NIHR Health Futures consultation from Alzheimer's Research UK

Alzheimer's Research UK is the UK's largest dedicated dementia research charity and we are responding to this consultation as part of the Association of Medical Research Charities (AMRC), on the wider health and healthcare landscape and independently here, to address and detail the specific dementia challenges we see into the future.

Dementia is the second leading cause of death in the UK, costs over £26bn a year to the economy and there are over 850,000 people living with dementia. It is the only condition in the top ten causes of death without a treatment to cure, slow or prevent the diseases which cause dementia and the numbers of people living with dementia are expected to rise to over one million by 2021. It is the single greatest health challenge of our time.

Our goal is to ensure that dementia research and the effects that dementia has on the UK are considered in the NIHR's 20-year plan, to improve the lives of people living with dementia now and in the future.

Differences between present and future health issues – in relation to your area of interest, what differences do you foresee in the state of health and provision of healthcare in England in 20-30 years' time? Are these changes likely to affect different socioeconomic, ethnic or geographic groups differently?

1. Dementia and holistic care

Increasing life expectancy will mean many more people in the oldest age groups where health and social care costs increase as multiple conditions including dementia are common, creating expensive and complex care needs. People over 65 have, on average two comorbidities while people over 65 with dementia have on average four comorbidities.[1]

Dementia is a particularly expensive comorbidity and erodes the ability of people to self-care which increases the intensity of support needed and increases preventable acute issues. The cost of dementia as a comorbidity has in a recent study been conservatively estimated at £1bn annually[2] to the health and social care system, by speeding the decline of health and increasing the severity of conditions. while the NHS Five Year Forward View for Mental Health states a much higher figure of £3bn.[3][4]

Holistic care and greater integration of health and social care will become the features of the new healthcare system to deal with these changing needs of the older population. Chronic health conditions with a variety of multi-morbidities are most effectively treated as a multi-disciplinary team, which treats the person rather than the disease.

Currently, the majority of formal dementia costs are situated in the social care sector and further integration of health and social care will allow for conditions such as dementia to be more coherently managed, especially as new treatments become available and healthcare becomes a greater part of dementia care. More importantly, patient outcomes will be improved as care is more coordinated.

This shift will require large investment and a greater awareness and understanding about dementia in both the health and social care sectors as well as the general population.

2. Dementia and risk reduction

The second trend we expect to see is a greater focus on healthy ageing which is will drive a shift in focus from curative to preventative medicine. In dementia research, prevention and risk reduction is a very active field and in diseases lacking an effective treatment, preventative strategies offer important

[1] Poblador-Plou B et al (2014). Comorbidity of dementia: a cross-sectional study of primary care older patients.

[2] Scrutton, J and Brancati, CU (2016); Dementia and comorbidities; Ensuring parity of care from The International Longevity Centre supported by Pfizer

[3] NHS Five Year Forward View for Mental Health A report from the independent Mental Health Taskforce to the NHS in England February

[4] p57

avenues to reduce the burden of disease. The Blackfriars Consensus (2014) was the first policy and academic recognition of this relationship for dementia, and given the relative infancy of this topic as a policy priority, there is much to do in terms of increasing public and professional awareness and joining up national and local health systems.

This shift will also affect the delivery and type health interventions. Overall, the majority of health interventions take place in acute clinical settings once a person is ill, such as hospitals and outpatient services, however, the implementation of risk reduction in the healthcare system will widen the delivery of healthcare to community and in-home settings, such as public health campaigns and behaviour changes. This will place a greater demand on education and simple behaviour interventions to ensure people stay healthy rather than treating them once they are ill.

Public health interventions to reduce the numbers of people who develop health conditions can be effective and are likely to become more important as the evidence base for dementia risk reduction improves. Recently, Public Health England (PHE) has developed dementia risk reduction information and, in partnership with Alzheimer's Research UK, produced a risk reduction booklet[5].

Case study

Alzheimer's Research UK, in conjunction with Public Health England and Alzheimer's Society recently led a pilot project to extend the dementia component of NHS Health Checks. Currently dementia risk reduction messaging is only offered to 65-74 year olds who attend an NHS Health Check, yet NICE guidelines recommendation risk reduction messaging for people in midlife. Four pilot sites across England offered dementia risk reduction messaging to 40-64 year olds, and the opinions of people and health check practitioners were sought to understand the impact of this extra information. Evaluation of the pilots is currently being finalised before recommendations for policy makers are made.

