Suffolk Dementia Needs Assessment: Update

March 2016

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Executive Summary

Although a full Needs Assessment (NA) for Dementia in Suffolk was completed in November 2013, since then national policy, prevalence estimates, guidance on service provision and research findings related to dementia have continued to evolve.

Taking these factors into account, this document updates and refreshes the 2013 Needs Assessment for dementia in Suffolk, and draws conclusions about the local population and the evidence for effective service models and interventions. This update does not cover every area in the 2013 Needs Assessment, for example, the work on stakeholder and user experience has not been repeated due to time constraints, and should therefore be read in conjunction with the 2013 Needs Assessment.

Key Findings and Recommendations

Building on the 2013 Needs Assessment

While progress has been made with regard to a number of the 2013 recommendations, notably in improving dementia diagnosis rates and the ongoing development of dementia friendly communities, dementia action alliances and dementia friendly employers, there remains work to do to meet all of the recommendations in full.

Recommendation 1: Commissioners should review the progress made against the 2013 Needs Assessment recommendations and, if still relevant, continue to make plans to address them.

Risk Factors and the Prevention of Dementia

The estimates of overall dementia prevalence in England have been revised downwards by a statistically significant 1.8%, compared to estimates made 20 years ago. This decline suggests that there is a cohort effect in dementia prevalence, with later-born populations having a lower risk of prevalent dementia than those born earlier in the last century.

There is a growing consensus that more dementias contain a vascular element than previously thought; therefore, actions to prevent or reduce cardiovascular risk are also important in reducing the prevalence of dementia. However, the importance of cardiovascular risk management for the promotion of brain health is not widely understood and needs to be explicitly communicated. Recent NICE guidance on “Dementia, Disability and Frailty in Later Life – Mid-life Prevention Approaches” highlights the need for people to stop smoking, be more physically active, reduce alcohol consumption, eat healthily and maintain a healthy weight in order to optimise their brain health in later life. Although the precise roles of loneliness and isolation as risk factors for dementia are not fully understood, they may reduce resilience to the onset and progression of dementia, so are also important to consider within the context of prevention.

Recommendation 2: The Commissioners of dementia services in the Suffolk CCGs and Suffolk County Council should note that more dementias have a vascular element than previously thought, and may therefore be amenable to prevention through the recognition and effective treatment of risk factors as part of the Suffolk Prevention Strategy.

Descriptive Epidemiology of Dementia in Suffolk
Since the 2013 Needs Assessment was published, the Office for National Statistics has updated the population projections for Suffolk, and the national prevalence estimates for dementia by age-band have been updated by the Alzheimer’s Society in their recent report Dementia UK: 2014.

These revised data suggest that there are currently approximately 12,800 people with dementia living in Suffolk. By 2035, it is estimated that there will be nearly 25,000 people with dementia in Suffolk, an increase of 90% compared to the current prevalence. Despite recent rises in local dementia diagnosis rates, it is estimated that 40 - 45% of people with dementia in Suffolk have still not received a formal diagnosis, and therefore do not have access to therapeutic interventions and support; this equates to over 5,000 people.

Although relatively rare, the number of people estimated to have early onset dementia in Suffolk (occurring between the ages of 60 and 69) has doubled compared with the 2013 estimates; these younger people may have specific needs relating to employment and family life.

**Recommendation 3:** The Commissioners of dementia services in the Suffolk CCGs and Suffolk County Council should take account of the newly increased estimates for dementia prevalence in Suffolk, both now and in the coming years, and plan accordingly.

There is a three and a half-fold variation in the rates of dementia diagnosis between GP practices in Suffolk; this level of variation is unlikely to be explained by clinical variation alone, and may be contributing to health inequalities. Alzheimer’s disease remains the most common sub-type of dementia, followed by vascular dementia, but rates of death attributed to vascular dementia in Suffolk in 2009-13 have risen compared to 2007-2011, possibly indicating greater awareness of this type of dementia.

**Recommendation 4:** The Commissioners of dementia services in the Suffolk CCGs and Suffolk County Council should support GP practices to reduce the current variation in dementia diagnosis rates, with the underlying aim of reducing potential inequalities in access to care and support.

As well as considering people with dementia alone, it is important to recognise that many people with dementia will also be frail. Recognition and understanding of the concept of clinical frailty is increasing, and as services develop to prevent deterioration and manage crises in those with frailty, there is also an opportunity to recognise, assess and support more people with dementia and their carers.

**Recommendation 5:** The recognition of frailty as a clinical syndrome is becoming easier to achieve and more widespread. The Commissioners of dementia services in the CCGs and Suffolk County Council should consider the extent to which the needs of people with dementia and their carers overlap with the needs of people with frailty, and ensure there are effective links between services when required.

**Evidence review – Diagnosis and Post-diagnostic Support**

Systematic reviews were conducted to review the evidence base published since 2013 for the diagnosis of dementia and the provision of post-diagnostic support. Very few recent systematic
reviews were found regarding diagnosis, but there were a sizeable number of publications relating to post-diagnostic support. While some of this evidence was of a very low quality, there is recent evidence of better quality which found a number of different types of post-diagnostic intervention to be clinically effective.

**Recommendation 6:** The Commissioners of dementia services in the Suffolk CCGs and Suffolk County Council should note the evolving evidence base for post-diagnostic interventions, and ensure that commissioned services take account of the recent research findings with relation to support for carers, case management, interventions within care homes, withdrawal of antipsychotic medication, and occupational therapy.

**Policy review – Recommendations for Post-Diagnostic support services in England**

There is NICE guidance in place for the provision of post-diagnostic support, but it was published in 2006 and will not be updated until 2017. While this guidance should be adhered to, there is also additional guidance from the Royal College of Psychiatrist’s Memory Services National Accreditation Programme (MSNAP) Service Standards, which is recommended for use by NHS England.

**Recommendation 7:** The Commissioners of dementia services in the Suffolk CCGs and Suffolk County Council should ensure that commissioned service specifications meet current NICE guidance and the MSNAP service standards, including the non-mandatory standards covering psychosocial intervention.

In addition to the service standards, the Royal College of Psychiatrist’s Memory Services National Accreditation Programme also offers an accreditation service. Services follow a process of self-assessment and eventual peer review. Service criteria are assessed at one of three levels, Type 1, where failure to meet these criteria would results in a significant threat to patient safety, rights or dignity and/or would breach the law; Type 2, which are criteria that an accredited services would be expected to meet; or Type 3, which are criteria that an excellent service should meet or criteria that are not the direct responsibility of the service. An increasing number of memory services across the country are now Members of MSNAP and are being accredited through the programme, allowing assurance of service quality and recognition and support with areas where improvements are required. None of the three memory services in Suffolk are currently Members of MSNAP, or undergoing accreditation.

**Recommendation 8:** The Commissioners of dementia services in the Suffolk CCGs and Suffolk County Council should strongly encourage all three locally commissioned memory services to join and seek accreditation with the RCP MSNAP programme, aiming to achieve accreditation at level 2 by all three local services within an agreed timescale.

In addition to service accreditation, NHS England also recommends the creation of an online Dementia Roadmap specific to different areas, typically counties. Navigating so-called dementia “pathways” feels more like trying to navigate a labyrinth for many people with dementia and their carers. While it is recognised that online provision is not the right method of communication for everyone, many older people and their carers are increasingly active online, as are health and social care professionals. The Roadmaps are hosted on a common software platform for an annual fee, and can be easily updated as statutory and third sector services change and develop in each area.
Recommendation 9: The Commissioners of dementia services in the Suffolk CCGs and Suffolk County Council should consider the difficulties reported by people with dementia and their families both nationally and locally in understanding and navigating dementia services; consider whether the creation of a Dementia Roadmap for Suffolk would meet the identified information needs of local residents and professionals; and commission accordingly.

Evidence review – Costs and Cost Effectiveness of Dementia Care

The evidence for cost-effectiveness in dementia interventions is again limited. However, recent systematic reviews have indicated that a number of post-diagnostic interventions, including cognitive stimulation therapy, tailored activity programmes, occupational therapy, carer support packages, and care or case managers are cost effective.

Recommendation 10: The Commissioners of dementia services in the Suffolk CCGs and Suffolk County Council should consider the recent evidence on cost-effectiveness of services for people with dementia, and take account of this in their commissioning decisions.

NHS England has recently published a cost analysis for three different types of memory assessment and treatment models. Analysis to date of the primary care in-reach model suggests that it may be significantly cost-saving at CCG level, and that model is in the process of being rolled out from one practice to over CC. The other two models (primary care out-reach and specialist led and delivered) have not been assessed for cost-effectiveness, but costs per patient have been calculated for both approaches, which could provide useful comparators for an assessment of the efficiency of local services.

Recommendation 11: The Commissioners of dementia services in the Suffolk CCGs and Suffolk County Council should review the three service models suggested by NHS England as best practice, consider which model is the best approximation for local services, and compare current service costs against NHS England’s cost estimates to identify opportunities for optimising current service spend.
1. Introduction
Dementia is a syndrome characterized by impaired cognitive functioning and is most common in older people. The ICD-10 definition of dementia is:

A syndrome due to disease of the brain, usually of chronic or progressive nature, in which there is disturbance of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language and judgement. The impairments of a cognitive function are commonly accompanied, and occasionally preceded, by deterioration in emotional control, social behaviour, or motivation.

Dementia therefore has a significant impact on the quality of life of those living with the condition and the family and friends who care for them. It is a complex condition which can cause extensive physical, psychological, emotional and financial stresses to individuals living with dementia, their family carers and the wider community.

A Needs Assessment (NA) for dementia in Suffolk was completed in November 2013. This considered the number of people living with dementia in Suffolk, the number of people forecast to have dementia in the future; the dementia services existing in Suffolk at that time; the views of service users; the evidence of effectiveness of different services; and information gaps.

Since then, national policy concerning dementia and dementia services has continued to evolve; estimates of the prevalence have been updated; dementia diagnosis rates have increased nationally and locally; and the numbers of Dementia Friendly Communities and Dementia Friends have increased; updated audit standards which suggest the evidence-based functions that effective dementia services should provide are now available, and there is also new consensus emerging on the possibility of preventing some types of dementia.

Taking these factors into account, this document updates and refreshes the 2013 NA for dementia in Suffolk, draws conclusions about the local population and the evidence for effective service models and interventions and makes recommendations for commissioners of dementia services in Suffolk. This update does not cover every area in the 2013 NA, (for example, the work on stakeholder and user experience has not been updated), and should therefore be read in conjunction with the 2013 NA.
2. Descriptive Epidemiology of Dementia in Suffolk

Descriptive Epidemiology – Summary

This section presents data on the expected numbers, distribution and patterns over time of people living with dementia and their family carers in Suffolk. This information helps to paint a picture of the local need which can then be compared with the current services on offer.

Who is affected by dementia?
- It is estimated that there are currently approximately 12,800 people with dementia living in Suffolk.
- By 2035, it is projected that there will be nearly 25,000 people with dementia in Suffolk, an increase of 90% compared to the current prevalence.
- Despite recent rapid rises in local dementia diagnosis rates, it is estimated that 40 - 45% of people with dementia in Suffolk have still not received a formal diagnosis, and therefore do not have access to therapeutic interventions and support; this equates to over 5,000 people.
- There is a three and a half-fold variation in the rates of dementia diagnosis between GP practices in Suffolk; this level of variation is unlikely to be explained by clinical variation alone, and may be contributing to health inequalities.
- If we apply national estimates of incidence to the local population, we would expect to see approximately 500 new cases of dementia per year in those aged over 65 years.
- The risk of developing dementia increases with age - 80% of people with dementia in Suffolk are over the age of 75 years.
- Overall, there are more women with dementia in Suffolk than men, with a ratio of 2:1.
- Alzheimer’s disease is the most common sub-type of dementia, followed by vascular dementia.
- Rates of death attributed to vascular dementia in Suffolk in 2009-13 have risen compared to 2007-2011, possibly indicating greater awareness of this type of dementia.
- Although relatively rare, the number of people estimated to have early onset dementia in Suffolk (occurring between the ages of 60 and 69) has doubled compared with the 2013 estimates.

Where do people affected by dementia live?
- Of the three key local areas (Ipswich & East Suffolk Clinical Commissioning Group (CCG), West Suffolk Clinical Commissioning Group and Waveney local authority), Ipswich and East Suffolk CCG has the greatest number of people living with dementia and Waveney has the least. This reflects both population size and age structure.
- The greatest proportional increases over time in people living with dementia are expected in Mid Suffolk and Babergh. The area with the highest total number of people with dementia is expected to be Suffolk Coastal District.
- An estimated 75% of people in Suffolk with dementia live in the community and 25% live in residential care.

What are the patterns over time?
- The number of people with dementia in Suffolk is expected to rise by approximately 40% over the next 10 years, to approximately 17,700 by 2025, and by over 90% over the next 20 years to
2.1 Current Epidemiology of Dementia in Suffolk

The number of older people in Suffolk will continue to increase over the coming decades. In 2012, 21% of the population of Suffolk was aged 65 or over; this will rise to 31% by 2037. The number of people aged 85 or over will also increase by almost three-fold in the same time period\(^4\). These longer lives are, of course, a success story in very many ways; but as people live longer, many more people will develop dementia and will need access to efficient and effective interventions and support. A good understanding of the epidemiology of dementia locally is therefore crucial to guide the commissioning of services that meet existing and future need.

2.1.1 Prevalence

Prevalence describes the proportion of a population that has a condition at a specific point in time or over a specific period. We do not know the true number of people with dementia in Suffolk because there are large numbers of people living with the condition who have not been formally diagnosed. This means that we have to estimate the number of people with dementia in Suffolk.

