 90 countries signed up to a Call for Action which included dementia risk reduction.
- For the first time, we have available, in one place, a suite of healthy lifestyle dementia risk indicators on the Dementia Intelligence Network (DIN) This means that local authorities and Clinical Commissioning Groups can easily understand the level of risk in their local population, in addition to the coverage of diagnosis and treatment.
- Work has progressed to build on the Blackfriars Consensus and strengthen the evidence base for dementia risk reduction, and the recently published NICE guidance on mid-life approaches to delay or prevent the onset of dementia, disability and frailty in later life sets out the case for risk reduction approaches, based on underpinning evidence. Action on Smoking and Health (ASH) and PHE jointly published a factsheet setting out the links between smoking and dementia.
- There has been a continued focus on tackling inequalities in relation to dementia risk reduction. PHE published a literature review on the 'Prevalence of dementia in population groups by protected characteristics'¹⁵ and is currently piloting an Equity Profiling tool for Local Authorities, which was created by Wessex PHE Centre.
- Partnerships across the system have been strengthened both nationally and locally. The Wessex Dementia Timeline was launched at the Dementia Collaboration Event on 21 October 2015 showcasing collaborative work on dementia projects across clinical, community, education, research and social care boundaries.
- Dementia Awareness week communications were rated as the most engaging PHE social media communications in May 2015. We now have available a 'Reducing your risk of dementia' booklet for the public, jointly published by Alzheimer's Research UK and PHE.
- MRC and the Wellcome Trust have invested £34m in UK Biobank to undertake an imaging study on 100,000 of its participants, which in combination with genetic, cognitive, clinical history and lifestyle data, will provide the world's largest dataset to help elucidate the risk factors that impact upon the development of dementia.

¹⁵ <https://www.gov.uk/government/publications/dementia-prevalence-in-groups-by-protected-characteristics>

- The Dementia Awareness raising component of the NHS Health Check has now been running for two years. A revised leaflet has been published and further work is underway to evaluate its effectiveness and, where necessary, refine it.

Key Priorities

5.31 Three distinct delivery priorities were established to inform the work programme and actions based on consultation with our stakeholders,¹⁶ namely:

- Raising awareness on reducing the risk of onset and progression.
- Building on and promoting the evidence base for dementia risk reduction and health inequalities.
- Enhancing the dementia component of the NHS Health Check.

5.32 These priorities then directly informed the risk reduction Implementation Plan and the impact measures, led by PHE in consultation with partner organisations. For a breakdown of the specific activity for each of the risk reduction aspirations in the 2020 Challenge please see **Annex 2**.

Raising Awareness

5.33 Raising public awareness of how healthy lifestyle choices can reduce personal risk of developing dementia is a priority.

5.34 **The NHS Health Check includes a mandatory dementia awareness raising component for people over the age of 65** and PHE will evaluate this component to explore the drivers for behaviour change and the programme's effectiveness in raising dementia awareness.

5.35 Alzheimer's Society, Alzheimer's Research UK, Health Education England and PHE will review the training materials available for the dementia awareness raising component of the NHS Health Check Programme. Revised training materials and a refreshed dementia awareness leaflet have been published to support a training and education programme for health and care professionals.

5.36 Building on the recent NICE Guidance on mid-life approaches to preventing frailty, disability and dementia, Public Health England is continuing to enhance the evidence base on the impact of delivering dementia awareness via the NHS Health Check. The case for expanding the dementia current awareness raising component was presented to the Expert Scientific and Clinical Advisory Panel (ESCAP) in November 2015, as part of the content review process.

¹⁶ Alzheimer's Society, Alzheimer's Research UK, Age UK, Alzheimer's Disease International, Housing and Dementia Research organisation, PHE centres and national teams, local authorities, NHS trusts, GPs, CCGs and SCNs and carers of people with dementia.

- 5.37 **PHE will work with the leading dementia charities and up to three pilot sites during 2016/17 to test and evaluate approaches to incorporating dementia awareness and risk reduction messages within NHS Health Checks for people under 65 years.** Further research will also be commissioned and the findings considered by ESCAP. PHE will identify opportunities to embed risk reduction within its wider workstreams and incorporate the NICE guidance into the work of partner organisations, raising the profile of brain health alongside heart health.
- 5.38 **Social marketing and public communications** will play a key role in raising public awareness of dementia risk reduction and mid-life approaches to healthy lifestyle. **PHE will launch a major social marketing campaign in Spring 2016 to promote healthy lifestyles for 40-60 year olds. PHE's 'One You' campaign** will not focus specifically on dementia, but will incorporate key messages around healthy lifestyle that are relevant for dementia risk reduction. Local dementia partnerships will use the branding of One You to develop tailored local campaigns and promotional material.
- 5.39 PHE is working with University College Partners to develop **a personalised brain age calculator** which will enable individuals to understand their personal risk of cognitive decline, based on lifestyle factors. The brain age calculator will complement the recently published heart age tool, which is available on NHS Choices, along with the One You Campaign products and NHS Health Check.
- 5.40 PHE will continue to work with Health Education England and training providers to ensure that **risk reduction messages form a core part of dementia awareness raising training.**
- 5.41 **Alzheimer's Society and PHE will explore opportunities for embedding risk reduction messages** across the Dementia Friends programme and how the role of Dementia Friends Champions can be strengthened to promote risk reduction across different settings.
- 5.42 **PHE will continue its work to make dementia an integral part of routine healthy lifestyle and behaviour change conversations.** For example, we have embedded dementia risk reduction into the work to upskill health professionals, including the clinical champions training programme and promotion of the Chief Medical Officers' recent infographic on the Health Benefits of Physical Activity for Adults. We will also engage employers through development of a dementia topic guide linked to the Workplace Wellbeing Charter in place across most local authorities.

Enhancing the data and evidence

- 5.43 **The Dementia Intelligence Network (DIN)'s dementia fingertips tool**¹⁷ brings together for the first time dementia indicators right the way across the pathway. This is a powerful tool that gives commissioners in local authorities and CCGs major opportunities to improve the delivery of dementia and dementia healthcare in their area. Public Health England will continue to develop and enhance the DIN, in collaboration with NHS England and the Health and Social Care Information Centre. A series of intelligence data briefings will be published in the next few years, with particular focus on dementia inequalities.
- 5.44 **A Return on Investment tool** will be made available along with a Joint Strategic Needs Assessment commissioning resource for dementia, which will support commissioning. Led by PHE, these tools will be signposted through DIN, helping local authorities to access key dementia material, tools and resources.
- 5.45 PHE, alongside Alzheimer's Research UK (ARUK) will build on the Blackfriars Consensus by providing leadership in influencing further research into dementia risk reduction. Researchers and funders will be brought together to identify collaborative solutions for building and promoting the evidence base for dementia risk reduction. PHE will work with ARUK and other charity partners to develop a prevention fund which will be used to invest in further risk reduction research.

Reducing dementia inequalities

- 5.46 **Reducing health inequalities** is an important priority and one that applies to all themes of the 2020 Challenge. We know there is local variation in dementia care, support and access. However variation is not limited to geography and variation needs to be tackled across age, gender, ethnicity as well as wider determinants of health such as multiple deprivation and rural communities. We are committed to address this by:
- NHS England and PHE establishing a working group to advise on the support of people with dementia from a variety of communities, (for example those with learning difficulties, black and minority ethnic groups, or who may fall within one or more of the protected characteristic categories).
 - Ensuring health equity considerations are woven across all programmes of work, with health equity assessments undertaken, where appropriate, to improve programme outcomes. We support the aspirations within the *Race Against Dementia Call to Action*,¹⁸ and will work with partner organisations to ensure equality considerations are embedded within all of our work.
 - Working with NHS England through the Prevention of Diabetes, CVD and blood pressure programmes, PHE will identify opportunities for raising awareness of dementia risk reduction amongst those that have pre-disposing conditions that are at higher risk of getting dementia.

¹⁷ <http://fingertips.phe.org.uk/profile-group/mental-health/profile/dementia>

¹⁸ <http://www.raceagainstdementia.com/>

- PHE (working with HSCIC and NHS England) to improve the quality of data available through the DIN on protected characteristics. **Access to ethnicity data** will be a priority area of focus over the next year. The DIN will publish a series of data briefings, with dementia inequalities being a key area of focus throughout.
- ARUK and PHE will work to stimulate the research agenda, ensuring that health inequalities are, where appropriate, a key component of all risk reduction research. We will work with Alzheimer's Society and third sector partners to ensure that inequalities are addressed in all research and evaluation into health and social care interventions.
- Health Education England are commissioning a film that focuses on the specific needs of the African Caribbean community within the care process – to be made available free of charge to health and social care providers.
- CQC is building partnerships with national organisations and engaging with community groups to increase access to the experiences of people with dementia. CQC have promoted inspections to local dementia groups to get feedback about services, and will continue to explore ways of hearing from a range of people living with dementia, encouraging contributions from local dementia groups, volunteers and carers. CQC is expanding its Experts by Experience programme, which includes people in the early stages of dementia and family carers of people with dementia.
- Working with Skills for Care, to develop a resource to support the social care workforce that is working with people with dementia from different cultures and backgrounds. The resource will focus on supporting people to obtain a diagnosis and to seek post-diagnosis support. It will be disseminated via Skills for Care's networks with social care providers and through six regional workshops.

How will we know that we have made a difference?

Commitment 2: Improved public awareness and understanding of the factors which increase the risk of developing dementia and how people can reduce their risk by living more healthily. This should include a new healthy ageing campaign and access to tools such as a personalised risk assessment calculator as part of the NHS Health Check.

Lead Organisation (and partners)	Action	Start date	What will success look like?
Public Health England (PHE) (ADASS, NHSE, HEE, SfC, ARUK, Alzheimer's Society)	Raise awareness of actions the public can take to reduce their risk of dementia and protect their brain health, through NHS Health Checks, social marketing and communications and provision of tools and resources for the public. Supported by local authorities via their local public health initiatives/teams and delivered internally to staff and to other local partners.	March 2016	By 2020 people at risk of dementia and their families/ carers will have a clear idea about why they are at risk, how they can best reduce their risk of dementia and have the knowledge and know-how to get the support they need.
	Alongside Health Education England, Skills for Care and Alzheimer's Society, raise professional awareness of dementia risk reduction through training and education of health and care professionals, and through enhancing the role of Dementia Friends Champions as part of the Dementia Friends initiative.	April 2016	
	Enhance the evidence and data for dementia risk reduction through the provision of evidence based tools, data and guidance on the Dementia Intelligence Network portal (DIN). ADASS and Skills for Care will promote use of information contained in the DIN through their extensive national and local partnerships.	January 2016	This will contribute towards the national ambition of reduced prevalence and incidence of dementia amongst 65-74 year olds, along with delaying the progression of dementia amongst those that have been diagnosed.
	Alongside ARUK, provide leadership in bringing together researchers and funders to identify collaborative solutions for building and promoting the evidence base for dementia risk reduction and healthy brain ageing.	February 2016	
	Reduce health inequalities, and target population groups who are at high risk of dementia. Provide support for those at high risk through focus on health equity across all programmes. Provide analysis and dissemination of intelligence, research and data.	Ongoing	

c) Health and Care

We want England to be recognised as the best country in the world for dementia care and support

- 5.47 The key aspirations of the 2020 Challenge are to improve quality and levels of care, so that England is recognised as the best country in the world for dementia care and support.
- 5.48 Our vision is to create a society by 2020 where **every person with dementia, their families and carers** – whatever their background, geographical location, age, gender, sexual orientation, ability or ethnicity – **receive high quality, compassionate and culturally competent care**. This is from diagnosis through to end of life care, and in all care settings whether at home, in hospital or in a nursing/care home. We want the best services and innovation currently delivered in only some parts of the country to be available nationwide, so there is more consistency of access, care and less variation.
- 5.49 We want the person with dementia – with their carer and family – to be at the heart of everything we do. We want their wellbeing and quality of life to be first and foremost in the minds of those commissioning and providing services, recognising that each person with dementia and their carer is an individual with specific and often differing needs including co-morbidities.