Increasing public awareness of the action that individuals can take to reduce their risk of developing dementia will pay dividends in the future and health services need to be willing and able to make changes now to ensure these returns can be collected.

3. Dementia diagnosis

Specifically related to dementia, we expect to see is a greater focus on earlier detection and diagnosis to enable more effective treatment of the diseases which cause dementia, especially when new treatments become available. There has been significant progress in dementia diagnosis rates over the last several years however, while this benefits patients and improves the accessibility of support and treatment, the stage of the diagnosis and specificity of it have not received as much attention. Evidence indicates that a new drug will likely be delivered as early as possible to affect the course of the diseases which cause dementia, even at the pre-symptomatic stage, which necessitates earlier diagnosis.

To improve the diagnoses of dementias requires changes in targets, from diagnosis rate to specificity of diagnosis, and improvements in capacity and infrastructure. Currently, there are around 220 memory assessment services in England and despite an average increase of 25% in the number of appointments between 2013 and 2014, this number has not grown[6]. New treatments will likely require more frequent and detailed assessments meaning even more intensive use of these services and requiring an increase in capacity to maintain waiting time targets.

Not only will there need to be an increase in capacity but there also has to be an increase in availability and utilisation of genetic, imaging and clinical data. These advanced tools have accelerated research progress in stratification of diseases that cause dementia and it is likely that this need for infrastructure and expertise to allow genetic testing and imaging for risk and disease stratification will be translated into common practice and dementia treatment.

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[5] Reducing your risk of dementia: http://www.alzheimersresearchuk.org/wp-content/uploads/2015/01/RRD-0515-0517-Risk-Reduction-Low-Res.pdf

[6] Hodge, S et al (2015). Second English National Memory Clinic Audit Report conducted by the Royal College of Psychiatrists funded by the Department of Health

4. Embedded research involvement

The public are becoming more informed about their health and healthcare needs. The emergence of services such as Join Dementia Research (JDR) is allowing greater numbers to participate in research studies, increasing appetite for research involvement. Through the advent of smart phone apps and wearable devices, people are now able to monitor their lifestyles and this is increasingly being incorporated into academic research.

These changes are likely to cause increased focus on research and data utilisation in the NHS and public health system. The UK currently recruits around one in five cancer patients to cancer research studies, higher than any other comparable nation, credit to work conducted in part by NIHR. This level of engagement must be translated across health categories, including dementia, to increase research participation and help develop new treatments and to help diminish the stigma surrounding dementia.

Key drivers – what do you think are the key drivers of the changes you have described?

1. Population demographics

Over the next several decades the health and social care sectors will be facing an unprecedented shift in demand for services due to changes in population demographics, namely population ageing and higher life expectancies than ever before. While there are a number of health conditions associated with ageing, dementia is the most feared.

The number of people living with dementia in England is expected to increase from over 700,000 today, to 1.4m by 2040[7]. Along with this large rise in prevalence of dementia goes an equivalent increase in estimated costs, rising from £22bn to over £46bn[8] per year [see Annex for prevalence and cost projections]. Dementia and Alzheimer's disease is now the leading cause of death in England[9].

The key drivers of this rapid increase in the numbers of people living with dementia are the aforementioned demographic changes of an ageing population and an increase in life expectancy. As age is the greatest risk factor for dementia, by 2040 these two changes will lead to a 24% of the population being over 65[10] and therefore being at a significantly higher risk of developing dementia; risk of developing dementia doubles every five years after the age of 65[11].

These changes will continue to have a huge impact on the health and social care sector if unaddressed. The current trend towards greater integration between health and social care will improve coordination and efficient delivery of services.

A further change that will drive holistic care is technology. Introducing interventions which support and help to monitor people living with dementia in their own homes for a longer period of time is both desired by the majority - 85% of people prefer to remain at home as long as possible[12] - and on average, less expensive for the health and social sector compared to care homes[13].