In this report we use two different ways to estimate the number of people with dementia in Suffolk:

(i) The first method applies the national prevalence estimates from the Dementia UK Report (2014)\(^2\) to the Office of National Statistics (ONS) 2012 population estimates and projections for the County of Suffolk, including Waveney. Unless specifically stated, this is the technique used in most sections of the report. Using 2012 population figures, it is estimated that in 2015 there are 12,757 people with dementia living in Suffolk, compared to 10,799 in 2013, an increase of 18% in two years.

(ii) The dementia prevalence calculator is a tool that produces estimates using general practice registered populations, age and gender profiles rather than ONS population figures. As this is a different technique, it produces different estimates. As at March 2015, it estimates there are 11,772 people with dementia living in Suffolk, using the national prevalence estimates adjusted for care home residents, and assuming that 54% of the Great Yarmouth and Waveney CCG population live in Suffolk. This report specifically states when the dementia calculator has been used.

In figure 1, the dementia prevalence calculator has been used to determine the number of people living with dementia (including those who have not received a formal diagnosis) within the population of the Ipswich & East Suffolk Clinical Commissioning Group (IES CCG), the population of the West Suffolk Clinical Commissioning Group (WS CCG), and the proportion of the population of approximately 24,400 by 2035.

- The greatest absolute increase will be in the over 85 age group.
- It is expected that the number of people with dementia from BME groups in Suffolk is likely to increase over time. These people may have specific needs relating to vascular risk, access to services and awareness or stigma attached to the condition.
- There are approximately 3,452 people over 65 years who have a learning disability in Suffolk, and this number is expected to increase to 4,746 by 2030. These people are at increased risk of developing dementia.
the Great Yarmouth & Waveney Clinical Commissioning Group (GYW CCG) who are resident in Suffolk.

Figure 1: Estimated number of people with dementia by CCG, and by severity of dementia

![Bar chart showing estimated number of people with dementia by CCG and severity of dementia.]

Source: Dementia Prevalence Calculator, March 2015 data; Public Health Suffolk analysis

The dementia prevalence calculator estimates that 55% of people have disease of mild severity, 33% of people have disease of moderate severity, and 13% of people have severe disease. These proportions are estimated to be the same for each of the three Suffolk CCGs, and are illustrated in figure 2 below. Dementia is a progressive disease, meaning that as more people live longer with dementia these proportions of disease severity may change over time. This in turn may have implications for the amount and type of care local people with dementia in Suffolk require in the future.

Figure 2: Estimated Proportions of Dementia Severity Levels in Suffolk

![Pie chart showing estimated proportions of dementia severity levels.]

Source: Dementia Prevalence Calculator, March 2015 data; Public Health Suffolk analysis

Within these overall estimates of the numbers of people with dementia of different degrees of severity, there are significant numbers of people who have not had their dementia diagnosed. Within the three Clinical Commissioning Groups (CCGs) in Suffolk, the numbers and proportion of undiagnosed people with dementia have been falling, particularly since the introduction of an
enhanced service to support case-finding for people with dementia in primary care. The following charts demonstrate how dementia diagnosis rates have improved locally over time, and how the so-called “dementia gap” (the number of people with the disease but without a diagnosis) has been reducing.

**Figure 3:** Estimated dementia diagnosis rate and dementia gap, Ipswich & East Suffolk CCG, April 2009 – March 2015

![Dementia Diagnosis Rate Over Time](image)

*Source: Dementia Prevalence Calculator, March 2015 data*

**Figure 4:** Estimated dementia diagnosis rate and dementia gap, West Suffolk CCG, April 2009 – March 2015

![Dementia Diagnosis Rate Over Time](image)

*Source: Dementia Prevalence Calculator, March 2015 data; Public Health Suffolk analysis*
These charts demonstrate that the rates of dementia diagnosis in all three Suffolk CCGs have risen over the last six years, with the numbers of undiagnosed people with dementia falling. The method for calculating the dementia diagnosis rate changed in April 2015, so it is not possible to compare more recent data with the charts above. Using the updated diagnosis rate calculation, by January 2016, Ipswich & East Suffolk CCG had achieved a diagnosis rate of 62.8%, West Suffolk CCG 64.3%, and Great Yarmouth & Waveney CCG 64.2%. All three Suffolk CCGs are therefore very close to the two-thirds diagnosis rate mandated in NHS guidance for 2016/17.

2.1.2 Variation in diagnosis rates

The latest data for dementia diagnosis rates can also be analysed at the level of individual GP practices. Diagnosis rates among Suffolk practices range from 22.8% of a practice’s estimated number of patients with dementia to 85.5% of a practice’s estimated number of patients with dementia, a 3.7 fold variation. As illustrated in figure 6 below, only 17 out of 78 practices (22% of the total) have diagnosis rates above the 67% target which was set in the Prime Minister’s Challenge on Dementia 2012. A similar pattern of variation can be seen within each of the three Suffolk CCGs, where the average diagnosis rate at CCG level in March 2015 was still below 60%. Such a high degree of variation in diagnosis rates is unlikely to be explained by clinical differences alone, and warrants further local investigation, as it may be contributing to health inequalities within Suffolk.
**Figure 6**: Dementia diagnosis rates by GP Practice, Suffolk, March 2015

![Graph showing dementia diagnosis rates by GP Practice, Suffolk, March 2015.](image)

Source: Dementia Prevalence Calculator; Public Health Suffolk analysis

Figure 7 shows the variation between GP practice diagnosis rates in West Suffolk CCG which is 3.4 fold, and ranges from 22.8% to 78.2%

**Figure 7**: Dementia diagnosis rates by GP Practice, West Suffolk CCG, March 2015

![Graph showing dementia diagnosis rates by GP Practice, West Suffolk CCG, March 2015.](image)

Source: Dementia Prevalence Calculator; Public Health Suffolk analysis

The variation between GP practice diagnosis rates in Ipswich & East Suffolk CCG is 2.4 fold, and ranges from 35.6% to 85.5% (Figure 8). The Ipswich & East Suffolk practice which had diagnosed 85.5% of its expected dementia patients was achieving the highest rate in the county at the time this data was reported.
Figure 8: Dementia diagnosis rates by GP Practice, Ipswich and East Suffolk CCG, March 2015

Source: Dementia Prevalence Calculator; Public Health Suffolk analysis

The variation between GP practice diagnosis rates in Great Yarmouth and Waveney CCG (Suffolk practices only) is 2.6 fold, and ranges from 27.8% to 73.6%. This is illustrated in figure 9 below.

Figure 9: Dementia diagnosis rates by GP Practice, Great Yarmouth & Waveney CCG (Suffolk practices only), March 2015

Source: Dementia Prevalence Calculator; Public Health Suffolk analysis

Following the change in the diagnosis rate calculation methodology in April 2016, NHS England no longer publishes diagnosis rate data at practice level. The relatively low number of dementia diagnoses at practice level led to large swings in practice level diagnosis rates. The updating of estimates of dementia prevalence following the CFAS 11 study (see page 26) meant that confidence intervals were available for the estimates of dementia prevalence for the first time. The majority of GP practices have counts of registered patients too low for their dementia prevalence estimates to have sufficiently tight confidence intervals that their diagnosis rate could be meaningfully distinguished from the norm. Therefore, it is no longer possible to comment on the extent of variation in dementia diagnosis rates between practices in Suffolk, and the suggested variation in diagnosis rates quoted in the charts above should be treated with caution.

2.1.3 Incidence

Incidence is a measure of new occurrences of a condition within a population over a specific time period. Local incidence data for dementia is not collected, so estimates for Suffolk have to be based on national figures.
The incidence of dementia in England has been estimated at 0.3% per year for people aged 65 and over. If applied to the Suffolk population, this would equate to 500 new cases of dementia in 2015 in the 65+ age group based on ONS 2012-based population projections of 166,700 people aged 65 and over living in Suffolk in 2015. This is an increase from 435 new cases as reported in the 2013 Needs Assessment, based on the 2011 population. There are no revised estimates of national incidence since the 2013 Needs Assessment was published.

2.1.4 Mortality
The mortality data in figure 10 below updates the 2007-11 figures given in the previous Needs Assessment for the number of people who have died, and who have dementia listed on their death certificate. Mortality rates for both Alzheimer’s disease and vascular and unspecified dementias in the over 85 age group have seen a large increase from the rates for 2007-2011. There has been a particularly large increase in number of people who had vascular and unspecified dementias recorded as a cause of death. There are now approximately 400 additional deaths per 100,000 residents recorded in this category, compared to the rates in 2007-2011. This apparent change in the types of dementias being recorded as a cause of death has important implications for the prevention of future cases. It suggests that a higher proportion of dementias may be preventable than was previously thought.

It is important to note that this data should be used with caution. It is highly probable that some people who have dementia die of other causes and do not have dementia recorded on their death certificate. The increase shown below could therefore be partly due to better recording of dementia diagnoses on death certificates, as well as to an overall increase in dementia-related deaths.

Figure 10: Age-specific mortality rates for Alzheimer’s disease (ICD-10: G30) and vascular and unspecified dementia (ICD-10:F01, F03); Suffolk 2007-2011 and 2009-13

Source: ONS Vital Statistics; ONS population estimates for the County of Suffolk; Public Health Suffolk analysis

2.1.5 Age and Sex Distribution
The chart below (figure 11) describes the estimated numbers of people with dementia in Suffolk in 2015, by age band and by gender.
**Figure 11:** Age and sex distribution of people with dementia in Suffolk, estimated number by age group, 2015.

![Age and sex distribution of people with dementia in Suffolk, estimated number by age group, 2015.](image)

Source: ONS 2012-based subnational population projections for the County of Suffolk; prevalence estimates from Dementia UK 2014 update (Alzheimer’s Society); Public Health Suffolk analysis

The increasing dominance of females amongst people with dementia as they age can clearly be seen, with over three quarters of the people aged over 90 with dementia being female.

It is interesting to consider how these estimates have changed when compared to the 2013 Needs Assessment, which was based on Alzheimer’s UK 2007 prevalence estimates and the 2011 ONS population projections. The changes from the 2011 estimates (Figure 12 below) show the impact of people living longer, with the number of people in Suffolk who are over the age of 90 and estimated to have dementia rising from 2,240 to 3,160 in the space of four years.

Relatively little change is seen in the estimated number of dementia cases amongst people in their 80s, but increases are seen in younger age groups. Compared to the 2011 estimates, the number of people in Suffolk estimated to have dementia who are aged between 60-64 has increased five-fold, from 81 to 408, and the number of people in Suffolk estimated to have dementia who are aged between 65-69 has increased by two thirds, from 532 to 874. Alzheimer’s UK acknowledges that their 2007 estimates for the prevalence of early onset dementia were too low, and these estimates were increased in 2014. This change has driven the increased prevalence estimates for younger people.
Figure 12: Estimates of the Suffolk population with dementia, 2011 and 2015

Source: ONS 2012-based subnational population projections for the county of Suffolk; prevalence estimates from Dementia UK 2014 update (Alzheimer’s Society); 2013 Suffolk Dementia Needs Assessment; Public Health Suffolk analysis

Figure 13 below illustrates how the proportions of people with dementia at different ages have changed since 2011. People aged 90 and over now make up a largest proportion (24.8%) of the population with dementia compared to 2011 (21%) when the largest proportion was aged 85-89. The proportion of people with dementia aged 85-89 has now dropped, from 25% in 2011 to 21% in 2015. Similarly, the proportion of those aged 80-84 has fallen from 24% in 2011 to 20% in 2015. As alluded to earlier, the proportion of those with early onset dementia increased between 2011 and 2015. The proportion of people aged 60-64 went up from 1% to 3% while the proportion of people aged 65-69 rose from 5% to 7%.

Figure 13: Estimated cases of dementia by age group (as proportion of total), Suffolk, 2011 & 2015

Source: ONS 2012-based subnational population projections for the County of Suffolk; prevalence estimates from Dementia UK 2014 update (Alzheimer’s Society); 2013 Suffolk Dementia Needs Assessment; Public Health Suffolk analysis
2.1.6 Ethnicity
There are no new estimates available concerning the prevalence of dementia within different Black, Asian and Minority Ethnic (BAME) communities in Suffolk since the estimates derived from the 2011 census and included in the 2013 Needs Assessment¹. Within Suffolk, the districts of Forest Heath and Ipswich have the highest proportion of residents of Black, African, or Caribbean descent⁶. 2.2% of the population of Forest Heath, and 2.3% of the population of Ipswich are of Black, African, or Caribbean descent, in comparison to 1.8% of the population of England as a whole.

Recently, Public Health England has published a systematic review of dementia prevalence in relation to characteristics protected under the 2010 Equality Act⁷. The systematic review suggests that there may be increased prevalence in the Black-Caribbean population, a finding which remained after controlling for socio-economic position. The review also notes that diagnostic and screening tools need to be culturally appropriate, as BAME populations may be at higher risk of misdiagnosis, in particular of mental illness, and subsequent inappropriate treatment. These factors are all relevant for Suffolk and must be taken account of in the commissioning of effective services.

2.1.7 Frailty
Frailty develops as a consequence of age-related decline in multiple body systems. People with frailty are vulnerable to sudden changes in their health status triggered by a seemingly minor event, for example an infection, or a fall at home. Between 25-50% of people aged over 85 are estimated to be frail. People with frailty have a substantially increased risk of falls, disability, long-term care and death.

The recognition of frailty as a clinical syndrome is becoming easier to achieve and more widespread, particularly since the introduction of the electronic frailty index within the SystmOne primary care clinical system.

