

Dementia today and tomorrow
A new deal for people with
dementia and their carers



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This Report has been prepared by the Deloitte LLP (“Deloitte”) Centre for Health Solutions (the Centre) in conjunction with the Alzheimer’s Society. It has been prepared under the Pro-Bono Terms of Business Agreement dated 25 July 2014. The Report is based on evaluating and interpreting two roundtable discussions attended by leading experts in the field of dementia, supplemented by a survey of attendees and a wider group of leading experts to understand what improvements have been seen in dementia care since the launch of the five year dementia strategy in February 2009. The Report is provided exclusively for the Alzheimer’s Society under the terms of the agreement. No party other than the Alzheimer’s Society is entitled to rely on the Report for any purpose whatsoever and the Centre accepts no responsibility or liability or duty of care to any party other than the Alzheimer’s Society in respect of the Report or its contents. The scope of the independent analysis has been limited by the discussion that took place at the roundtable, the information provided by the survey respondents and evaluation of relevant literature. The completed questionnaires are held by the Alzheimer’s Society who retain ownership of and are responsible for their security and any further use.

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Foreword

Dementia today and tomorrow: A new deal for people with dementia and their carers has been produced by the Deloitte UK Centre for Health Solutions and Alzheimer's Society. The report presents the outcome of a series of events and initiatives aimed at collecting the views of people with an interest in continuing to drive improvements in services for people with dementia and those caring for them. As a result the report reflects the views of the individual participants and does not necessarily mean endorsement by the organisations to which they belong.

Launched in February 2009, the Department of Health's five year strategy, *Living well with dementia: a national dementia strategy for England*, was the first of its kind in the UK. The strategy included 17 objectives developed in the wake of reports by the National Audit Office and Alzheimer's Society which demonstrated the enormous scale of the challenge of dementia and the inadequacy of the response to it. The strategy received a significant boost when the Prime Minister launched his three year challenge on dementia in 2012. This was reinforced still further in February 2015 with the launch of the next phase of his dementia challenge, which acknowledges the progress made to date and sets out what more needs to be done.

Today, an estimated 850,000 in the UK have dementia (both diagnosed and undiagnosed), 62 per cent of whom have Alzheimer's disease. There are also some 670,000 people acting as primary carers for people with dementia. These figures are set to rise dramatically over the coming years as the UK's population ages. Recently published research by Alzheimer's Society puts the likely number of people with dementia at over one million by 2021. As the number of people with dementia rises, so will the costs. The latest estimates of the total cost to the UK economy of dementia are some £26.3 billion or £32,250 per person per year, comprising social care, health care and unpaid carers. The Prime Minister, in launching his Dementia Challenge, described it as "a national crisis".

Over 300,000 people with dementia live in a care home and, at any one time, a quarter of hospital beds are occupied by people with dementia. While there is no cure for Alzheimer's disease or the many other forms of dementia, it is possible to improve lives and save costs by: increasing the number of people who receive a timely diagnosis; and providing more equitable access to quality care and support that allows people with dementia and their families to plan for their future. Timely diagnosis and support could also save public money in the long term by reducing the need for unplanned admissions to care homes and unnecessary admissions to hospital.

Importantly, there is a growing body of evidence emerging that demonstrates how modifying behaviours can reduce the risk of dementia. This includes reducing tobacco use and better control and detection for hypertension and diabetes, and other cardiovascular risk factors. Indeed, "What is good for your heart is good for your head".

This report identifies the steps we believe are needed to maintain and drive improvements and make dementia care fit for the 21st century. In particular it:

- evaluates the progress made against the National Dementia strategy
- considers this progress against the progress identified in the Prime Minister's Dementia Challenge
- identifies the issues and challenges that remain
- considers what more needs to be done over the next five years if the progress to date is to be maintained and improved upon further
- envisages what good dementia care and support should look like by 2020.

This report brings together the views of people with dementia, their carers and supporters, and expert practitioners from across health and social care. It is their experience that has informed our assessment of progress over the past five years. Likewise it is for all to heed their expectation of what should happen in the next five years.

England led the world in implementing a National Dementia Strategy in 2009, alongside France and Australia. Today there are 18 countries in Europe with dementia plans, and globally from Chile to Korea, governments are following England's lead.

Now is the time to renew that leadership, expressed globally at the G8 Dementia Summit in London in December 2013, and stand firmly behind the Prime Minister's challenge on dementia 2020 and support a new national commitment to prioritise dementia care in England and ensure that people with dementia and their carers receive world class dementia care and support.

Karen Taylor OBE
Director, Deloitte UK
Centre for Health Solutions

Jeremy Hughes
Chief Executive
Alzheimer's Society

Executive Summary

Launched in 2009, “Living well with dementia: a national dementia strategy for England” set out the government’s intentions to improve care and support for people living with dementia. The strategy was developed in the wake of reports by the National Audit Office and Alzheimer’s Society which demonstrated the scale of the challenge of dementia and the inadequacy of the response to it.

More than six years later, the Alzheimer’s Society and the Deloitte UK Centre for Health Solutions sought to obtain the views of key individuals, organisations and people affected by dementia as part of an assessment about the progress that has been made, and the challenges that remain in improving services and support for people with dementia and their carers. The methodology included literature reviews, two roundtable events and a survey of experts. These views were supplemented by a further six workshops involving people affected by dementia, during autumn 2014.

Since the launch of the National Dementia Strategy in 2009 there have been numerous national initiatives aimed at improving awareness of and tackling dementia. In particular, the Prime Minister’s Dementia Challenge in 2012 raised the profile of, and provided significant impetus to, the need to improve dementia care. This resulted in a sustained focus on improving awareness, diagnosis and quality of care and increasing the resources needed for research. Further impetus was provided by the Government’s decision to host the G8 Dementia Summit in December 2013, which has given a new momentum to tackling the global challenge of dementia. Cementing the political priority given to this issue, in February 2015 the Prime Minister launched the next phase of his challenge on dementia, setting out what he wants to see in place by 2020 so that England is seen as:

- the best country in the world for dementia care and support for people with dementia, their carers and families to live
- the best place in the world to undertake research into dementia and other neurodegenerative diseases.

It also highlights the progress to date on improving dementia care, support and research while acknowledging that there is still much to do.¹

Importantly, the significant health reforms, following the Health and Social Care Act 2012, have changed the way in which strategic policy and commissioning decisions are made and how resources are allocated. Most recently, the Care Act 2014 has put into statute some welcome commitments towards improving care for people with dementia and their carers. However, the ability to implement these changes within local authorities is yet to be fully determined. These changes have created some uncertainty, particularly in the voluntary and charitable sectors, as to the availability of resources for dementia and the sustainability of their role in providing services and support. This uncertainty needs to be addressed as a matter of urgency.

The situation today

The views of those contributing to this report confirm the findings of a number of academic research reports, specifically that general awareness of dementia among the public has improved, as has professional awareness and understanding, with some excellent examples of care now emerging. However there is also evidence of wide variations in the quality of care, and that for far too many people with dementia and their carers, the overall standard of care remains inadequate and is still not fit for purpose. Almost everyone with, or living with, someone with dementia finds life difficult, with care and support still a long way from meeting many peoples’ needs. In particular there remains a common belief that a timely diagnosis is critical and consistency of care, and care givers, is essential.

It is also clear that community support services are critically important in providing a lifeline to the person living with dementia, their families and carers. Indeed community services are essential if peoples’ choice to live independently for as long as possible is to be met. The wide variations in people’s ability to access such care and support suggests an urgent need for more research to understand what works and why, and how adoption could be improved.

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There is also a clear need for an overarching formal assessment of the implementation and impact of the National Strategy. Expert opinion, including recent political pronouncements, indicates a consensus on the need for further strategic guidance and direction in relation to a new deal, commitment or plan, aimed at continuing to improve services and support for people with dementia. While recognising the importance of the February 2015 launch of the “Prime Minister’s Challenge on dementia 2020”, this report provides additional evidence of what good practice might look like. Using primary research supplemented by relevant literature reviews, it seeks to present policy makers with an independent view of the ideas and actions that the Alzheimer’s Society and other expert commentators (many of whom contributed to the original National Dementia Strategy in 2009) believe are still necessary. Specifically it identifies the future priorities for dementia care and support over the next five years.

Actions for tomorrow

In developing a new commitment or plan for dementia care and support, there are five key actions that need to be prioritised over the next 5-10 years if the lives of people with dementia are to be improved:

- continue to raise awareness of and access to information on dementia, covering both primary and secondary prevention, through public awareness campaigns and by promoting initiatives such as the Alzheimer’s Society’s Dementia Friends and Dementia Friendly Communities programmes
- continue to develop services and incentives to ensure that people get access to timely diagnosis and, following diagnosis, provide people with dementia and their carers with access to a dementia care coordinator and 24/7 help-line/advice services. This could also include a national rollout of dementia information prescriptions, customised to each local area
- provide everyone with dementia and the person caring for them with a personalised care package that is regularly reviewed and updated - recognising that there is no single care pathway for dementia and that dementia is an exemplar of a condition that requires a complex mix of health and social care support. This package should include support and respite care for informal carers

- ensure all health and social care staff that care for people with dementia have appropriate education and training in dementia care and introduce targeted initiatives matched to incentives to recognise the knowledge and skills needed to care for someone living with dementia by general practice, district nursing, NHS community and social care staff
- provide all formal carers of people with a diagnosis of dementia with at least a minimum wage and indeed a pay package that recognises the skills needed to care for someone with dementia; and ensure all home care staff assigned to care for people with dementia are appropriately trained in understanding the complexity of the disease, its impact on daily living and that the time allocated to this care is commensurate with the person’s care needs.