Another reason for the rising impact of dementia is a historical one. Research into dementia and the diseases that cause it has been under-funded for decades meaning knowledge of the underlying biology and disease mechanisms needs to be better understood. Because of this lack of knowledge, there are

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[7] Prince, M et al (2014) Dementia UK: Update Second Edition report produced by King's College London and the London School of Economics for the Alzheimer's Society

[8] Prince, M et al (2014) Dementia UK: Update Second Edition report produced by King's College London and the London School of Economics for the Alzheimer's Society

[9] Deaths registered in England and Wales (Series DR) 2015: https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/bulletins/deathsregisteredinenglandandwalesseriesdr/2015

[10] Office of National Statistics: 2014-based National Population Projections 29 October 2015

[11] Corrada MM, Brookmeyer R, Paganini-Hill A, Berlau D, Kawas CH. Dementia Incidence Continues to Increase with Age in the Oldest Old The 90+ Study. *Annals of Neurology*. 2010;67(1):114-121. doi:10.1002/ana.21915.

[12] YouGov poll (June 2014) commissioned by Alzheimer's Society

[13] Prince, M et al (2014) Dementia UK: Update Second Edition report produced by King's College London and the London School of Economics for the Alzheimer's Society

no treatments that can alter the course of diseases such as Alzheimer's and furthermore, this limited understanding could lead to unforeseen changes in the future.

For instance, evidence suggests that poor cardiovascular health and diabetes may increase the risk of developing dementia and with the recent increases in obesity, prevalence of dementia may rise to a higher level than currently predicted. Further research can clarify and predict these changes but requires investment.

2. Technology

The changing demands of the population and developments through research will drive the shift to a more prevention-based health system. In order to be sustainable and meet rising demand, interventions to ensure a healthier life and ageing will be necessary and cost effective to reduce the prevalence of conditions such as dementia. Several examples are currently in their early stages.

People are more aware of their health today than ever before, with personalised technology ubiquitous in modern life, everything from phones to fridges can be used to record exercise and diet in real-time and with minimal burden to people. Translating these advances into healthcare tools and common practice could transform the way we think about health and treatment of chronic health conditions such as dementia. Mid-life interventions on a population-wide scale could be the key to reducing the numbers of people living with dementia by a significant amount.

The potential impacts of technology and big data are enormous for dementia where monitoring and early interventions can be crucial. Technology advances can be used to collect real-time patient level data which in turn can bring warning signs to health professionals' attention and allow care to be given before a situation becomes serious, reducing the cost to the health service and improving the health of the patient.

These population-wide ambitions will have to be matched by population awareness and communication, such as the One You campaign, which will aid both research and wider health.

3. Disease modifying treatment for dementia

It is likely that in the next 10 years we will have the first disease modifying treatment for dementia and this will provide huge benefits to patients and carers as well as the health and social care sectors.
A treatment that delays the onset of dementia by two years could save £12bn a year after 30 years and reduce the numbers of people living with dementia by 383,000. Delaying onset by five years could save £21bn and reduce prevalence by 666,000[14] after 30 years. They are also likely to significantly impact the way health care is delivered and transform pathways of dementia care.

The first disease modifying treatment for dementia will be for one of the diseases that cause dementia, most likely Alzheimer's disease as current research is focussed on Alzheimer's disease. Being able to accurately diagnose Alzheimer's disease and at an early stage will be a pre-requisite for treatment, driving early diagnosis research and integration into the health services. A first ever treatment for Alzheimer's disease is also likely to be demanded by a large number of people, providing significant public pressure on the health service to deliver it.

Technology is likely to be a driving force in diagnostics as well. As treatments will likely be introduced for an asymptomatic population, genetic tests to determine inherited risk factors are likely to be used as an initial screening method. Imaging and cerebrospinal fluid (CSF) diagnostics are the most common methods of further diagnostic test. A combination of these significant and sensitive enough to recommend treatment for a particular disease such as Alzheimer's disease at the asymptomatic stage would constitute a marked advance in research and would force large changes in the formation and capacity of current health and care systems, in the same way that advances in cancer therapies and diagnostics have driven healthcare provision.

[14] Lewis et al (2014). Trajectory of Dementia in the UK - Making a Difference, report produced the Office of Health Economics for Alzheimer's Research UK
[15] https://www.dementiasplatform.co.uk/

Given the state of the science, it is difficult to predict the exact formation of these services meaning that health services must remain agile and responsive, with effective horizon scanning and communication. Proactive translational initiatives, engagement with commissioners and early-stage collaboration between biopharmaceuticals and NICE are all methods of improving uptake and reducing delays to patient access.