While there is not a direct overlap between frailty and dementia (not everyone who is frail will have dementia, and not everyone with dementia will be frail), many people who have dementia will also be systemically frail. As services designed to proactively prevent frailty and support people with frailty in crisis, including neighbourhood networks, integrated neighbourhood teams, crisis action teams and frailty assessment services, develop further, there is an opportunity to use these same approaches to also identify patients with undiagnosed dementia, and to offer ongoing assessment and support to carers. Ideally, staff working in services for people with dementia should be trained in the recognition of frailty and knowledgeable about local support available in this area, and staff working in services for people who are frail should be similarly knowledgeable about effective approaches and the available local support for people with dementia.

2.1.8 Place of Residence of people with dementia by CCG
The Dementia Prevalence Calculator provides estimates of the place of residence of people with dementia by CCG, split between people living in the community, and people who are resident in care homes. Three quarters of the people estimated to have dementia live in the community, with one quarter living in a care home. The proportion of people with dementia living in care homes is very slightly greater in Ipswich & East Suffolk CCG than in West Suffolk CCG and Great Yarmouth & Waveney CCG, but the overall picture in each CCG is very similar.
As the population with dementia continues to age, and their dementias become more severe, there is a risk that more people with dementia will require a care home place to meet their increasing needs.

2.1.9 Existing Service Provision

Memory Services

Recent activity data from Great Yarmouth and Waveney CCG show that the number of patients attending the Great Yarmouth and Waveney Memory Treatment Services appears to have increased over the past two and a half years, as shown in figure 14. The number of contacts which individual patients have with the services also shows an increase over this time period.

**Figure 14:** Number of patients attending Memory Treatment Services by month, Great Yarmouth & Waveney CCG (whole CCG), 2013/14 – 2015/16 (up to M7)

![Graph showing the number of patients attending Memory Treatment Services by month, Great Yarmouth & Waveney CCG (whole CCG), 2013/14 – 2015/16 (up to M7).](image)

Source: GYW CCG activity data (whole CCG); Public Health Suffolk analysis

The number of contacts per unique patient attending the Great Yarmouth and Waveney Memory Treatment Services each month also appears to have increased over the past two and a half years, as shown in figure 15.
**Figure 15:** Number of patient contacts with the Great Yarmouth and Waveney Memory Treatment Services per number of unique patients, by month, Great Yarmouth & Waveney CCG (whole CCG), 2013/14 – 2015/16 (up to M7).

![Graph showing number of contacts and trendline](image)

*Source: GYW CCG activity data (whole CCG); Public Health Suffolk analysis*

A new Memory Assessment and Treatment Service (MATS) for West Suffolk CCG and Ipswich & East Suffolk CCG, and provided by NSFT, was introduced at the start of the current financial year (2015-16). Although only eight months of data were available, it suggests that after an initial spike in referrals (to be expected for a new service), once the capacity became available (at around 100 appointments per month) the referrals levelled out, as shown in figure 16.

**Figure 16:** Number of referrals and appointments attended for new NSFT Memory Assessment and Treatment Service, for both West Suffolk and Ipswich and East CCGs, by month, 2015/16 (up to M8).

![Graph showing referrals and appointments](image)

*Source: NSFT activity data; Public Health Suffolk analysis*
**Care Cluster Activity**

The introduction of a tariff-based payment system to mental health services requires that patients within mental health services are matched to so-called ‘care clusters’. Clusters are determined by the patient’s diagnosis, and, in some clusters, by the severity of their disease. Each care cluster has a number, and clusters 18-21 are appropriate for dementia patients to be matched to.

NSFT has provided activity data for service users on Care Clusters 18-21 in Suffolk. The data is divided into three localities: Suffolk East, Suffolk West and Suffolk CountyWide. Although the number of service users has increased in the two larger localities (West and East), the numbers appear to have decreased since last financial year, as shown in figure 17.

**Figure 17**: Number of NSFT service users on Care Clusters 18-21, Suffolk (by locality), by month, 2012/13 (M10) to 2015/16 (up to M9)

![Graph showing number of NSFT service users on Care Clusters 18-21, Suffolk (by locality), by month, 2012/13 (M10) to 2015/16 (up to M9).]

*Source: NSFT activity data; Public Health Suffolk analysis*

In contrast to the apparent decline in the number of service users since the end of the last financial year, the number of contacts per month has steadily increased in the two larger localities since the start of 2013/14, as shown in figure 18.
**Figure 18:** Number of contacts by NSFT service users on Care Clusters 18-21, Suffolk (by locality), by month, 2012/13 (M10) to 2015/16 (up to M9)

Source: NSFT activity data; Public Health Suffolk analysis

The ratio of contacts per service user per month in the two larger localities has shown a sharp increase since the start of the current financial year (see figure 19). The reasons behind this are unclear.

**Figure 19:** Number of contacts per service user (for NSFT service users on Care Clusters 18-21), Suffolk (by locality), by month, 2012/13 (M10) to 2015/16 (up to M9)

Source: NSFT activity data; Public Health Suffolk analysis
Dementia Intensive Support Team (DIST) Referrals

Referrals per month to Dementia Intensive Support Teams for West Suffolk CCG and Ipswich and East CCG show a rising trend over the past two years, as shown in figure 20.

**Figure 20:** Number of referrals to Dementia Intensive Support Teams, West Suffolk and Ipswich and East CCGs, by month, 2013/14 to 2015/16 (up to M9)

Source: NSFT activity data; Public Health Suffolk analysis

Wider Support Services and Awareness Raising in Suffolk

Suffolk is already active in raising awareness of dementia, and providing wider support services. In January 2015, the Suffolk Health and Wellbeing Board became a Strategic Dementia Alliance, as part of its Joint Health and Wellbeing Strategy priority of focussing on the quality of life of older people. The Health and Wellbeing Board is also providing ongoing leadership across Suffolk in the development of Dementia Friendly Communities, including an investment of £60,000 in the Suffolk Community Foundation to support the work of establishing more Dementia Friendly Communities. Member organisations of the Health and Wellbeing Board have also undertaken to increase their staff’s dementia awareness levels, and have provided a number of development and learning sessions to facilitate this. Some, for example West Suffolk CCG, are also working towards being “dementia friendly employers” by using tools such as The Alzheimer’s Society leaflet “Employers”, or the DEEP (Dementia Engagement and Empowerment Project) key messages document produced by the Dementia Action Alliance.

Suffolk has seen an increase in the amount of activity to support people affected by dementia and their family carers. New local Dementia Action Alliances are being formally registered all the time, including one in Felixstowe, and the long-standing Debenhams Project. The benefits of local action include not only local solutions being devised for and by local people, but also the development of community capacity and connections generally, which in turn benefits the wider community. In December 2015 an event was jointly staged by the Suffolk Health and Wellbeing Board and the
Alzheimer’s Society to further promote dementia friendly communities, with the theme being “best practice in employment”. At a similar event in 2014, over 80 people and organisations came together to pledge to make positive change.

2.2 The Future Forecast Epidemiology of Dementia in Suffolk

2.2.1 Forecast Future Dementia Prevalence by age and location
Using the Office for National Statistics population forecasts up to 2035, it can be seen that the number of people with dementia in Suffolk is expected to increase by 91%, to just below 25,000 people, over the next 20 years (between 2015 and 2035).

**Figure 21**: Estimated future prevalence of dementia in Suffolk, by age group, 2015-2035

![Graph showing future prevalence of dementia in Suffolk by age group](image)

*Source: ONS 2012-based subnational population projections; prevalence estimates from Dementia UK 2014 update (Alzheimer’s Society); Public Health Suffolk analysis*

Figure 21 above shows how the greatest increase in the number of people with dementia is expected to occur in people aged 85 and over. There will be nearly two and a half times the number of people with dementia in that age group by 2035 compared to 2015.

These projections for the future numbers of people with dementia in Suffolk are higher than those given in the 2013 Needs Assessment. The 2013 Needs Assessment suggested that there would be 14,400 people with dementia in Suffolk by 2021; the revised projections suggest that there will already be 14,900 people with dementia in the county by 2020, increasing further to 24,300 people by 2035.

Recent work by Matthews et al. in their Cognitive Function and Ageing Study II (CFAS 11) study suggests that the estimates of dementia prevalence in the over 65’s completed in the early 1990s were too high, and that more recent prevalence estimates are lower. It is assumed that these revised estimates were available when the Alzheimer’s Society Dementia UK 2014 prevalence estimates were being constructed, and it is not known why the Alzheimer’s Society Dementia UK 2014 estimates are higher than those made by Matthews and colleagues. Looking 20 years into the future can never be an exact science; and if the “cohort effect” of better population health over time
postulated by Matthews is correct, it may imply that current estimates of prevalence are also too high when applied to future populations.

Figure 22 below provides an alternative scenario of future dementia prevalence in Suffolk based on the estimates by Matthews and colleagues, and compares this to the estimates derived from the Alzheimer’s Society Dementia UK 2014 report. We have no way of knowing if this scenario is more accurate or more probable, but include it for comparison purposes. If the estimates made by Matthews and colleagues are more accurate, there would still be an increase in the number of people living with dementia in Suffolk by 2035, particularly in those aged 85 and over. However, their projected estimate 20,900 people would imply that there will be nearly 3,500 fewer people with dementia compared to the estimates derived from the Alzheimer’s Society Dementia UK 2014 report.

**Figure 22:** Comparison of Future Prevalence Estimates for Dementia in Suffolk, 2015-2035

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Source: ONS 2012-based subnational population projections; prevalence estimates from CFAS II (Matthews et al. 2013) and Dementia UK 2014; Public Health Suffolk analysis

Returning to the forecasts based on the Dementia UK 2014 report, it is also important to consider whether this predicted growth in the numbers of people with dementia across Suffolk is uniform, or whether some districts and boroughs will see higher increases than others. Figure 18 below shows that the districts of Mid Suffolk and Babergh will see the highest proportionate increases in the number of people with dementia between 2015 and 2035 (107% and 104% respectively), but that the Suffolk Coastal district will have the highest total number of people with dementia by 2035, predicted to be nearly 5,000.
2.2.2 Forecast Future Dementia Prevalence by Subtype

The Dementia UK Report (2007) published by the Alzheimer’s Society suggested that the most common cause of dementia is Alzheimer’s disease, which leads to 62% of cases. The next most common subtypes of dementia are vascular dementia (17%) and mixed dementia (10%). These estimates were not updated in the 2014 Dementia UK Report, but the future population estimates for Suffolk have changed, which means that the numbers of people forecast to have each type of dementia in the future have increased.

Figure 24: Forecast number of people with dementia in Suffolk by dementia sub-type, 2015 – 2035

Source: ONS Population Statistics; Alzheimer’s Society Dementia UK 2014; Public Health Suffolk analysis
Applying these proportions to the forecast number of people with dementia in Suffolk shows that there are approximately 8,000 people with Alzheimer’s disease in Suffolk in 2015. This number is expected to almost double to over 15,100 people by the year 2035. The number of people forecast to have vascular dementia is lower, but is also predicted to almost double to 4,150 people by 2035.

2.2.3 Learning Disabilities

The 2013 Needs Assessment highlighted the fact that people with a learning disability are at increased risk of developing dementia, and are more likely to develop the condition at a younger age. This is particularly true for Down’s syndrome. Figure 20 below shows that the number of people aged 65 and over who have a learning disability in Suffolk is predicted to rise by 37% over the next 15 years. Although detailed estimates are not available, this increase suggests that there are likely to be more people with both a learning disability and dementia in the future in Suffolk than there are currently.

**Figure 25:** Population aged 65 and over predicted to have a learning disability, Suffolk, 2015 - 2030

![Graph showing population aged 65 and over predicted to have a learning disability, Suffolk, 2015 - 2030](image)

Source: PANSI website; Public Health Suffolk analysis

2.2.4 Early onset dementia by gender over time

Some patients will develop dementia while they are still relatively young, and before the age of 65. This is known as early onset dementia. The Alzheimer’s Society Dementia UK 2014 report now estimates that there are over 40,000 people with early onset dementia in UK; this is a substantial increased from their previous 2007 estimate.

Locally, this increased estimate of prevalence is offset by the aging of Suffolk’s population, which means that there are smaller numbers of people in the younger age groups over time. Figure 21 below sets out the estimates for the numbers of people with early onset dementia in Suffolk between 2015 and 2035. While the numbers do increase, peaking at over 600 in 2025 compared to below 530 in 2015, by 2035 the numbers are predicted to decline again to approximately 575. The predominance of females seen in the prevalence estimates for the over 65s is not repeated for cases of early onset dementia, where the gender mix is almost equal.
Figure 26: Predicted number of people in Suffolk aged 30-64 with early onset dementia, by gender, 2015-2035.