Progress since March 2015

- 5.50 There has been good progress across a number of areas:
- **NHS England has achieved the aim of increasing the proportion of people with dementia who are able to get a formal diagnosis from under half, to at least two-thirds of people affected.**¹⁹ However, we need to maintain this minimum level over time and address the underlying variation between CCGs in diagnosis rates and availability of post-diagnosis support.
 - NHS England, working with all key stakeholders, has implemented incentives and initiatives in primary/community and secondary care services in order to promote more timely and accurate diagnosis, improve knowledge and understanding of dementia amongst non-specialist staff as well as adapting the hospital environment to provide better support. Good progress has been made with support from the Strategic Clinical Networks to ensure that person-centred care planning is nationally consistent and completed to a high standard. NHS England has been working to support carers by promoting the adoption of John's Campaign²⁰ which advocates the right for carers to stay with the person with dementia in hospital.

¹⁹ The dementia diagnosis rate as of the end of January 2016 was 67.2%, meaning NHS England has achieved the national ambition.

²⁰ <http://johnscampaign.org.uk/#/>

- In January 2016, CQC launched a consultation on a new strategy for the next five years. This looks at how CQC might develop methods to assess quality for populations and across local areas. Whilst the current provider-based approach to inspection will continue to be necessary, more can be done to encourage improvements in people's experiences of care by looking at how organisations work together to coordinate care to better meet people's needs. CQC will develop and test approaches to assessing how well services are meeting the needs of particular population groups – this could include people living with dementia.
- The Care Act 2014 is now embedded in local authorities, meaning clear national consistency in how care and support is delivered. All service users and carers now have the right to a social care assessment and if eligible a personal budget, which gives choice and control over how services are provided. People with dementia and their carers can choose to have a combined health and care assessment if they so wish.
- We know that many people with dementia want to live at home for as long as possible, and homecare is absolutely vital to supporting them in being able to do this. As part of the 2012 to 2015 PM Dementia Challenge, a report on Dementia and Care at home was launched. '*Dementia & Homecare: Driving Quality & Innovation*'²¹ provides clear recommendations and practical ideas and suggestions to further dementia care in the community. Driving improvements in homecare will not only help ensure people stay independent for longer but will also support our ambition for people to receive meaningful care following a diagnosis of dementia.
- Building on the OECD dementia framework, NHS England has developed a draft treatment and care pathway, the 'Well Pathway for Dementia'.

Key Priorities

5.51 This Implementation Plan sets out the activity required to support the 'well pathway' for people with dementia so that by 2020 they have a better experience of health and social care support from diagnosis through to end of life. The 'well pathway' sets an overarching framework to align and co-ordinate the contribution of health and social care partners to meet our key commitments on:

- Improving diagnosis
- Support and care after diagnosis
- Enabling people to live well in their own homes for longer
- End of life care
- Education training and workforce

²¹ <http://www.ukhca.co.uk/downloads.aspx?ID=488>

- 5.52 The Mandate to NHS England underlines an ongoing focus towards delivering the 2020 Challenge within health and care. A key deliverable for 2016/17 is for NHS England to “agree an affordable implementation plan for the Prime Minister’s Challenge on Dementia 2020, including to improve the quality of post-diagnosis treatment and support”.

Diagnosing well

- 5.53 We recognise that efforts to increase the dementia diagnosis rate are taking effect, with a **67.2% national dementia diagnosis rate as of January 2016** (achieving the two thirds ambition). Through the NHS Mandate and the CCG Planning Guidance, there is a commitment to maintain the diagnosis rate to at least this level and through transparency of data and support where needed, NHS England and other arms-length bodies are working to reduce local variation between CCGs in rates of diagnosis and availability of post diagnosis support. There is also variation in the length of time taken to have the diagnosis confirmed. The Mandate to NHS England reflects the ambition that (by 2020) we will “increase the numbers of people receiving a dementia diagnosis within six weeks of a GP referral”.
- 5.54 Timely diagnosis unlocks the door to appropriate care and treatment and personalised care plans should be integrated and used across the whole health, social care and community economy to ensure that all organisations understand the needs of the person with dementia, including recognising co-morbidities and their potential impact. This will help drive the personalisation agenda across health and care, ensuring that patients, families and carers are at the centre of their care and have a choice of what services and support they wish to receive to meet their needs and outcomes. This applies wherever people are resident, including people who may have been in care homes for some time and where a formal diagnosis of dementia may not have been made. Reports suggest that around 80% of people in care homes have dementia. A diagnosis of dementia in residents of care homes, where clinically appropriate, is essential to ensure high quality post-diagnosis support and care planning.

Supporting Well (including support for carers of people with dementia)

- 5.55 Stakeholder feedback that informed this Implementation Plan emphasised the importance of support following diagnosis for people with dementia and their carers. We heard a consistent message from people who reported that on receiving their diagnosis, they faced a bewildering future and felt alone in facing this. People with dementia and carers told us of their urgent need for information, advice and support both immediately after diagnosis and to help them throughout the stages of their journey with dementia.

Ensuring that people with dementia receive “meaningful care”

5.56 By 2018 and towards 2020 we will take a series of actions to focus the health and care system towards providing person-centred and meaningful post-diagnosis support, which meets the needs of people affected by dementia:

- The Department of Health will publish and promote **a joint declaration on post-diagnostic dementia care and support**.²² This commitment between Government, health, social care, the third sector and other relevant parties to deliver better quality post-diagnostic care is a truly collaborative approach to improving dementia care. The Department of Health will work with all signatories during the life of this Implementation Plan to ensure concrete action, nationally and locally supports this commitment.
- In 2016, the Department of Health will work with a national partner organisation to roll out the declaration locally, to ensure that each area puts in place a local joint action plan between health and care and to monitor the depth of these plans and their implementation.
- In addition, there is an important role for the Dementia Action Alliance (DAA) in supporting the implementation of key areas of the 2020 Challenge in relation to health and care. The DAA's specific contribution is being agreed as part of ongoing discussions with its Board and members, including people with dementia and carers.

5.57 The Department of Health will commission a number of projects under the ‘Supporting Well’ pathway, this will build on work that is already underway which includes:

- Work with National Museums Liverpool to develop a dementia training programme for family carers and community volunteers in four regions across England. The new training programme will build on National Museums Liverpool's successful ‘House of Memories’ training day for staff working in the health, social care and housing sectors, in order to enable greater community understanding of the different ways of working with and supporting people with dementia.
- Leeds Beckett University and the TIDE network of family carers, will lead a project to develop a training programme designed to meet the educational needs of carers of people with dementia following a diagnosis. The training programme will provide participants with the knowledge, skills and psychological resources they need to enable them to live well with dementia, to know where and when to access resources and support and for carers to know how to ensure they remain well themselves throughout the caring journey.
- The Dementia Innovation Hub, based at Newcastle University, will develop an evidence-based online course for carers of people with dementia, aimed particularly at working and/or remote family carers. The project will also deliver training for carers and employers, with a particular focus on small and medium-sized enterprises, to support carers to remain in the workplace.

²² <https://www.gov.uk/government/publications/dementia-post-diagnostic-care-and-support>

- Commissioners in both health and social care need support to improve their awareness of effective practice in the provision of post diagnostic care and support. We are looking to build on the existing infrastructure of the SCIE Dementia Gateway so it becomes a central collection of published material, case histories, tools and other practical resources. Bringing all relevant information together on post-diagnostic dementia care and support enables commissioners and other health and social care professionals to rapidly evaluate what works best for them based on evidence and evaluation.

5.58 There is published evidence²³ showing that both signposting through a dementia advisor or equivalent and support for carers can have a positive impact in reducing or delaying people diagnosed with dementia entering residential care.

- The Department of Health will publish and promote the findings of a survey to better understand how local health and care systems are providing this type of service, (particularly through joint commissioning) during 2016. The Greater Manchester 'Dementia United'²⁴ programme will further build on existing provision by testing link worker models across the region.
- To complement this, system partners including the Department of Health and NHS England will build on the findings of the above survey and the emerging evidence from the Greater Manchester "Dementia United" programme by working together to understand the number of people who are supported by a dementia adviser or similar outreach service relative to the need in each local area.

²³ <https://www.gov.uk/government/publications/peer-support-networks-and-dementia-advisers-evaluation>

²⁴ <http://dementiaunited.net/>

Case Study: Dementia personal assistants (Walsall)

Building on the lessons learned from the provision of dementia advisers and dementia support workers in the area, Walsall CCG has developed the Personal Assistant – Dementia role (PAD).

Since their launch in October 2015, there are six PADs in Walsall, with one specialising in working age dementia and learning disabilities. Referrals come from all parts of the system where a person can receive a diagnosis of dementia, for example via the memory assessment service, the learning disabilities service (there is a learning disability dementia specialist nurse in Walsall), via the acute hospital's older people mental health liaison team, or GPs.

The PADs work with people for up to three months immediately from diagnosis offering information, support and advice, as well as signposting to other forms of longer term support in the area. The person with dementia and their carer have full control over how they are supported, the only thing a PAD doesn't do is personal care. Their role can be varied from supporting colleagues in promoting and encouraging best practice in dementia care, as well as directly encouraging the use of memory aids & assistive technology to reduce risk and promoting independence and making every effort to equip the person diagnosed with dementia and their carers to manage 'their dementia' as well as possible.

They also encourage people with dementia to visit their GP where long term conditions are not being managed effectively and emphasise the importance of good nutrition, hydration and exercise. Planning for the future is an important part of the role to encourage people to plan whilst they still have capacity for example, wills, advanced decisions and any information considered appropriate by the Walsall-wide end of life group for dementia.

The PADs also support carers, and Walsall has a dedicated carer's team and eight dementia cafés to support carers – with one of the cafes being housed in the acute hospital.

5.59 The Department of Health, NHS England, Local Authorities, ADASS and the LGA are committed to demonstrating system leadership across health and care, delivering more consistent access to personalised support.

- From April 2016, the Department of Health and NHS England will build on existing governance structures to make progress on meaningful care for people with dementia, focusing on post-diagnosis support, and involving a wide range of organisations.

5.60 ADASS will encourage its members to:

- Ensure all people with dementia and their carers will receive a social care assessment, and if eligible for funding will receive a personal budget. If not eligible for state funding, people will still receive information and advice and appropriate signposting to services and as a minimum support to navigate the social care system.

- Work in partnership to develop integrated care in the community and to work towards joint health and social care support planning and the development of joint health and social care personal budgets.
 - Provide appropriate signposting to dementia information and advice and local services including community services that can provide alternative support.
 - Ensure their regions are dementia and carer-friendly workplaces.
- 5.61 All parts of the system need to come together to deliver support, but clearly primary care is at the forefront, particularly as people with dementia often have other long term conditions and need additional support to manage these. The NHS Planning Guidance²⁵ sets out the commitment to improve access to primary care at weekends and evenings. Enabling access to out of hours care by achieving better integration and redesign of 111, minor injuries units, urgent care centres and GP out of hours services will enhance the patient offer and reduce unnecessary or inappropriate visits to hospital.
- 5.62 **The Better Care Fund (BCF)** announced in June 2013, is the biggest ever financial incentive for the integration of health and social care. In 2015/16 it required the NHS and local authorities in England to create pooled budgets, resulting in £3.8bn of mandatory pooled health and social care budgets nationally. Local leaders and clinical experts have worked together to plan how local pooled budgets should be used to commission joined-up services that better fit the needs of their local population.
- 5.63 The key impetus for integration is providing care in the best setting for those with complex needs and multiple conditions. Dementia clearly falls into these categories, and people with dementia are a priority for the improvements to care that the BCF is designed to deliver.
- 5.64 Building on the BCF, the 2015 Spending Review and Autumn statement²⁶ prioritised the integration of the National Health Service and social care, spending £120 billion a year by 2020-21 to create a 7 day NHS and introducing a new social care precept. The Department of Health will ensure that dementia care is prioritised within this policy, resulting in factors such as integrated discharge planning, single assessments and care plans, and integrated community support teams becoming the norm for dementia care and support. Emerging evidence from the Department of Health commissioned survey of dementia advisors shows that integrated commissioning is a feature in a number of areas.