4. Data Sharing

Although the shift toward big data is not unique to dementia, there are large, dementia-specific initiatives ongoing worldwide aiming to build on the power sharing data offers for new discoveries and analysis. AMRC have discussed the wider landscape in their response, which we fully support. Initiatives include Dementia Platforms UK[15], open data imaging platforms such as Alzheimer's Disease Neuroimaging Initiative (US) and open data repositories such as GAAIN (US). These data sharing initiatives and increases in the amount of data produced will lead to greater integration.

Analysing large data sets is particularly relevant to dementia as we have limited understanding of the earliest stages of the diseases which cause dementia and it is only by collecting data on large numbers of people, that we can determine disease risk factors and progression.

Case study;

Alzheimer's Research UK partnered with Deutsche Telekom's Sea Hero Quest project in 2016. This was a mobile game developed by leaders in gaming, technology, academia and research, to create the biggest spatial navigation study in history. This research aims to set new standards in dementia research, establishing the first ever global benchmark for human spatial navigation – a key indicator in the development and diagnosis of dementia. More than 2.4 million people have now taken part in Sea Hero Quest since it launched in May 2016, generating over 63 years of gameplay – which equates to over 9,400 years' worth of equivalent lab-based research in this area. The second largest study of this kind contained just 599 participants.

Dr Hugo Spiers of University College London has been leading the analysis of the anonymous player data. Initial findings presented today indicate that our spatial navigation abilities begin to decline from early adulthood (sample analysis began at 19) and that they continue on this trajectory across the lifespan. Those aged 19 were 74% likely to accurately hit a target during the game, whereas this figure had reduced to 46% amongst those aged 75. This progression is in stark contrast to previous smaller scale studies of around 100 people, which had suggested such a decline to be expected in later life.

Future healthcare trends – in your opinion what will be the major trends in health and healthcare in England over the next 20-30 years? (Extending beyond your immediate area of expertise)

We have responded to this question as part of the AMRC's response and in the earlier questions.

Overstated health and healthcare issues – are there commonly discussed issues related to the future of health and healthcare in England which you believe to be overstated? If so, why do you believe them to be overstated?

We do not believe that any area of health and healthcare can be overstated, rather we consider that areas such as dementia require increased investment and consideration.

Underrepresented health and healthcare issues – are there any issues that are underrepresented in the debates around the future of health and healthcare in England? If so, what are they and why do they require greater attention?

1. Momentum

Over the last several years, the dementia research field has come a long way; investment in dementia research has risen annually both in the UK and abroad, the global awareness of dementia has increased and there have been more late-stage clinical trials for disease modifying treatments. While this is encouraging, it is still the case that there is no treatment for these diseases and each year Alzheimer's disease and dementia rises on the rankings of causes of death.

The next decade could be crucial for dementia research and it is of vital importance that momentum generated thus far is built on. The UK dementia research field is currently world-leading, with the £250m Dementia Research Institute recently formed, the Medical Research Council driving forward with the Dementia Platform UK, and a number of European initiatives with UK partners but if focus is lost now then it will be patients in the future who will be left behind.

Case study;

Currently, a diagnosis of Alzheimer's disease can only be confirmed at post mortem. This makes human brain donation vital for not only the patient but the tissue is also a vital resource for dementia research. There are excellent brain banking initiatives ongoing across the UK, including BRAIN UK and the dementia specific initiative Brains for Dementia Research, a prospective cohort all signed up for brain donation. Investment for brain bank support is at a crossroads, with support being withdrawn by both major government funders, MRC and NIHR. This poses a huge risk to dementia research as charities are now having to fund NHS support for this work, severely restricting the potential for research that can therefore be supported to use this invaluable resource.

The value of brain donation is highlighted by work funded by Alzheimer's Research UK at University of Southampton. Prof James Nicoll followed up on a failed Alzheimer's clinical trial - the first to try to clear amyloid protein from the brain, by studying the brains of participants once they had died. In 2006, they revealed the first evidence to suggest that treatments designed to clear amyloid are likely to have the greatest impact if given in the earliest stages of disease – altering the design of subsequent trials. In 2011, their careful investigation into the adverse effects brought on by the original drug influenced a change in the healthcare regulation guidelines issued by the US federal agency for monitoring side effects in clinical trials. This would not have been possible without the collection of the brains of participants of this trial.