Source: ONS 2012-based subnational population projections; prevalence estimates from Dementia UK 2014 update (Alzheimer’s Society); Public Health Suffolk analysis
3. Review of Policy relating to Dementia in England since 2013

Dementia Policy in England since 2013 – Summary

Dementia Policy continues to evolve at a national level in England. Key developments since the 2013 Needs Assessment include:

- The introduction of the Care Act 2014 which includes a new statutory principle on local authorities to promote wellbeing whenever they make a decision about an adult; a new statutory requirement on local authorities to ensure the provision of preventative services which help prevent or delay the development of care and support needs, including carers support needs; and a new legal duty for local authorities to undertake a ‘carer’s assessment’ on the basis of the appearance of a need for support;
- The end of the 2012 Prime Minister’s Challenge on Dementia which saw increased rates of diagnosis nationally, but a failure to hit the overall 67% target;
- The 2020 Prime Minister’s Challenge being launched; there is no specified target diagnosis rate, but there is an aspiration that patients should wait no longer than 6 weeks from their referral to memory services to their first specialist appointment;
- The 2020 Challenge also stipulates that people with dementia should receive meaningful and measured post-diagnostic care including access to advice and support, and assessment and support for carers;
- The 2020 Challenge stipulates that all NHS staff and social care provider staff to have received training on dementia which is appropriate for their role; that all hospitals and care homes to meet agreed criteria to be a dementia friendly health and care setting; that there will be an additional 3 million Dementia Friends in England; that over half of people in England will be living in areas which are recognised as Dementia Friendly Communities; that all businesses and government/public sector organisations to be supported to become dementia friendly, industries to adopt Dementia Friendly Charters, and all employers with formal induction programmes to include dementia awareness training; and that funding for dementia research to be doubled by 2025 with an International Dementia Institute to be established in England;
- The inclusion of the aims of the 2020 Challenge within the NHS Planning Guidance 2016/17 – 2020/21;
- The introduction of NHS England’s “Well Pathway for Dementia”, which highlights five key areas of dementia care; preventing well; diagnosing well; living well; supporting well; and dying well. These domains are reflected in new online Public Health England Dementia Profiles, which aim to include metrics at Local Authority and CCG level within each domain, and provide benchmarking information; and in recent Health and Social Care Information Centre analysis drawn from GP and mental health services cluster coding, reflecting elements of the “well pathway”;
- The publication of a dementia data catalogue by Public Health England, designed to provide easy access to all published information on dementia for commissioners and service providers;
The 2013 Joint Strategic Needs Assessment for Dementia in Suffolk gave an overview of recent health policy with regard to dementia in England. This included the National Institute for Health and Care Excellence & Social Care Institute for Excellence Guideline CG42: Dementia. This was initially published in 2006, and was updated in 2007, 2011, and 2012, and again in 2014, when additional guidance on the use of structural imaging as part of the diagnostic process was included. This guidance is currently scheduled for further revision in 2017.

NICE has also published two Dementia Quality Standards, QS1 – Dementia: Support in Health and Social care (June 2010) and QS30 – Dementia: Independence and Wellbeing (April 2013). “Living well with dementia - A National Dementia Strategy” was published in 2009, and this was followed by the 2012 “Prime Minister’s Challenge on Dementia”.

The 2014 Care Act, which largely came into force in April 2015, gives carers the right to a needs assessment, and entitles carers to support if they meet the eligibility criteria. Given how important carers are for many people with dementia, and the evidence that caring for someone with dementia can be detrimental to the carer’s health, these new statutory duties should have positive consequences for people with dementia and their carers.

In 2015 a second Prime Minister’s Challenge (“Dementia 2020”) was launched, which sets out a number of improvement aspirations to be met by 2020. Because of the creation of NHS England in 2012, these ambitions will need to be included in successive Annual Mandates from the Department of Health to NHS England. The House of Commons Health Select Committee expressed some reservations about whether this matrix approach will deliver the clarity and momentum required to improve care for all long term conditions, including dementia, but in the absence of an over-arching strategy the Prime Minister’s Challenge sets the direction for dementia policy for the coming few years.

The key ambitions within the Prime Minister’s Challenge for 2020 include:

- Improved awareness of individual risk factors, healthy ageing campaigns, and the introduction of a personalised risk assessment calculator as part of NHS Health Check;
- Equal access to diagnosis across the country, and first assessment appointments being provided within 6 weeks of referral (on a national average basis);
- GPs to continue to play a leading role in co-ordination and continuity of care for people with dementia;
- For people who are diagnosed with dementia, meaningful care after diagnosis tracked by effective metrics. This could include information on locally available post-diagnostic support through an “information prescription”; access to relevant advice and support; and appropriate assessment and support for carers;
- All NHS staff and social care provider staff to have received training on dementia which is appropriate for their role;
- All hospitals and care homes to meet agreed criteria to be a dementia friendly health and care setting;
- An additional 3 million Dementia Friends in England, and Dementia Friends becoming a global movement;
- Over half of people in England living in areas which are recognised as Dementia Friendly Communities;
- All businesses to be supported to become dementia friendly, industries to adopt Dementia Friendly Charters, and all employers with formal induction programmes to include dementia awareness training;
- All government departments and public sector organisations becoming dementia friendly and all tiers of local government to be part of their local Dementia Action Alliance;
- Funding for dementia research to be doubled by 2025; an International Dementia Institute to be established in England; increased investment and research partnerships to be established; open access to all publicly funded research; and 25% of people who are diagnosed with dementia registered with the “Join Dementia Research” online platform, and 10% of those diagnosed actively participating in research.

An Implementation Plan for the 2020 Challenge was published in March 2016. This focuses on priorities and actions in the period 2016-2018, and gives a summary of further actions to be completed between 2018 and 2020. The Implementation Plan focuses on 18 of the commitments identified in the 2020 Challenge, which require early focus to enable later work to take place. The Implementation Plan focuses particularly on:

- Transforming the approach to risk reduction, and using the NHS Health Check programme to start advising on the steps individuals can take to decrease their risk of from the age of 40. Specific tools to support this, including a Brain Age calculator, will be developed to support this, alongside the One You mid-life health campaign;
- Reducing local variation in diagnosis rates, and achieving joined up health and care services for people with dementia, including personalised care plans for all;
- Renewing the focus on creating dementia-friendly health and care settings, including staff training, and a new comparative improvement and assessment framework for dementia services;
- Building on the progress made to date regarding awareness and social action, including the establishment of at least 100 more Dementia Friendly Communities, and increasing the number of Dementia Friends to 2,000,000 by 2018;
Continuing to increase the pace and scale of investment in dementia research, including having 12% of the people diagnosed with dementia each year registered on Join Dementia Research by 2018;

Capturing the views of people with dementia and their families more effectively, to provide evidence on whether the interventions are making a difference. A newly-established Dementia 2020 Citizen’s Panel will play an important role in this.

The 2020 ambition challenges have been given additional weight by their subsequent inclusion in the NHS Planning Guidance 2016/17 – 2020/21. This Planning Guidance states that by 2020 there should be a measurable improvement in all areas of the Prime Minister’s Challenge on Dementia 2020, including:

- maintaining a diagnosis rate of at least two thirds;
- increasing the numbers of people receiving a dementia diagnosis within 6 weeks of a GP referral;
- improving the quality of post-diagnosis treatment and support for people with dementia and their carers.

During 2016/17, the NHS is required to deliver a number of achievements which will support these longer term aims. These deliverables include:

- maintaining a minimum of two thirds diagnosis rates for people with dementia;
- working with National Institute for Health Research on location of Dementia Institute;
- agreeing an affordable implementation plan for the Prime Minister’s challenge on dementia 2020, including improving the quality of post-diagnosis treatment and support.

Because of changes made to the underlying prevalence estimates for dementia in April 2015, as a result of the CFAS II study, it is no longer accurate to compare diagnosis rates longitudinally over time at practice level. NHS England are therefore no longer publishing diagnosis rates, but will be suggesting that a so-called ‘dementia comparator’ locally calculated at practice level should be considered instead. This will be defined as follows:

\[
\frac{\text{The number of people in practice population diagnosed with dementia and recorded for QOF}}{\text{The number of people in practice population aged over 65}} \times 100
\]

While this method will not give a diagnosis rate by practice, it should allow local estimates of the size of the dementia diagnosis gap to be made when compared to national prevalence estimates. It is not clear at the time of writing whether national estimates of the dementia diagnosis rate will still be published, in response to the requirements in the 2020 Dementia Challenge and the NHS Planning Guidance. It is of note that the Quality and Outcome Framework for primary care in 2016/17 no longer includes the Enhanced Service relating to dementia diagnosis in primary care, which may have a negative impact on the numbers of diagnoses. This will be kept under review for future years.

In January 2016, the UK Department of Health published a joint declaration on post-diagnostic support for people with dementia, and NHS England published a new approach to considering the elements of high quality dementia care, known as the ‘Well Pathway’.
The *declaration on post-diagnostic* support stresses the need to take into account the views of people living with dementia and their families; the health, physical and emotional needs of families; providing families with appropriate support and training; ensuring that people know about the support available to them locally; the need for more evidence to be available on best-practice in post-diagnostic care, including initiatives which are cost effective; the need for professionals to be knowledgeable about the condition, and about what good post-diagnostic services are comprised of; the need for health and care services to be co-ordinated and integrated, and to collaborate and cooperate to improve outcomes; and for people living with dementia and their families to be aware of, and given the opportunity to participate in, relevant research.

Although not overtly evidence based, the *Well Pathway* aims to simplify the complexity of dementia pathways and services by suggesting that if five things are done well by local services, dementia care should be consistent and of high quality as a result. The five things are:

- Preventing Well;
- Diagnosing Well;
- Supporting Well (defined as what happens after a service has ‘done’ something to a patient, for example, given them a diagnosis);
- Living Well (defined as the background, every day lived experience of having dementia);
- Dying Well.

The Well Pathway does not aim to introduce new elements of practice. It overlaps with existing guidance referred to in this document, as shown below.

**Figure 27:** ‘Crosswalks’ between Dementia Well Pathway and Dementia Policy and Guidance

Partly in support of the ‘well pathway’, Public Health England has produced online Dementia Profiles, which mirror the five elements of the well pathway, as well as providing information about the prevalence of dementia and national benchmarks. Some elements of the pathways do not have
many indicators within them currently, but the inclusion of further indicators is planned for the future. The Profiles are available for every CCG and Local Authority, and the profiles for Suffolk are included in appendix 1 for reference.

At County level, the following indicators are outside the interquartile range, meaning that Suffolk’s performance is either in the top or bottom 25% of Local Authorities in England. These figures have to be interpreted with care, recognising that for some indicators being in the top or bottom quartile will be good, and for other indicators being in the top or bottom quartile is indicative of adverse outcomes.

- Recorded dementia prevalence (all ages) – top quartile
- % of adult carers reporting that they has as much social contact as they would like – bottom quartile
- Deaths in usual place of residence for people with dementia aged 65+ - top quartile
- Place of death - care home for people with dementia aged 65+ - top quartile
- Place of death - hospital for people with dementia aged 65+ - bottom quartile
- Place of death - home for people with dementia aged 65+ - top quartile

For Great Yarmouth & Waveney CCG, the following indicators are outside the interquartile range, meaning that the CCG’s performance is either in the top or bottom 25% of Local Authorities in England.

- Recorded dementia prevalence (all ages) – top quartile
- Smoking: recorded prevalence aged 15 plus – top quartile
- Obesity: recorded prevalence aged 16 plus – top quartile
- Hypertension: recorded prevalence all ages – top quartile
- Stroke: recorded prevalence all ages – top quartile
- Diabetes: recorded prevalence aged 17 plus – top quartile
- CHD: recorded prevalence all ages – top quartile
- Depression: recorded prevalence aged 18 plus – top quartile
- Dementia: ratio of inpatient service use to recorded diagnoses – bottom quartile
- Dementia: DSR of emergency admissions (aged 20+) - bottom quartile
- Dementia: DSR of emergency admissions (aged 65+) - bottom quartile
- Dementia: Short stay emergency admissions (aged 20+) - bottom quartile
- Dementia: Short stay emergency admissions (aged 65+) - bottom quartile
- Alzheimer’s Disease: DSR of inpatient admissions (aged 20+) - bottom quartile
- Alzheimer’s Disease: DSR of inpatient admissions (aged 65+) - bottom quartile
- Vascular Dementia: DSR of inpatient admissions (aged 20+) - bottom quartile
- Vascular Dementia: DSR of inpatient admissions (aged 65+) - bottom quartile
- Unspecified Dementia: DSR of inpatient admissions (aged 20+) - bottom quartile
- Unspecified Dementia: DSR of inpatient admissions (aged 20+) - bottom quartile

For Ipswich & East Suffolk CCG, the following indicators are outside the interquartile range, meaning that the CCG’s performance is either in the top or bottom 25% of Local Authorities in England.
• Recorded dementia prevalence (all ages) – top quartile
• Recorded blood tests (denominator including excluded patients) – bottom quartile
• Deaths in usual place of residence for people with dementia aged 65+ - top quartile
• Place of death - care home for people with dementia aged 65+ - top quartile
• Place of death - hospital for people with dementia aged 65+ - bottom quartile
• Dementia: ratio of inpatient service use to recorded diagnoses – bottom quartile

For West Suffolk CCG, the following indicators are outside the interquartile range, meaning that the CCG’s performance is either in the top or bottom 25% of Local Authorities in England.

• Recorded dementia prevalence (aged 65+ ages) – bottom quartile
• Dementia: DSR of emergency admissions (aged 20+) - bottom quartile
• Dementia: DSR of emergency admissions (aged 65+) - bottom quartile
• Deaths in usual place of residence for people with dementia aged 65+ - top quartile
• Place of death - care home for people with dementia aged 65+ - top quartile
• Place of death - hospital for people with dementia aged 65+ - bottom quartile
• Place of death - home for people with dementia aged 65+ - top quartile

With reference to the “supporting well” element of the pathway, Professor Alistair Burns, the National Clinical Lead for Dementia, has described the key element of this as care planning. Specifically, for care planning to be meaningful, it needs to be timely, bespoke and ‘unitary’, defined as one person providing the support. Professor Burns suggests the following key elements of a meaningful care plan:

D – Diagnosis reviewed
E – effective support for carers reviewed
M – medication reviewed
E – evaluation of risk
N – new symptom inquiry
T – treatment of medical conditions
I – Individual issues
A – advanced care planning
4. Review of Clinical Evidence and Guidance relating to Dementia since 2013

To inform this section of the Dementia Needs Assessment Update 2015, a literature search was conducted in Medline using the search term “dementia”. This was then limited to publications in English, relating to humans, and published between 2013 and 2015. Literature reviews were prioritised. The Cochrane database was searched separately for systematic reviews relating to dementia published between 2013 and 2015. These searches were then augmented with snowballing and a search of grey literature to identify further relevant papers and reports. In addition, a number of websites were reviewed including the Royal College of Psychiatrists, the National Institute for Health and Care Excellence, Alzheimer’s UK, The Alzheimer’s Society, the National Audit Office, Public Health England, the World Health Organisation and the Personal and Social Services Research Unit.