Further detail on these actions can be found in Appendix A

The second part of this report envisages what care might look like in 2020, and provides policy makers, commissioners and providers with ideas of what good dementia care can and should look like.

Most of the suggestions are not new, and many do not require huge amounts of investment but all require stakeholders that are involved in the dementia journey to think and work differently in order to achieve what is needed.

Part 1. Dementia Today – Challenges and Priorities

In setting the scene for the roundtable meetings, the Chief Executive of Alzheimer's Society noted that the aim was not to discuss all 17 elements of the National Dementia Strategy but to focus on the areas where more attention was needed and on the issues, old and new, that participants thought should be addressed as part of any further strategy or equivalent.

This part of the report is focused on exploring the specific issues and concerns highlighted by participants in the discussion and were not limited to the existing elements of the strategy. It describes what the group considers are the underlying challenges within the health and social care system, along with the issues that need to be prioritised.

Challenges within health and social care

Changes to the policy environment

It was recognised that when the strategy was published it reflected the then structure of the health and social care landscape. Any future plan will need to be refined to reflect the changes that have occurred as a result of the Health and Social Care Act 2012, so that decisions that affect people with dementia are taken at the appropriate level. The changes that are most likely to impact on how dementia care is commissioned and provided include:

- the new commissioning landscape and the extent to which clinical commissioning groups prioritise dementia
- the changes to the regulatory environment including the new Care Quality Commission inspection regime
- responsibility for public health now vested in Health and Well Being Boards
- the move to a more integrated health and social care service.

Participants felt that the implementation of the Care Act 2014, should provide a window of opportunity to get national minimum standards implemented locally and address the current wide variations in local implementation of national guidelines, for example the National Institute of Care Excellence (NICE) guidelines on dementia. While there is a lot of activity aimed at improving dementia care, too much of it is still being done in isolation. The focus should be on building a solution with continuity, rather than having excellent work being performed in silos.

For this to happen local decision makers have to be given the tools they need to implement the various solutions. These include capturing and evaluating evidence of people's extremely varied experience of dementia, taking into account the community and/or culture they come from.

The need for dementia pathway re-configuration and re-design

Questions were raised about the ability of current health and social care providers to deliver improvements for people with dementia. The current system remains one of siloed health and social care budgets that inhibit the development of a more integrated approach to care. This is compounded by the fact that healthcare is free at the point of need and social care is means tested. The availability of continuing care funding for people with dementia is particularly challenging. This funding challenge has been, and continues to be, a largely insurmountable barrier for many people. However some health economies are addressing this issue more effectively, for example through the development of Year of Care tariffs and use of personal budgets. New commissioning models, for example accountable care providers or the House of Care model, capitation based funding models or pooled funding approaches are all aimed at improving integration of services.

The government's Better Care Fund of £3.8 billion per year which is expected to be available from 2015 is seen as a critically important initiative with the power to galvanise joint working. However, it will need to be implemented carefully if it is to realise its full potential. For most Clinical Commissioning Groups (CCGs), finding money for the Better Care Fund will involve redeploying funds from existing NHS services and ensuring that 'hospital emergency activity will reduce by up to 15 per cent'. Achieving this reduction is seen in many quarters as very challenging and unlikely to happen.

If integration could be made to work for people with dementia this would be a giant leap forward in improving the funding and consequently the availability of good care. However, the funding of health and social care provision needs to be put on a sustainable footing for the longer-term and this will be challenging.

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Any new strategy would need to demonstrate that it provides value for money by improving cost-effectiveness, and raises the quality of patient care. For example:

- the State currently spends on average approximately £2,000 per head on healthcare (£200 in primary care, £500 in community care/ mental health, £1000 on acute care and around £300 on 'other' forms of health and social services) – people with dementia usually cost much more in each setting
- assuming investment remains flat, if costs associated with acute care increase by the projected increase in demand of around four per cent, this suggests a 20 per cent disinvestment in primary care
- recent analysis shows that general practice has already seen a significant reduction in its share of the NHS budget putting general practice under increasing pressure. For example in 2004-2005, 10.33 per cent of the British NHS budget was spent on general practice but by 2011-2012 this figure had declined to only 8.39 per cent.² This decline comes despite the fact that that demands for primary care are at an all-time high and the political mantra for more care closer to home. Importantly, GP feedback suggests that the slump in funding is compromising the standard of care they feel they can offer patients, leading to longer waiting times and increasing pressure on hospitals. This can be particularly detrimental to people with a dementia diagnosis or seeking one.

The whole issue of the economics of care and its impact on quality of life raised considerable comment and discussion, for example:

- the focus needs to be on value for money, not just short-term savings. Some people go into a care home too early or inappropriately, when the right type of services and support in the community could enable them to lead better quality lives in familiar surroundings
- measures need to be set that will enable the capture of activity, cost and outcomes information which can demonstrate tax-payers' money is being well spent
- there was strong support for the idea that giving those living with dementia and their carers control over their care would deliver monetary savings and improve quality.

An issue was raised about the practice of private payers subsidising the care of those who are funded by their local authority, with participants suggesting that this was a hidden tax on self-funders. Self-funders are generally charged a higher price for care home places or home care services than those paid by the local authority for the same service. This is likely to come under increasing scrutiny and to change with the introduction of the Care Act, which is proposing a £72,000 cap on self-funders before they are eligible for local authority funding.

For the 80 per cent of people in care homes who are estimated to have some form of dementia, this level of funding is not unusual and will have significant impact on overall funding. There is also likely to be an impact on the capacity of local authorities due to the number of people inundating local authorities to register to have the amount of care they pay for "metered" or monitored. This will enable their spending to be tracked to identify the point at which they have reached the cap or limit on the amount they have to pay before becoming eligible for local authority support.

There was also a strongly held view that the current tariff process of funding hospitals is a disincentive to the idea that people with dementia would be better cared for in their homes and should not be admitted to hospital unless they have an acute healthcare need. Examples of solutions that were suggested by attendees were proposals to move to a Year of Care tariff and the concept of a House of Care funding model.

The impact of the current economic environment on services

There were concerns that funding from commissioners appears to be 'drying up' and is becoming more difficult to access for voluntary and third sector organisations, especially those who provide support to carers. This could be detrimental to improving care for people with dementia and their carers. Indeed, the impact of the current NHS funding crisis and its impact on sustaining the progress made with the NDSE go much deeper. Participants raised a number of key aspects of the changing economic and political environment that they thought were having a specific impact on progress. These included:

- the fact that the external financial environment in 2014 is radically different to the two years 2007-2009 when the strategy was being developed. During the two financial years when development of the strategy took place, NHS funding increased by four and six per cent respectively. Since 2010-11, however, there has been four years of almost flat rate funding for the NHS in the face of growing demand of around four per cent per year, requiring efficiencies and reduction in NHS spending.³ Healthcare and social care funding, particularly for people with dementia, are very interdependent, however social care funding has also been reducing with a nine per cent reduction in number of older people eligible for funding support since 2012-13 and a 25 per cent decline since 2007-8.⁴ Funding over the next five years is expected to be at least as constrained while demand will continue to increase at similar rates
- the political attention and focus provided by the Prime Minister's Challenge has had a very positive impact but there are uncertainties and concerns about providers' ability to implement a consistent national commissioning framework at a local level
- care homes and hospital admissions currently consume a disproportionate amount of the money spent on caring for people with dementia and this needs to be tackled. While there are clearly people with dementia for whom a hospital or care home admission is the appropriate and necessary response, there are also far too many examples of inappropriate or premature admission when additional support services in the community could have maintained the person in their own home for longer. The aim therefore should be to make hospital admission the option of last resort. This will only happen if there is up-front investment in support services in the community, up-skilling of care home staff and improved access and equity for care home residents to local NHS services
- while there are strong economic arguments centred on prevention and identifying the risk factors associated with dementia, the challenge remains that spending in one area results in benefits in another; there are also difficulties developing successful business cases for investing in prevention when the benefits are unlikely to be realised within a short enough time frame

- statutory funding for dementia care (even when the financial eligibility criteria is met) is increasingly only for those whose needs are assessed as 'substantial' or 'critical'. Increasingly, by the time these stricter eligibility criteria are reached the persons quality of life has deteriorated to such an extent that amelioration often requires interventions that are more radical and more costly. This suggests that tightening criteria may be a false economy, especially compared to the benefits of an earlier intervention
- increasing numbers of people have to self-fund their dementia care. In this respect the Dilnot proposals, though limited in their scope, are welcomed as an opportunity to improve the situation for people with high care needs.⁵

Although two-thirds of people with dementia live in their local community, they often find it difficult to access timely and personalised home care. This is in part due to the financial pressures facing Local Government as they respond to increasing demand from an ageing population, particularly people living with dementia, in their local health economy.

Public health and prevention need to have a higher profile

There was a general consensus that public health and prevention needs to form part of everyone's agenda. Public Health England's (PHE's) decision to make dementia one of its top priorities was a welcome development. Participants highlighted the following issues:

- there needs to be greater awareness of the lifestyle issues that increase the risk of dementia and an emphasis given to the fact that people need to pay greater attention to their own health and how they can to help prevent or reduce the risk of the onset of dementia. Ensuring symmetry with other key public health campaigns which align the common message about cardiovascular health and diabetes risk can strengthen the public's role in prevention of dementia

- there are organisations that are helping people (young and old) to live as well as possible with dementia. However, there is a need to determine what can be done to help these organisations to continue to support the well-being of patients in the face of funding cuts (the YMCA was used as an example of one such organisation who is providing support but whose funding is under threat). Indeed, the availability and cost of support services, such as gyms and YMCA type activity, is an area that commissioners need to clarify including how they should be funded. One suggestion was that this is an area where the personalisation agenda may help
- initiatives such as the Dementia Friends programme and Worried About Your Memory? are helping to raise awareness, however there needs to be an even clearer and longer term focus in this area to challenge stigma and change attitudes.