2. Minority groups

Dementia in ethnic minority groups is currently poorly understood and poorly researched and needs greater attention to ensure these groups are not left behind. There is some evidence that BAME communities are under-represented in memory services and in the numbers of people in contact with health services around dementia. Research carried out in memory assessment services found that just 6% of people in memory assessment services were from non-white ethnic groups[15]. In some communities there appears to be a lack of understanding around the fact that dementia is a disease and cultural barriers to accessing support. Without specific actions to tackle this, BAME communities are likely to continue to be under-represented.[16]

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Carla Cox, Research Knowledge Manager at Carla.Cox@alzheimersresearchuk.org

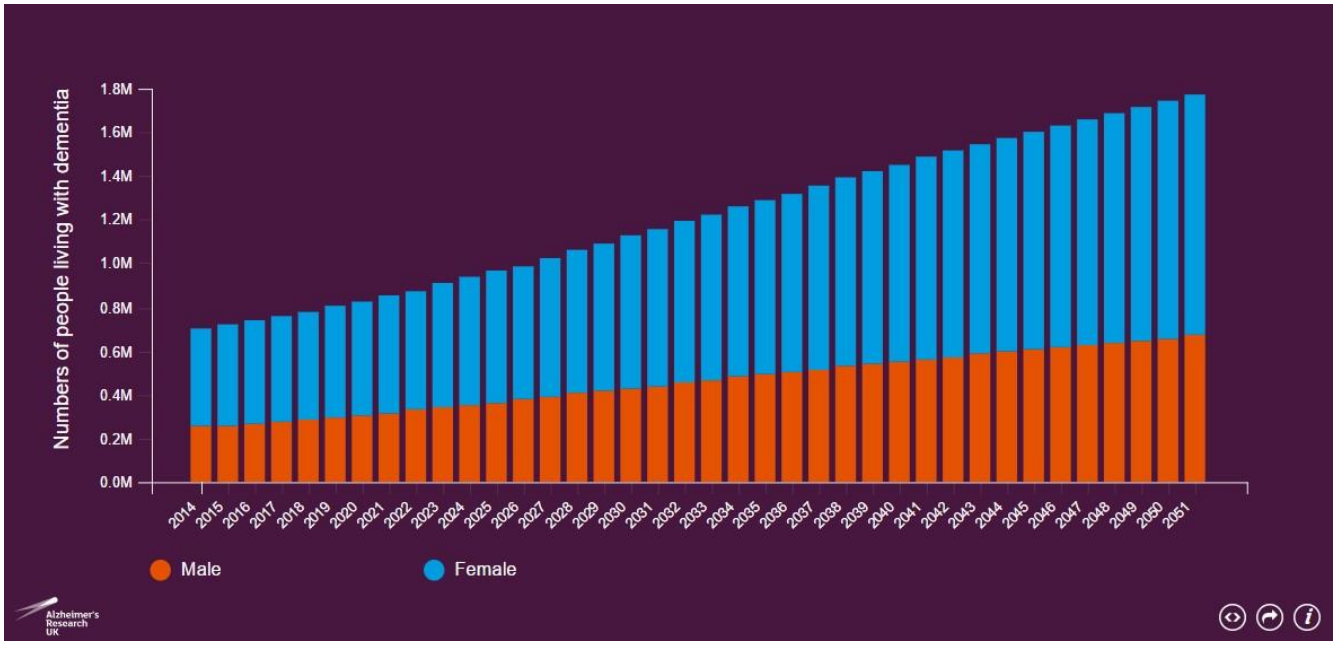
[16] Sociodemographic Characteristics, Cognitive Function, and Health-related Quality of Life of Patients Referred to Memory Assessment Services in England. (2016) Park, Smith, Neuburger, Chrysanthaki, Hendriks, Black

[17] Dementia does not discriminate; The experiences of black, Asian and minority ethnic communities (2013) House of Commons All-Party Parliamentary Group on Dementia.

Annex

Graph 1

England; Male and female dementia prevalence projections– see **Table 1** for details.



Graph 2

England; Cost projections by sector – see **Table 2** for details.