The results of the evidence review are presented in the following order:
- Risk factors and prevention;
- Early or Timely Diagnosis;
- Post-diagnostic therapy and support;
- Pathway design;
- Cost effectiveness.

4.1 Evidence Review - Risk Factors & Prevention

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<td>A recent study found that estimates of overall dementia prevalence in England were 1.8% lower (OR 0.7, 95% CI 0.6-0.9; p = 0.003) compared to estimates made 20 years ago. This decline in prevalence suggests that there is a cohort effect in dementia prevalence, with later-born populations having a lower risk of prevalent dementia than those born earlier in the last century.</td>
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<td>There is a growing consensus that more dementias contain a vascular element than previously thought; therefore, actions to prevent or reduce cardiovascular risk are also important in reducing the prevalence of dementia. The importance of cardiovascular risk management for the promotion of brain health is not widely understood and needs to be communicated much more widely;</td>
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<td>Recent NICE guidance on “Dementia, Disability and Frailty in Later Life – Mid-life Prevention Approaches” highlights the need for people to stop smoking, be more physically active, reduce alcohol consumption, eat healthily and maintain a healthy weight in order to optimise their brain health in later life. Although the precise roles of loneliness and isolation as risk factors for dementia are not fully understood they may reduce resilience to the onset and progression of dementia, so are also important to consider within the context of prevention.</td>
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Both the formal evidence base and the consensus of expert opinion regarding the prevention of, and risk factors for, dementia have progressed since 2013.
In July 2013, Matthews et al reported updated dementia prevalence estimates from three geographical areas of England. Following the same methodology used to produce earlier estimates of dementia prevalence between 1989 and 1994, and looking at the same areas, this study found that although the expected prevalence of dementia in individuals aged 65 and over was 8.3%, the actual prevalence was only 6.5%. This statistically significant decrease in prevalence of 1.8% (Odds ratio 0.7, 95% confidence intervals 0.6-0.9, p=0.003) provides evidence that there is a cohort effect in dementia prevalence, with later-born populations having a lower risk of prevalent dementia than those born earlier in the last century. This suggests that the higher overall levels of health seen in later-born populations has a protective effect against dementia, with vascular health and risk factors perhaps being the most important element within this. While the total effect of this lower estimated level of prevalence on the total numbers of dementia sufferers is outweighed in Suffolk by our ageing population and increases in life expectancy, as shown in figure 22, it does suggest that lifestyle risk factors may offer a preventative effect.

This argument was further developed through the publication in 2014 of the “Blackfriars Consensus on promoting brain health: Reducing risks for dementia in the population”. This consensus statement, published jointly by Public Health England and the UK Health Forum, and signed by 29 national organisations, 32 dementia and public health specialists and UK government ministers, found that the risk of dementia in the population may be reducible, and that most people with dementia have a mix of pathologies including Alzheimer’s disease and an element of vascular dementia; this is a change to earlier thinking, which tended to assume that patients had either Alzheimer’s Disease or vascular dementia in isolation. Vascular risk factors are estimated to contribute to between 3% and 20% of predicted new cases in 20 years’ time, which offers the possibility of reducing these dementia cases through prevention strategies not usually incorporated into dementia strategies.

In particular, addressing vascular risk factors and disease precursors, including hypertension, high cholesterol, obesity and type 2 diabetes, should help to also reduce the risk, progression and severity of dementia, as well as reducing the risk of cardiovascular disease. Other risk factors which may be reducible include excess alcohol consumption and head injuries. The Consensus concludes that an integrated health and wellbeing approach including the opportunity to protect and promote brain health as part of wider non-communicable disease prevention would be of benefit, and is justified.

Leading on from this Consensus statement, in October 2015, NICE published NICE Guideline NG16, “Dementia, Disability and Frailty in Later Life – Mid-Life Prevention Approaches”. This guideline recommends that, to age successfully, people should be supported to stop smoking, be more physically active, reduce their alcohol consumption, adopt a healthy diet and achieve and/or maintain a healthy weight. These key messages are not commonly communicated or well understood in the context of dementia. In addition, there is a socio-economic gradient present in the adoption of these behaviours which clearly contributes to health inequalities, and may require more targeted action in relation to some population groups. The report goes on to note that although the role of isolation and loneliness in the development of dementia is not yet clearly understood, this may reduce resilience to disease onset and progression. High levels of education appear to have a preventative effect, so access to training and education in mid-life may also provide a further opportunity to reduce risk.
Recent evidence published by the Health and Social Care Information Centre assesses the extent to which the mid-life population of England, defined as aged 45-64, are currently adopting this healthy lifestyle advice. Overall, cigarette smoking is declining in this group, but alcohol consumption was the highest of any age group in those aged 55-74. Obesity increases with age, with 69% of 45-54 year olds, and 74% of those aged over 55 being overweight or obese. Physical activity declines with age, with 66% of 45-54 year olds, and 55% of 55-64 year olds reaching the recommended levels of 150 minutes of physical activity each week. Only 27% of those in middle age are eating the recommended 5 portions of fruit and vegetables per day. People aged 55-64 have higher than average blood pressure. Overall, these indicators suggest that there is more that people in mid-life could be doing to decrease their risk of cardiovascular disease, and dementia.

4.2 Evidence review – The Diagnosis of Dementia

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<th>The Diagnosis of Dementia – Summary</th>
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<td>There has been very little high-quality literature published between 2013 and 2015 which relates to the diagnosis of dementia. The key findings from the completed literature reviews are that:</td>
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<td>• While a novel PET scan showed some promise in improving the early diagnosis of dementia, defined sensitivity and specificity thresholds are currently lacking, meaning it cannot be used in routine clinical practice. It is also high cost.</td>
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<td>• Trials of the so-called “Mini-Cog” test for diagnosis in the community were inconclusive.</td>
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<td>• One American review highlighted the large extent to which intra-clinician practice varies in the diagnosis of dementia, which may also be pertinent in the UK;</td>
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<td>• Despite the lack of compelling evidence, early diagnosis is felt to be optimal for patients with dementia, as it facilitates medicines optimisation, future planning, the potential to stabilise cognitive function, risk reduction and access to services.</td>
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This section presents the findings from a review of evidence published between 2013 and 2015 concerning the effectiveness of different approaches to diagnosis and the benefits of early diagnosis of dementia.

Regarding different approaches to diagnosis, two systematic reviews including only randomised controlled trials published since 2013 were identified in the Cochrane database of systematic reviews. One review considered the use of 11C-PIB-PET, an expensive and novel brain scan, on diagnosis. The review concluded that scan may offer some promise in improving the accuracy of early diagnosis, and hence treatment options, but that defined thresholds for specificity and sensitivity are required before it can be routinely used in clinical practice. The second review, considering whether the Mini-Cog test was suitable for cognitive screening in the community, could not make recommendations either for or against this diagnostic test. It concluded that additional well-designed studies comparing the Mini-Cog to other brief cognitive screening tests are required in order to determine the accuracy and utility of the Mini-Cog in community based settings.
The literature review conducted in addition to the search of the Cochrane database did not identify any further systematic reviews concerning the diagnosis of dementia which have been published since 2013, apart from one review by Sivananthan and colleagues which considered the extent to which doctors in America followed the recommended guidelines for dementia care in the areas of formal memory testing, imaging, lab testing, interventions, counselling, community services and specialist referrals. This review found that there was broad variation in the proportion of doctors who reported completing each recommended process, with the widest variation in formal memory testing, recorded as completed on between 4% and 96% of occasions. While this is data from the USA it may also have relevance in the UK context.

This lack of recent evidence regarding dementia diagnosis was recognised in the earlier World Alzheimer Report 2011, which includes a thematic summary of the arguments for timely dementia diagnosis derived from expert opinion. These themes are as follows:

- the opportunity to optimise current medical management, recognising treatable causes, exacerbating factors, and medication review;
- the relief gained from better understanding and the validation of concerns, and a framework for understanding the origin and nature of symptoms;
- the ability to maximise decision-making autonomy – the chance to make important decisions about the future while still retaining mental capacity;
- providing access to services – timely access to medical care, advice and support, all of which require a diagnosis;
- the opportunity to reduce risks, including safety at home, driving assessments, anticipating and avoiding adverse effects of medication;
- the opportunity to plan for the future, including early retirement, financial planning, safety and security issues;
- the potential to improve clinical outcomes by slowing or stabilising cognitive and functional decline;
- the potential to avoid or reduce future costs – chiefly through delaying or avoiding transition into a care home;
- the concept of diagnosis as a human right – both to have access to an accurate diagnosis, and to be informed of it, or not, according to personal preference.

The theme of diagnosis unlocking access to post-diagnostic support is particularly relevant for Suffolk, as better post-diagnostic support and information was identified as a key need by the stakeholders who participated in the 2013 Joint Strategic Needs Assessment.

4.3 Evidence Review - Post Diagnostic Therapy and Support

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<tr>
<th>Post Diagnostic Therapy and Support – Summary</th>
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<td>Despite the publication of a number of systematic reviews since 2013 concerning post-diagnostic interventions for patients with dementia, the overall evidence base remains weak. There are considerable variations between studied interventions, numerous weaknesses in study design, and follow-up periods are generally too short. Taking this into account, the key findings which are supported by evidence of reasonable quality for pharmacological interventions are:</td>
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...
• There is some evidence for the use of rivastigmine to improve cognitive function, activities of daily living and clinician rated global performance. Many patients were unable to tolerate it and the rate of adverse side effects was double that of the control group, however transdermal administration could reduce side-effects while maintaining efficacy.

• There is some evidence to support the use of cerebrolysin to improve cognitive function in patients with vascular dementia, but longer and more powerful studies are required.

• There is evidence to suggest that many dementia patients can tolerate the withdrawal of antipsychotic drugs without an increase in their behavioural symptoms.

Considering **psychosocial or physical post-diagnostic interventions**, many studies have methodological weaknesses. The key findings are as follows:

• The recent evidence for cognitive training is mixed, with two systematic reviews concluding that it provided cognitive benefits, and one review concluding that it did not.

• There is reasonable evidence for the use of occupational therapy or other exercise interventions to improve functional decline in patients with dementia, but no evidence of effect on cognition, neuropsychiatric symptoms, or depression.

• There is low-quality evidence to suggest that interventions to reduce depression and anxiety in patients with mild dementia (i.e. cognitive behavioural therapy, interpersonal therapy and counselling) are effective at reducing depression but not anxiety.

• There is some evidence that teaching carers dementia-specific care skills is effective and reduces carer burden and carer depression by small amounts; that online carer support can improve carer confidence, self-efficacy and levels of depression; and that interventions aimed at training both the patient and their carer in specific functional domains are also efficacious.

• There is strong evidence that interventions for carers effectively reduce behavioural symptoms in the person with dementia, and hence the extent of time that the carer felt they were “on duty”; the effect size for the intervention with carers was greater than that found in trials of antipsychotics for problem behaviours.

• There is evidence that supervised person-centred care, communication skills training and modified dementia care mapping all reduced clinically significant agitation amongst people with dementia living in care homes at the time of the intervention, and at follow up, for relatively little cost.

• There is poor quality evidence that social support groups for people with dementia may reduce depression, improve quality of life and increase self-esteem, and poor quality evidence that spending time in a garden reduces agitation in people with dementia living in care homes.

• There is some evidence that high intensity case management, with small case-loads, regular proactive follow up by the case manager, and regular contact between the case managers and the primary care medical team, can reduce behavioural symptoms, length of hospital stay, and carer’s burden and depression.

• There is some evidence that case management can reduce short-term (18 months) needs for long-term care placements.

• There is some evidence that using a multi-skilled team to comprehensively assess patients in hospital can reduce length of stay and readmissions for people with dementia.

• There is some evidence that the use of case conferences for people with dementia who are living in care homes improves medicines and palliative symptom management, and care
outcomes by engaging the patient’s family and all the health and social care providers in prospective care planning.

The post-diagnostic interventions which are not supported by evidence are as follows; it should be noted that for most of these, there is no or very limited evidence of effectiveness, rather than there being clear evidence that they are ineffective. As research work progresses, it is possible that evidence of effectiveness for these interventions does become available.

- There is no evidence that statins improve cognitive performance in patients with dementia.
- There is no evidence to support the use of aromatherapy in patients with dementia.
- There is no evidence to support the use of cognitive tests as predictors of safety while driving.
- There is no evidence for the use of light therapy in patients with dementia.
- There is little evidence on effective practice for people with dementia who are approaching the end of their life; with ethnic status and families living a long way away identified as potential barriers to effective advanced care planning.

The detailed findings from the literature review in relation to post-diagnostic therapies and support have been divided into two categories; pharmacological interventions and psychosocial interventions.

4.3.1 Summary of evidence relating to post-diagnostic pharmacological interventions

A search of the Cochrane database of systematic reviews yielded six systematic reviews published since 2013 concerning pharmacological post-diagnostic support. All the reviews only considered evidence from randomised controlled trials.

One review considered whether statins improved cognitive performance in patients with Alzheimer’s disease and vascular dementia, and found no evidence that they did. A second review considered the effectiveness of rivastigmine for patients with vascular cognitive impairment, and concluded that the evidence was equivocal, with two studies showing no difference in neurocognitive function, abilities, symptoms and performance, and one study suggesting that cognitive response was improved compared to placebo, but that significant numbers of patients were unable to tolerate the intervention.

A further review considered the use of rivastigmine for Alzheimer’s disease, and found a statistically significant improvement in cognitive function, activities of daily living and clinician rated global performance compared to placebo, but also that many patients were unable to tolerate the therapy and that they were twice as likely to experience an adverse event during the trial compared to those on placebo. Transdermal delivery of the drug may reduce side-effects without reducing efficacy.