Priorities for a new Strategy to address

A new strategy will need to recognise that the future is non-linear and needs to incorporate different scenarios. These scenarios need to raise awareness of what may potentially happen in the future if the strategy is not well managed. Scenarios should also include the eventuality of a cure being identified and also be mindful of the potential impact of future changes in regulations.

Improving specific aspects of the systems and processes of care

A number of clear themes emerged from the different strands of research and point to specific aspects of the systems and process of care that need to be improved as a matter of urgency. The rest of this part of the report considers these themes.

Providing earlier diagnosis and post-diagnosis support for people with dementia

Early diagnosis and treatment were seen as essential and, as well as focusing on people with suspected dementia, also requires a focus on the population who may have cognitive issues but do not meet the dementia diagnostic criteria. People who are worried about memory loss should be given entitlements to assessments. Any future strategy will need to address ‘the wilderness years’ – the period between diagnosis and when the disease becomes severely life limiting. A diagnosis needs to be turned into an act of empowerment and a positive experience for both the patient and carer with hospitals and care homes “speaking dementia”.

There are already a number of good services available to patients and carers however they currently exist in silos which need to be joined up to make the most of what is on offer. Examples like the Guidepost Trust’s Dementia Information Prescription⁶ and the Dementia Advisers pilot⁷ now need to be scaled up.

Over the next five years there needs to be a renewed focus on care in the community including:

- providing information and support to carers
- preventing factors that lower the quality of care provided, for example carer depression, early non-drug interventions, maintaining patients’ physical health
- building wider community support beyond that provided by the health and social care system.

Providing more effective support to carers

The carer is seen as absolutely critical in considering the needs of someone with dementia, and there was a consensus that their needs were equally important and should not be over-looked. Carers were described as the ‘glue’ that hold everything together. Given the impact on the carer of caring for someone with a progressive terminal illness like dementia, carers needs to be given a much higher priority and focus in any new strategy. While measures to support carers in the Care Act were welcomed, concerns were expressed that the carers’ specific needs and ability to access carer support should be clearly identified.

Care in the community is reliant on the informal carer and, accordingly, the strategy needs to focus on the carer to make sure this important element of the solution does not break down. In particular, ways of improving communication with carers was identified.

For many people with dementia the largest proportion of care is provided by informal carers. In general over the past decade the proportion of informal carers providing more than 50 hours a week has doubled but few are provided with any training or support. Estimates suggest that informal carers save the NHS and social care around £50 billion a year but increasing demand is placing the informal carers under substantial pressure that often impacts on their own health. Carers of people with dementia are likely to be at the top end of this range in terms of the time provided, costs incurred, and the lack of training and support received. The argument to improve the support provided to carers is compelling.

Using technology to support people to live well with dementia

There was a call for more recognition to be given to the benefits that technology could bring, in helping health and social care staff to support people with dementia and their carers; and improving the way specialist and generalist staff work together. Currently health and social care is heavily reliant on face to face care with knowledge residing with the professional – creating an imbalance of power. With the significant developments in digital health technology people are accessing information for themselves; people are talking to each other through social media; and people want to be able to email and Skype each other and their families and carers. Indeed mobile technology using Apps can and is already starting to provide a wide range of support to people with dementia and their families. More needs to be done to evaluate and promote the use of such technology and to support people in adopting the technology.

Improving workforce development and training

There was a great deal of discussion around the need for a robust strategy for training and preparing doctors and nurses early in their formal education and particularly at undergraduate level. The general view was that training of all healthcare professionals is outdated and is still fixated on the ‘hospital only’ model of care instead of addressing the shift towards community care. There was also a concern that training may be restricted to facts of education rather than the experience of training.

The focus of NHS training was questioned. The direction of training seems to be on discrete, high tech and increasingly bespoke aspects of care; this needs to reflect and include the sensitivities of the needs of people with dementia.

For those in contact with dementia patients, this must change to give them the tools to provide holistic care, addressing patients’ multiple and varying needs. Training on dementia (of varying detail based on roles) must be provided to all primary care staff, from receptionists to the GPs.

Recruiting and retaining homecare and care home workers is regarded as particularly difficult with high turnover rates (24.8 per cent) due largely to poor pay and conditions. The training and education standards of homecare staff, like care home staff, are low (almost 40 per cent of the social care workforce do not have a relevant qualification with 28 per cent at entry level (or Level 1) and 14 per cent Level 2).⁸ There are no national funding streams for training of social care staff.

The perception and reputation of staff working in the care industry should be addressed. It was felt the health professionals generally did not give sufficient recognition to the care and support provided, particularly in care homes. This was demonstrated in recounting one conversation where care home staff were told the pay and reward is poor; “but it may help you to go on to something better”. The focus should be on making this profession more enticing/aspirational, recognising the complex care that is delivered and valuing the work of staff. This should be through new carer roles and nurse practitioner posts. This creates a career pathway, and career progression through an identifiable expert Care Home route. The litmus test on the quality of a care home – asking whether you’d be happy with your parents being in this care home – can be extended to include: “*would you also be happy with one of your children working there?*”

An example of good training was in a local authority where trainees were assigned to a family living with dementia in order to gain a better insight on the changing requirements as the illness developed. This approach was endorsed as a good model for all health and social care professionals at graduate level.

Improving the transfer of information within and between services

The need for sufficient relevant and reliable data to improve the systems and processes of care emerged as a recurrent theme in the discussion, particularly the need for routine data focused on patients with high needs.

In general over the past decade the proportion of informal carers providing more than 50 hours a week has doubled but few are provided with any training or support.

It was recognised that the new *care.data* initiative will potentially provide value in the future by providing information on the bigger picture and the impact of interventions across both primary and secondary care. However, special attention needs to be given to the issue of consent on the use of this data by people with dementia and their carers. Developing a national database by using a standardised assessment of needs could generate data sets which inform commissioners, support learning and development needs of staff and provide reliable national data. Reference was made to the 'Elsa' survey which already has cognitive aspects to it but which has the potential to be applicable to dementia.

However, it was felt the data quality is quite 'patchy' and that any new strategy or initiative should set out how each initiative will be measured and the data required to enable an objective evaluation of progress.

Developing a strong and sustainable research agenda to underpin delivery of effective dementia services

Investing in a robust research strategy and agenda was seen as especially critical to improving health outcomes for people with dementia. Key issues discussed at the roundtable included the need:

- to continue to invest in research in order to find disease modifying drug by 2025
- for investment in research infrastructure and researcher career pathways to ensure research community can meet demand for further research
- to focus on research into quality of care for people living with dementia today, as well as a search for a cure
- to understand that dementia is a term that encapsulates a myriad of illnesses, that all need to be addressed in the research agenda, not just Alzheimer's disease.

Improving quality of care in each place of care

A great deal of the discussion focused on the need to improve the quality of care in each of the places of care where people with dementia are to be found, from home care settings, to hospitals, to care homes.

Effective homecare to enable people to remain in their own homes for longer

Effective homecare was identified as the key to supporting people to remain independent for longer, to maintaining their independence and quality of life, while enabling them to live in their own homes amidst familiar people and surroundings. However, there was a consensus that people with dementia and their carers are not receiving sufficient home care and support to meet their needs.

Despite reasonable user satisfaction with homecare services, the participants agreed that the homecare sector is facing major challenges. Over the last five years, both the level of provision of social care has reduced and real term funding has fallen. Furthermore, reductions in services are most common amongst those people living in their own homes. The perception was that people living in their own homes had less severe needs, and therefore lower requirements, so local authorities consider it a lower risk strategy to cut homecare services for all but those meeting the highest eligibility thresholds for social care. Many thought the opposite was true, that providing higher levels of support to people with dementia and their carers to enable them to live in their own homes for longer was likely to be more cost-effective.

Inadequate commissioning of homecare services was also highlighted as an issue. Although 60 per cent of local authorities now commission 15-minute visits, there is overwhelming agreement from service users that a 15-minute visit is not long enough to support a disabled or older person to do everyday things like wash, dress and get out of bed in the morning. The implementation of the new Care Act regulations in 2015 will help to address this. For some, homecare is provided by charities, often tailored to specific needs, for example the British Red Cross and Hospice at Home service. Mostly it is provided by some 9,660 registered private homecare providers operating in the UK.

In general one of the key concerns was around the quality of the workforce providing homecare. Issues, such as the low status, low pay and training levels were all identified as major concerns affecting the quality of care people receive. The discussion around homecare concluded that there is a significant lack of understanding about the level of unmet need in the community. A better understanding of levels of unmet need would support the policy case for prioritising social care services to meet the growing needs of people with dementia who wish to remain living at home for longer.

Improving quality of dementia care in hospitals

Participants highlighted the fact that at any one time more than 25 per cent of hospital beds are occupied by someone with dementia, often staying in hospital for a significant amount of time after the medical reason for admission had been addressed. Recognition was given to the fact that many hospitals have run initiatives to improve the environment for dementia patients and to provide support with eating and drinking, an example is the dementia buddy schemes that some hospitals have introduced.

Discussions focused on the need to ensure that early interventions are made to prevent individuals simply presenting with confusion or delirium who have no medical need for admission being admitted unnecessarily to hospital – believing that this will be both better for the patient and will save money for the health service.