²⁵ <https://www.england.nhs.uk/wp-content/uploads/2015/12/planning-guid-16-17-20-21.pdf>

²⁶ <https://www.gov.uk/government/publications/spending-review-and-autumn-statement-2015-documents/spending-review-and-autumn-statement-2015>

Case Studies: Integrated Care

1) Leeds Eldercare Facilitators (via BCF plans)

The Eldercare Facilitator role will be mainly post-diagnosis: to befriend and build trust; support people to come to terms with living with dementia and what this means for each person; to inform and connect people and carers reliably and consistently to post-diagnosis support. Local evaluation has shown failures to link people to the range of support and services available in Leeds.

The Eldercare Facilitator will support self-management plans and case management interventions, a resource to support the capacity of primary care and help implement interventions. There will therefore be more capacity for practices to stay in touch with people and monitor situations, rather than people 'falling off the radar' until an emergency happens.

2) Whitstable Medical Practice Vanguard Multispecialty Community Providers – moving specialist care out of hospitals into the community

The Vanguard for Whitstable in Kent is made up of the Whitstable Medical Practice, Northgate Medical Practice and the Saddleton Road & Seasalter Surgeries. They will be working in partnership with local health, care and support organisations including Canterbury & Coastal CCG, Kent County Council, East Kent Hospital University Foundation Trust, Kent Community Health Trust, Kent Partnership Trust, Alzheimer's Society and Age UK.

Patients, including older people with dementia living in residential care, will see the benefits of the new model of care through better trained care workers looking after them each day.

These care workers will have learnt in a new setting, alongside colleagues from other disciplines and with access to new technology. This will result in a team looking after the patient that has better insight into dementia and specialist input from a geriatrician with expert knowledge of the condition.

The patient and their family will feel fully involved in all decisions about their care plan, and will be able to set goals and personalised outcomes for their care and support.

Mental Health and Wellbeing

- 5.65 Dementia is more prevalent in older people, and this can often be accompanied by other health issues, including mental health conditions such as depression. Recognising the links between dementia and other programmes of work is key, particularly those focused on mental health. NHS England is committed to treating mental health and physical health as equally important, ensuring that mental and physical health have parity of esteem within the NHS.

- 5.66 The Improving Access to Psychological Therapies (IAPT) programme began in 2008 and has transformed the treatment of adult anxiety disorders and depression in England. People with dementia and their carers can often be affected by depression and/or loneliness so the IAPT programme has an important role to play in helping people get access to the help they need to tackle this. IAPT for older people is a particular focus over the coming year.
- 5.67 The independent Mental Health Taskforce²⁷ reported in February 2016, setting out transformative plans for mental health, including for IAPT. Additional funding will enable NHS England to put in place a five year plan to improve IAPT services across the country, increasing access to evidence-based psychological therapies to reach 25% of need, and helping 600,000 more people to access care each year by 2020 with a focus on people living with long-term physical health conditions and supporting people into employment.

Mental Capacity

- 5.68 Individuals with dementia who may lack the mental capacity to make their own decisions have their rights enshrined in the **Mental Capacity Act 2005 (MCA)**. The MCA makes clear that individuals should not be assumed to lack capacity unless assessed otherwise and that they should be supported to make their own decisions and have the right – as all adults do – to make their own lifestyle decisions, even if these appear “unwise”. Awareness of the MCA among the public and professionals is less than adequate. As such the Government has launched the National Mental Capacity Forum chaired by Baroness Ilora Finlay to advocate nationally for the importance of this fundamental Act and to encourage and spread front-line best practice.
- 5.69 The MCA also contains safeguards to ensure that individuals with dementia, who may lack the mental capacity to consent to accommodation that might amount to a “deprivation of liberty”, have their care reviewed to ensure the restrictions are proportionate and in the best interests of the individual. This system is known as the Deprivation of Liberty Safeguards (DoLS). Use of DoLS has increased ten-fold since a judgment in the Supreme Court in March 2014. The Government has issued guidance, cut red-tape and provided additional funding in 2015/16. We have asked the independent Law Commission to review the legislation underpinning DoLS to determine if legislative change could reduce the bureaucracy on the health and care system while providing tangible benefits for individuals. The Law Commission’s broad proposals are expected in April 2016, with full proposals by end December 2016.

Hospital care

- 5.70 It is estimated that at least one quarter of acute hospital beds are occupied by people with dementia, many of whom would not need to be there were it not for their dementia. We will continue to work with NHS England, CQC and partners to ensure that hospitals are dementia friendly. Building on the Dementia Action Alliance 2013

²⁷ <https://www.england.nhs.uk/wp-content/uploads/2016/02/Mental-Health-Taskforce-FYFV-final.pdf>

Hospital Care Call to Action,²⁸ we will continue to promote good practice in hospital care.

5.71 Older people with dementia in A&E departments or who are admitted to hospital, need **access to specialist mental health liaison services**. As part of the Mental Health Taskforce Report,²⁹ it has been recommended that NHS England should ensure that:

- People being supported in specialist older-age acute physical health services have access to liaison mental health teams – including expertise in psychiatry of older adults – as part of their package of care; and
- By 2020/21 no acute hospital should be without all-age mental health liaison services in emergency departments and in-patient wards.

5.72 ADASS will encourage its members to:

- Work in partnership with system-wide partners to facilitate timely and safe discharges from hospital back into the community to reduce delayed transfers of care.

Case Study: Dementia Friendly Hospitals

To improve the experience of people with dementia and their carers in hospital, Leicester Royal Infirmary employs Alzheimer's Society Dementia Support Workers to provide practical and emotional support for people with dementia and their families and carers before, during and following a stay in hospital. The support workers talk through any concerns that people with dementia and carers may have and provide tailored information and guidance on how to live well with dementia. They liaise with hospital staff so that they understand an individual's needs and are better able to care for them. They help patients and carers to understand the hospital process, for example which staff members they might be in contact with or the hospital discharge process, and provide details of local support services available in the community when patients leave hospital. This vastly improves the quality of someone's stay and ensures they are well supported in the community once they leave, helping prevent avoidable readmissions to hospital in the future.

Living well

5.73 The NHS Five Year Forward View states that 'almost 500,000 unpaid carers look after people living with dementia'. The contribution that carers bring to society is well-established, and supporting the carer ensures that they can continue in their caring role. Providing carer support has been shown to improve outcomes and be cost-effective. We will explore new ways to train and support carers so that they feel better equipped and more confident in looking after someone with dementia, building on the NHS England Commitment to Carers³⁰ and new rights created by the Care Act 2014, and especially helping the most vulnerable amongst them – the approximately 225,000

²⁸ http://www.dementiaaction.org.uk/joint_work/dementia_friendly_hospitals

²⁹ Five Year Forward View for Mental Health in England – February 2016.

³⁰ <https://www.england.nhs.uk/ourwork/pe/commitment-to-carers/>

young carers and the 110,000 carers who are themselves aged over 85. The Department of Health will also publish its new Carers Strategy in 2016/17, setting out the national vision for ensuring carers are supported both in their caring roles and in living fulfilling lives.

- 5.74 CQC will continue to work with the Department of Health and partners on carers issues. Through a partnership with Mumsnet and Gransnet, CQC are reaching hundreds of thousands of family carers and older women who may care for someone with dementia or be in the early stages of dementia. This valuable information informs CQC's regulatory activities.
- 5.75 CQC will continue to develop the CQC Insight,³¹ and improve, wherever possible, the quality and quantity of data obtained about people living with dementia who use registered services. This will also help to inform regulatory activities.

Housing

- 5.76 People living with dementia should be supported to live independently in their own homes for as long as they are comfortable and safe to do so. Often, this will require considering adapting accommodation or exploring housing options as well as social care support to preserve independent living for as long as possible. There are many innovative programmes occurring around the country aimed at keeping people independent and mentally and physically active, and we will continue to support and promote best practice.
- 5.77 The recent spending review announced an increase to the budget of the Disabled Facilities Grant by 2019. The increase provides an opportunity to review current practice, local implementation and national policy responsibility. Exploring options for supporting people with dementia (such as assistive technologies) through the grant will be factored into the overall review.
- 5.78 We continue to support the Health and Housing Memorandum of Understanding³² in particular the specific workstreams around integrated pathways to dementia and equipping the workforce with training to facilitate integrated delivery.
- 5.79 The Department of Health will:
- work with the Dementia and Housing working group to raise the profile of housing, highlight and promote good practice, and further the integration of housing in health and social care policy on the issue of dementia;

³¹ 'CQC Insight', is a comprehensive surveillance model that combines numerical data with feedback from service users.

³² http://www.housinglin.org.uk/library/Resources/Housing/Support_materials/Other_reports_and_guidance/A_Memorandum_of_Understanding_MoU_to_support_joint_action_on_improving_health_through_the_home.pdf

- work with Sitra, the Association for Dementia Studies at the University of Worcester and the Housing Learning and Improvement Network to deliver specialised training for staff working in the housing sector on working with people with dementia. The project will build on work initially piloted in the West Midlands in early 2014, supported by the Department for Communities and Local Government.
- work closely with the Life Story Network to focus on older people and people with dementia who live in social housing to ensure they are supported to live in their homes for longer with a greater focus on independent living, avoiding costly crisis care and emergency admission to hospital as well as delaying admission to residential care.

5.80 More widely, Healthy New Towns is a new initiative between NHS England and Public Health England, to put health at the heart of new neighbourhoods and towns across the country, to build new communities that support social cohesion, physical and mental wellbeing across all age groups. Building strong communities and healthy places to live is a key component of the NHS's Five Year Forward View. Good urban and housing design promotes healthy lifestyles and can help prevent illness. It can also keep older people independent and healthy, supported by the latest technology to live in their own homes rather than in care homes. New developments also give us the opportunity to radically reshape health and care services, testing what can be achieved with fewer legacy constraints. The first ten sites have been announced covering more than 76,000 new homes with potential capacity for approximately 170,000 residents.

5.81 Options to be tested at some of these sites include designing safe and appealing green spaces, building dementia-friendly streets and ensuring people can access new GP services using digital technology. At least two of the sites will have a focus on care, for example, Whitehill and Bordon, Hampshire, will have 3,350 new homes on a former army barracks. A new care campus will co-locate 'care-ready homes' specially designed to be adaptable to the needs of people with long term conditions with a nurse-led treatment centre, pharmacy and integrated care hub. In Darlington there will be 2,500 residential units across three linked sites in the Eastern Growth Zone. Darlington is developing a 'virtual care home' offer where a group of homes with shared facilities are configured to link directly into a digital care hub, avoiding institutionalisation in nursing homes. Healthy New Towns will work towards building communities in which more older people live independently and safely in their own homes, backed by better technology and social support.³³

Taking steps to unlock the role of technology

5.82 For people with dementia, **technology and assistive technology** offers huge potential benefits. Technology and assistive technology can enable people to live independently for longer and can potentially enhance the quality of life for people with dementia, their families and carers. Whether it is a familiar gadget such as a mobile phone or TV or a specific piece of technology to remind someone to take medication, opportunities are numerous.

³³ <https://www.england.nhs.uk/2016/03/healthy-new-towns/>

5.83 The Department of Health will:

- work with the Social Care Institute of Excellence (SCIE) to develop a simple to use design tool that allows people to adapt their own home environment to be more dementia friendly by creating a proxy of their own living space and identifying where there is scope for improving the environment by changing fixtures, fittings, colourways, furniture positions, as well as highlighting where the provision of more specialist equipment would be beneficial.

5.84 The OECD indicates that technology has the potential to transform dementia care, improve the lives of people with dementia and reduce strain on carers but progress to date has been limited. If this potential is to be unlocked, the OECD identifies that developments must be more user-focused, and that there needs to be more robust evaluation.

5.85 To that end the Department of Health, with partners will:

- explore opportunities to both increase uptake of already available technology and assistive technology and ensure any future developments in this field are people and care focused.

5.86 The development of new technology offers the opportunity to significantly improve services and information provision for people living with dementia and their carers. Over the course of the Implementation Plan period the Department of Health, NHS England, the LGA and other public bodies will work in partnership with businesses and charities to encourage the development of technological innovation in dementia care and information provision and will explore ways to stimulate this through, for example offering challenge prizes. Alzheimer's Society will support the development of technological innovation through its research grants and will develop its online information offer including Dementia Connect to ensure people living with dementia and their carers can access information and support.