Chen and colleagues considered the use of cerebrolysin for vascular dementia. This review suggests more promising results, with a statistically significant improvement in general cognitive function and global clinical function, with only non-serious adverse effects observed. Further longer studies are required to test these findings.

Declerq et al. considered whether patients could tolerate the withdrawal of antipsychotic drugs without a decline in their behaviour. Rapid and gradual withdrawal schedules were tested, and
overall, the findings suggest that many patients with Alzheimer’s can tolerate the withdrawal of antipsychotic medicine without an increase in behavioural symptoms. Patients with more severe neuropsychological symptoms, and those who responded particularly well to antipsychotics, may not tolerate withdrawal so well, and continuation may be advised for these patients\textsuperscript{39}.

The wider literature search identified one further review in relation to pharmacological post-diagnostic therapy, published by Cooper and colleagues and considering the impact of pharmacological interventions on the quality of life experienced by people with dementia; the review found no consistent evidence that any drug improves the quality of life for people with dementia\textsuperscript{40}.

The NHS National Institute for Health Research’s Horizon Scanning Research and Intelligence Centre website was reviewed for forthcoming innovations relating to dementia\textsuperscript{41}. Only two innovations were identified, the first one concerning the development of genetic testing for Alzheimer’s disease, and the second one concerning the use of hybrid PET/MR for whole-body diagnostic imaging. Both reports were written in 2010 and no updates on the progress of either technology are available.

4.3.2 Summary of evidence relating to psychosocial or physical interventions

A similar evidence review was conducted in relation to post-diagnostic psychosocial or physical interventions. The Cochrane database was searched for systematic reviews on the subject of dementia published in English since 2013, and a further search was completed in Medline for systematic reviews in English published since 2013, with the search term “dementia”.

The evidence has been grouped into four categories:

- Interventions which aim to prevent or delay cognitive or functional decline;
- Interventions which aim to reduce behavioural and psychological symptoms, and which include:
  - Interventions for family carers;
  - Approaches targeting the person with dementia;
  - Environmental approaches;
- Interventions which aim to prevent increased use of resources, for example by preventing or delaying admission to a care home, or by reducing hospital bed days;
- Interventions which aim to improve the patients’ experience at the end of life.

4.3.2.1 Interventions which aim to prevent or delay cognitive decline

The systematic reviews held within the Cochrane database are considered first, as they only include data from randomised controlled trials and rigorously quality review the included studies.

Bahar-Fuchs and colleagues examined the evidence from 11 randomised controlled trials in relation to cognitive training and cognitive rehabilitation for patients with mild to moderate Alzheimer’s disease and vascular dementia\textsuperscript{42}. Cognitive training was not associated with any positive or negative effects, although cognitive rehabilitation was associated with positive outcomes for both patients and carers in one study. The authors concluded that overall the quality of the included studies was low, and that further research was required. They also argue that current outcome measures may not capture some of the gains from this type of intervention, again indicating the need for further research.
Forbes et al considered the effectiveness of light therapy on cognition, activities of daily living, sleep, behaviour and psychiatric symptoms, and found no evidence of benefit, apart from one study which found the ability to perform activities of daily living improved\(^43\). Overall there is insufficient evidence to justify the use of bright light therapy in dementia to improve cognitive or functional decline.

From the wider literature review, three systematic reviews were identified which considered interventions which aim to prevent or delay cognitive or functional decline. Gates and colleagues considered restorative cognitive training (the introduction of novel and complex cognitive interventions for healthy adults and those with mild Alzheimer’s disease) and concluded that cognitive training may provide cognitive benefits in both the short and longer term, with supervised small-group multi-domain training providing the most benefits\(^44\).

The second review by Alves et al. considered four randomised controlled trials of cognitive intervention. The four cognitive interventions considered were a small-group memory training programme, running for 45 minutes per week over 6 weeks; attention stimulating activities offered on an individual basis for an hour a week over 5 weeks; individual computerised cognitive training for an hour, twice a week for six months; and individual cognitive stimulation therapy focusing on tasks requiring executive functions and working memory, delivered for 45 minutes per week, twice a week for 10 weeks. The review concluded that global cognitive functioning (evidenced by the Mini Mental State Examination) significantly improved as a result of the intervention, and found high levels of compliance and adherence to the interventions, but stressed that these findings should be treated with caution and that more research is required\(^45\).

Finally, McLaren and colleagues reviewed 18 controlled trials considering the impact of occupational therapy, exercise, or multi-faceted interventions, on functional impairment in patients with dementia and found that half of the studies reported a statistically significant improvement in functional decline compared to the control group\(^46\). Again, further large-scale research is required to confirm this preliminary finding.

4.3.2.2 Interventions which aim to reduce behavioural and psychological symptoms

Returning again to the systematic reviews from the Cochrane database, five relevant systematic reviews were identified.

Orgeta et al. considered 6 randomised controlled trials which aimed to evaluate the effectiveness of interventions to reduce anxiety and depression in patients with dementia or mild cognitive impairment\(^47\). The studies used the approaches of cognitive behavioural therapy, interpersonal therapy and counselling, and the meta-analysis found that the treatments had a significant effect on depression and clinician-rated anxiety, but not on self-rated anxiety or carer-rated anxiety. The evidence was of moderate to low quality and further research is required.

The impact of exercise programmes on the ability of people with dementia to perform the activities of daily living was assessed in a review by Forbes et al\(^48\). While some evidence of benefit was found, the quality of the evidence was considered to be very low, and overall there was no clear benefit from exercise on cognition, neuropsychiatric symptoms or depression.

Forrester and colleagues considered whether aromatherapy was an effective intervention for people with dementia, and concluded that the benefits were equivocal, with more research required\(^49\).
Maayan and colleagues considered the impact of respite care for people with dementia and their carers, and again found that no benefits or adverse effects of respite care were demonstrated in the four studies included in the review\textsuperscript{50}. The authors suggest that this finding may be as a result of poor-quality research.

Finally, Martin et al. considered whether there is evidence to support the use of cognitive tests as a predictor of safety while driving, and conclude that there is no evidence to support driver assessment for either maintaining transport mobility, or reducing accidents\textsuperscript{51}.

From the wider literature review, ten systematic reviews were identified which considered interventions which aim to reduce behavioural or psychological symptoms, some of which were targeted at patients, some at carers, and some at both (the pairing of patient and carer is referred to as a “dyad” in some of the literature).

Focusing on the interventions for carers, Jensen and colleagues considered whether educational programmes for carers aimed at teaching skills relevant to dementia caring were effective. They found, through a meta-analysis of five trials, that the programmes have a moderate effect on carer burden, and a small effect on carer depression\textsuperscript{52}. Boots et al. also considered interventions for carers, which delivered carer support over the internet\textsuperscript{53}. While the quality of the evidence was low the results suggest that internet interventions for informal carers can improve their confidence, self-efficacy and levels of depression, provided they are tailored to the needs of the individual. Van’t Leven and colleagues studied the impact of interventions aimed at both the person with dementia and their carer; the so-called “dyad”\textsuperscript{54}. 20 studies which were assessed to be moderate to high quality were included in their review, and 19 out of the 20 studies showed significant effects on the patient, the carer, or both. Interventions that train one or more specific functional domains for the patient and/or the carer were the most effective.

Kale et al. have recently completed a detailed “State of the Art Review” of interventions, which includes a summary of the evidence on supporting carers\textsuperscript{55}. Their review includes the American REACH II and REACH-VA programmes which provided general training in good dementia care, support programmes for carers and a tailored problem solving approach. Both trials showed a significant reduction in the frequency of behavioural symptoms. Kale also considers the Tailored Activity Programme (TAP) which used occupational therapists to train carers in a customised activity based on the patient’s previous interests and cognitive and physical abilities. At four months there was a significant reduction in the level of problem behaviours, and in the carer’s perception of the amount of time they were “on duty”. The Care of Persons with Dementia in their Environment (COPE) and Advanced Caregiver Training (ACT) also both demonstrated a significant reduction in problem behaviours, and an increase in carer’s wellbeing and confidence, and reduced carer upset. Finally Kale and colleagues consider a meta-analysis of 3,300 community dwelling patients within 23 randomised controlled trials, which demonstrated that interventions for family carers significantly reduced behavioural symptoms. Although the effect size was relatively small, it was greater than the effect size found in trials of antipsychotics for behavioural symptoms, and cholinesterase inhibitors for memory symptoms, suggesting that interventions to support carers should be considered amongst the most effective interventions for reducing behavioural and psychiatric symptoms.

It is also important to consider the effectiveness of interventions aimed at the person with dementia. Kale and colleagues conclude that no positive or negative conclusions can be made for the
effectiveness of the following interventions for reducing behavioural and psychiatric symptoms - reminiscence therapy; validation therapy; simulated presence therapy; aromatherapy; snoezelen (placing the patients in a dedicated soothing and stimulating environment, known as a snoezelen room); cognitive training and rehabilitation; acupuncture; light therapy.

Livingstone and colleagues completed a very comprehensive review for the Health Technology Assessment programme of the clinical and cost-effectiveness of sensory, psychological and behavioural interventions for managing agitation in older adults with dementia in care homes. 33 studies were included. Supervised person-centred care, communication skills and modified dementia care mapping all reduced clinically significant agitation in care home residents immediately and at 6 month follow-up; activities and music interventions reduced average levels of agitation immediately but not at follow up, and sensory interventions reduced average and clinically significant symptoms. Training paid caregivers in person-centred care and communication cost between £31-339, activities cost between £80-696, music therapy £13-27, and sensory interventions £3-527.

Leung et al. completed a systematic review of randomised controlled trials looking at the impact of social support group interventions for people with dementia. They found limited evidence that support groups may reduce depression, improve quality of life and raise self-esteem for people with dementia, but the evidence supporting this was of very poor quality.

Considering wider environmental factors, Whear and colleagues completed a review of both qualitative and quantitative studies of the impact of gardens and outdoor spaces on people with dementia. While the evidence was again of poor quality, results suggested a reduction in levels of agitation in care home residents with dementia who spent time in a garden.

4.3.2.3. Interventions which aim to prevent increased use of resources, for example by preventing or delaying admission to a care home, or by reducing hospital bed days

Phelan and colleagues conducted a systematic review to determine whether there were interventions which could reduce admissions to acute hospital among community-dwelling adults with dementia. 10 studies were included using intervention strategies which included face-to-face assessments of the person living with dementia and their carer, and the development and implementation of a care plan. There was no significant reduction in hospital admissions in any of the studies, although one study reported a reduction in length of stay.

Burton et al. carried out a systematic review and meta-analysis to evaluate the effectiveness of exercise programmes to reduce falls and subsequent hospital admissions amongst community-dwelling adults with dementia. Four studies, including 3 high-quality randomised controlled trials, were included. The findings suggested that exercise programmes may reduce falls in older people with dementia in the community, but that further research is needed.

Khanassov and colleagues have published two systematic reviews considering the impact of case management for patients with dementia. 43 quantitative and qualitative studies were included. Case management was found to have a limited positive effect on the behavioural symptoms of dementia, length of hospital stay, and on carer’s burden and depression. High intensity case management, with a small caseload, regular proactive follow up and regular contact between the case managers and primary care doctors, was required to produce positive clinical outcomes for the
patients, and optimal service use. The authors suggest that significant variation in these factors, and in the communication ability of case managers, may account for the inconsistent evidence for primary-care case management of people with dementia.

Another systematic review by Tam-Tham et al. also considered the effectiveness of dementia case management on reducing long-term care placements, admissions to hospital and A&E attendances\textsuperscript{63}, and included 17 studies in their meta-analysis. Dementia case management demonstrated a short term (less than 18 months) reduction in the risk of long-term care placement, but no impact on admissions to hospital or A&E attendances. Longer-term evaluation of dementia case management is required.

Zabelgui and colleagues also considered the impact of case management on patients with dementia living at home\textsuperscript{64}. They note that the variation in practice makes comparison of different practice difficult, but suggest that case managers did reduce the rate of institutionalisation and use of community services, although the follow up periods were short.

Some areas have invested in \textit{dementia specialist nurses} (sometimes called Admiral Nurses), dementia advisors and support workers. These workers help with the need for the care plan to be unitary – i.e. delivered by one person. Earlier evidence found that Admiral Nurses were valued by family carers, but that the impact of their work in terms of specific outcomes was difficult to measure\textsuperscript{26}. Mid Norfolk and West Norfolk have both recently trialled the introduction of an Admiral Nursing team, working to the following model:

\textbf{Figure 28: West Norfolk Admiral Nursing Team Model}

The recently published initial assessment of this service in West Norfolk, which received 92 referrals in 8 months, suggests that it:

- improved the wellbeing of the people with dementia;
- highlighted a number of safeguarding situations;
- allowed timely referrals to other services;
- improved the dementia pathway, strengthening links between tier 1 information and advice services and other interventions;
- encouraged more calls to the national Admiral Nurse helpline;
• ensured that all relevant patients were offered the opportunity to have an Advanced Care plan and to have End of Life discussions; improved the signposting of specialist services to staff;
• reduced the risks of medication mismanagement by offering psycho-social interventions as an alternative to prescription drugs;
• and saved an estimated £156k in 8 months through avoided admissions to acute hospitals, residential homes and nursing homes.

While this review was not independently conducted, and could not offer any statistical analysis of the observed changes, the findings echo the positive responses to Admiral Nurse services reported in other settings and areas of the country.

Finally, Singh and colleagues have published a review of their Rapid Assessment Interface and Discharge service (RAID)\textsuperscript{65}. This is a service within an acute hospital which uses a multi-skilled team to comprehensively assess hospital inpatients’ physical and psychological well-being in hospital, and is effective at reducing length of stay and avoiding readmission.