Participants also raised the need to ensure that all hospital staff have received dementia awareness training, with concerns expressed that there were still too many staff who failed to recognise the impact dementia could have on patients' other conditions or on their concordance with expected behaviours. There is a need for regular evaluation of care provided in hospitals to ensure that there is continuous quality improvement in dementia care and strong leadership. Adoption of good practice should be encouraged, for example use of the Alzheimer's Society's "This is Me"⁹ form for all people who have dementia, to drive a fundamental baseline needs assessment.

Delivering high quality care to people with dementia living in care homes

Care homes employ predominantly low-skilled and low paid social care staff caring for over 400,000 older people, a fifth of whom are over the age of 85. Eighty per cent of care home residents have some form of dementia. Increasing frailty and average life expectancy of only one to two years means the low level of skills and training opportunities fails to equip care home staff to handle the increasingly complex healthcare requirements. Access to GP surgeries and outpatient clinics can also be difficult leading to overuse of A&E and emergency admissions. This is compounded by the poor understanding of the Care Home sector and the private sector stigma which can prevent a timely response to care home residents who are some of the CCG's most vulnerable patients and can face inequity of service access. Residents living in a care home should have access to a GP who has specialist training in dementia.

During the 1990s, demand for care home places dropped as local authorities applied increasingly strict eligibility criteria and many small scale private sector homes exited the market. Capacity has started to grow in recent years, driven by demographics and the difficulties maintaining older people with high care needs in their own homes. Capacity and demand in the care home sector is expected to continue to grow in response to the increase in the numbers of very frail people and people with dementia.

There was nevertheless a prevailing view that people are still admitted too early to care homes and as a result can become very lonely and unhappy. There was also discussion of the prevailing fear of going into a care home, fuelled by negative media coverage, despite the fact that there are some excellent care homes. The problem lies with the wide variation in the quality of care homes and an urgent need to tackle this variation in quality and address the negative reputation that some care homes now have.

Examples were given of people with dementia in a care home “sitting in a circle of doom in front of a booming TV” with their individual needs being subjugated to the lowest common denominator. Improving dementia care in care homes was seen as an immediate and necessary requirement.

Where good practice exists, care homes are integrated into communities and have strong social links across schools, faith groups and social interests with the emphasis on living with dementia. Care homes need to be vibrant communities and part of the community in which they operate. Care homes have the potential to become resource services for local people and their carers living with dementia. This has potential benefit for both rural and urban communities. Care homes could act as local resource centre, create partnerships and host Dementia Advisers. They could create flexible day services, night care and respite care which can be a valuable resource for carers. We need the sector to become better champions of change and work in partnership with statutory services to address local needs and create responsive partnerships.

Care homes need to be designed with specific needs of people with dementia in mind and the space and facilities created to maximise independence and freedom. The development and leadership of the care team is vital to sustaining a level of enthusiasm and quality improvement which enables creativity and support to help people with dementia continue to reach their potential and maintain key relationships. Investment in leaders as change agents and pioneers for improvement is key.

Other concerns included the fact that:

- care homes are currently funded about two thirds by taxation and a third by private funding, but are expected to require 50:50 funding in the not too distant future. Currently the provision of care is not seen as a two tier system, as private payers simply subsidise publicly funded residents. However, this appears to be changing with a two tier system in danger of emerging. The ethics of this approach was challenged and concerns expressed at the direction of travel. Providers are starting to separate the private and public pay markets and there will be an inevitable difference in quality of experience and subsequent disquiet
- new mobile technology presents a threat and an opportunity for care homes. The threat is that people will take pictures or recordings of care on their mobile phones, or even by hidden cameras and these could be posted on the internet or sent to the media out of context, which impinges on human rights and raises the issue of capacity to consent. In some cases there is discussion of having this surveillance as a matter of policy. In terms of presenting an opportunity, technology can be used to support care homes to deliver more effective care, especially healthcare, by improving the interface between hospitals and care homes and general practice and care homes – using telehealth technology. Caution should be exercised so that technology is used to enhance rather than become a care substitute.

Part 2. Dementia in 2020

The group explored what a further review might find in five years' time, if a new strategy had successfully been implemented and the challenges and issues for dementia had been met.

In reflecting back over the last five years there was a consensus that remarkable things have happened politically and in a number of areas of dementia care; and that there is a need to build on this and ensure the sustainability of improvements already achieved while addressing those areas where progress has been limited. Stakeholders agreed that "there has never been a better time and never been a worse time". Key to this is the need for national leadership and national prescription.

The sentiment that dementia is disrespectful of the boundaries we create resonated strongly as did the need to build on what's worked and learn from what hasn't and to capture and spread best practice so as to enable people with dementia and their carers to focus on living well with dementia. Against this consensus the roundtable participants were asked to put themselves in the position of someone with dementia in the year 2020 and to answer the questions:

- what did they hope dementia care look would like in 2020?
- What support did they hope would be in place at various stages of their illness?

The dementia care pathway in 2020

At diagnosis:

- you could go on-line to get access to lots of highly relevant, consistent information
- you could ask for help and receive it, quickly and easily
- you could talk to your employer about your condition without fearing for your livelihood
- you would have access to a specialist who could advise you on what would happen next and how you will be supported through the journey.

Shortly after diagnosis:

- you could spend time with a volunteer care co-ordinator who would tell you what options are available

- you could ask for a vision of what might happen (in terms of your care) over the next 20 years
- you would receive a personal prognosis based on your own circumstances
- there would be clear, consistently applied guidelines on treatment options
- if you were a carer of someone in the post diagnosis period, you would receive support from your employer as well as from the health and social care system.

Three to four years after diagnosis:

- you would not feel alone or abandoned
- you would have someone available to speak to you on demand
- you would receive proactive care which you would control
- if you moved to be nearer to your family your care would be continuous and co-ordinated
- you would not 'need' to move to receive the appropriate care, care entitlements would travel with you
- you would not have to worry if you had assets (greater than £23,000 or £75,000 or whatever – money would be a secondary consideration after the right care in right place at right time)
- you would want to feel secure and assured that your loved ones are supported
- you would want to be still 'living life' and having fun
- dementia friendly communities would be the norm not the exception and, if you wanted to, you could go on a dementia friendly cruise.

Care and support is needed, possibly residential:

- you require consistency in relation to the carer and the support provided

- you would want to be able to stay in your own home for as long as possible
- if you didn't want to go into a care home you wouldn't have to, but if you did agree to go into a care home it would comprise a community of people that did fun, stimulating things at a time that suited you, as opposed to a 'circle of doom' (sitting around a television with no say on what you watch)
- you would want extra care housing to be available within your existing community
- you would want earlier decisions to be made about your own care and for your wishes to be remembered and honoured when you are no longer able to make your own decisions (this was extended to include a specific earlier discussion to record your wishes for when you reach this point)
- you would not feel embarrassed or ashamed
- you would not want to be frightened of meeting your grandchildren or for them to be frightened of meeting you
- you would want to maintain your dignity at all times.

End-of-life support:

- you would want to have discussed your preferences long in advance while you had capacity to make decisions
- you would want your earlier discussions to have been recorded and to be respected
- you would want to be offered the chance to change your mind
- you would want to know that if you are dying of cancer, for example, the impact of your dementia is also understood and care designed accordingly.

Finally, it was noted that much of the discussion has been focussed on dementia in the elderly and that any and all strategies must not overlook those younger people living with dementia.

In reflecting back over the last five years there was a consensus that remarkable things have happened politically and in a number of areas of dementia care, and that there is a need to build on this and ensure the sustainability of improvements already achieved while addressing those areas where progress has been limited.

Appendix A – Actions for Tomorrow

There are five key actions that need to be prioritised over the next 5-10 years if the lives of people with dementia are to be improved.

1. Continue to raise awareness of and access to information on dementia, covering both primary and secondary prevention, through public awareness campaigns and by promoting initiatives such as the Alzheimer’s Society’s Dementia Friends and Dementia Friendly Communities programmes.

2. Continue to develop services and incentives to ensure that people get access to timely diagnosis and, following diagnosis, provide people with dementia and their carers with access to a dementia care coordinator and 24/7 help-line/advice services. This could also include:

- implementing a national rollout of dementia information prescriptions, customised to each local area, which includes access to advice 24/7 from someone trained in understanding dementia
- continuing to develop public awareness including introducing public awareness campaigns in schools, libraries, supermarkets, etcetera
- building on the success of the Dementia Friends initiative, run by Alzheimer’s Society
- providing support to charities and other voluntary sector groups to help them set up dementia awareness groups
- determining a set of criteria and standards for memory clinics and establishing multi-purpose hubs that include a memory clinic, with an Alzheimer’s Society or similarly dementia focused charity representative present in every memory clinic
- raising awareness of the importance of prevention or mitigation activities and the connection between physical and mental health, including having questions that might indicate dementia as part of the National Health Checks. Publicise the fact that the strongest evidence for causal associations with dementia are those of low education in early life, hypertension in midlife, and smoking and diabetes across the life course

- continuing to support public awareness campaigns for the general public on their own health risks and understanding of people living with dementia more generally within their communities

- investing more money in research to make it commensurate with the levels of spend on research in cancer care.

