



# Dementia 2020 Challenge: 2018 Review Phase 1

Published 22 February 2019

## Contents

1. Introduction: Background .....	2
The Dementia 2020 Challenge and the 2018 Review .....	2
2. The Progress of the Challenge So Far: Summary of responses to Q1 by theme .....	5
A. Risk Reduction and Prevention.....	5
B. Health and Care Delivery .....	7
C. Dementia Awareness and Social Action (including Dementia Friends and Dementia-Friendly Communities).....	12
D. Research (including funding) .....	16
3. Plans for meeting the Challenge's Commitments by 2020 .....	21
Revised actions .....	21
List of organisations that responded to the stocktake .....	26

# 1. Introduction: Background

## The Dementia 2020 Challenge and the 2018 Review

- 1.1 In 2015, the Dementia 2020 Challenge was launched. The Challenge aims to make England, by 2020, the best country in the world for dementia care, support, research and awareness. The Challenge identified 18 key commitments under four themes: Dementia Awareness; Health and Care Delivery; Risk Reduction; and Research and Funding.
- 1.2 The subsequent 2016 Implementation Plan set out a series of commitments and objectives for a range of organisations. You can read more about the Challenge on the [implementation plan webpage](#).
- 1.3 Since then, significant progress has been made. The Dementia Diagnosis Rate is above the Challenge's target of 66.7%. There are now 2.78 million Dementia Friends and 412 Communities have committed to becoming Dementia Friendly in England and Wales (as of January 2019), and over one million NHS staff have attended dementia awareness raising sessions.
- 1.4 Progress of the Challenge is overseen by the Dementia Programme Board, which is chaired by the Minister of State for Care, and includes delivery partners from across Government, health, social care, research and the charitable sector.
- 1.5 In the Dementia 2020 Challenge: Implementation Plan, we committed to conduct a Review during 2018 to "assess whether we have achieved the actions included in the plan. It will also look ahead to the actions up to 2020 and develop more detailed delivery plans for them."

## The 2018 Review

### Our Approach

- 1.6 The Review is composed of two Phases; the first Phase, the Stocktake, reflects on the progress of the Challenge between 2015 and 2018, and identifies the revised actions to fulfil the Commitments by 2020. The second Phase will be a forward look to the potential next stage of the Challenge, beyond 2020.
- 1.7 To support the Stocktake phase of the Review, we devised a set of questions in April 2018 and created a questionnaire on Citizenspace, our government digital platform. The commitments were divided into four themes: Dementia Awareness; Health and Social Care; Risk Reduction; and Research (including funding).

## What we asked

- 1.8 Respondents were asked for their views on what progress had been made on the Commitments; whether the Commitments could be achieved by 2020; and what actions should be prioritised to help deliver the Commitments by 2020. Respondents were also asked to identify priorities for beyond 2020, which will be addressed in Phase 2 of the Review.
- 1.9 The stocktake phase closed on 2nd May and a total of 17 responses from a range of delivery partners, stakeholders and their members were received.

**Table1: Number of responses received**

Theme	No. of responses to Q1	No. of responses to Q2	No. of responses to Q3
Dementia Awareness & Social Action	11	11	10
Health & Care	16	14	14
Research	12	11	11
Risk Reduction	9	10	9

- 1.10 The Department of Health and Social Care (DHSC) then collated the responses in table form and analysed the responses for common themes and actionable points, including the relevant organisations to take them forward. DHSC contacted the organisations identified to inform them of the findings to allow time to prepare for further discussions at the Dementia Programme Board.
- 1.11 The Dementia Programme Board made comments on the new actions identified during the stocktake as being needed to drive progress up until 2020 and ensure that the commitments are met.
- 1.12 This Stocktake Report is the output of the first Phase of the Review and builds upon the 2020 Challenge and Implementation Plan. It does not establish new commitments or objectives, but adds detail on actions needed to meet the ambitions initially set out in 2015.
- 1.13 The actions identified in the Report will build upon previous and ongoing work by delivery partners, and will be added to the implementation plan, the progress of which is monitored by the Dementia Programme Board.

1.14 The content of this Report was presented to and approved in principle (subject to preparation of a final draft for publication) by the Dementia Programme Board in October 2018.