\textbf{4.3.2.4 Interventions which aim to improve the patients’ experience at the end of life}

Considering interventions for patients who are approaching the end of their life, Perrar and colleagues considered the needs of people with dementia in the last stages of their lives\textsuperscript{66}. 10 studies were identified, and key themes including physical, social and psychological needs were defined, but there was very little evidence about what was effective in meeting the various needs. The authors concluded that there is a paucity of evidence on the needs of people with severe dementia, and called for further research in this area along the themes identified.

Van der Steen et al. completed a systematic review of 33 studies into the initiation of advanced care planning for people with dementia\textsuperscript{67}. The main factors influencing or hindering advanced care planning were the family’s reluctance or willingness to engage with the process, with professional’s initiative, or lack of it, and the patient’s health status. The studies suggested that ethnic minority status of those involved, and families who are located a long way away from the person with dementia may also be barriers to advanced care planning.

The use of case conferences to improve the care of dementia patients at the end of life and living in nursing homes is reviewed by Phillips and colleagues\textsuperscript{68}. 9 studies were included, of which 2 were randomised controlled trials. These trials demonstrated enhanced medicines management for the patients, and other studies suggested that palliative symptom management and care outcomes were improved for patients by introducing case conferences, which provided an opportunity to engage the patient’s family and all the health and social care providers in prospective care planning. Further research is required to assess the cost-effectiveness of this type of intervention.
4.3.3 Current national recommendations for post-diagnostic interventions in England

### Current National Recommendations for Post-Diagnostic Interventions – Summary

- NICE guidance relating to interventions for dementia is due to be revised and will be updated in 2017.
- NICE currently advocate the use of a multidisciplinary care plan; providing opportunities for people with mild to moderate dementia to receive group cognitive stimulation therapy; the prescription of donepezil, galantamine, rivastigmine and memantine; and the use of therapies including music, dance, aromatherapy, sensory stimulation and massage for people with dementia and comorbid agitation. The more recent evidence base does not support all of these suggested therapies.
- The Royal College of Psychiatrists has launched the National Accreditation Programme for Memory Services which defines a number of service standards for the assessment, diagnosis and treatment of dementia at three different levels. None of the three Memory Services in Suffolk are MSNAP members, and none have applied for or received accreditation, making it impossible to assess how well Suffolk services are performing against current best practice.
- The Alzheimer’s Society has also made recommendations concerning post-diagnostic support including the provision of comprehensive information, access to universal support services, expert practical guidance from a dementia advisor, and the provision of individual and group support.
- NHS England has recently published a “Well Pathway for Dementia”, with five domains of preventing well, diagnosing well, living well, supported well and dying well. This pathway draws heavily on existing NICE guidance, quality standards and pathways. Regional Clinical Networks are seeking innovative projects to develop the Well Pathway further.

The NICE guideline “CG42: Dementia: supporting people with dementia and their carer’s in health and social care” was published in 2006 and is currently being updated\(^2\). The updated guidance is due to be published in September 2017. Further guidance considering pharmaceutical treatments for non-Alzheimer dementia patients is also being developed by NICE, but there is no publication date for this at present.

The 2006 NICE guidance advocates the following post diagnostic interventions for people with dementia:
- a care plan, including advice and skills training to support the Activities of Daily Living (ADL) from an occupational therapist, incontinence guidance, physical exercise, environmental modifications;
- the opportunity for people with mild to moderate dementia to participate in a structured group cognitive stimulation programme;
- the prescription of donepezil, galantamine and rivastigmine for people with mild to moderate Alzheimer’s disease;
- the prescription of memantine for people who with moderate Alzheimer’s disease who cannot tolerate the other recommended drugs, or for people with severe Alzheimer’s disease;
• the use of a range of therapies including aromatherapy, multisensory stimulations, therapeutic use of music/dancing, animal-assisted therapy and massage for people with dementia and comorbid agitation.

The recently published NHS England “Well Pathway for Dementia” draws heavily on this NICE guidance in its key areas of integrated services, supporting carers, carers respite, co-ordinated care, promoting independence, relationships, leisure and safe communities.\(^6^9\)

Updated NICE guidance will not be published until 2017, so the Royal College of Psychiatrist’s Memory Services National Accreditation Programme (MSNAP) Standards for Memory Services provides helpful guidance in the interim.\(^7^0\) The standards focus on functional outputs rather than service organisation so that services which are configured in different ways can still apply for accreditation. The standards are typically updated every year to reflect changes to the evidence base, and categorise interventions into three levels;

• Type 1, where failure to meet these criteria would result in a significant threat to patient safety, rights or dignity and/or would breach the law;
• Type 2, which are criteria that an accredited service would be expected to meet;
• Type 3, which are criteria that an excellent service should meet or criteria that are not the direct responsibility of the service.

Clearly these service standards overlap with the NICE Guidance and the NICE Quality Standard for Dementia (QS1). Further information on the overlap with the Quality Standard is included for information in Appendix 1. A positive audit against the MSNAP service standards, and the granting of accreditation, therefore provides assurance that local services are of an acceptable (level 2) or excellent standard (level 3) and also that many areas of the NICE Quality Standard are being achieved.

The key recommendations made in the latest 2014 MSNAP Service Standards in relation to ongoing care management and follow up, pharmacological post-diagnostic interventions and psychosocial post-diagnostic interventions are included in Appendix 2. They include the provision of a care plan and detailed signposting to other services; access to anti-dementia medication and antipsychotics when required; and access to group therapies, therapies for anxiety and depression, life story work, reminiscence therapy, group cognitive stimulation therapy (CST) and ongoing maintenance CST, cognitive rehabilitation, cognitive behaviour therapy (CBT), personally tailored occupational therapy and interventions for behaviour which challenges; and support for carers including coping strategies, family interventions, counselling and CBT.

It is of note that none of the three memory services in Suffolk were included in the 2013 MSANP audit\(^7^1\) (the latest currently available), and that none of the three have applied for accreditation according to the latest MSNAP interactive map of services, dated 29th October 2015.\(^7^2\) It is suggested that the local services are encouraged to apply for accreditation, which would serve the dual purpose of identifying which parts of local service provision are working well, and which elements need improvement.

The Alzheimer’s Society have also made recommendations for a minimum standard of post-diagnostic support which they suggest should be available to all people with dementia.\(^7^3\) The suggestions should be modified so that they are appropriate for the individual with dementia, and
recorded in their care plan, which should then be reviewed at least annually so that changing needs can be reflected.

The suggestions are as follows:

1. The provision of **comprehensive information** on all aspects of the condition and **access to universal support services**, such as a helpline;
2. The provision of expert practical guidance on how to navigate services, support and decisions given by a **dementia adviser** or equivalent;
3. The provision of **support to manage and live well with the condition**. This can be delivered individually and/or in a group.

### 4.4 Evidence Review – Overall Pathway design

<table>
<thead>
<tr>
<th>Pathway Design Evidence Review – Summary</th>
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<tr>
<td>• The experience of many people with dementia and carers does not feel like a “pathway” but more like a “labyrinth” characterised by uncertainty and anxiety.</td>
</tr>
<tr>
<td>• NHS England advocate the development of online Dementia Roadmaps as an information resource for people with dementia, their carers and local health and social care teams, using a standardised platform at relatively low cost.</td>
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</table>

Samsi and colleagues have recently published some perspectives on pathway design within dementia services, which provide useful context to service development work. In particular, they conducted significant work to understand the patient and carer’s views of being diagnosed with, and then living with dementia, an experience often typified by uncertainty and anxiety\(^4\). The condition itself is characterised by an uncertain disease trajectory and a lack of clarity about symptoms and treatments. In this context, the term “dementia care pathway” appears to offer certainty, clarity and reassurance which are attractive to patients and carers, but there are many constructions of the term, which can add to the confusion if used carelessly.

In contrast to a friendly-sounding “pathway”, patients and carers often described the process of being assessed for dementia as “entering a labyrinth”. Patients were often affected by long waiting times, with little advice or support in the meantime. Many patients found that the process of taking the memory assessment tests made them very anxious, and felt that they were not supported. They could not understand the outcomes of the tests, and did not know what the scores implied, which added further to their anxiety. Better information about how long the process will take, what will actually happen, and what the different tests and results might signify could help to aid patients and families through the process, and should be considered in the light of local services.

Considering these factors, a further national initiative of interest is the creation of local Dementia Roadmaps. This is recommended by NHS England and echoed in the Alzheimer’s UK suggestions for post-diagnostic support. The Dementia Roadmap ([http://dementiaroadmap.info](http://dementiaroadmap.info)) is a web based platform that provides high quality information, easily accessible information about the dementia “journey”, alongside local information about services, support groups and care pathways to assist primary care staff to more effectively support people with dementia, their families and carers. The main audience is staff working in primary care, including GPs, nurses, dementia navigators and
practice managers. The local roadmaps also benefit other professionals supporting people with dementia, their family and carers, people worried about memory problems, and people living with dementia and their carers and families.

The website was launched nationally in May 2014, and there are now 14 Dementia Roadmaps visible to the public, and a further 6 currently in development. The suggested benefits of developing a Roadmap include support for GPs in introducing questions about memory functioning, in reassuring patients and families by signposting them to local resources and support, in referring patients on, in supporting carers, ensuring that memory loss is coded appropriately, and in case finding of at risk patients. From the information which is publically available, Suffolk does not seem to have either a finished Roadmap or be in the process of developing one despite strong stakeholder feedback in the 2013 Needs Assessment on Dementia that there is a lack of clarity about which services are available, and how these can be accessed. The creation of a Dementia Roadmap for Suffolk should be considered as part of the efforts to improve local care provision.
## 4.5 Evidence Review - Cost effectiveness of Interventions for Dementia

### Cost Effectiveness Evidence Review – Summary

Overall, there is a paucity of good quality evidence concerning the cost effectiveness of different interventions for dementia. It should also be noted that, although some interventions are cost-effective, there are issues with budgetary crossover which require a system-wide approach, to deal with the problem of investment being made in the health budget but leading to savings in social care.

- NICE estimates that the statutory services cost saving from delaying one case of dementia for one year is £15,050, which divides approximately into 1/3 NHS costs, 1/3 local government costs and 1/3 central government costs.
- NICE suggests that up to 56% of dementia cases may be preventable due to modifiable risk factors; if only 1% of these cases could be delayed or prevented by one year, £60m of public funding would be saved per annum. Within Suffolk, this equates to 83 cases of dementia being prevented or delayed each year, reducing public spending by £1.3m per year.
- As well as costs to statutory services, dementia entails costs to wider society as well, including lost earnings and the impact on carers; the Dementia UK 2014 report estimates that total annual costs per person with dementia are £32,250.
- The drug therapies recommended by NICE are deemed to be cost-effective.
- There is some evidence that cognitive stimulation therapy and tailored activity programmes may be more cost effective than usual care and support.
- There is evidence that occupational therapy may be both cost effective and cost saving compared to usual care and support.
- There is evidence that carer support packages are cost effective, with carers counselling sessions and conversation groups resulting in considerable delays to nursing home placement.
- There is evidence that case management is cost effective, leading to improved quality, outcomes and delayed institutionalisation. Case management may also help to prevent other problems which can lead to hospitalisation in dementia patients, notably falls and fractures, infections and stroke.
- Using a much broader “social return on investment” approach, different models of facilitated peer support groups were all found to generate a positive social return on investment, of between £1.17 - £5.18 per £1 invested.

NHS England has reviewed the costs of three different dementia care models, finding that the Gnosall primary care with specialist in-reach model may be significantly cost-saving at CCG level; that there is no evidence that the Newcastle specialist care with primary care support model is cost-effective or cost-saving but the model has produced detailed service costing for each element of the pathway, and is likely to be cost saving due to rapidly increasing referral rates and a reduction in service duplication; and that the Rotherham specialist service model has also been able to estimated pathway costs, and has been able to cope with significant increases in demand while achieving high levels of patient satisfaction.
In general, the assessment of the cost effectiveness of interventions for dementia suffers from the same paucity of high-quality evidence as other aspects of research into dementia care. Overall, there is more cost-effectiveness evidence on drug therapies than other interventions, although there is some cost-effectiveness evidence in other areas. It is important to bear in mind that an intervention which can demonstrate cost-effectiveness is not the same as an intervention which is cost-saving; cost-effective interventions may cost the same or more than usual care, but may deliver proportionately greater benefits, and so be cost-effective.

A further point relevant to the cost assessment of dementia care is that many of the benefits accrue to informal caregivers; if this ultimately prevents carer breakdown, this may save health and care costs associated with institutionalisation, but if the benefits take the form of fewer unpaid caring hours being required, this is perhaps less likely to save money within formal services, at least in the short term. This may mean that dementia interventions are subject to a degree of so-called budget crossover, meaning that savings accrue in different areas or services to the spending.

The National Institute for Health and Care Excellence in its costing report accompanying Nice Guideline 16 (Delaying or preventing dementia, disability and frailty, NICE, 2015) considers the impact on costs of delaying dementia by one year. It includes the costs to the NHS, Local Authorities and Central Government through payment of the attendance allowance. The estimated avoided costs per person per year that dementia is delayed are as follows:

<table>
<thead>
<tr>
<th>Public Sector Area</th>
<th>Saving over 1 year per person with dementia (£)</th>
</tr>
</thead>
<tbody>
<tr>
<td>NHS</td>
<td>5,285</td>
</tr>
<tr>
<td>Local Government</td>
<td>5,537</td>
</tr>
<tr>
<td>Central Government</td>
<td>4,228</td>
</tr>
<tr>
<td>TOTAL</td>
<td>15,050</td>
</tr>
</tbody>
</table>

This NICE guidance recognises that it is likely to take at least 10 years for any prevention or delaying activities to take effect, but it also suggests that up to 56% of dementia cases, an estimated 403,350 out of a total prevalence of 720,200 nationally may be due to modifiable risk factors. If 1% of these cases (4033 cases), each costing £15,050 per year, could be delayed or prevented by a year, this would save over £60 million of public spending per annum. Applying these figures to the 14,902 people estimated to have dementia in Suffolk by 2020 suggests that 8,345 of these cases may be due to modifiable risk factors. If 1% of these cases were prevented or delayed by one year, 83 people in Suffolk would have their dementia prevented or delayed each year, saving £1.3m of public spending in Suffolk.