3. Provide everyone with dementia and the person caring for them with a personalised customised care package that is regularly reviewed and updated. This could include:

- delivering care packages designed around the needs of the person with dementia, recognising that there is no single care pathway for dementia and that dementia is an exemplar of a condition that requires a complex mix of health and social care support. This package should include support and respite care for informal carers
- providing all informal carers of people with a diagnosis of dementia with access to free or low cost respite care
- providing support and advice to carers on how to access grants and other forms of financial support, recognising that carers often have to reduce their working hours or indeed give up their jobs
- ensuring all people diagnosed with dementia and who want to remain in their own homes, have access to the help and support needed to facilitate this, while prioritising the safety of the patient and carer
- providing free care home places to all people with dementia who need to be admitted to a care home, recognising that caring for them in an appropriate care home will be cheaper than them being admitted, unnecessarily, to hospital
- ensuring that care homes are dementia friendly and recognise the needs of people with dementia and how they can and should be supported to live well
- giving care home staff equal access to learning resources available to their NHS colleagues

- giving every Care Home access to a GP who has a specialist interest in dementia
 - where a person with dementia is admitted to a hospital, hospital staff should ensure the patient notes recognise that dementia is a co-morbidity and that care and treatment is planned and provided accordingly, including allocating to a multi-disciplinary team with appropriate skills and training, with access to a psychiatrist or mental health team; and agreeing from the outset a plan for discharge, in discussion with the family and carer.
- 4. Ensure all health and social care staff that care for people with dementia have appropriate education and training in dementia care and are paid commensurate to the levels of training obtained and care provided. This could include:**
- introducing targeted initiatives matched to incentives to improve the knowledge of the understanding of dementia and skills needed to care for someone living with dementia by general practice, district nursing and NHS community and social care staff
 - having someone trained as a dementia care co-ordinator in every general practice, care home, pharmacy and supermarket.
- 5. Provide all formal carers of people with a diagnosis of dementia with at least a minimum wage and indeed a pay package that recognises the skills needed to care for someone with dementia and ensure all home care staff who are allocated to people with dementia are appropriately trained and that the time allocated to this care is commensurate with the persons care needs.**

Appendix B – The roundtable discussions

The focus of this work is on England; however the findings should resonate with the wider UK. It is based on the results of two cross-sector roundtable discussions to evaluate progress on the 17 objectives of the National Dementia Strategy for England (2009-2014). These findings were then supplemented by a Deloitte survey of 14 other experts and eight research network volunteers and six Alzheimer's Society led workshops involving over 60 people affected by dementia. Further information was derived from literature reviews and research on prevalence and costs presented at the Alzheimer's Society's 2014 Conference early October 2014.

Objective of the roundtable discussions

The aim of the roundtables was to bring together a cross section of experts in different aspects of dementia care to evaluate progress against the National Dementia Strategy (the Strategy) for England and to consider what might be the next step in continuing to drive improvements. The five year Strategy, which ran from February 2009 to February 2014, was supplemented in March 2012 by the introduction of the Prime Minister's Challenge on Dementia. This challenge was aimed at building on the progress made with the Dementia Strategy, with a view to delivering specific improvements in dementia care and research by March 2015.

The Challenge on Dementia is the only health challenge to have been issued by a British Prime Minister and as such tackling dementia has received a very high political profile. In line with expert opinion, including recent political pronouncements, the need for further on-going strategic guidance and direction after 2015 was welcomed so that progress on improving dementia care can be maintained. The roundtables therefore sought to consider the achievements of the Strategy, identify the ongoing needs and develop ideas on how these might be met.

While recognising the importance of the Prime Minister's Challenge, the focus of the roundtables was specifically on the National Dementia Strategy for England. The questions they sought to address were:

- what is the evidence on the need for a new strategy or similar to maintain and further drive improvements in dementia care and support
- how well have we done over the last five years
- what, if anything, is missing from the current strategy and dementia challenge
- how to maintain the impetus after 2015, given the end of the strategy and the conclusion of the current Prime Minister's challenge?

A specific outcome from the first roundtable was a chart ranking the progress in meeting the 17 objectives of the Strategy (Appendix D). These findings were then supplemented by a short follow-up survey to participants and a wider stakeholder group, and six workshops led by the Alzheimer's Society (held throughout July, August and September 2014) involving over 60 people affected by dementia – the findings of both these two strands of research are amalgamated in Appendix E. The overall findings from all three strands of research have then been used to inform the rest of this report.

Note:

At the time of the research and evaluation the next phase of the Prime Minister's Challenge on dementia 2020, published in February 2015, was not anticipated. However, the authors believe the findings are such that they remain relevant to and support its implementation.

The Roundtable Discussions

National Dementia Strategy for England – securing a long-term vision for dementia: A joint roundtable with Deloitte Centre for Health Solutions and Alzheimer’s Society

Friday 28th February 2014

Attendees

Mr Jeremy Hughes, Chief Executive, Alzheimer’s Society

Ms Karen Taylor, Director, Centre for Health Solutions, Deloitte

Mr George McNamara, Head of Policy and Public Affairs, Alzheimer’s Society

Professor Sube Banerjee, Professor of Dementia & Associate Dean, Brighton & Sussex Medical School

Ms Tamsin Berry, Head of Policy and Programmes, Public Health England

Ms Sarah Bickerstaffe, Fellow in Health, Institute for Public Policy Research

Professor Dawn Brooker, Director of Dementia Studies, University of Worcester

Mr Tim Curry, Assistant Head of Nursing, Royal College of Nursing

Peter Watson, Carer

Baroness Sally Greengross, Chair of APPG on Dementia and Institute of Longevity Centre

Ms Josie Dixon, Research Fellow, Personal Social Services Research Unit, London School of Economics

Professor Murna Downs, Head of Bradford Dementia Group, University of Bradford

Ms Hilary Evans, Director of External Affairs, Alzheimer’s Research UK

Ms Kristina Glenn, Director, Cripplegate Foundation

Maelenn Guerchet, King’s College London

Mr Phil Hope, Former Minister of Care Services

Mr Martin McShane, Director, Enhancing quality of life for people with long term conditions, NHS England

Dr Jill Rasmussen, Clinical Champion for Dementia, Royal College of GPs

Ms Amanda Scott, Managing Director, Sunrise Senior Living

Ms Deborah Sturdy, Red and Yellow Care

Ms Sheena Wyllie, Director of Dementia Services, Barchester Healthcare

National Dementia Strategy for England – securing a long-term vision for dementia: Second roundtable discussion

Wednesday 1st October 2014

Attendees

Ms Sarah Bickerstaffe, Strategy Lead, Care Quality Commission

Ms Anne-Marie Hamilton, Deputy Director- Strategic Programmes at Public Health England

Ms Sarah Pickup, Deputy Chief Executive at Hertfordshire County Council

Mr Jonathan Walden, Public Health England

Ms Helen O’Kelly, Strategic Clinical Network Assistant Lead (London Region) at NHS England

Ms Sandra Evans, Fellow, Royal College of Psychiatrists

Mr Gavin Terry, Policy Manager, Alzheimer’s Society

Appendix C – Roundtable evaluation of the impact of the strategy

By February 2014, the National Dementia Strategy had achieved measurable success against a number of its objectives. In particular:

- a number of national public awareness campaigns focussing on improving public understanding of dementia have been conducted. This includes the Department of Health and Alzheimer's Society television campaign which encourages people to talk to loved ones showing signs of dementia, as well as story lines in popular soap operas. As a result general public awareness and understanding of dementia has improved
- diagnosis, in particular early diagnosis, of dementia was a key priority in the strategy. When published in 2009, diagnosis rates stood at only 33 per cent. This has risen to 48 per cent in 2013, but remains behind the rate in many other countries, including Scotland where the rate is 65 per cent. Further commitments to improve dementia diagnosis rates to 66 per cent have been announced by NHS England
- in hospitals, pathways for management of patients with dementia are being developed, many hospitals have focussed on making the environment more dementia friendly and clinicians are being appointed as dementia champions
- the need for better workforce knowledge and understanding is widely recognised. Health Education England has identified dementia as a priority but there still is a long way to go to make sure those who spend the most time providing care have the education and training needed to provide effective care. This has to be a priority across the whole health and social care system with access to resources to implement the changes needed
- pilot programmes for peer support and dementia advisor services have demonstrated that these services provide valuable post diagnostic support and potentially prevent or delay need for acute or long term care services, but availability is still a challenge.

Despite progress on the strategy, its implementation is far from complete with progress and action in some areas particularly patchy and, in some cases, non-existent. In particular:

- many people felt that the process of getting a diagnosis was difficult and could take years, with early symptoms often misdiagnosed as depression, resulting in the prescribing of anti-depressants which made matters worse. There were also strong concerns that the diagnosis was delivered as a blunt matter of fact with limited support or information offered to the people diagnosed or the people who care for them
- commissioning and provision of memory services in England is patchy and highly variable and, in many instances, support was limited to web-based information and support
- despite objectives around improving community support for people with dementia there is no evidence of consistent improvements in provision. Although there has been some good feedback about some carer support programmes, such as the Alzheimer's Society Carers Café's, most carers felt they lost their own independence and were confused and intimidated by the process of applying for support, especially financial support
- many people with dementia struggle to access support until their needs reach crisis point. Also, interventions that might enable people to stay in their own homes were patchy and concerns remain over the pay and conditions of home-care staff and the timing and length of visits
- while there have been some positive steps by care operators around dementia care in care homes, access to specialist in-reach mental health services and wider health services is patchy and often poor with a high number of agency staff and a general shortage of suitably trained staff

- end of life care for people with dementia remains under-developed with little or no progress. While recognising the difficulties in exploring sensitive issues with people with cognitive impairment, there was a general consensus in the need for counselling and other support services
- while there is recognition of the need to improve workforce understanding and skills in dementia in England, this was not informed by an assessment of core competencies essential to dementia care, nor is it consistent across professional groups. Clinicians often fail to listen to the carer or understand the impact that dementia can have on the responses provided by the patient. Accessing services, including travelling to the surgery or hospital, can cause high levels of stress and exacerbate the condition, risking further misunderstanding and misdiagnosis.