Case Studies: Technology

NHS Innovation 'Test Beds'

NHS England announced in January the first wave of NHS Innovation 'Test Beds'.³⁴ Through collaboration between the NHS and innovators the aim of these test beds is to harness technology to address some of the most complex issues facing patients and the health service.

To help people with dementia to live in their own homes for longer, Surrey and Borders Partnership NHS Foundation Trust is working in partnership with an array of health technology providers. The test bed will provide individuals and their carers with sensors, wearables, monitors and other devices comprising an 'Internet of Things' to monitor their health at home. This will empower people to take more control over their own health and wellbeing, as well as enabling health and social care staff to deliver more responsive and effective services.

The Test Beds are part of IoTUK, an integrated £40 million, three-year Government programme designed to increase the adoption of high quality Internet of Things technologies and services throughout businesses and the public sector.

Technology Airedale NHS Foundation Trust – Enhanced health in care homes – offering older people better, joined up health, care and rehabilitation services

The Airedale Partners' Vanguard objective is to enhance the quality of life, and end of life experience of thousands of nursing and care home residents living in Bradford, Airedale, Wharfedale, Craven and East Lancashire. The Vanguard application was made in partnership with a number of organisations including CCGs and their member practices, NHS providers, care home providers, social services and the third sector, technology partners and academic partners including the University of Bradford have also supported the bid.

The partners have a track record of innovative enhanced care delivery for this group of vulnerable, frail elderly people, many with multiple long term conditions including dementia and often approaching end of life. By using enabling technologies, such as telemedicine, the Gold Line and Intermediate Care Hub, nursing and care home residents and their carers are already benefitting from being able to access expert advice and support remotely 24/7.

Through the Vanguard programme, partners intend to go further and develop a more proactive health and social care enabling model focusing on optimising residents' individual capabilities and building new clinical models of care. This model will be enabled through technology and an extended use of telemedicine providing a single point of access to all aspects of specialist health and care advice.

In addition, the enhanced care model provides links to social care to complete a falls prevention assessment of the layout of the patient's room, and a multidisciplinary team including carers, nurses, therapists, social care and the voluntary sector work in partnership to deliver care and support, promoting independence and improving quality of life.

³⁴ <https://www.england.nhs.uk/2016/01/embracing-innovation/>

Dying well

- 5.87 **Dementia and the End of Life Care Strategy:** Everyone, including people with dementia, approaching the end of life, should experience high quality, compassionate and joined-up care. Many people already receive good care at the end of life, but building on the findings of the independent review of choice and end of life care,³⁵ we recognise that there are opportunities to improve, particularly to ensure that people from all parts of society, and the most vulnerable, have the same opportunities to receive high quality care.
- 5.88 NHS England's *Actions for End of Life Care (2014-16)* set out the actions it would take to improve end of life care now. *Ambitions for Palliative and End of Life Care*,³⁶ produced jointly by 25 national statutory and voluntary organisations, sets out a framework for encouraging local action by health and social care commissioners, service providers, clinicians, the voluntary sector community and community leaders.
- 5.89 NHS England will:
- work with partners including the National Council for Palliative Care (NCPC) to make clear the specific considerations that should be provided to people with dementia.
- 5.90 The Department of Health will:
- work with NCPC to establish a pilot scheme to give care home staff and carers the knowledge, skills and behaviours to deliver co-ordinated, compassionate and person-centred end of life care for people with dementia. As part of the project, NCPC will also develop recommendations for dissemination of the findings across the country.

Training well

- 5.91 **Staff training:** It is vital that health and care professionals have an awareness and understanding of dementia, and how it can affect people with dementia and their carers. We have already trained in excess of 600,000 NHS and social care staff in better supporting people with dementia. All providers of care need to be encouraged to make available suitable training materials to their staff. The Department of Health is currently refreshing *Making a Difference in Dementia*, its Nursing Vision and Strategy for dementia, published in March 2013. The strategy reinforces the fundamental role nurses play in providing care and support to people with dementia, so they can live well with the condition. It aims to support all nurses to be responsive to the needs of people with dementia, to continue to develop their skills and expertise and to improve the contribution they make to achieving the best outcomes for people with dementia, their carers and families.

³⁵ <https://www.gov.uk/government/publications/choice-in-end-of-life-care>

³⁶ <http://endoflifecareambitions.org.uk/>

5.92 The Dementia Core Skills Education and Training Framework was commissioned and funded by the Department of Health and developed in collaboration by Skills for Health, Health Education England, Skills for Care and an expert advisory group that ensured multi-organisational and multi-stakeholder representation. Launched in October 2015, it is a comprehensive resource which details the essential skills and knowledge necessary for staff across the broad and varied spectrum of health and social care settings and will support organisations to:

- standardise the interpretation of dementia education and training
- guide the focus and aims of dementia education and training delivery through key learning outcomes
- ensure the educational relevance of dementia training
- improve the quality and consistency of education and training provision.

5.93 It sets out standards needed in dementia education and training including raising dementia awareness, knowledge and skills for those that have regular contact with people affected by dementia and knowledge and skills for those in leadership roles.³⁷

Case Study: Dementia E-Learning Resources

E-Learning for Health (e-LfH) is a Health Education England Programme which provides high quality content free of charge for training the NHS workforce across the UK. In October 2015 e-LfH successfully launched an updated Dementia e-learning programme.³⁸ This programme, developed by the University of Bradford in conjunction with 'experts by experience' consists of 11 sessions (with a twelfth being added in March 2016) that offer a rich learning experience through use of high-quality videos of personal experiences, interactive quizzes and opportunities for self-reflection.

5.94 The Department of Health is working with the Social Care Institute for Excellence (SCIE) to consider ways in which its Dementia Gateway³⁹ may be used to support the implementation of the 2020 Challenge with regard to the social care workforce. We also plan to work with SCIE to create a set of films demonstrating and promoting effective practice in person-centred care as the method for managing distress and challenging behaviours among people with dementia. The films will be embedded in SCIE's Dementia Gateway e-learning resource and made available to social care staff, and will also be available to NHS staff through e-learning for Healthcare.

³⁷ <https://hee.nhs.uk/our-work/hospitals-primary-community-care/mental-health-learning-disability/mental-health/dementia>

³⁸ <http://www.e-lfh.org.uk/programmes/dementia/>

³⁹ Dementia Gateway is for anyone who wants to understand dementia better: what it is, what it means for daily life, and what we can do better to support people living with dementia, including family and friends. www.scie.org.uk/dementiagateway

Case Study: 'What Works?' in dementia education and training

What Works,⁴⁰ a research study led Professor Claire Surr, Professor of Dementia Studies at Leeds Beckett University, in collaboration with the University of Bradford and the University of Leeds, is investigating what components lead to the most effective approaches to training health and social care staff about dementia. The study will identify the types of training programmes, approaches and setting conditions, which lead to the best outcomes for people with dementia and their families, helping to share good practice and ensure that funding is invested in effective training that supports better care for people with dementia. The study has been commissioned for Health Education England by the Department of Health Policy Research programme. It is due to be completed in July 2017.

5.95 ADASS will encourage its members to

- Support the development of appropriately skilled workforce to improve quality of care delivered;
- Ensure that commissioned services contractually specify the minimum standards of training required for providers who care for people with dementia including residential, nursing and domiciliary care setting;
- Improve awareness of dementia among staff, partners and providers through the roll-out of Dementia Friends.

5.96 Skills for Care has committed to:

- Work in conjunction with ADASS, social care providers and other partners to support the development of an appropriately skilled workforce to improve quality of care provided;
- Develop resources to support the social care workforce to deliver culturally competent care for people with dementia from differing cultures and backgrounds;
- Support dementia workforce planning and workforce commissioning in relation to integrated care settings. This will be in conjunction with NHSE and HEE and link to the Care Home Vanguard sites.

5.97 HEE:

- Has commissioned the National Association of Primary Care to develop, implement and independently evaluate dementia training for primary care staff. HEE and NHSE will continue to work with the primary care sector to promote this training;
- Will work with NHS Trusts to ensure (a) availability of tier 1 dementia awareness training to all staff and (b) all staff treating NHS patients working regularly with people with dementia undertake more in depth training appropriate to their role as outlined in the Dementia Core Skills Education and Training Framework.

⁴⁰ www.leedsbeckett.ac.uk/pages/what-works/

5.98 We recognise the need to better understand the scale of the workforce challenge within social care to mirror the progress made in healthcare workforce development.

5.99 The Department of Health will commission a study to:

- gain an accurate assessment of the number of people in the social care workforce who are providing care and support to people with dementia;
- identify relative levels of education and training for this workforce;
- identify gaps and challenges to up-skilling the social care workforce supporting people with dementia;
- identify options to address these challenges and gaps by 2020.

Case Study: 'The Appointment' Training Resource

The Appointment,⁴¹ developed by Health Education England, is a short film inspired by an award-winning series of films called *Barbara's Story* developed to highlight issues around caring for people with dementia in an acute hospital setting. *The Appointment* is a powerful and moving account of Barbara's experiences during a dental appointment. It shows how confusing such an appointment can be for someone with dementia and highlights the crucial role played by the whole dental team in supporting vulnerable patients. The lessons learnt are transferable to many other outpatient appointment settings.

The training package, which is aligned to the Dementia Core Skills Education and Training Framework is being used to support dementia awareness training for dental trainees and in dental practices. Evidence is emerging that this training package is being adopted by some service provider organisations as part of their Tier 1 dementia awareness training. Health Education England is continuing to develop further short films during 2016 to improve dementia awareness.

Developing health and social care professionals to increase confidence in dementia care

5.100 We will work with leaders in the care provider sector, (including Care England and the National Care Forum) to develop a practice-based module for emerging social care leaders building on (for example) the SCIE Innovation Exchange and resources available from Skills for Care. The ambition is to create a new virtual leadership academy so that the next generation of health and social care leaders have access to tools and peer support to assist in commissioning high quality dementia care services. This will cover the full range of dementia care and support, from homecare to nursing, residential and hospice care, including services provided to self-funders as well as local authority funded clients.

5.101 Working with the Chief Social Worker for England, we will begin work with universities to explore the potential to create a new professional qualification in dementia social

⁴¹ <https://www.youtube.com/watch?v=EnPUq00UA8c&feature=youtu.be>

work. In addition to increasing investment in and recognition of specialist social work practice, this will set the pace internationally in ensuring England has a social care workforce that possesses a high standard of knowledge, skills and application in social work and dementia.

How will we know that we have made a difference?

Commitment 3: In every part of the country people with dementia having equal access to diagnosis as for other conditions, with an expectation that the national average for an initial assessment should be six weeks following a referral from a GP (where clinically appropriate), and that no one should be waiting several months for an initial assessment of dementia.

Lead Organisation (and partners)	Action	Start date	What will success look like?
NHS England (NHSE) (Alzheimer's Society, DH, NHS Improvement)	Drive quality improvement by reducing variation in diagnosis rate across CCGs by providing and publishing transparent data on diagnosis rate and post diagnostic support.	Jan 2016	National dementia diagnosis rate maintained at two-thirds prevalence, and reduced local variation between CCGs following agreement and implementation of an appropriate and affordable plan to bring services into line within the national framework for treatment and care.
	Develop an evidence based framework for a national treatment and care pathway and agree an affordable implementation plan by March 2017 for the Prime Minister's Challenge on Dementia 2020, including to improve the quality of post-diagnosis treatment and support.		
	Provide bespoke support to areas where assistance has been requested or identified as having lower diagnosis rates including in the development and delivery of recovery plans.		

Commitment 4: Every person diagnosed with dementia having meaningful care following their diagnosis, which supports them and those around them, with meaningful care being in accordance with published National Institute for Health and Care Excellence (NICE) Quality Standards. Effective metrics across the health and care system, including feedback from people with dementia and carers, will enable progress against the standards to be tracked and for information to be made publicly available.