## 2. The Progress of the Challenge So Far: Summary of responses to Q1 by theme

### A. Risk Reduction and Prevention

#### The Commitments

- 2.1 There is a growing body of evidence to suggest that it is possible to reduce an individual's 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. With this in mind, healthcare practitioners and public health bodies can aid the population to reduce or mitigate their risk of developing dementia, along with other conditions such as diabetes.
- 2.2 The Challenge seeks to improve public awareness of the risk factors associated with developing dementia, as well as promote healthy ageing.

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.

#### Respondents' Assessment of Progress

- 2.3 National delivery partners and stakeholders were asked to answer the following questions. Their collated and summarised responses are below.
- (a) Do you think we are on track to meet the Commitments in the Dementia 2020 Challenge?
- (i) Can you share any evidence that shows if we are/are not on track?
- (ii) Do you think the objectives are achievable by 2020?
- 2.4 Overall, respondents felt that we are on track to meet this target; however, there is still work to be done to help reduce risk in high-risk but not yet reached communities, particularly members of Black and Minority Ethnic (BAME) and non-

English speaking communities, or people who are already identified as having factors associated with an increased risk of developing dementia.

## **NHS Health Check**

- 2.5 The 'One You' campaign focuses on risk factors that most people can address within their daily lives and the NHS Health Check helps identify dementia risks and assist individuals in lowering them. However, some respondents raised concerns that there are a number of people who are 'at risk' of dementia that are not sufficiently engaged in "health" to utilise this service. These respondents highlighted particular issues in BAME and non-English speaking communities and other not yet reached groups.

## **Public Messaging**

- 2.6 Respondents expressed that there is still a gap in public understanding of the link between lifestyle behaviours and dementia risk and there are reports that citizens are not taking on board the risk reduction advice. This is countered by concerns of "patient-blaming" with the perception that someone living with dementia could have done more to avoid the condition. Respondents also raised concerns regarding missed opportunities in existing messaging, such as the One You initiative that has a lack of specificity about how risk factors might influence individual diseases or conditions. In light of the responses received, we believe it would be appropriate to continue to explore ways to measure levels of public awareness of dementia, and how to reduce their risk of developing the condition.
- 2.7 Importantly, many respondents expressed additional concerns about accessibility and health inequalities, including providing information resources in more languages, including South Asian languages (such as Hindi and Punjabi) and Arabic. Respondents reported that the level of public health funding is a further barrier to spreading the message and there is concern amongst most contributors that we will not be able to wholly achieve this commitment despite the good progress being made. It would be appropriate to focus on engaging these groups with prevention messages.

## **Training and Support**

- 2.8 Most adult social care providers reported that meeting this commitment would require increased awareness, education and training for the NHS and social care workforce to see improvement in this area.

## B. Health and Care Delivery

### The Commitments

2.9 The Challenge's ambition is for every person with dementia, and their carers and families, to receive high quality and compassionate care from diagnosis to end of life; with consistent access and care standards across the country. It aims for people with dementia to be involved with their care decisions, and for a focus on their wellbeing and quality of life to underpin the commissioning and providing of dementia services.

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

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.

## **Respondents' Assessment of Progress**

- 2.10 National delivery partners and stakeholders were asked to answer the following questions. Their collated and summarised responses are below.
- (a) Do you think we are on track to meet the Commitments in the Dementia 2020 Challenge?
- (i) Can you share any evidence that shows if we are/are not on track?
- (ii) Do you think the objectives are achievable by 2020?

## **Dementia diagnosis rate**

- 2.11 The Challenge focusses on increasing the dementia diagnosis rate, to bring it into parity with other conditions, with two-thirds of the estimated number of people with dementia to receive a diagnosis, to enable them to access the right care at the right time. It also set out an ambition to increase the proportion of individuals who receive an initial assessment (following GP referral) within 6 weeks.
- 2.12 All respondents recognised the increased dementia diagnosis rate as a key achievement of the Challenge, as the national rate has been above the ambition of 66.7% since July 2016, with an ongoing commitment from partners to continue to increase the number of diagnoses.
- 2.13 Respondents acknowledged the excellent progress that has been made so far, but emphasised the inconsistency in the diagnosis rate across the country, with variation between localities. However, it was noted that this variation has also reduced since 2015.
- 2.14 Respondents also proposed exploring dementia diagnosis in more detail: enhancing ethnicity data, reviewing whether a new prevalence measure is required and exploring how to diagnose young onset dementia more effectively. Exploring how dementia metrics can inform and be included in the Clinical Commissioning Group Impact Assessment Framework (CCG IAF) was also highlighted.