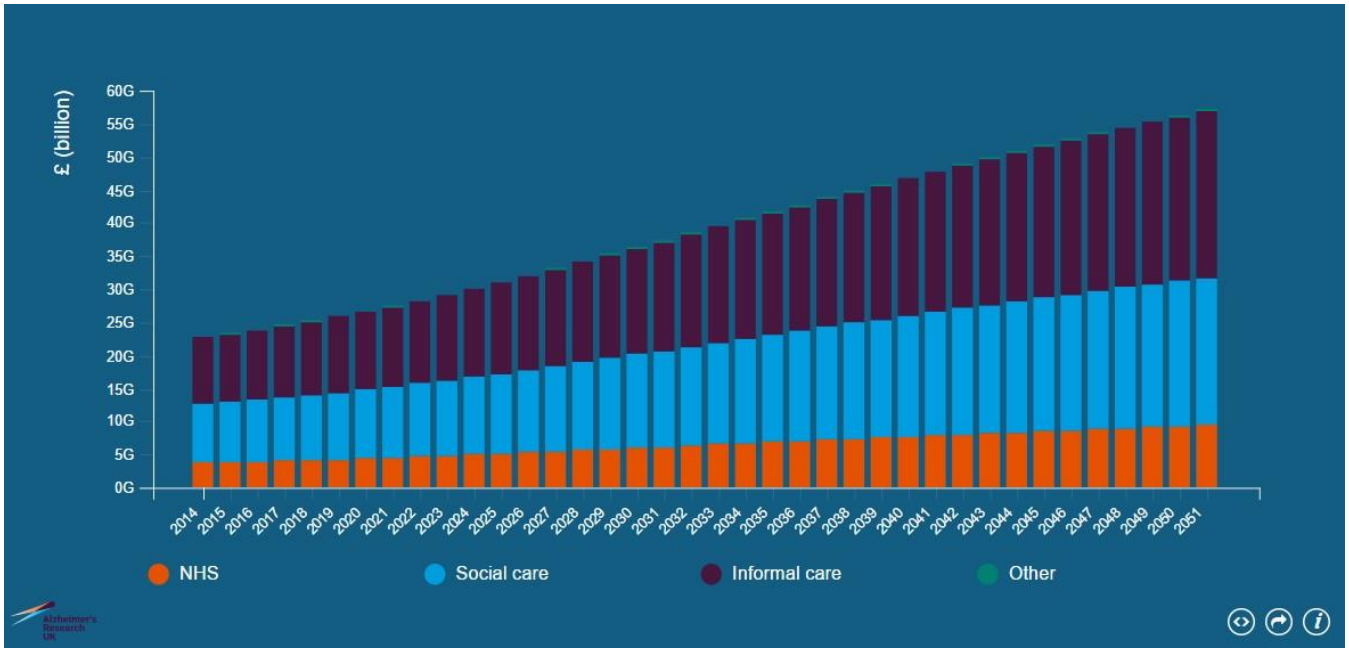


Table 1 – Prevalence of dementia in England

Year	Male	Female	Total
2014	251105	452264	703369
2015	259070	461830	720900
2016	267149	471495	738644
2017	276879	482606	759485
2018	286649	494185	780834
2019	296528	506492	803020
2020	306329	519322	825651
2021	315855	532207	848062
2022	327540	548644	876184
2023	339516	565300	904816
2024	351618	582216	933834
2025	363284	599060	962344
2026	374643	615308	989951
2027	389118	635783	1024901
2028	402930	656351	1059281
2029	416062	676679	1092741
2030	428160	695814	1123974
2031	439673	713941	1153614
2032	453356	737204	1190560
2033	466583	759752	1226335
2034	479157	781284	1260441
2035	490631	800956	1291587
2036	501818	819712	1321530
2037	515091	843287	1358378
2038	526628	863062	1389690
2039	538165	882836	1421001
2040	549702	902611	1452313
2041	561240	922385	1483625
2042	572216	941029	1513245
2043	583192	959673	1542865
2044	594168	978316	1572484
2045	605145	996960	1602105

2046	616121	1015604	1631725
2047	626544	1033639	1660183
2048	636966	1051675	1688641
2049	647389	1069710	1717099
2050	657811	1087745	1745556
2051	668234	1105781	1774015