Lead Organisation (and partners)	Action	Start date	What will success look like?
NHSE/NHSE Improvement (Department of Health, PHE, ADASS)	<p>Explore and develop a nationally agreed template to support services to move towards delivery of personalised and integrated care across the Well Pathway by April 2017.</p> <p>Identify best practice, impact in terms of improved clinical and non-clinical outcomes and facilitate adoption at scale with consistent national coverage by March 2020.</p>	April 2016	<p>People with dementia and their carers are able to access quality dementia care and support, enabling them to say “I have support that helps me live my life”, “I know that services are designed around me and my needs”, and “I have personal choice and control or influence over decisions about me”</p>
ADASS	<p>Encourage its members to enable people to have access to high quality, relevant and appropriate information and advice, and access to independent financial advice and advocacy, which will enable access to high quality services at an early stage to aid independence for as long as possible.</p>	Ongoing	

Commitment 4: continued			
Lead Organisation (and partners)	Action	Start date	What will success look like?
ADASS <i>continued</i>	Encourage its members to ensure that as many people as possible with dementia and their carers have a right to a social care assessment. If the national eligibility criteria is met, the service user and the assessor will work together to develop a support plan whether funded or a self funder, giving greater choice and control to the individual. The plan will be monitored at six weeks and reviewed annually. If the eligibility criteria is not met support will be given to the individual via signposting to appropriate and relevant universal services.	Ongoing	
	Encourage its members to enable independence and self-reliance and support people living with dementia and their families and carers to live the best life that they can by using an asset based approach which will inform decision making at the right time and place.	Ongoing	
Department of Health	Publish a Carers Strategy which will set out the evidence about the economic impact of caring and its relationship with the health and care sectors and wider society as a whole as well as international and national good practice about support for carers.	Dec 2016	
CQC	Continue to strengthen the way it registers, monitors, inspects and rates health and adult social care services, putting people at the heart of what it does, including people with dementia. Continue to build on the strong foundations of the new regulatory model.	Ongoing	
NICE	Publish revised Dementia Quality Standard.	Sep 2017	

Commitment 5: GPs playing a leading role in ensuring coordination and continuity of care for people with dementia, as part of the existing commitment that from 1 April 2015 everyone will have access to a named GP with overall responsibility and oversight for their care.

Lead Organisation (and partners)	Action	Start date	What will success look like?
Health Education England (HEE) (NHSE, DH)	HEE has commissioned the National Association of Primary Care to develop, implement and independently evaluate dementia training for Primary Care Navigators.	Ongoing	GPs ensuring everyone diagnosed with dementia has a personalised care plan that covers both health and care and includes their carer. This will enable people to say "I know that services are designed around me and my needs", and "I have personal choice and control or influence over decisions about me"
NHSE (HEE)	GPs should play a leading role in the development and implementation of personalised care plans including specific support working in partnership with memory assessment services and care plan design and implementation.	September 2015	
ADASS/ NHSE	ADASS will work nationally with NHSE and other NHS Arms Length Bodies to develop joint health and care assessment processes and agree to trial emerging processes in a number of localities . ADASS will share good practice of person centred assessment processes as a result of Care Act 2014 changes to practices.	Ongoing	

Commitment 6: All hospitals and care homes meeting agreed criteria to becoming a dementia-friendly health and care setting.

Lead Organisation (and partners)	Action	Start date	What will success look like?
Alzheimer's Society/ Dementia Action Alliance (DAA) (DH, NHSE, ADASS)	Promote the Dementia Friendly Hospitals Charter (previously titled "Right Care"), the national DAA's Call to Action on dementia friendly hospitals, and develop plans to promote dementia friendly care homes.	Ongoing	Hospitals and care homes to become and stay dementia-friendly.
ADASS	Promote the learning from the Dementia Friendly Environments pilot project through the National Dementia Network and encourage all local authorities to promote to all care settings within their local areas.	February 2016	
Department of Health (DH)	Work with leaders in the care provider sector, (for example Care England and the National Care Forum) to develop a practice-based module for emerging social care leaders building on (for example) the SCIE Innovation Exchange and resources available from Skills for Care.	2016/17	

Commitment 7: All NHS staff having received training on dementia appropriate to their role. Newly appointed healthcare assistants and social care support workers, including those providing care and support to people with dementia and their carers, having undergone training as part of the national implementation of the Care Certificate, with the Care Quality Commission asking for evidence of compliance with the Care Certificate as part of their inspection regime. An expectation that social care providers provide appropriate training to all other relevant staff.

Lead Organisation (and partners)	Action	Start date	What will success look like?
HEE (DH, NHSE)	HEE will work with NHS Trusts to ensure (a) availability of tier 1 dementia awareness training to all staff and (b) all staff treating NHS patients working regularly with people with dementia undertake more in depth training appropriate to their role as outlined in the Dementia Core Skills Education and Training Framework. HEE will monitor delivery with the roll out of tier 1 dementia awareness training via a biannual survey.	Ongoing	People with dementia and their carers will be supported by health and care staff in all types of service that will have the appropriate level of dementia awareness and training.
Skills for Care/CQC	Work with social care providers and partners to continue to improve standards of workforce development for staff supporting people with dementia. This will include promoting a) the implementation of the Care Certificate b) dementia specific vocational training pathways.	Ongoing	
ADASS	Encourage its members to ensure that commissioned services contractually specify the minimum standards of training required for providers who care for people with dementia including residential, nursing and domiciliary care settings.	Ongoing	
	Encourage local authorities to monitor training standards within residential and domiciliary care settings where there is a contractual agreement to ensure that all staff have the relevant training as specified within the contractual agreement.	Ongoing	

d) Dementia Awareness and Social Action (including Dementia Friends and Dementia-Friendly Communities)

Our vision is for a country where there is widespread awareness and understanding of dementia, so that everyone with dementia can live fulfilling lives.

5.102 Dementia remains the biggest health concern of people aged over 55. There is still an unacceptable stigma surrounding dementia, and people with dementia are affected by discrimination. To overcome this and to support people in living well with dementia, we need to continue to make progress on improving awareness and understanding of dementia to transform the way society thinks and acts about dementia. Every organisation and every person who makes up a community has both a role and a responsibility to act.

“For many reasons people with dementia and carers can become cut off from the community leading to social isolation and resultant worsening of health.”

(View from engagement session with people with dementia and carers)

5.103 This section sets out how we will help businesses, local authorities, the wider public sector and civil society work together to achieve real change. This change will not happen overnight, but we will continue to build on the solid foundations made during the first Prime Minister’s Challenge on Dementia, to take further action and accelerate progress. This will be enhanced by a new work programme, outlined in section 5 a) of this plan, to support the uptake of global dementia friendly communities around the world.

5.104 As part of the first Prime Minister’s Challenge, Alzheimer’s Society led the dementia friendly communities programme working with a range of other organisations. At the end of the first Challenge there were over one million Dementia Friends, with major businesses such as Marks and Spencer and Lloyds Banking Group creating Dementia Friends in the workplace, and over 80 Dementia Friendly Communities in England. This work provided the important building blocks needed for improving dementia awareness across all sectors of society.

5.105 A range of other work also took place as part of the first Prime Minister’s Challenge, across a variety of sectors and organisations. Eleven task and finish groups produced a range of guidance materials to promote the inclusion of people affected by dementia, including the Dementia-friendly Financial Services Charter, the Dementia Friendly Technology Charter and a practical guide for employers on creating more dementia friendly workplaces. A pilot with 22 schools determined ways to create a more dementia friendly generation through education and the Local Government Association developed a toolkit for local authorities which are working to become dementia friendly. In celebration of all these achievements, the inaugural Dementia Friendly Awards

ceremony in 2014 recognised individual and community achievements in improving the lives of people living with dementia and their carers.

Progress since March 2015

- 5.106 Dementia awareness and understanding has continued to increase through the creation of an additional 400,000 Dementia Friends and through the launch of Black and Minority Ethnic materials for Dementia Friends. There are also a further 50 Dementia Friendly Communities in England, supporting people with dementia to live more independent and fulfilling lives.
- 5.107 The sector specific task and finish groups have continued their work on dementia, with the Arts group producing a practical guide on becoming a dementia friendly arts venue and the Power of Attorney group launching its guidance on acting on behalf of a person with dementia with regard to accessing and sharing information. The task and finish groups on rural communities, transport and retail have made good progress and are due to report in 2016. Building on an Alzheimer's Society's pilot programme, dementia resources for schools have been launched, targeting Key Stage 2 and 3 students, and quality assured by the Personal Social and Health Education Association and the Council for the Curriculum, Examinations and Assessment. Continuing this focus on engaging with young people, Alzheimer's Society is one of five charity partners delivering *A Million Hands*, a programme established in partnership with The Scouts Association to enable and empower 450,000 young people to take social action on dementia.
- 5.108 On business, the Dementia Friendly Businesses pilot was launched in October 2015, working with ten businesses to test the viability of an initial framework for work on dementia. The framework outlines steps for businesses to take to become dementia friendly.
- 5.109 Alzheimer's Society is increasing international engagement in dementia friendly communities and licencing Dementia Friends for use by other governments and partners. A number of other countries have launched their own Dementia Friends programmes. The second Dementia Friendly Awards ceremony in September 2015 showcased the work and achievements over the previous 12 months to create dementia friendly communities and improve the lives of people living with dementia and their carers.

Key Priorities

- 5.110 The engagement workshops with Dementia Friends Champions, business leaders and leaders from local government resulted in clear priorities in this theme:
- delivering three million additional Dementia Friends
 - developing communities to be Dementia Friendly
 - encouraging businesses to be Dementia Friendly
 - ensuring national and local Government play a leadership role in increasing public sector dementia awareness.

5.111 People affected by dementia helped to develop these work programmes and their feedback continues to shape the ongoing work. **The full delivery roadmap for this theme is captured in the Annex 2.**

Dementia Friends

5.112 The Dementia Friends programme is a social movement which is key to improving dementia awareness, through a combination of face-to-face and online Dementia Friends information sessions. Dementia Friends gives people a basic understanding of dementia and the things we can all do to support people with dementia to live more independent lives in their own communities. There are now over 1.4 million Dementia Friends and **Alzheimer's Society is working to reach a total of four million by 2020**, raising awareness of dementia across all aspects of society.

5.113 In order to deliver the additional three million Dementia Friends by 2020, Alzheimer's Society will, working in partnership with others:

- ensure a sustained push through social media to reach digital audiences;
- target the involvement of businesses, Government departments and other large employers;
- maintain a coordinated network of staff to induct and support Dementia Friends Champions.

5.114 In response to the key themes emerging from the engagement workshops, Alzheimer's Society will also take forward a number of other actions in support of these key actions. These include:

- recruiting additional Dementia Friends Champions, continuing to provide structured support for existing Champions to create more Dementia Friends and ensuring diversity in the opportunities to become a Dementia Friend,
- driving the delivery of inter-generational awareness through the continued roll-out of Dementia Friends in schools and youth organisations and building on social action by Dementia Friends and Dementia Friends Champions.

Dementia Friendly Communities

5.115 We have made great strides in establishing Dementia Friendly Communities, where people with dementia feel supported to continue in the day-to-day activities they enjoy and to lead more fulfilling lives. However, there is still much more to do to ensure that, by 2020, over half of people with dementia are living in Dementia Friendly Communities, and that those communities are working to provide the best possible support to people with dementia and their carers.

5.116 To meet this commitment, Alzheimer's Society will:

- **launch a revised recognition process for dementia friendly communities**, incorporating the British Standards Institute guidance. Alzheimer's Society will use the result of the Dementia Friendly Business pilot described below to drive local branches of national businesses to become part of local Dementia Friendly Communities. Alzheimer's Society will also work with local authorities to assist them in supporting and/or setting up Dementia Friendly Communities;
- promote the role of Dementia Friendly Communities and Dementia Friends in delivering integrated health and social care, and develop further activity to support this. Through research and evaluation, they will also promote the impact of the work on dementia friendly communities more generally;
- build on its existing networks to support new communities and encourage the progress of existing communities who are working to become dementia friendly;
- recognise the achievements of dementia friendly communities through its annual Dementia Friendly Awards programme.

5.117 In addition to these specific actions, widespread social action and volunteering, building on the engagement of Dementia Friends and Dementia Friends Champions, will be key to delivering more Dementia Friendly Communities.