## **Referral Ambition**

- 2.15 The Commitment relating to increasing the proportion of people who are assessed within 6 weeks of referral is now being measured, (as of summer 2018), through revised Mental Health Services Data Set coding. This will provide an indication of waiting times for assessment in due course.

## Regional Targets

- 2.16 Overall, the commitment has been met nationally, but additional focus is required to bring all regions into line with the ambition, and to reduce variation across the country. It would be appropriate to focus on the uptake of the dementia support offer currently available to improve dementia diagnosis rates and other metrics, and to consider, in due course, the implications of new intelligence regarding prevalence, being collated by Alzheimer's Society and Alzheimer's Research UK. It would also be appropriate to consider how we could better capture information on identification and diagnosis of young onset dementia, including building upon existing work on prevalence and diagnoses rates; and how primary care can be better equipped to diagnose young onset dementia.

## Meaningful Care

- 2.17 Meaningful care after a diagnosis of dementia has been made underpins the quality of life and standards of care that people living with dementia and their families can expect and partners recognise it as a key commitment in the Challenge. The Challenge aims to deliver meaningful care to all people with dementia, in line with National Institute for Health and Care Excellence (NICE) guidance.
- 2.18 Respondents reported that improvements have been made to post-diagnostic support since the launch of the Challenge, and there are examples of excellent care. However, standards of care still vary greatly across the country.
- 2.19 Respondents stated that work is still needed to ensure people with dementia and their families/carers can access information and consistent, high quality post-diagnostic support.
- 2.20 A range of factors were highlighted by respondents as potential barriers to achieving the commitment, including a transient workforce, restricted budgets and increasing demand for beds and nursing. Respondents said that hospital care for people with dementia, and end of care life planning, still needed further improvement. Respondents recommended continued implementation of NICE guidelines, more focus on end of life care, and linking dementia care and housing needs as early as possible.
- 2.21 Respondents highlighted the need to complete the delivery of, and monitor, the recommendations of the Meaningful Care Task and Finish Groups. These groups identified pragmatic, achievable, high impact changes to improve the post-diagnostic care in three key areas: Clarity of the offer for commissioners, providers

and people affected by dementia; Experience and satisfaction measures; and supporting the development of a skilled workforce.

- 2.22 Overall, respondents felt progress has been made but there are still challenges to overcome to ensure people with dementia receive meaningful care. Respondents felt that the recommendations made by the Meaningful Care Task and Finish Groups should be delivered and incorporated into the existing tracker for the Challenge.

## **Dementia data and metrics**

- 2.23 The Challenge aims to establish effective metrics across the health and care system, to track progress against the commitments, and to make the data publicly available.
- 2.24 Respondents agreed that the quality and range of dementia data has significantly improved since 2015, enhanced by the launch of the Dementia Intelligence Network. A number of key activities, for example the creation of the Public Health England Fingertips Dementia Profile, have been completed and the commitment to improve data collection and reporting is considered to be on track.
- 2.25 Respondents identified the potential to develop metrics relating to carers, enhance ethnicity data collection and establish ways to monitor delivery of meaningful care, some of which is already being pursued by delivery partners. Some respondents sought more clarity as to how the new metrics were being used to drive progress and improve quality.
- 2.26 Overall, respondents felt good progress has been made and the commitment is on track, but there are areas of opportunity to enhance the data available further.

## **Dementia Friendly hospitals and care homes**

- 2.27 The Challenge set out the ambition for all hospitals and care homes to meet established criteria to be considered as being 'dementia friendly' health and care settings.
- 2.28 Generally, respondents reported that hospitals and care homes were willing to engage with the programme and that the commitment is mostly on track to be achieved, particularly with the reinvigorated approach to the [Charter](#) in 2018 by the National Dementia Action Alliance (NDAA).
- 2.29 Respondents emphasised the need for a particular focus on hospital care, where people with dementia are still experiencing care that they felt fell short of the 2020

ambitions, as identified in the [National Audit of Dementia 2017](#) by the Royal College of Psychiatrists, for example not meeting the nutritional needs of people with dementia, and not assessing the patient for delirium.

- 2.30 Overall, the commitment is considered to be on track but there needs to be additional support from national partners to meet the aims, and to ensure that the principles of Dementia Friendly hospitals are embedded and that the dementia friendly charter is not seen to be a 'tick box' exercise.