There now needs to be an official and systematic review of the National Dementia Strategy by the government. This is needed to create a credible platform of the success and gaps in progress to date and is essential in ensuring that future resources are appropriately deployed to meet the ongoing and emerging needs of people living with dementia in years to come.

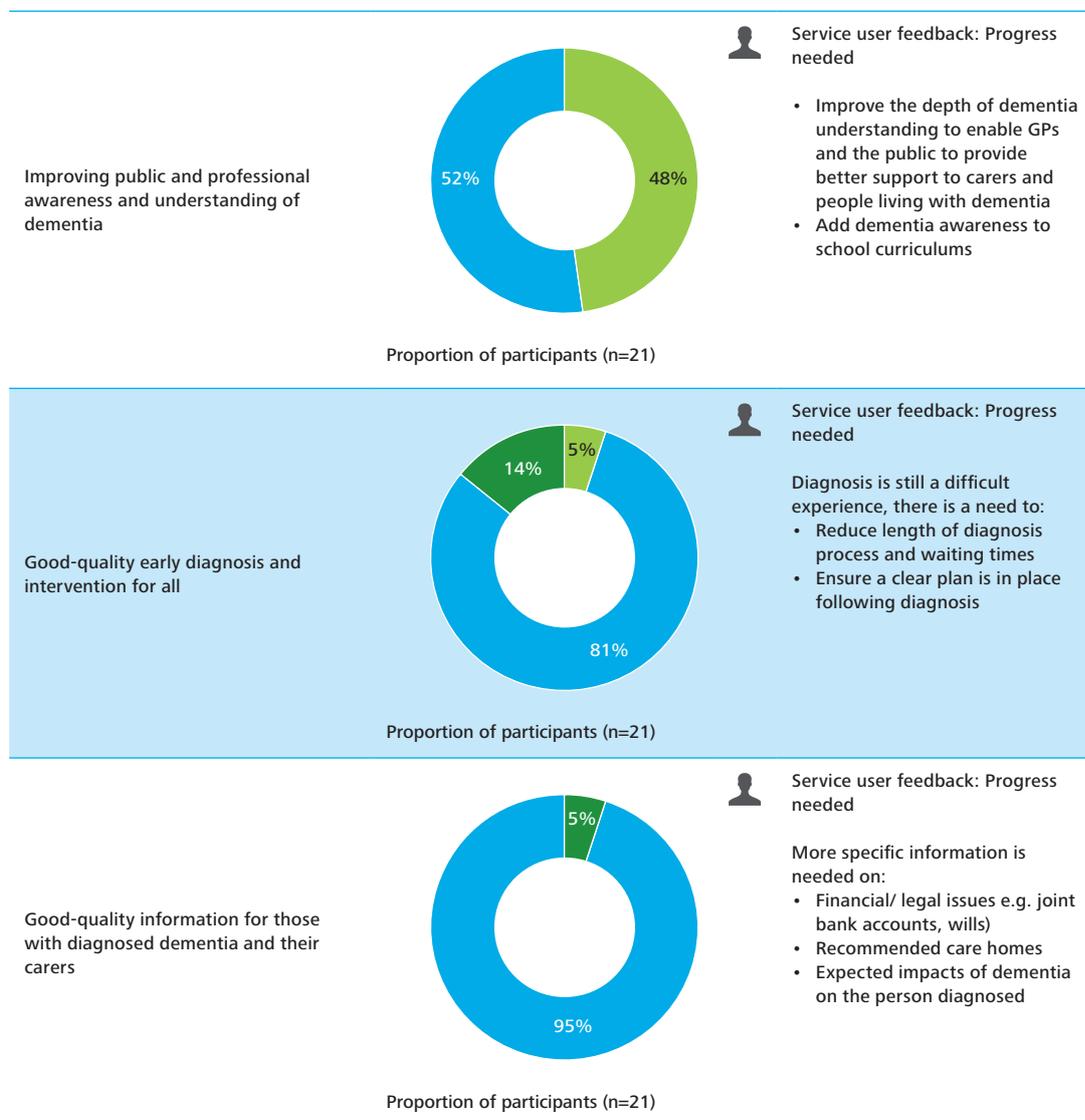
Appendix D – Ranking of elements of the strategy

Each participant in the round table discussion was given three green and three red stickers and asked to put the green stickers on the elements of the strategy where they considered the most progress had been made and the red ones on the areas where the least progress had been made. A ranking was then derived by subtracting the reds from the greens to give a score.

	Red	Green	Total responses	Overall Sentiment (Green – Red)
Improving public and professional awareness and understanding	2	7	9	5
Good quality early diagnosis and intervention for all	1	4	5	3
Good quality information for those diagnosed with dementia and their carers	2	5	7	3
Enabling easy access to care, support and advice following diagnosis	6	0	6	-6
Development of structured peer support and learning networks	2	0	2	-2
Improved community support services	4	1	5	-3
Implementing the carers strategy	5	0	5	-5
Improving quality of care for people with dementia in general hospitals	0	5	5	5
Improved intermediate care for people with dementia	6	0	6	-6
Considering the potential for housing support, housing related services and telecare to support people with dementia and their carers	2	0	2	-2
Living well with dementia in care homes	0	5	5	5
Improved end of life care for people with dementia	5	0	5	-5
An informed and effective workforce for people with dementia	2	2	4	0
A joint commissioning strategy for dementia	3	0	3	-3
Improved assessment and regulation of health and care services and of how systems are working for people with dementia and their carers	2	1	3	-1
A clear picture of research evidence and needs	1	5	6	4
Effective national and regional support for implementation of the strategy	0	3	3	3
Total	43	38	81	-5

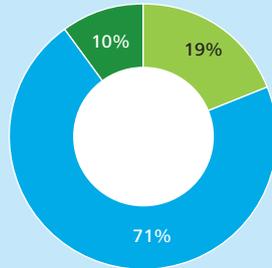
Appendix E – Progress towards the 2009 National Dementia Strategy for England

The findings of the roundtables were supplemented by a short follow-up survey to participants and a wider stakeholder group, and six workshops led by the Alzheimer's Society (held throughout July, August and September 2014) involving over 60 people affected by dementia. The overall findings from all three strands of research have then been used to inform the rest of this report.



■ Considerable progress
 ■ Some Progress
 ■ No Progress

An informed and effective workforce for people with dementia



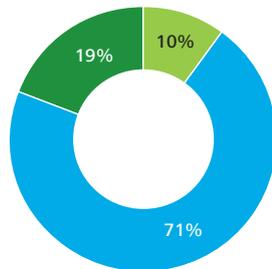
Proportion of participants (n=21)



Service user feedback: Progress needed

- More explanation about treatment – why specific treatments have been chosen
- Increase awareness of how best to interact/ support people living with dementia and their carers – focus on all staff not just health care professionals (HCPs)

Clear picture of research evidence and needs



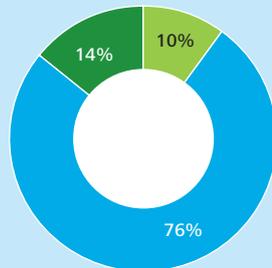
Proportion of participants (n=21)



Service user feedback: Progress needed

- More investment into research:
- Includes research into a cure/ treatment and
 - Research into living well with dementia

Living well with dementia in care homes



Proportion of participants (n=21)



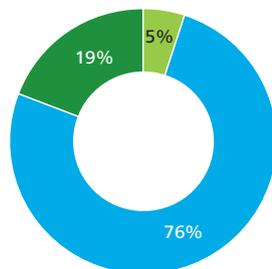
Service user feedback: Progress needed

Care home standards were thought to be extremely low.

There needs to be:

- More, better trained, staff who are able to spend time providing the care that residents living with dementia need