Case Study: Dementia Friendly Communities

Plymouth City Council, Alzheimer's Society and Plymouth University have worked effectively with local partners, including businesses, voluntary groups and the Royal Navy, to transform the experiences of people affected by dementia. With regular reports on BBC Radio Devon, local Dementia Friends Champions have created thousands of Dementia Friends. In March 2016 over 300 delegates attended the fifth Plymouth Dementia Conference committed to continued action that changes daily lives. With people with dementia and their carers involved throughout, action plans now extend beyond the City itself, for example five rural parishes on the River Yealm jointly running outreach to isolated communities.

Dementia friendly businesses

5.118 The response to dementia from businesses is increasing, reflecting the challenge which the condition poses across society.

5.119 Alzheimer's Society has committed to:

- continue leading the engagement with business publishing findings of a dementia friendly business pilot in summer 2016.

5.120 As a result of this work, Alzheimer's Society and Government will provide business with a central online point for dementia information, including:

- a resource which businesses can signpost their customers to when it is needed;
- a detailed business case for being dementia friendly – what it is, why it is important, the commercial benefits and the consequences of not being dementia friendly;
- best practice case studies and recommendations for changes to practice and policies (such as dementia/carer passports for employees);
- sector-specific 'Dementia Friendly Charters' to set expectations and drive performance.

5.121 Alzheimer's Society and Government will encourage businesses over a certain size to incorporate Dementia Friends into their induction programmes. Employees will also be offered further volunteering opportunities to engage with social action on dementia, both within and outside the workplace.

National and local government

5.122 We will focus on the leadership of both national and local government in working to create a more dementia friendly society. For national government, we will increase engagement across Whitehall to promote and support Departmental leadership for the creation of Dementia Friendly Communities. To do this, Alzheimer's Society will produce a Dementia Friendly Whitehall Charter for government departments to commit to becoming dementia friendly. We will also encourage government departments to have a named lead across Whitehall, to drive roll out of Dementia Friends and help deliver a Dementia Friends Champion network by 2018. Alzheimer's Society, the Department of Health and Cabinet Office will also consider hosting a cross-government event to raise awareness of dementia-friendly communities and the role of government departments.

5.123 For local government, we will work with key partners to continue to refresh online materials and resources for local councils who wish to take forward the commitment to creating dementia friendly communities. As with all areas of the dementia friendly communities programme, Alzheimer's Society will recognise and reward action through the Dementia Friendly Awards.

Evaluation

5.124 Alzheimer's Society has commissioned New Philanthropy Capital and the University of Hertfordshire to carry out a large-scale evaluation of the impact of the work of building Dementia Friendly Communities, Dementia Friends and Dementia Action Alliances. The Department of Health is also commissioning an independent evaluation of the evidence base for Dementia Friendly Communities. These evaluations will contribute valuable information to enable us to assess whether these statements have been met and to inform future actions.

How will we know that we have made a difference?

Commitment 8: Alzheimer's Society delivering an additional 3 million Dementia Friends in England, with England leading the way in turning Dementia Friends in to a global movement including sharing its learning across the world and learning from others.

Lead Organisation (and partners)	Action	Start date	What will success look like?
Alzheimer's Society (All government departments, local government, business, volunteering and community organisations)	<p>Recruit Dementia Friends champions and promote Dementia Friends sessions. Build on social action by Dementia Friends and Dementia Friends Champions by diversifying opportunities for action and delivering new engagement channels:</p> <ul style="list-style-type: none"> • New volunteering opportunities • Campaigning on and offline • Champion Forum network <p>Maintain a coordinated network of staff who induct Dementia Friends Champions.</p> <p>Deliver a sustained push through social media to reach digital audiences.</p> <p>Target involvement of big employers with the aim of reaching over 1.5m Friends through this route by 2020.</p> <p>Package Dementia Friends to business using the three days per year workforce volunteering model.</p>	Ongoing	There will be 4 million Dementia Friends in England covering all aspects of society, business and community, and connected to a global network of Dementia Friends and Dementia Friendly Communities. This movement will normalise dementia awareness, care and support, and people affected by dementia will be able to say 'I have support that helps me live my life'
Alzheimer's Society (DH, ADI)	Increase awareness of Dementia Friends internationally and license the development of Dementia Friends programme with governments and civil society partners in other countries.	Ongoing	
ADASS/LGA	Continue to work in partnership to enable the creation of Dementia Friends at both a national level and at an individual local authority level in conjunction with other local partners in all sectors.	Ongoing	

Commitment 9: Over half of people living in areas that have been recognised as Dementia Friendly Communities, according to the guidance developed by Alzheimer’s Society working with the British Standards Institute. Each area should be working towards the highest level of achievement under these standards, with a clear national recognition process to reward their progress when they achieve this. The recognition process will be supported by a solid national evidence base promoting the benefits of becoming dementia friendly.

Lead Organisation (and partners)	Action	Start date	What will success look like?
Alzheimer’s Society (Government, LGA, ADASS, Partners in business, voluntary sector and public service)	Launch a revised recognition process incorporating the BSI guidance on dementia-friendly communities.	May 2016	There will be dementia-friendly communities across the country which means that people affected by dementia will be able to say ‘I have a sense of belonging and of being a valued part of family, community and civic life’
	Use the results of the dementia friendly business pilot to drive local branches of national businesses to become part of local dementia-friendly communities.	June 2016	
	Work with local authorities and ADASS/LGA to set up/support Dementia Friendly communities.	Jan 2016	
Recognise progress achieved through the Dementia Friendly Awards.	Oct 2016		
ADASS/LGA	Promote the BSI guidance and disseminate good practice through the National Dementia Network.	March 2016	

Commitment 10: All businesses encouraged and supported to become dementia friendly, with all industry sectors developing Dementia Friendly Charters and working with business leaders to make individual commitments (especially but not exclusively FTSE 500 companies). All employers with formal induction programmes invited to include dementia awareness training within these programmes.

Lead Organisation (and partners)	Action	Start date	What will success look like?
Alzheimer's Society (Government, Partners in business, voluntary sector and public service)	<p>Develop a clear and simple toolkit on becoming a dementia friendly organisation (with targeted variations of guides and checklists) promoted to businesses.</p> <p>Pilot programme with ten businesses from October 2015.</p>	Ongoing	Increasing numbers of businesses will be involved in dementia-friendly practices which means people affected by dementia will be able to say 'I live in an enabling and supportive environment where I feel valued and understood'

Commitment 11: National and local government taking a leadership role with all government departments and public sector organisations becoming dementia friendly and all tiers of local government being part of a local Dementia Action Alliance.

Lead Organisation (and partners)	Action	Start date	What will success look like?
Alzheimer's Society (DH, ADASS, LGA)	<p>Deliver continued support for the Prime Minister's Champion Group on Dementia Friendly Communities to deliver action across key sectors of industry, voluntary sector and public service.</p> <p>Government departments encouraged to have a Dementia Friends lead to roll out internally. Dementia Friends is a part of the Civil Service E-learning.</p> <p>Promotion of a clear and simple offer to become a dementia friendly local government organisation and develop a Dementia Friendly Whitehall Charter.</p>	Ongoing	Local and national government will be involved in dementia-friendly communities across the country which means that people affected by dementia will be able to say 'I have a sense of belonging and of being a valued part of family, community and civic life'
ADASS/LGA	Disseminate good practice through the National Dementia Network and encourage local authorities to join local Dementia Action Alliances.	Ongoing	

e) Research

'I know that there is research going on which will deliver a better life for people with dementia, and I know how I can contribute to it.'

5.125 A great deal had been achieved during the first Prime Minister's Challenge and this has created a strong foundation to build on up to 2020. We doubled Government research funding between 2012 and 2015, to over £60m a year. This money, alongside increased investment from charities and the private sector, was used to develop key infrastructure and research activity that has placed the UK at the forefront of dementia research.

5.126 The 2020 Challenge sets the ambition to see total research funding from all sources on track to double by 2025. We are delivering new research infrastructure to support and catalyse research, and so attract investment. We are supporting more people than ever before to be available to take part in research studies. Importantly, we are training new researchers and developing capacity across the spectrum of disciplines that need to be engaged. This strategy is transforming and expanding the field, to deliver better care and treatments.

Progress since March 2015

5.127 The Government has committed to a further £300m for funding for dementia research by 2020, and announced up to £150m for a Dementia Research Institute (DRI). The Government has also spearheaded the launch of the Dementia Discovery Fund a global investment fund that aims to invest over £130m on the early-stage development of potential treatments.

Engaging with the research community and people with dementia

5.128 Five key priority themes emerged during the engagement exercise:

- providing more opportunities for people with dementia and their carers to get involved in research.
- improving collaboration across the sector by creating new opportunities and improving communication.
- developing capacity in the field – ensuring a diverse, engaged researcher workforce to deliver the aspirations.
- providing coordination and alignment of current and future research initiatives.
- encouraging inter-disciplinary working and innovation in research.

5.129 There is significant activity in place or in the pipeline to deliver against these themes. This Implementation Plan ensures there is a coherent and sustainable strategy, to deliver benefits for people with dementia, their carers and the wider community. Initiatives across the research spectrum from basic research, through to translational and applied research have been funded such as the Medical Research Council

Dementias Platform UK (DPUK), NIHR Dementia Translational Research Collaboration, NIHR-ESRC investments in Living Well with Dementia, the Dementia Consortium, Alzheimer's Research UK Drug Discovery Institutes and the Alzheimer's Society Doctoral Training Centres.

5.130 These initiatives are important as they foster links between academics, industry and practitioners of care. However, more can be done and it is important that initiatives such as DPUK, the Clinical Research Networks (CRNs) and the future Dementia Research Institute continue to work together.

5.131 Many of these flagship initiatives are in the early stages, with funding over five year cycles. It is important to evaluate these initiatives so lessons can be applied in future iterations.

Key Priorities

5.132 This Implementation Plan sets out the activity required to deliver the 2020 Challenge with a clear set of goals. It provides an overarching framework to coordinate and align the contribution of the research community and ensure the UK is the best place to do dementia research. As research is the largest theme in terms of commitments within the 2020 Challenge, the commitments have been separated into four research sub-themes:

- Delivering increases in research funding;
- Increasing dementia research capacity;
- Delivering better treatments, faster;
- Improving the lives of people with dementia.

5.133 The breakdown of the specific activity for each of the research commitments in the 2020 Challenge is detailed at **Annex 2**.

Delivering increases in research funding

5.134 Our strategy is to provide the infrastructure and people (including potential research participants) to support dementia research, and to draw in investment and innovation from the commercial and charity sectors. The building blocks include the national Dementia Research Institute, the NIHR Dementia Translational Research Collaboration, Dementias Platform UK, Join Dementia Research, NIHR Clinical Research Networks, and the NIHR Office of Clinical Research Infrastructure. Together, these make research easier to do and a less risky enterprise, which in turn is drawing in more industry and charity funding, alongside continued Government investment.

5.135 **The Government has already committed to spend at least £300m on dementia research by 2020**, with an ambition for overall funding from all sources to double between 2015 and 2025. **The Prime Minister announced that the national Dementia Research Institute will receive up to £150m in funding.** Alzheimer's Research UK has committed to invest £80m between 2014 and 2019, with the

Alzheimer's Society committing to spend at least £10m each year on research. There are a number of non-dementia charities with an overlapping remit, such as vascular dementia (The Stroke Association, British Heart Foundation), Lewy Body Dementia (Parkinson's UK) and FTD (MND Association) whom can make substantial contributions to research into these often neglected dementias. The funding will:

- increase dementia research capacity over the long-term.
- stimulate and support innovation.
- support researchers to draw in additional funding and investment.
- ensure that better diagnosis, prevention, treatment, and care is available for people living with dementia and at risk of developing the condition.

Case study: Alzheimer's Research UK

The Prime Minister's Challenge on dementia has delivered significant increases in infrastructure and resources for the dementia research field and created an environment that has facilitated increases in investment across the sector.

The improvements in the UK landscape and increasing awareness of the condition have created a platform for Alzheimer's Research UK to increase investment in research by over 160% from £4.6m in 2010 to £12.5m in 2015. It is their ambition to defeat dementia and they will not stop until they do, continuing to increase their investment to 2020 and beyond.