## Training

- 2.31 The Challenge aims for all NHS staff to receive dementia training appropriate to their role, for new healthcare assistance and social care support to undergo training as part of the Care Certificate, and for the Care Quality Commission to ask for evidence of compliance as part of their inspection.
- 2.32 Respondents reported that significant progress has been made in meeting this commitment, with 98% of training programmes including Tier 1 training, and 85% of homecare and residential staff who regularly work with people with dementia having now completed Tier 1 training. Passing the milestone of one million health care staff trained in Tier 1 was recognised as a key achievement.
- 2.33 Around 50% of the direct social care workforce have also received Tier 2 training, but under current arrangements it was considered unlikely that the entire workforce would receive the necessary level of training by 2020.
- 2.34 Although good progress is being made against the commitment and it is largely on track, respondents reported that a continued focus is required to achieve the commitment, and additional support such as ring-fenced time, additional resource, and mandated training could be implemented to maximise uptake.
- 2.35 Respondents also reported the need to ensure training is meaningfully embedded and that participants are given the opportunity to put their learning into practice. [The Dementia Core Skills Education and Training Framework](#), updated in 2018 and now known as the 'Dementia Training Standards Framework' needs to be continued to be used within health and care settings. Some respondents commented that there should be more ambitious targets set for the Tier 2 to be a baseline minimum training requirement for all staff that care for people with dementia.
- 2.36 Overall, respondents felt significant progress has been made but there are still some examples of health and care staff not fully equipped to fully care for and support people with dementia. A sustained focus is needed to maintain momentum, and fully embed the Framework and continue to drive improvements.

## **GPs taking a leading role**

- 2.37 The Challenge set out the ambition for GPs to play a leading role in ensuring co-ordination and continuity of care.
- 2.38 Respondents welcomed the publication of the [dementia treatment and care pathway](#) (Feb 2017) and the Care Plan template for dementia, with its focus on quality of GP care plans. Respondents were not specific as to whether the commitment was 'on track' but did highlight the inconsistent quality of support provided by GPs across the country, and their lack of capacity to fulfil their role as leaders in co-ordinating care.
- 2.39 Respondents recommended further training and support for GPs to implement quality care plans, particularly in areas where diagnosis rates are low.
- 2.40 Overall, there have been improvements but respondents felt that GPs could take more ownership and more of a leading role in coordinating care. Therefore it would be appropriate to consider whether this commitment should be modified by looking at alternative ways to coordinate dementia care, for example, with other staff groups being more involved.

## **C. Dementia Awareness and Social Action (including Dementia Friends and Dementia-Friendly Communities)**

### **The Commitments**

- 2.41 The 2020 Dementia Challenge committed to promoting awareness and understanding of dementia, building social action through the actions of individuals, communities and businesses. It emphasised the need for continued engagement with businesses to encourage them to play their part in creating a dementia friendly society, to continue to support areas in their on-going work to become Dementia Friendly Communities, and for national and local government to take a lead to promote Dementia Friendly programmes.

Commitment 8: Alzheimer's Society delivering an additional 3 million Dementia Friends in England, with England leading the way in turning Dementia Friends into 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.

## Respondents' Assessment of Progress

2.42 National delivery partners and stakeholders were asked to answer the following questions. Their collated and summarised responses are below.

- (a) Do you think we are on track to meet the Commitments in the Dementia 2020 Challenge?
  - (i) Can you share any evidence that shows if we are/are not on track?
  - (ii) Do you think the objectives are achievable by 2020?

## Dementia Friends

2.43 Dementia Friends is an initiative run by the Alzheimer's Society, which equips those who take part with more understanding of what dementia is and the small ways they can help, and turns that understanding into action. The Challenge commits to turning Dementia Friends into a global movement, and reaching 4 million Dementia Friends in England by 2020.