A joint commissioning strategy for dementia



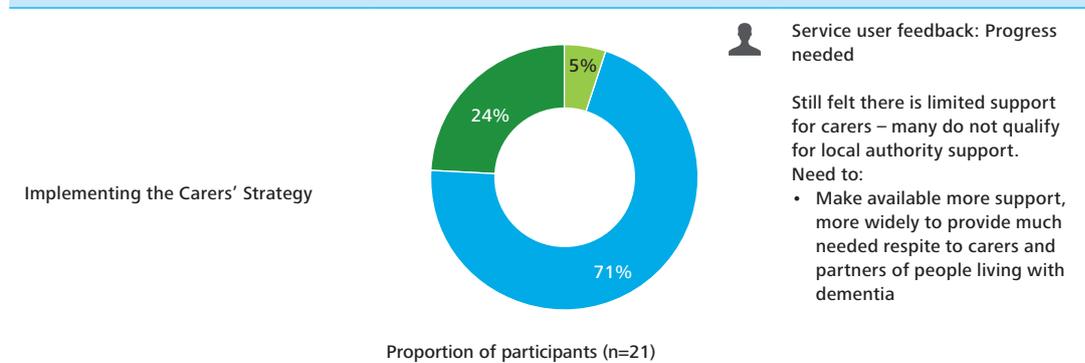
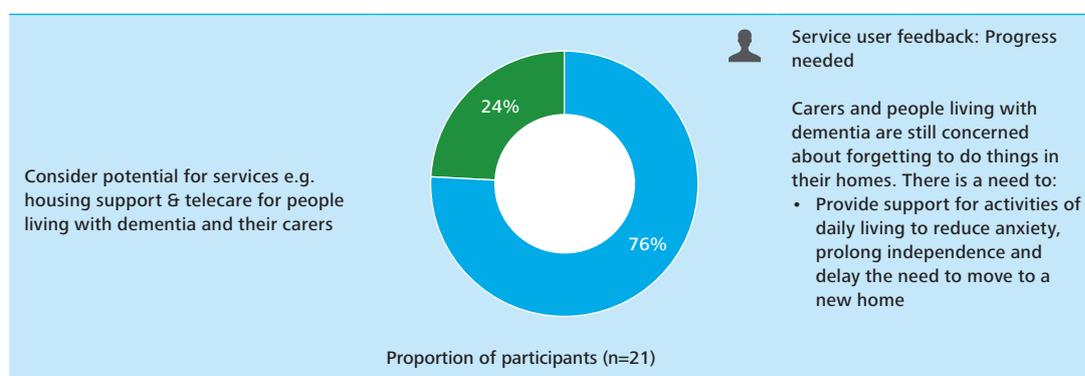
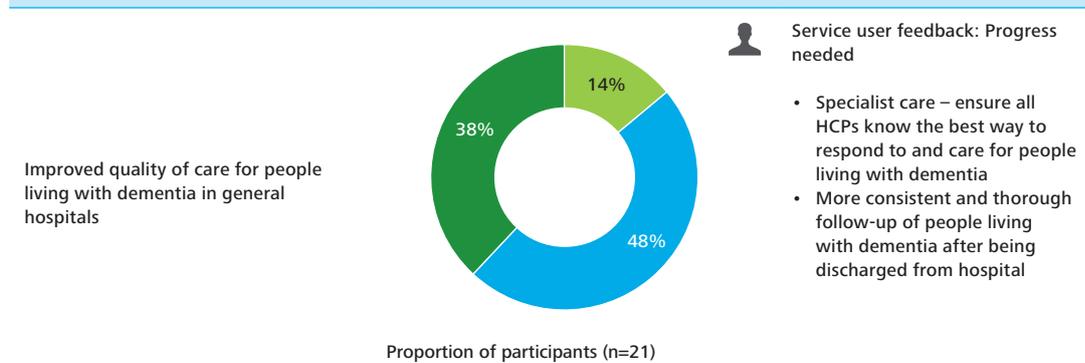
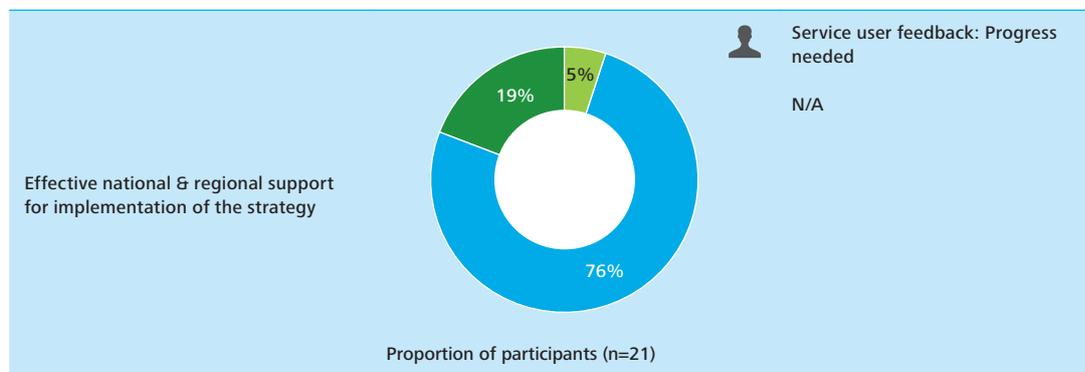
Proportion of participants (n=21)



Service user feedback: Progress needed

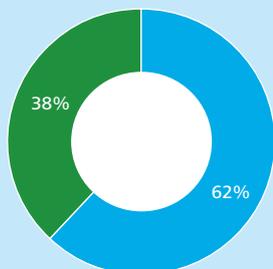
N/A

■ Considerable progress ■ Some Progress ■ No Progress



■ Considerable progress
 ■ Some Progress
 ■ No Progress

Improved end of life care for people living with dementia



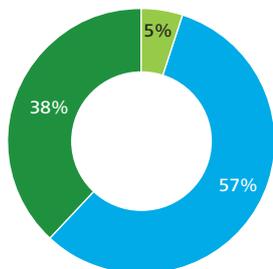
Proportion of participants (n=21)



Service user feedback: Progress needed

- More counselling services provided to people living with dementia as they get older as well as to their carers and family members
- Care quality and intensity to increase with age and care needs

Improved assessment and regulation of health and care services and of how systems are working



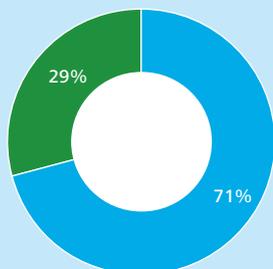
Proportion of participants (n=21)



Service user feedback: Progress needed

N/A

Development of structured peer support and learning networks



Proportion of participants (n=21)

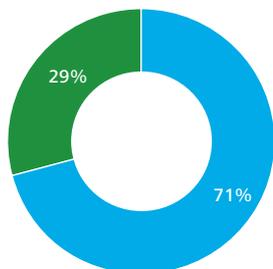


Service user feedback: Progress needed

Good feedback when services are available e.g. Dementia Cafes but there is a need to:

- Increase awareness and use of structured peer support services. Potentially through care navigators or charity representatives

Improved intermediate care for people living with dementia



Proportion of participants (n=21)

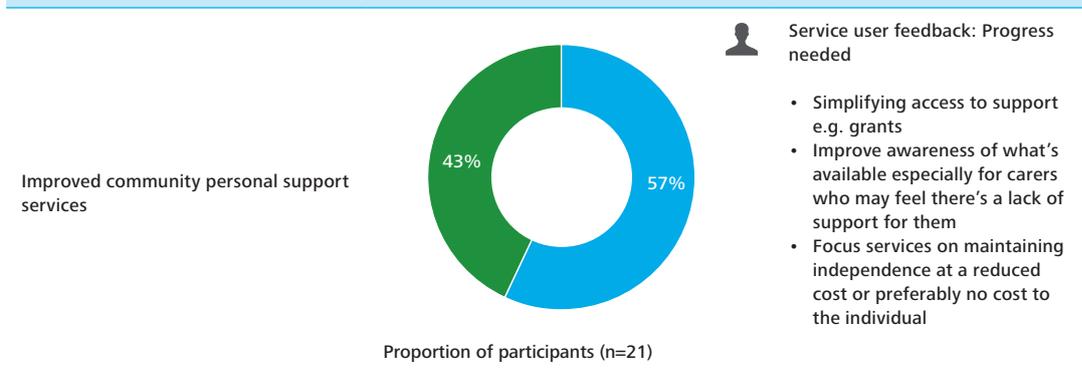
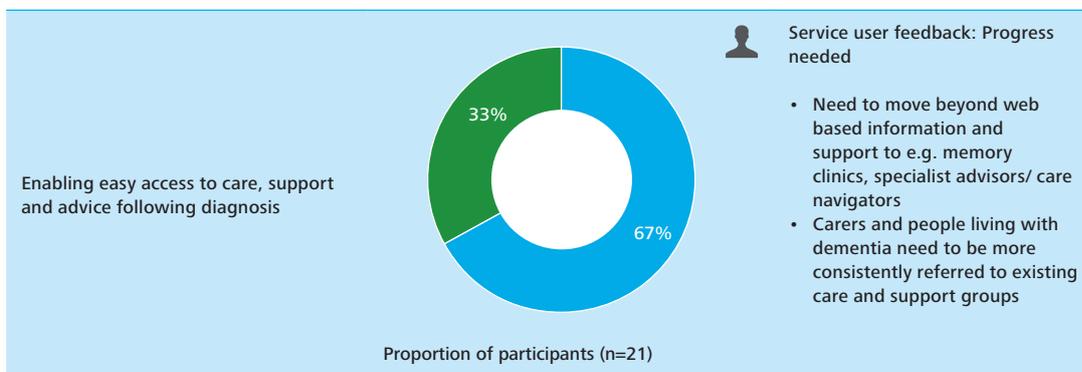


Service user feedback: Progress needed

Interventions designed to keep people in their own home are patchy. There is a need for:

- More widespread intermediate care services to be made available
- Access to be improved

■ Considerable progress ■ Some Progress ■ No Progress



■ Considerable progress
 ■ Some Progress
 ■ No Progress

Appendix F – Latest Information on the extent, scale and impact of dementia (October 2014)

The Alzheimer's Society's 2014 Conference: Dementia: Today and Tomorrow provided an update on the current costs and prevalence of dementia and highlighted some of the key concerns that need to be addressed:

- in 2014 there are now 685,812 people in England with dementia and 815,827 in the UK (62 per cent have Alzheimer's disease) and around 670,000 people act as primary carers for people with dementia
- the total cost to the UK economy of dementia is now £26.3 billion or £32,250 per person, comprising £4.3 billion healthcare costs, £10.3 billion social care (44 per cent publicly and 56 per cent privately funded) and the cost of unpaid care is some £11.6 billion
- dementia is also estimated to cost UK business £1.6 billion per year with 89 per cent of employers believing that dementia will become a bigger issue for their organisation and their staff
- two-thirds of people with dementia live in the community with approximately 60 per cent of people receiving home care having some form of dementia. As the symptoms of dementia progress many people need the support of a care home. In 2014 a third of people with dementia were living in care homes and 70 per cent of care home residents had some form of dementia.¹⁰

Growth in the prevalence of dementia is largely driven by population ageing with the oldest old at most risk. Findings from the research suggests that future prevalence predictions for the 65s and over may need to be revised downwards as improvements in education levels and public health, particularly better prevention of cardiovascular risk factors, start to impact on the risk of dementia.

Diagnosis rates are also improving but wide variations still exist both within the UK and between the English regions (ranging from less than 40 to over 75 per cent). Waiting times for a diagnosis vary considerably depending on where people live with unnecessarily long waits causing undue stress.