Table 2 – Cost of dementia in England

Year	Informal care	NHS	Other	Social care	Total
2014	£10,013,864,000	£3,717,305,000	£95,658,000	£8,851,195,000	£22,678,022,000
2015	£10,263,453,000	£3,809,956,000	£98,042,000	£9,071,806,000	£23,243,257,000
2016	£10,516,075,000	£3,903,734,000	£100,456,000	£9,295,096,000	£23,815,361,000
2017	£10,812,788,000	£4,013,878,000	£103,290,000	£9,557,359,000	£24,487,315,000
2018	£11,116,734,000	£4,126,708,000	£106,193,000	£9,826,015,000	£25,175,650,000
2019	£11,432,610,000	£4,243,966,000	£109,211,000	£10,105,216,000	£25,891,003,000
2020	£11,754,793,000	£4,363,566,000	£112,289,000	£10,389,992,000	£26,620,640,000
2021	£12,073,844,000	£4,482,002,000	£115,336,000	£10,672,000,000	£27,343,182,000
2022	£12,474,232,000	£4,630,632,000	£119,161,000	£11,025,899,000	£28,249,924,000
2023	£12,881,865,000	£4,781,953,000	£123,055,000	£11,386,205,000	£29,173,078,000
2024	£13,294,995,000	£4,935,313,000	£127,001,000	£11,751,367,000	£30,108,676,000
2025	£13,700,892,000	£5,085,988,000	£130,879,000	£12,110,137,000	£31,027,896,000
2026	£14,093,932,000	£5,231,891,000	£134,633,000	£12,457,543,000	£31,917,999,000
2027	£14,591,516,000	£5,416,602,000	£139,387,000	£12,897,354,000	£33,044,859,000
2028	£15,080,984,000	£5,598,300,000	£144,062,000	£13,329,992,000	£34,153,338,000
2029	£15,557,339,000	£5,775,131,000	£148,613,000	£13,751,040,000	£35,232,123,000
2030	£16,002,018,000	£5,940,203,000	£152,860,000	£14,144,089,000	£36,239,170,000
2031	£16,424,003,000	£6,096,850,000	£156,892,000	£14,517,079,000	£37,194,824,000
2032	£16,950,003,000	£6,292,110,000	£161,916,000	£14,982,007,000	£38,386,036,000
2033	£17,459,317,000	£6,481,175,000	£166,781,000	£15,432,187,000	£39,539,460,000
2034	£17,944,899,000	£6,661,431,000	£171,420,000	£15,861,390,000	£40,639,140,000
2035	£18,388,324,000	£6,826,037,000	£175,656,000	£16,253,331,000	£41,643,348,000
2036	£18,814,623,000	£6,984,286,000	£179,728,000	£16,630,134,000	£42,608,771,000
2037	£19,339,228,000	£7,179,028,000	£184,739,000	£17,093,829,000	£43,796,824,000
2038	£19,785,017,000	£7,344,512,000	£188,998,000	£17,487,859,000	£44,806,386,000
2039	£20,230,791,000	£7,509,990,000	£193,256,000	£17,881,877,000	£45,815,914,000
2040	£20,676,580,000	£7,675,474,000	£197,515,000	£18,275,907,000	£46,825,476,000
2041	£21,122,369,000	£7,840,958,000	£201,773,000	£18,669,937,000	£47,835,037,000
2042	£21,544,069,000	£7,997,500,000	£205,801,000	£19,042,675,000	£48,790,045,000

2043	£21,965,769,000	£8,154,042,000	£209,830,000	£19,415,413,000	£49,745,054,000
2044	£22,387,469,000	£8,310,583,000	£213,858,000	£19,788,151,000	£50,700,061,000
2045	£22,809,169,000	£8,467,125,000	£217,886,000	£20,160,889,000	£51,655,069,000
2046	£23,230,869,000	£8,623,667,000	£221,915,000	£20,533,627,000	£52,610,078,000
2047	£23,636,025,000	£8,774,067,000	£225,785,000	£20,891,743,000	£53,527,620,000
2048	£24,041,182,000	£8,924,468,000	£229,655,000	£21,249,858,000	£54,445,163,000
2049	£24,446,338,000	£9,074,868,000	£233,525,000	£21,607,974,000	£55,362,705,000
2050	£24,851,481,000	£9,225,263,000	£237,396,000	£21,966,077,000	£56,280,217,000
2051	£25,256,637,000	£9,375,664,000	£241,266,000	£22,324,192,000	£57,197,759,000