- 2.44 Most respondents explicitly acknowledged the good progress of this commitment, and that it had made a difference in raising awareness about dementia.
- 2.45 The respondents which discussed whether the commitment was on track reported that they believed that it was, with some suggesting the commitment would only be met if additional support to the initiative was offered, including additional promotion of the Friends programme and successful approaches to recruiting people to take part (including as trainers) ; and an enhanced focus on recruiting Dementia Friends by delivery partners, including central government.
- 2.46 Some respondents proposed widening the scope of the commitment to encompass other awareness raising activities, such as education based approaches and promoting dementia and arts, and acknowledged that awareness of dementia and how to prevent it was still relatively low amongst the general public.
- 2.47 Some respondents also sought to establish the impact of the Dementia Friends programme in changing the day to day life of people with dementia and their carers.
- 2.48 Overall, none of the respondents felt that the commitment needed revising but suggested that additional support may be required to meet the ambition to have 4 million dementia friends in England by 2020, but that overall the commitment should be achievable. All respondents agreed that the delivery partner, Alzheimer's Society, had made significant progress expanding the Dementia Friends network to 2.78m as of January 2019. On the current trajectory there should be 3.25million Dementia Friends by 2020.
- 2.49 It would be appropriate to develop additional actions relating to the impact assessment of dementia friendly programmes.

## **Dementia Friendly Communities**

- 2.50 The Dementia Friendly Communities initiative, run by the Alzheimer's Society, encourages communities to sign up and work on the continuous process of being dementia-friendly, improving inclusion and quality of life for people with dementia. The Challenge committed to over half of England's population to be living in a Dementia Friendly Community by 2020, underpinned by evidence based standards.
- 2.51 The delivery partners reported good progress for the Dementia Friendly Communities programme. Technically, the Commitment has already been met, with over half of all of England's population (65%) now living in communities committed to the ongoing work of being Dementia Friendly. In 2016, there were

132 areas signed up to becoming Dementia Friendly Communities (31% of England's population); in 2019 there are 346 (65%). However, these communities have committed to become dementia friendly and therefore are not yet fully dementia friendly. Being dementia friendly is an ongoing process with milestones but no defined "end".

- 2.52 Other respondents recognised the success of the National Association of Local Councils signing a commitment to encourage uptake of Dementia Friendly Communities. Some respondents, similarly to the Dementia Friends commitment, believed that additional central government leadership would build on the success of the programme, and that additional promotional work was needed to articulate the required standards of a Dementia Friendly Community, and what benefits it can bring.
- 2.53 Overall, the commitment was deemed to be on track and still to be relevant and appropriate.

## **Dementia Friendly Businesses**

- 2.54 Dementia Friendly Businesses is Alzheimer's Society's programme to encourage businesses to focus on how people, processes and places can become Dementia Friendly. Over 11,000 organisations (as of April 2018) have committed to becoming Dementia Friendly, indicating the expansive progress of this Commitment.
- 2.55 Overall, respondents felt that the commitment was on track and the delivery partner reported it to be achievable. Respondents stated that additional encouragement from central government for businesses to become Dementia Friendly would be welcomed, and could be incentivised through regulatory bodies and industry frameworks.

## **Dementia Friends in local and central government**

- 2.56 National and local government committed to take a leadership role in the Challenge, expanding the Dementia Friends programme in their workforce and for local government taking part in their Dementia Action Alliance.
- 2.57 The Alzheimer's Society estimated that 30-35,000 Dementia Friends have been trained through the civil service Dementia Friends programme. Overall, respondents reported that although progress has been made, some felt that progress has slowed and that it would require reinvigoration to ensure that central and local government are leaders in becoming dementia friendly. Respondents felt that options for making more progress in this area could include incorporating

dementia friends into formal training for new certain groups of central or local government employees and setting a target for the percentage of central and local government employees to become Dementia Friends.

- 2.58 Respondents suggested it would be appropriate for The Alzheimer's Society to continue to work with DHSC to establish accurate civil service Dementia Friends baselines and set goals based on numbers or percentages of employees becoming dementia friends up until 2020.

## **D. Research (including funding)**

### **The Commitments**

- 2.59 The Dementia 2020 Challenge sets the ambition to see total research funding from all sources on track to double by 2020. We are delivering new research infrastructure to support and catalyse research, and to 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. The Challenge is helping to transform and expand the field, to deliver better care and treatments.

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.

## Respondents' Assessment of Progress

- 2.60 This commitment is on target to be met, although some respondents felt that the current funding target was not sufficiently ambitious.
- 2.61 The UK Dementia Research Institute is funded by the Medical Research Council, Alzheimer's Society and Alzheimer's Research UK, a total of £290m investment. Additionally, Government funding for dementia research doubled to around £60m per year under the Prime Minister's Challenge on Dementia, with the Government's Dementia 2020 Challenge committed to maintain this level of spending to 2020.