5.136 Crucial to overall progress is maintaining a strategic balance between priorities and areas of research. Investment in basic science, translational activities, clinical research, and care and applied research including public health and developing technologies are important. Efforts to gain an overview include the EU Joint Programme – Neurodegenerative Disease Research (JPND)'s 2012 mapping exercise, which will be repeated in 2017 to measure progress at the EU-level, and the National Institute of Aging (NIA)'s International Alzheimer's Disease Research Portfolio (IADRP)). Other efforts such as James Lind Alliance and more recently by the World Health Organization (WHO) have sought to set priorities for dementia research, working alongside the existing strategies of JPND and the Obama Plan. The WHO is also setting up a global Dementia Observatory, with support from the UK Government, to monitor and collate research information from all member states. This will provide a resource to help direct and facilitate joint working.

5.137 Targeted investment in research capacity and infrastructure will lead to increased research funding through more general, (i.e. non-targeted), response-mode mechanisms and public-private investment. This creates a virtuous circle of research growth. Initiatives like Dementias Platform UK (DPUK), the Dementia Translational Research Collaboration (TRC-D), Innovative Medicines Initiative (IMI), Neurodegeneration Medicines Accelerations Programme (NeuroMAP) and the Dementia Consortium provide collaborative models of potential co-investment for the pharmaceutical industry and others.

- 5.138 **The UK will continue to play a strong role in EU-level funding** and further afield, such as involvement in priority setting and collaborative funding calls with JPND and Network of Centres of Excellence in Neurodegeneration (COEN). The UK has to date been successful in winning major Innovative Medicine Initiative (IMI) grants in the field, which support multinational academic-pharma partnerships.
- 5.139 Alongside these flagship initiatives it is important to continue to fund more traditional, researcher-initiated research. Together with providing an infrastructure to support both industry and non-industry trials through the NHS, this represents a comprehensive plan for dementia research, bench to bedside.

Increasing dementia research capacity

- 5.140 The dementia research field remains small relative to the prevalence and challenges of the condition. We need more of the best researchers to enter and progress in the field, to grow the sector and to develop dementia research in the medium and longer term. However, there are challenges. Concerns about limited positions and long term job security are common amongst academic researchers, as well as industry, and provide a barrier to entry and retention. A recent report⁴² from RAND Europe found that historically 70% of dementia PhD graduates had left academic dementia research within four years, possibly reflecting general issues of attrition in biomedical research careers.
- 5.141 In response to these challenges, **funding from NIHR, the Research Councils, charities and private sources is providing increasing opportunities for new researchers** to enter, and current researchers to remain in the field. Over the period to 2020 there will be continued investment in clinical and non-clinical studentships and fellowships at all levels, from a range of research funders. Alzheimer's Society has launched a Dementia Research Leaders programme providing funding for individuals as well as career mentorship. As part of this programme eight Doctoral Training Centres will train a significant cadre of PhD students across a range of disciplines. There is increasing recognition of the importance that the nursing profession must have in dementia care research, leading to focused investments for nursing PhD Fellowships linked to NIHR CLAHRCs.
- 5.142 In addition to attracting and training early-career researchers, there is an opportunity to draw in more senior, established researchers from other fields and from outside the UK. Dementia research can benefit from new ideas, perspectives and expertise and dedicated funding streams, such as the Alzheimer's Research UK Interdisciplinary Research Grant, and investment in major cross-disciplinary flagship activities such as the DPUK and as envisaged through the new Dementia Research Institute will provide means of encouragement.
- 5.143 As more of the best, creative and resourceful researchers are brought into the field and develop as committed dementia researchers, they will increasingly seek out further

⁴² Marjanovic et al. (2015) A review of the dementia research landscape and workforce capacity in the UK. RAND Europe report. Available at www.rand.org/t/rr1186

research funding, including funding which is allocated on a responsive basis to the highest quality proposals from all disease areas. This will have the effect of drawing more funding into dementia research, as well as driving up quality across the board.

- 5.144 In order to build partnerships it is important to have clear understanding of the current research landscape. The Dementia Research Funders Forum, a group representing all major publicly funded and charity funders, is working to further develop a co-ordinated strategy for capacity development and recommend further ways of increasing capacity through collaboration and coordination.
- 5.145 There is an ever-growing understanding of how to best to involve public and patients (PPI) in all elements of research. National organisations such as NIHR INVOLVE, Alzheimer's Society Research Network, and local PPI networks such as through the Collaboration for Leadership in Applied Health Research and Care (CLAHRCs) provide routes to new academic-patient partnerships.
- 5.146 **The national Dementia Research Institute (DRI) will drive a step change in capacity development**, particularly in discovery and preclinical science and the early end of the translation pathway. The DRI will support collaboration and work closely with current strategic initiatives notably the DPUK and TRC-D. This will consolidate the UK's world-leading research infrastructure for dementia research. Working in collaboration with the Institute, the ARUK Drug Discovery Alliance will aim to recruit up to 90 scientists to work on dementia drug discovery within three academic centres at Cambridge, Oxford and UCL.
- 5.147 All public funding bodies are committed to open access publishing and have well established policies in this area. All funders of dementia research are committed to reviewing their policies with the aim of ensuring a lack of availability of data and/or results do not hinder progress.
- 5.148 Key to increasing delivery of clinical studies is encouraging more people with dementia to take part in research. Since its launch in 2014 Join Dementia Research (JDR) has been successful in increasing the numbers of people taking part. Figures from the NIHR show a 60% increase in the numbers of people coming forward to take part in research between 2014 and 2015, and JDR is on target to have 12% of people diagnosed with dementia in 2018 join the register with support from NHS England. In order to increase recruitment towards the target of 25% of people diagnosed with dementia in 2020, it will be necessary to increase the marketing of JDR and work with NHS England to develop a plan to cascade through GPs, community pharmacies and memory clinics.

Delivering better treatments, faster

- 5.149 Research from basic science, through the translation pathway to late stage clinical trials all ultimately contributes to the goal of cure or disease-modifying therapy by 2025.

- 5.150 The Dementia Research Institute (DRI), through a national hub and spoke model which will promote connectivity to established resources and cutting edge discovery science, will enable scientists to better understand the causes of dementia and the mechanisms underlying disease progression. This basic science understanding will be fundamental to developing new treatments.
- 5.151 In terms of developing new drugs, **the Dementia Discovery Fund (DDF), instigated by the Government, will invest over £130m globally by 2025** to develop promising research into potential new treatments and improving the drug discovery pipeline. Alongside investment in the DDF, Alzheimer's Research UK is investing £30m in three Drug Discovery Institutes to bring together world leading academics with industry-standard drug discovery. ARUK has also introduced a £20m global fund for clinical trials. Alzheimer's Society is funding several drug repurposing programmes with international partners.
- 5.152 It is important to build on these initiatives and strengthen them through collaboration, both across the UK and globally. **The UK will continue to play a leading role in initiatives such as the EU Joint Programme** – Neurodegenerative Disease Research (JPND), COEN and the European Prevention of Alzheimer's Disease Consortium (EPAD), funded by the Innovative Medicines Initiative (IMI).
- 5.153 A considerable amount of analysis has been carried out by the WHO, OECD and others to identify gaps in research and areas for further action and collaboration. In order to facilitate further expansion of the global research agenda, ARUK is working with the Department of Health to build on the work of Raj Long in her report *Finding a Path for the Cure for Dementia*. This work will bring together international partners, including the OECD and WHO, to deliver a Global Dementia Platform that will focus on collaboration and coordination of international drug development.
- 5.154 The pharmaceutical industry is central to the aim of delivering a disease-modifying therapy by 2025. As well as investing strategically in key collaborative projects, such as DPUK and IMI programmes in neurodegeneration,⁴³ such as EPAD and EMIF, the pharmaceutical sector is continuing to invest in dementia research. The pipeline of dementia treatments in clinical development is steadily growing, and there have been a number of promising results recently (for example the promising data on mild Alzheimer's disease patients for Solanezumab⁴⁴). With the strong infrastructure that has been established since the beginning of the Dementia Challenge and promising candidate treatments in the later stages of clinical development, we are on target to have a disease-modifying therapy that will make a difference to patients' lives by 2025. These first treatments will have modest impact, but importantly will represent the turning point in drug development and act as the precursor to many more effective treatments soon after.

⁴³ In 2015, IMI announced that three existing projects addressing Alzheimer's Disease and other neurodegenerative disorders – AETIONOMY, EMIF and EPAD, with a combined budget of €138 million – have been linked under a single collaborative platform to enable faster progress. The latter two are led from the UK, and have strong linkage to DPUK.

⁴⁴ Siemers et al 2015.

Advisory Group on Dementia Research

The Advisory Group on Dementia Research met in December 2015, co-Chaired by Professor Dame Sally C. Davies, Chief Medical Officer and Patrick Maxwell, Regius Professor of Physic, Cambridge Institute for Medical Research. The group comprises dementia research experts and research funders from charity, government, research councils, and from industry. Members of the group were asked to consider how best to help achieve the Prime Minister's 2020 Dementia Challenge aspirations for research. Many of the matters identified related to increasing industry engagement in dementia research in the UK, acknowledging difficulties in quantifying this. Issues included:

- The pressing need to increase numbers of people available to participate in research, and participating in dementia research, including those at risk of the condition.
- The need for more basic research to understand risk and progression of dementias, and for research to include people from across the spectrum of disease, including in active disease, to support better understanding of conditions and in order to develop potential treatments.
- The need to integrate burgeoning research initiatives without increasing bureaucracy. This could be supported by ensuring ready access to information about planned and current research for potential collaborators, including from industry.
- The need to ensure that effective use is made of Dementias Platform UK. This could involve integrating cohorts, and boosting appropriate access to information.
- The need to identify 'early pipeline' research which may be ripe for translation/adoption by industry.
- The possibility of repurposing existing medications, including 'off-label' drugs as a cost-effective route to potential new treatments.
- The importance of partnership funding arrangements for charities and government.

Improving the lives of people with dementia

5.155 Whilst research on understanding and treating dementia is vital and has the potential to transform how the condition is managed, an increasing number of people are living with dementia. This poses a growing challenge in terms of finding the best ways to care for people with dementia, to provide services, and to support them to live well in their own homes and neighbourhoods. Non-pharmacological interventions are increasingly being used to help people with dementia and their carers to manage the cognitive and emotional symptoms of dementia. For example, cognitive stimulation therapy, an intervention developed by UK researchers, is found to be as clinically effective as current Alzheimer's disease symptomatic treatments, is cost effective to deliver and is recommended in NICE guidelines for people with all types of dementia.

- 5.156 **Research into dementia care is essential** to find new and innovative ways for our health and social care systems to support the increasing numbers of people living with dementia and to help them live well in all community and care settings. Knowledge transfer – from research to practice – is also vital in care and health services research and clinical research, to ensure research findings have appropriate impact. This happens most effectively when the professionals involved in delivering care are also doing the research into the care and services they help to provide. However, there remain a relative few health and care professionals able to lead research on dementia services and care, given the size of the sector and extent of need.
- 5.157 To address this situation, National Institute of Health Research (NIHR) research training programmes will continue to increase the numbers of doctors, nurses, and allied health and care professionals becoming researchers in dementia care. These programmes include Integrated Academic Training for medical researchers, the ICA HEE/NIHR Integrated Clinical Academic Programme for non-medical healthcare professions, and training for researchers of all relevant disciplines provided by NIHR Collaborations for Leadership in Applied Health and Care (CLAHRCs). Communities of practice, bringing together academics and practitioners in areas of mutual interest offer opportunities to increase the delivery of research into practice. Alzheimer's Society's expanding Dementia Research Leaders programme makes funding and development opportunities available for individuals from all clinical and social care professions to conduct dementia research.
- 5.158 NIHR themed calls for research on dementia, as well as related topics such as comorbidity in older adults, and research commissioned through the NIHR School for Social Care Research, have pump primed the field. In addition, the ESRC and NIHR have funded £20m of research into care and support through the Living Well with Dementia programme. This research is ongoing and NHS bodies must work with charities to ensure services or programmes that are shown to be cost-effective at improving the lives of people with dementia are implemented. As these programmes reach their conclusions, further work will be needed to put new knowledge into practice and make available new funding for emerging research areas. Investment in technology-assisted care, through public bodies and charities also has substantial potential, particularly where it can offer a bridge between academia and care or technology industries. Alzheimer's Society has launched dedicated funding streams in care and services research, as well as in implementation science, and has ambitious plans to greatly increase its investment into care and public health research in the period to 2020.