Once diagnosed many people are left without support. Numerous projects are underway across the UK, focused on making communities easier places for people with dementia to access services, socialise and live well, but there are also wide geographical variations in access to and people's ability to pay for such services.

The Alzheimer's Society 2014 survey, presented at their annual conference, shows there is still a long way to go. The survey found that only 58 per cent of people with dementia say they are living well and less than half feel part of their community. Sixty-one per cent have felt depressed or anxious recently, largely due to a lack of access to support. Around 40 per cent have felt lonely recently and 10 per cent only leave the house once a month. Forty-three per cent of carers consider they do not receive enough support and are over-worked. Indeed, Seventy-five per cent don't think society is geared up for dementia.¹¹ The international research community is making dementia a global priority and investment in dementia research is set to double in the UK.

Feedback from Alzheimer's Society led workshops and further background information

Participants in the different strands of research acknowledged to varying degrees the role played by national reports, reviews and changes to inspection.

There was widespread acknowledgement that care for frail older people, including those with dementia, has been under increasing scrutiny over the past few years with a plethora of high profile national reviews highlighting serious concerns about the care provided to this vulnerable group. These reviews include:

- Fairer Care Funding – The Report of the Commission on Funding of Care and Support – the Dilnot Commission (July 2011).¹²
- The Francis Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry, (February 2013).¹³
- Review into the Quality of Care and Treatment Provided by 14 Hospital Trusts in England, led by Professor Sir Bruce Keogh, the NHS Medical Director in NHS England (July 2013).¹⁴
- The Cavendish Review: An Independent Review into Healthcare Assistants and Support Workers in the NHS and Social Care Settings, by Camilla Cavendish (June 2013).¹⁵

- A Review of the NHS Hospitals Complaints System: Putting Patients Back in the Picture by Rt Hon Ann Clwyd MP and Professor Tricia Hart (September 2013).¹⁶
- Care Quality Commission on the State of Healthcare and Adult Social Care in England 2012-13 (November 2013).¹⁷

In England, the NHS reforms introduced in the Health and Social Care Act 2012 were a response to the need to change the way that the healthcare system commissions and delivers care. The reforms introduced major changes to the organisations, commissioning and provider structures and processes and require care provision to be monitored at the local level using locally determined impact and outcome measures.

These reforms are largely structural and organisational and on their own are unlikely to tackle the underlying challenges in caring for people with dementia. The Government's response, Patients First and Foremost, set out plans to prioritise high quality care, improve transparency and ensure that, where poor care is detected, there is clear action and clear accountability. In its final response, in November 2013, the Government accepted the need to implement the majority of Francis's recommendations but it is not clear how this will be monitored at the local level, nor are the cost implications and source of funding clear.

Meanwhile the Department has put in place:

- a tougher approach to the inspection and regulation of all health and social care providers, including general practice and private sector providers
- a range of centrally determined initiatives to develop the capability of individual organisations and the system as a whole to improve quality and safety.¹⁸

In 2013 the Care Quality Commission appointed chief inspectors of hospitals, adult social care and primary care and consulted on a new system of ratings. In January 2014, as part of its commitment in 'Hard Truths' NHS England issued practical guidance for commissioners, providers, nursing medical and allied health professional leaders on the provision of safe compassionate care for frail older people using an integrated care pathway.

The Care Quality Commission has also been undertaking a themed inspection of dementia comprising reviews of:

- the quality of support provided to people with dementia to enable them to maintain their physical and mental health and wellbeing
- how the care provided aims to reduce admissions to hospitals from care homes and avoid unnecessary lengths of stay in hospital
- how services work together when people move from one service to another.

It has inspected 129 care homes and 20 acute hospitals looking at how people's care needs were assessed, how the care was planned and delivered, how providers worked together, and how providers monitored the quality of their care. The national report Cracks in the Pathway was published in October 2014 and has some evidence things are improving and cites examples of excellent practice. However, there is too much inconsistency and variable quality and the report says that there will be inevitable episodes of poor care along the care pathway. It is unacceptable that there is an expectation of failure. The inspection found that:

- 29 per cent of care homes and 56 per cent of hospitals were found to have aspects of variable or poor care regarding assessment of need
- 34 per cent of care homes and 42 per cent of hospitals were found to have aspects of variable or poor care regarding how people's physical, emotional, mental and social needs were met
- 27 per cent of care homes and 22 per cent of hospitals were found to have aspects of variable and poor care regarding how information was shared between services
- 27 per cent of care homes and 56 per cent of hospitals were found to have aspects of variable or poor care regarding staff's knowledge and understanding of dementia

- 33 per cent of care homes and 61 per cent of hospitals had aspects of variable or poor care regarding the patient not being involved in decisions about their care and how they spend their time
- 37 per cent of care homes and 28 per cent of hospitals were found to have variable aspects of poor practice in the way they monitored the quality of dementia care.

The evidence of the report demonstrates further that there are considerable improvements to be made in creating a world leading dementia service in the UK.

In relation to dementia, NHS England has acknowledged the need for more research, better diagnosis and improved support, with an explicit aspiration to increase the diagnosis rate and close the gap in variability of services. Indeed the Government's original NHS Mandate in 2012 and the refreshed Mandate in November 2013 identified as a goal that the NHS's diagnosis, treatment and care of people with dementia should be among the best in Europe; including making measurable progress by 2015.¹⁹ NHS England has developed a number of tools to support the implementation of the Mandate.²⁰ Training, however, remains a weak area in terms of progress to date.

In response to concerns about training, the Government announced in May 2014 that specialist training in dementia will be introduced for all 1.3 million NHS workers between now and 2018 to improve the care given to thousands of patients with dementia, as experts claim not enough healthcare workers know enough about the condition. This still leaves however, the 1.6 million social care staff that are increasingly expected to care for people with dementia, with very limited, if any, training.²¹

Furthermore, the Government has launched a number of actions to help people cope with the symptoms of dementia in recognition that the diagnosis rate in England is only 48 per cent, and is lower than Scotland and Northern Ireland. The aim is therefore to increase diagnosis rates by:

- making sure that doctors give 65 to 74 year olds information about memory services as part of the NHS health check programme and refer them for assessment if they need it (from April 2013) – (notably people 75 and over who are at much higher risk of developing dementia and who would clearly benefit from these annual health checks are currently excluded- the Deloitte Centre for Health Solutions recommends that the checks should be extended to all people aged 75 and over.²²
- providing £1 million for innovative NHS projects to increase diagnosis rates through the Innovation Challenge Prize for Dementia
- launching a new toolkit to help GPs provide better support.

Other actions to improve the health and care services that treat people with dementia include:

- asking every hospital in England to commit to becoming dementia-friendly with £54 million in funding linked to hospital dementia risk assessments
- providing £90 million to incentivise diagnosis and increase rates to two thirds
- asking care homes and services to sign up to the Dementia Care and Support Compact, which sets out new standards for dementia care
- providing £50 million of funding to adapt wards and care homes for people with dementia
- providing dementia training resources for health and care workers
- helping to fund a £300 million programme to build or renovate housing for people with long-term conditions, including dementia
- providing £400 million to help fund breaks for carers.²³

Finally, given that scientists understand less about dementia than they do about other major diseases like cancer or heart disease the Department has committed to increase scientific knowledge of dementia – aimed at developing new treatments – by increasing annual funding of dementia research to around £66 million by 2015.

Following the June 2013 Government Spending Round review, the Department announced a new initiative aimed at supporting the wider health and social care integration agenda – the creation of a £3.8 billion Better Care Fund – “a single pooled budget to enable health and social care services to work more closely together in local areas from April 2015”. Each local area was required to submit its plans by March 2014.²⁴ An initial evaluation suggests that many local areas have included initiatives targeted at improving dementia care in their plans.

NHS England has published its business plan for 2015-16, summarising the headline goals and priorities for the year ahead. The plan sets out ten priorities to improve quality and access to services for patients, drive better value for money and to build the foundations for the future health and care system. The second of these priorities is to upgrade the quality of care and access to mental health and dementia services. More specifically in relation to dementia its plan aims to increase diagnosis rates (by March 2016 to have achieved and maintained the national dementia diagnosis rate of 67 per cent) and develop a five year transformation plan to ensure good post-diagnostic services for people with dementia across England. Its priority for dementia also includes improving access to support and information about living with the condition and enabling better advanced care planning and access to support for carers. NHS England aims to work with its partners, including the Alzheimer’s Society and other voluntary organisations, to develop a cross-organisational programme of services for people, following their diagnosis, to achieve greater consistency in services across England.²⁵

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Contacts

Karen Taylor

Research Director

Deloitte UK Centre for Health Solutions

Tel: +44 (0) 20 7007 3680

Email: kartaylor@deloitte.co.uk

Rebecca George

Lead Partner, Public Sector Health

Deloitte LLP

Tel: +44 (0) 20 7303 6549

Email: regeorge@deloitte.co.uk

Jeremy Hughes

Chief Executive, Alzheimer's Society

Tel: +44 (0) 20 7423 3511

Email: jeremy.hughes@alzheimers.org.uk

George McNamara

Head of Policy and Public Affairs, Alzheimer's Society

Tel: +44 (0) 20 7423 3550

Email: george.mcnamara@alzheimers.org.uk

David Jones

Partner, Corporate Finance Advisory Healthcare and Life Sciences

Tel: +44 (0) 20 7007 2259

Email: davidljones@deloitte.co.uk

Contributors

Nick Allen, Oliver Whight, Sam Gould,
Phil Freeman, Gavin Terry

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Contact information

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