## Funding

- 2.62 With regard to funding for research, the commitment is being met and will be met if research spending continues at the current rate; however, respondents expressed concern that Brexit has created uncertainty about the immediate and long-term future of dementia research in the UK. However, the Dementia Research Institute report recognised that great strides have been made to ensure dementia research is a career of choice and thus this commitment is likely to be met.
- 2.63 The political uncertainty and set-backs in clinical trials, as well as the nature of the work, led many respondents to reiterate that whether we will have a disease modifying drug or cure for dementia by 2020 is difficult to predict, and respondents could not unequivocally state whether this ambition as set out in the Challenge could be met.
- 2.64 Respondents reported that the commitment for 25% of people diagnosed with dementia to be registered with the Join Dementia Research database is extremely unlikely to be met. Figures for registrations are currently low, and if this trend remains unchanged, the target will be missed by a considerable margin. This may in turn affect the success of other commitments, such as the Commitment to have a cure or disease modifying therapy by 2020. However, it should be noted that there are other routes into research programmes other than Join Dementia Research, and the combined research recruitment figures are largely on course. It

should also be noted that the main objective here is for people to participate in research not just to have registered an interest.

- 2.65 It would be appropriate to increase focus on recruitment to research projects up until 2020.
- 2.66 Respondents were keen to point out the need to conduct further research into the social aspects of dementia and not just the drug treatments. This commitment is on target to be met following contributions from non-pharmaceutical bodies.
- 2.67 The commitment to double funding by 2020 is on track to be met. However, some respondents felt that the current target was not sufficiently ambitious.

## **Brexit**

- 2.68 Respondents noted that the outcome of the Brexit negotiations will certainly have an impact on the research industry but until the agreement is finalised, we cannot be certain on the effects. However, most respondents to this question had concerns about access to funding as well as uncertainty around future mobility of researchers to gain international experience and bring learning back to the UK.

## **Treatment research**

- 2.69 The feedback from respondents involved with research indicated that it is difficult to predict whether this commitment (Cures or disease-modifying therapies on track to exist by 2025) is achievable due to its dependence on so many other factors. However, success in other commitments relating to funding, disseminating knowledge, and increasing numbers of people with dementia on the Join Dementia Research database, will help realise a cure or disease-modifying treatment, but potentially not in the time frame stipulated.
- 2.70 There have been a number of set-backs in clinical trials, including a number of drug trials that have failed and led the pharmaceutical industry to concentrate on mild cognitive impairment and the preclinical stages of the disease.
- 2.71 However, more drug trials are taking place including several in the late stages of clinical development, which, if successful, could bring about the first disease-modifying treatment by 2025.

## **Non-treatment research**

- 2.72 There has been substantial investment from non-pharmaceutical companies and organisations into dementia research and the Alzheimer's Society has published a

[roadmap](#) considering research away from new treatments that is required to improve the lives of people affected with dementia now and to reduce the risk for future populations.

- 2.73 The responses indicated that this investment will fund the care component of the Dementia Research Institute to look more at the social rather than medical aspects of dementias.

## Recruitment – patients

- 2.74 Currently only an estimated 1% of people with dementia are on the Join Dementia Research database so there are concerns that this commitment in its current iteration will be not met. However, combined with other research databases, the total number of people volunteering for research programmes means that the overall commitment is likely to be met with further work to maintain levels of recruitment generally (not just for JDR).
- 2.75 Respondents highlighted the difficulties in recruiting people into research both before and after diagnosis but noted that it is easier to do it in university towns, primarily due to the relative proximity of research facilities.
- 2.76 Some respondents commented that the lack of progress on this commitment alone is having a negative impact on other commitments, such as Commitment 16, (Cures or disease-modifying therapies on track to exist by 2025) as some studies are being delayed by up to one or two years due to insufficient suitable participants for the research.

## Recruitment – career

- 2.77 Responses indicated that the Dementia Research Institute will be a major attraction for healthcare researchers and the National Office for Dementia Research has created a website aimed to support early career researchers and attract and retain them in dementia research. Figures from 2017 show that the number of UK researchers has increased and attribute the high profile investments, increased awareness of dementia, global improvement in research techniques and the launch of the Dementia Research Institute as contributing factors to this, with dementia research becoming a career of choice.

## Information Sharing

- 2.78 Respondents report that a lot of progress has been made to share information and findings from trials and studies. The general consensus from the respondents was that this commitment is achievable by 2020, if some further actions are completed.