Case Study: dallas – delivering assisted living lifestyles at scale

The dallas programme⁴⁵ – developed by the UK's innovation agency, Innovate UK and joint funded by the National Institute for Health Research and the Scottish Government, tasks four consortia with running this huge scale innovation programme and testing it with communities throughout the UK. The consortia have been awarded £25 million of government money, to which they've added their own financial contributions.

The programme aims to involve nearly 170,000 people across the UK, benefitting from new and innovative products, systems and services and transforming their choices as they age.

- 5.159 Public Health England (PHE) alongside charities will provide leadership in bringing together researchers and funders to identify collaborative solutions for building and promoting the evidence base for dementia risk reduction. Alzheimer's Research UK has committed to funding at least £2m in risk reduction research and the Research Councils and other charities will also provide grant funding to the highest quality proposals.

⁴⁵ <https://connect.innovateuk.org/web/dallas>

How will we know that we have made a difference?

Commitment 12: Funding for dementia research on track to be doubled by 2025.

Lead Organisation (and partners)	Action	Start date	What will success look like?
Department of Health/ Department for Business Innovation and Skills/ Charity Partners	Government will invest £300m in dementia research by 2020.	Ongoing	Annual increases in funding from all sources, including Government, charities and the private sector. Annual funding for dementia research doubled by 2025
	Dementia Discovery Fund to invest over £100m globally in drug discovery and development by 2020.	October 2015	
Charity partners	<p>Charities to continue to increase investment and raise awareness to improve public understanding of the value of research and bring in new funds.</p> <p>Alzheimer's Research UK to spend at least £80m between 2014 and 2020 on research into the prevention, cause and cure of dementia.</p> <p>Alzheimer's Society will fund at least £100m in research over the next decade in to cause, care, cure and prevention of all forms of dementia.</p> <p>Other charitable funders including The Wellcome Trust, BHF, Stroke Association, Parkinson's UK to invest in dementia research related to the strategic aims of their organisations.</p>	Ongoing	

Commitment 13: Increased investment in dementia research from the pharmaceutical, biotech devices and diagnostics sectors, including from small and medium enterprises (SMEs), supported by new partnerships between universities, research charities, NHS and the private sector. This would bring world class facilities, infrastructure, drive capacity building and speed up discovery and implementation.

Lead Organisation (and partners)	Action	Start date	What will success look like?
Medical Research Council (MRC)	MRC-DPUK to formalise links with IMI-EPAD and GAP to ensure joint working between key initiatives focused on developing large cohorts for epidemiological research and to create 'trial ready cohorts'.	Ongoing	Annual increases in funding from pharmaceutical and biotech, devices and diagnostic sectors, including SMEs. Annual increases in the number of research partnerships focusing on dementia research.
MRC	DPUK is investing £53m in working collaboratively with biopharmaceutical companies to deliver public-private investment and foster sharing of ideas and insight.	Ongoing	
Alzheimer's Research UK (ARUK)	Dementia Consortium to increase the number of pharmaceutical partners and amount of funding from the current baseline of £3m.	Ongoing	

Commitment 14: Dementia research as a career opportunity of choice, with the UK being the best place for Dementia Research through a partnership between patients, researchers, funders and society.

Lead Organisation (and partners)	Action	Start date	What will success look like?
Alzheimer's Research UK (ARUK)/ Alzheimer's Society/DH/ NHSE/ and Research Councils	Dementia Research Funders Forum to consider strategies for developing capacity in dementia research.	June 2016	Annual increases in the numbers training in dementia research in all relevant professions and disciplines, and at all levels.
Research funders including DH/National Institute for Health Research (NIHR),	DH/NIHR will ensure that the clinical academic training pathway attracts clinicians to pursue clinical academic careers in dementia: NIHR infrastructure will continue to offer research training opportunities, notably within the NIHR Dementia Translational Research Collaboration (TRC-D), and Collaborations for Leadership in Applied Health and Care Research (NIHR CLAHRCs). In addition research awards will continue to be available via open competition, from Research Councils, NIHR and charities.	January 2016	

Commitment 15: Increased numbers of people with dementia participating in research, with 25 per cent of people diagnosed with dementia registered on Join Dementia Research and 10 per cent participating in research, up from the current baseline of 4.5 per cent.

Lead Organisation (and partners)	Action	Start date	What will success look like?
DH/ Alzheimer's Research UK (ARUK)/ Alzheimer's Society/ NHSE/ ADASS	<p>NHSE will continue to work closely with colleagues in NIHR to support the target that 25% of people diagnosed with dementia are registered on Joint Dementia Research (JDR) and to promote products being developed through the JDR SBRI Project (JDR NHS interface and Electronic Health Record interoperability).</p> <p>ARUK and AS continue to send out information on JDR to GPs and Memory Clinics to boost recruitment as well as signpost to JDR through their respective helplines.</p> <p>ADASS will promote opportunities to participate in Dementia research by signing up to JDR through the National Dementia Network, encouraging local authorities to promote opportunities locally.</p>	Ongoing	<p>More people being offered and taking up the opportunity to participate in research, and every person with dementia able to say: 'I know there is research going on which delivers a better life for me now and hope for the future'. 25 per cent of people diagnosed with dementia registered on Join Dementia Research by 2020. 10 per cent of people diagnosed with dementia participating in research by 2020.</p>

Commitment 16: Cures or disease-modifying therapies on track to exist by 2025, their development accelerated by an international framework for dementia research, enabling closer collaboration and cooperation between researchers on the use of research resources – including cohorts and databases around the world.

Lead Organisation (and partners)	Action	Start date	What will success look like?
Alzheimer's Research UK (ARUK)	<p>Support Raj Long to work with international partners to develop a Global Dementia Platform, which will incorporate:</p> <ul style="list-style-type: none"> • Oversight of existing initiatives and an international forum for enhancing collaboration • A strategy and mechanism to deliver collaborative approaches to basic science • An International Advisory Platform to speed up clinical development 	Ongoing	<p>A disease modifying therapy is available to patients by 2025, having successfully proved clinical efficacy and received market authorisation. There are more candidates in the drug discovery pipeline (combined from clinical trial phases 1 – 3) for dementia treatments by 2020 than the baseline in 2015.</p>
Alzheimer's Research UK (ARUK)	<p>ARUK invest £30m in three Drug Discovery Institutes between 2014 and 2019, with the ambition for this funding to continue, and ARUK to invest £20m in a global clinical trials fund.</p>	Ongoing	
MRC	<p>Dementia Platforms UK to grow our cohort resources and help accelerate therapeutic development and testing through more targeted clinical trials. The DPUK is partnered by the pharmaceutical industry.</p> <p>DRI to be established by MRC to promote discovery research to identify new targets for drug and therapeutic development.</p>	Ongoing	

Commitment 17: Open access to all public funded research publications, with other research funders being encouraged to do the same.

Lead Organisation (and partners)	Action	Start date	What will success look like?
DH/NIHR/MRC	All research funded by NIHR and Research Councils to require open access publications (policies are already in place).	Ongoing	All research funded by the NIHR and Research Councils is published in open access publications.

Commitment 18: More research made readily available to inform effective service models and the development of an effective pathway to enable interventions to be implemented across the health and care sectors.

Lead Organisation (and partners)	Action	Start date	What will success look like?
Alzheimer's Society	Commit dedicated funding towards implementation science to ensure more research is translated into service delivery models.	Ongoing	More research outputs on care and services.
	Invest in the development of research programme that evaluate and enhance the quality and effectiveness of health and care interventions.	Ongoing	
Alzheimer's Society/DH	Evaluation and research programmes into the content and effectiveness of Dementia Friends and Dementia Friendly Communities programme.	Ongoing	
DH/NIHR/ESRC	Effective dissemination of ESRC/ NIHR initiative on Living well with Dementia and other research on service models and care, including that carried out by NIHR Collaborations for Leadership in Applied Health Research and Care.	Ongoing	

Annex 1: 18 Key commitments from the Prime Minister's Challenge on Dementia 2020

Commitment 1: An international dementia institute established in England.

Commitment 2: Improved public awareness and understanding of the factors, which increase the risk of developing dementia and how people can reduce their risk by living more healthily. This should include a new healthy ageing campaign and access to tools such as a personalised risk assessment calculator as part of the NHS Health Check.

Commitment 3: In every part of the country people with dementia having equal access to diagnosis as for other conditions, with an expectation that the national average for an initial assessment should be 6 weeks following a referral from a GP (where clinically appropriate), and that no one should be waiting several months for an initial assessment of dementia.

Commitment 4: Every person diagnosed with dementia having meaningful care following their diagnosis, which supports them and those around them, with meaningful care being in accordance with published National Institute for Health and Care Excellence (NICE) Quality Standards. Effective metrics across the health and care system, including feedback from people with dementia and carers, will enable progress against the standards to be tracked and for information to be made publicly available.

Commitment 5: GPs playing a leading role in ensuring coordination and continuity of care for people with dementia, as part of the existing commitment that from 1 April 2015 everyone will have access to a named GP with overall responsibility and oversight for their care.

Commitment 6: All hospitals and care homes meeting agreed criteria to becoming a dementia-friendly health and care setting.

Commitment 7: All NHS staff having received training on dementia appropriate to their role. Newly appointed healthcare assistants and social care support workers, including those providing care and support to people with dementia and their carers, having undergone training as part of the national implementation of the Care Certificate, with the Care Quality Commission asking for evidence of compliance with the Care Certificate as part of their inspection regime. An expectation that social care providers provide appropriate training to all other relevant staff.

Commitment 8: Alzheimer's Society delivering an additional 3 million Dementia Friends in England, with England leading the way in turning Dementia Friends in to a global movement including sharing its learning across the world and learning from others.

Commitment 9: Over half of people living in areas that have been recognised as Dementia Friendly Communities, according to the guidance developed by Alzheimer's Society working with the British Standards Institute. Each area should be working towards the highest level of achievement under these standards, with a clear national recognition process to reward their progress when they achieve this. The recognition process will be supported by a solid national evidence base promoting the benefits of becoming dementia friendly.

Commitment 10: All businesses encouraged and supported to become dementia friendly, with all industry sectors developing Dementia Friendly Charters and working with business leaders to make individual commitments (especially but not exclusively FTSE 500 companies). All employers with formal induction programmes invited to include dementia awareness training within these programmes.

Commitment 11: National and local government taking a leadership role with all government departments and public sector organisations becoming dementia friendly and all tiers of local government being part of a local Dementia Action Alliance.

Commitment 12: Funding for dementia research on track to be doubled by 2025.

Commitment 13: Increased investment in dementia research from the pharmaceutical, biotech devices and diagnostics sectors, including from small and medium enterprises (SMEs), supported by new partnerships between universities, research charities, NHS and the private sector. This would bring world class facilities, infrastructure, drive capacity building and speed up discovery and implementation.

Commitment 14: Dementia research as a career opportunity of choice, with the UK being the best place for Dementia Research through a partnership between patients, researchers, funders and society.

Commitment 15: Increased numbers of people with dementia participating in research, with 25 per cent of people diagnosed with dementia registered on Join Dementia Research and 10 per cent participating in research, up from the current baseline of 4.5 per cent.

Commitment 16: Cures or disease-modifying therapies on track to exist by 2025, their development accelerated by an international framework for dementia research, enabling closer collaboration and cooperation between researchers on the use of research resources – including cohorts and databases around the world.

Commitment 17: Open access to all public funded research publications, with other research funders being encouraged to do the same.

Commitment 18: More research made readily available to inform effective service models and the development of an effective pathway to enable interventions to be implemented across the health and care sectors.

You may re-use the text of this document (not including logos) free of charge in any format or medium, under the terms of the Open Government Licence. To view this licence, visit www.nationalarchives.gov.uk/doc/open-government-licence/

© Crown copyright 2016

Published to gov.uk, in PDF format only.

www.gov.uk/dh