2.79 Respondents also responded that there is considerable work already being undertaken to make raw data of studies available.

### **3. Plans for meeting the Challenge's Commitments by 2020**

3.1 As part of the 2018 Review, stakeholders and national partners were asked to identify actions to help meet the commitments outlined in the Challenge by 2020. National partners and stakeholders were asked to respond to the following questions.

What actions do you think we need to prioritise to ensure we meet our commitments by 2020?

(i) Which organisations are best placed to take these forward?

(ii) Are new actions required to meet the commitments?

3.2 Any proposed new actions or changes to current ones were not intended to be new commitments per se, but instead build upon the work already completed between 2015 and 2018, with an aim to fulfil the Commitments already established in the Challenge. These revised or additional actions should drive progress in the final two years of the Challenge, between 2018 and 2020.

3.3 All proposed actions were reviewed and collated. From these collated proposed actions, ten actions were agreed as key focus points up until 2020. They have been identified as key levers to drive progress for the Challenge until 2020.

3.4 The ten revised actions were discussed with and approved by the Dementia Programme Board in July 2018.

#### **Revised actions**

3.5 The actions listed below have been identified as the top 10 revised actions up until 2020. These have been formulated as part of Phase 1, in response to the stocktake and in consultation with delivery partners. All identified revised actions have been agreed by the Dementia Programme Board and added to the Programme tracker for governance purposes.

## A. Risk Reduction and Prevention

Comm.	Current (reads in the tracker)	New (revised action in the tracker)	Date	Proposed owner
1	Risk Reduction: Improved public awareness and understanding of risk factors. Metrics will show improved awareness of dementia risk reduction and improved quality of dementia component of the NHS Health Check	Establish metrics to indicate public awareness levels of dementia and prevention, potentially exploring the use of the Dementia Attitudes Monitor (ARUK) and other current data. PHE are best placed to collate and manage the data, informed by ARUK and AS.	By 2020	Public Health England (PHE)  Alzheimer's Research UK (ARUK)  Alzheimer's Society (AS)  NHS England
1	Risk Reduction: Improved public awareness and understanding of risk factors. Metrics will show improved awareness of dementia risk reduction and improved quality of the dementia component of the NHS Health Check	Establish ways to engage with groups not yet reached e.g. Black And Minority Ethnic and non-English speaking groups; people with differing communication needs; people with mental or physical health challenges; those living in Gypsy and traveller communities, with dementia prevention messages offering alternative languages and adjusting to cultural differences and producing support literature appropriate to differing cultures and in a wider range of languages, including through the NHS Health Checks programme.  The not yet reached groups will be identified by the metrics above and the overall aim will be to achieve parity in risk reduction across the population	By 2020	PHE  AS  Association of Directors of Adult Social Services (ADASS)  Race Equality Foundation

## B. Health and Care Delivery

Comm.	Current (reads in the tracker)	New (revised action in the tracker)	Date	Proposed Owner
2	Equal access to diagnosis as for other conditions	Conduct exploratory work to develop a better understanding of young onset dementia, including prevalence and diagnostic rate, and training needs for primary care, building upon current research into commissioning a new prevalence measure	By 2020	AS ARUK PHE Young Dementia Network
2	Equal access to diagnosis as for other conditions	Establish the uptake of NHS England support for CCGs who are not meeting the dementia diagnosis rate, and how uptake can be increased, in order to improve diagnostic rate consistency  To consider new intelligence regarding prevalence by AS and ARUK and adopt a new calculator if appropriate	By 2020	NHS England AS NHS England ARUK AS
3	GPs playing a leading role in ensuring coordination and continuity of care for people with dementia. Improved training and support for primary care. GPs to support the development and implementation of personalised care plans.	Review the role of GPs in dementia care and coordination, and assess whether they or other staff groups are best placed to take this role through dialogue with key partners. If appropriate, amend commitment after discussions and approval of Dementia Programme Board. Continue to support the development and implementation of care plans.	By 2020	NHS England DHSC
4	1. Meaningful Care Group established (Q2	Agree finalised outputs from the Meaningful Care	By 2020	DHSC

<b>Comm.</b>	<b>Current (reads in the tracker)</b>	<b>New (revised action in the tracker)</b>	<b>Date</b>	<b>Proposed Owner</b>
	2016/17) 2. Outputs from the 3 Meaningful Care Task and Finish groups delivered (Q1 2018/19)	Task and Finish Groups and add these to the tracker		
5	People with dementia and their carers will be supported by health and care staff in all types of service that will have undertaken the appropriate level of dementia awareness and training.	Conduct a scoping study to develop a tier 2 training offer for social care staff (currently underway)	By 2019	Skills for Care (SfC)  Social Care Institute for Excellence (SCIE)

### **C. Dementia Awareness and Social Action (including Dementia Friends and Dementia Friendly Communities)**

<b>Comm.</b>	<b>Current (reads in the tracker)</b>	<b>New (revised action in the tracker)</b>	<b>Date</b>	<b>Proposed Owner</b>
7	An additional 3 million Dementia Friends in England, with England leading the way in turning Dementia Friends into a global movement, with a total of 4m Dementia Friends made.	Maximise the impact of the Dementia Friends programme: 1. Conduct an impact assessment to identify the most effective ways to deploy existing DFs; and to identify high impacts areas upon which to focus DF recruitment efforts. 2. Compare the ambition of 4 million DF with international examples	By 2020	AS
10	National and local government taking a leadership role with all government departments and public sector organisations becoming dementia friendly	DHSC will continue to work with Alzheimer's Society and Civil Service Learning to establish accurate numbers of civil servants completing Dementia Friends sessions, including through the	By 2020	AS  DHSC

<b>Comm.</b>	<b>Current (reads in the tracker)</b>	<b>New (revised action in the tracker)</b>	<b>Date</b>	<b>Proposed Owner</b>
	and all tiers of local government being part of a local Dementia Action Alliance.	Civil Service Learning platform: 1. Establish accurate number of current civil service Dementia Friends 2. In light of accurate baseline, set appropriate ambition for Dementia Friends in the civil service. 3. After ambition is agreed, DHSC to work with wider Civil Service to deliver ambition e.g. through induction training		Local Government Association

## D. Research

<b>Comm.</b>	<b>Current (reads in the tracker)</b>	<b>New (revised action in the tracker)</b>	<b>Date</b>	<b>Proposed Owner</b>
15	More people living with dementia participating in research, with 25% of people diagnosed with dementia registered on Join Dementia Research and 10% participating in research, up from the current baseline of 4.5%	Participation in research should be the primary focus with 10% of the number diagnosed being involved in dementia studies. Reaching out to those diagnosed with dementia to participate in dementia research is important, via Join Dementia Research and other methods, the supporting target being 25% of the number of people with dementia diagnosis registered on Join Dementia Research.  To continue to develop the use of Join Dementia Research and the Join Dementia Research 'brand' as an important mechanism to promote/raise awareness of research and the benefits of participating in research.	By 2020	NIHR  DIG (with assistance from ARUK and AS)

# List of organisations that responded to the stocktake

- Association of Directors of Adult Social Services
- Alzheimer's Research UK
- Alzheimer's Society
- British Geriatrics Society
- National Dementia Action Alliance\*
- Dementia Industry Group\*\*
- Dementia UK
- Health Education England
- Hospice UK
- Housing Learning and Improvement Network
- Local Government Association
- Medical Research Council
- NHS England
- National Institute for Health Research: National Director for Dementia Research
- Public Health England
- Skills for Care
- South Devon and Torbay Clinical Commissioning Group and New Devon and Devon County Council

\*The following members of National Dementia Action Alliance responded to the stocktake review:

- RMBI Care Company

- Royal College of Nursing
- The Butterfly Scheme
- Care England
- Solicitors for the Elderly
- Alzheimer's Research UK
- Royal College of General Practitioners
- Arts 4 Dementia
- Dementia Adventure
- Memory Tracks Ltd

\*\*At the time of response, the Dementia Industry Group was comprised of the following members:

- Biogen
- Eisai
- Janssen
- MSD
- Otsuka
- Roche

© Crown copyright 2019

Published to GOV.UK in pdf format only.

Dementia and Disabilities Unit

[www.gov.uk/dhsc](http://www.gov.uk/dhsc)

This publication is licensed under the terms of the Open Government Licence v3.0 except where otherwise stated. To view this licence, visit [nationalarchives.gov.uk/doc/open-government-licence/version/3](http://nationalarchives.gov.uk/doc/open-government-licence/version/3)

Where we have identified any third party copyright information you will need to obtain permission from the copyright holders concerned.