While these assumptions are only indicative, and require substantial further testing, it does suggest that investment in preventing type 2 diabetes, mid-life untreated hypertension, mid-life obesity, physical inactivity and smoking may pay dividends in the longer term by preventing or delaying cases of dementia. Promising as this is, it should still be noted that because of increasing life expectancy, numbers of dementia cases overall may still continue to rise, especially in the short to medium term.

Moving on from prevention towards diagnosis, the World Alzheimer Report 2011 notes that early drug therapy, psychosocial and psychological interventions can be effective in ameliorating...
symptoms for people with dementia, in particular cognitive and functional decline, and for reducing
the strain on individual’s carers in the early stages of disease. The report also suggests that
interventions for carers may be more effective when applied earlier in the pathway, keeping people
at home for longer. The report states annual societal costs of £21,700 per person with dementia (at
2011 prices; this is lower than the £32,250 annual costs suggested by Dementia UK 2014), and that
the costs of a high quality diagnosis are approximately £3,300. Overall, the report suggests that the
costs of diagnosis and early intervention are likely to be offset by future savings from delayed
institutionalisation, which are estimated to be in the order of £6,600 per person.

Knapp et al completed a systematic review in 2013, designed to assess dementia costs and
outcomes. A meta-analysis was not possible due to heterogeneity in the research data, and some
of the conclusions were only reported in one study. They considered the evidence of cost-
effectiveness in four areas; pharmacological interventions; non-pharmacological interventions;
interventions targeted on carers; and the organisation of care and support.

Regarding pharmacological interventions, although there were limitations with the data and the
studies, acetylcholinesterase inhibitors for mild-moderate disease and memantine for moderate to
severe disease were found to be cost-effective; this is in line with NICE guidance for dementia
treatment.

Considering non-pharmacological interventions, the following were found to be cost-effective:
- cognitive stimulation therapy;
- tailored activity programmes;
- occupational therapy;
- carer support packages;
- care or case managers.

Cognitive stimulation therapy has been shown to be effective as primary prevention for older people
with good cognitive functioning, and as secondary prevention for mild to moderate dementia. It was
also considered to have the potential to be more cost effective than usual care and support through
its effects on cognition and daily life, although the follow-up period was short. Tailored activity
programmes were found to be cost-effective compared with usual treatment, because they reduced
carer time required. Occupational therapy was found to be not only cost-effective, but cost-saving
compared to usual care, mainly as a result of reductions in the level of formal care required. This
intervention “yielded significant and clinically relevant improvements in daily functioning in patients
and sense of competence in carers” (Graff et al (2008) in Knapp et al (2013)).

With regard to interventions for carers, there is economic evidence which supports the provision of
day care, and of multi-dimensional carer support packages, which were found to have a favourable
cost-per-QALY ratio. One study found that counselling sessions and conversation groups for carers
resulted in significant delays in nursing home placements for people with dementia, compared with
standard care, and a second study found that an intervention providing carers with 12 hours of
individual support covering information, safety, caregiver health and well-being and behaviour
management led to a significant reduction in required caregiver hours.
Considering the organisation of care and support, Knapp et al. argue that, although the evidence is scarce, there are some well-conducted studies which demonstrate the impact of care management arrangements on delayed institutionalisation, leading to savings. These interventions include the introduction of a care manager, responsible for assessing problems in the person’s home, developing a care plan, referring on to other agencies as required, and reviewing each patient at least every six months. This was found to be cost-effective for payers, and to lead to improved patient and carer outcomes and to improvements quality of dementia care. In addition, research into dementia patients in UK hospitals highlighted the main causes of hospitalisation in individuals with dementia as falls (14%), broken/fractured hips (12%), urine infections (9%), chest infections (7%) and stroke (7%). It is possible that case finding and case management work providing integrated care for the frail elderly, many of whom will also have dementia, may also assist in reducing costs in these areas.

A recent report by the Health Innovation Network focuses on this issue of informal costs and burdens by adopting an approach to analysis called the “Social Return on Investment” model. This approach, developed by the New Economics Foundation, assesses the societal value gained from peer support groups offered as post-diagnostic support for people with dementia. In the peer support groups, people meet, supported by trained professionals or volunteers, for facilitated socialising including activities appropriate to those attending. Three different peer support groups were assessed, which varied in frequency, range and scope; the cheapest cost under £10,000 per year to run, with the most expensive costing £100,000 per year to run. Each of the three models was found to have a positive social return on investment, which ranged from £1.17 to £5.18 per £1 invested in the group. Benefits were derived by patients, carers and the volunteers involved, and all these benefits are included in the modelling to capture the return to society.

Cost issues in formal services are explored further in recent work by NHS England, examining the cost impact of different dementia care pathways. Three case studies are presented, covering a primary care managed service with specialist outreach, a specialist care led service with primary care support, and an entirely specialist led service. No one model is deemed more effective than the others, and local circumstances and resources are recognised as very important to the adoption of any particular model. Commissioners in Suffolk may wish to compare current services against these three costed models, and consider whether there are improvements which could be made to current pathways to align them more closely to these examples of best practice, with the expectation of improving services and either improving cost effectiveness or reducing costs.

4.5.1 Model One – a primary care managed service with specialist in-reach, Gnosall Surgery, Staffordshire

This innovative service was described in the 2013 Suffolk Needs Assessment for Dementia, but the evaluation of it has progressed since then. The service uses elderscare facilitators, working in conjunction with Consultant Psychiatrists, all based in a GP Practice. The practice has a population of 1,150 people who are aged 65 or over. The service is delivered according to a defined pathway, which starts with the practice identifying patients with a change in cognitive condition who want an assessment, and then progresses through GP review, diagnostic tests, and Consultant review and diagnosis, all of which are supported by an elderscare facilitator who works with the patient and their
family at all times. The end point is an agreed care and treatment plan, and ongoing support from the facilitator. The project is delivered in partnership with the local Mental Health Trust, and with a third sector end-of-life charity, which manages the facilitators, and provides 24 hour telephone-based decision support for carers. The service has dedicated IT which integrates with assistive technologies and with the EMIS GP system.

NHS England has estimated that the diagnostic element of the pathway costs £396 per patient; this includes the facilitator’s time (band 2), Consultant Psychiatrist’s time, blood test, ECG and MRI or CT scanning and travel costs. Obviously patients continue to receive support in the years after their diagnosis as well, and the costs of that are not made explicit; they may be lower than in the first year, particularly where a diagnosis is made early. Currently, total care acute care costs incurred by the over 65’s registered with Gnosall Surgery are £450,000 less per year than would be anticipated, and when they do get admitted to hospital, lengths of stay are shorter. There is no analysis presented of whether these reductions are statistically significant.

This cost reduction equates to £391 per year per patient aged 65 and over, regardless of whether they have dementia or not. Since the costs of diagnosis only apply to those with dementia, the costs of that diagnostic pathway can, at a simplistic level, be said to be more than offset by the cost savings in acute care, although there are many potential confounders present, and also an issue of budget crossover which is only resolved at CCG level (additional costs in primary care are spent by the CCG, but recouped through lower spending on acute services). This model is in the process of being rolled out to all 41 practices within the CCG, covering 360,000 people. The additional costs of this roll-out are estimated to be £426,200, with additional contributions from the third sector. The estimated acute savings accruing from this cannot be estimated from the paper but could potentially be modelled for local CCGs using basic assumptions.

4.5.2 Model Two - a specialist care led service with primary care support, Northumberland, Tyne and Wear NHS Trust

This Memory Protection Service was commissioned in 2012, and includes patients of all ages and those with learning disabilities. The service provides a key access point in each locality, and is commissioned for 84,000 people cared for by 155 GP Practices. GPs are asked to complete a cognitive screen prior to referral, but referrals can be made from a number of sources including intermediate care and self-referral. All referrals are triaged by a nurse practitioner, who may refer to community mental health for specific urgent needs, and will trigger the GP assessment for any patient who has self-refferred. Once within the service, a nurse will complete a full assessment with cognitive testing, and the patient will then see the Consultant and the nurse for discussion and planning. When all results and tests are complete, most patients are discussed at a professional MDT and then a diagnostic appointment is offered with either a consultant or a GP with a Special Interest (GPwSI) to deliver the diagnosis and make ongoing arrangements. Medication starts at the diagnostic appointment, and is followed up by a nurse three weeks later. If anything changes or medications are not tolerated, patients come back to the clinic or can be seen at home; occupational therapy or psychologist support can be offered if there are ongoing problems with medication.

Twelve weeks after diagnosis all patients are offered an appointment with a nurse, when education and access to support groups are offered again. Patients who decline are sign-posted to the third sector; patients who wish to take part in group work can choose between an education group for
both patients and carers, or a “closed” group run by a clinical psychologist just for patients, which runs for 6-8 weeks for an hour and a half each week. There are very positive outcomes from these groups. Patients are discharged from the process at 9 - 16 weeks if there are no complications.

The diagnostic costs per patient are estimated at £877, with costs of the post-diagnostic support groups estimated at £419 per patient. There is no estimate provided of potential cost-savings or improvements in cost-effectiveness, but the new service brought together three different pathways across three localities and three different Community Mental Health teams, so is likely to be making more efficient use of resources and has improved access and responsiveness. The service also seeks to use nurses and GPwSIs in innovative roles, although the ongoing recruitment of GPwSIs remains a challenge. Referrals to the service have increased 10-fold. Ongoing issues include further shortening of the pathways, particularly around access to tests, ongoing work to improve the quality of referrals into the service, and ensuring that the considerable input required to reach a diagnosis for some patients, particularly younger ones, is available in a timely way.

4.5.3 Model Three – a specialist care delivered service, Rotherham, Doncaster and South Humber NHS Foundation Trust

This model serves 50,000 people aged 65 or over, looked after by 45 GP surgeries. The service is delivered by one Trust, but that Trust emphasises the ongoing need for wider effective partnership working for effective delivery. The service is accredited by MSNAP and has recently moved from being a “ clinic” to a “service”, to provide a more personalised approach and a better response to increasing demand. GPs screen patients and refer to a Single Point of Access (SPA); the referral then goes to the Memory Service or the Community Mental Health team as appropriate. Patients are contacted on the day the referral is received, and are booked to attend a clinic within 4 weeks.

At clinic, the patient sees a Consultant Psychiatrist and a nurse, diagnosis is discussed, and the patient is considered for medication and advised on support. The patient’s case is then discussed at a professional multi-disciplinary team meeting, which helps to determine the patient’s plan and to “cluster” the patient appropriately into a care plan under Payment by Results. Patients “clustered” to cluster 18 receive medication and titration, cognitive stimulation therapy, advice and information, regular reviews and medication support. Patients “clustered” to cluster 19, who are more complex, receive everything offered to cluster 18 and also access to allied health professionals if required. The pathway costs per patient are £491. There is no analysis of suggested cost-savings or cost-effectiveness, but the service has been able to expand successfully to meet increasing demands, and achieves excellent patient satisfaction ratings.
5. Information Gaps
There are a number of gaps in the information about the epidemiology of dementia in Suffolk, service provision and the effectiveness of local services.

1. Epidemiology of dementia in Suffolk:
   - Local data about the true number of people with dementia in Suffolk is not available, hence the use of estimates in this report. QOF dementia register data significantly underestimates the true number of people with dementia. Information about the some of the characteristics of people with dementia (such as ethnicity, age, accommodation) is therefore also not available.
   - Local data about the incidence of dementia (i.e. the number of new cases of dementia within a time period) is not available.
   - Data about the number of family carers who care for someone with dementia is not available.

2. Service provision:
   - The needs assessment presents information about some services which are provided to people with dementia and their family carers in Suffolk.
   - There may be services provided by the community that have not yet been identified. In addition, there are a considerable number of generic services that support and care for people with dementia and their family carers that are not specifically identified as ‘dementia services’. More work needs to be done to get a full and accurate picture about where services are provided and their service offer.
   - Due to the complexity of dementia services, there is a significant lack of data about the cost of providing services to people with dementia and their family carers.

3. Activity data:
   - Data about the number and characteristics of people who use dementia services in Suffolk is presented where available. However, there are a number of information gaps. Notably, there is missing data about the volume of referrals and diagnoses made at memory assessment services in Ipswich & East Suffolk and West Suffolk.
   - For many services, including those provided to family carers, there is a lack of information about how many people use the services, the characteristics of these people and the outcomes of the services.
   - This means that it is not possible to clearly identify whether there are certain groups of people who are not accessing services, nor is it possible to make accurate statements about the effectiveness of these services.
6. Key Findings and Recommendations

Although a full Needs Assessment (NA) for Dementia in Suffolk was completed in November 2013, since then national policy, prevalence estimates, guidance on service provision and research findings related to dementia have continued to evolve.

Taking these factors into account, this document updates and refreshes the 2013 Needs Assessment for dementia in Suffolk, and draws conclusions about the local population and the evidence for effective service models and interventions. This update does not cover every area in the 2013 Needs Assessment, for example, the work on stakeholder and user experience has not been repeated due to time constraints, and should therefore be read in conjunction with the 2013 Needs Assessment.

6.1 Building on the 2013 Needs Assessment

While progress has been made with regard to a number of the 2013 recommendations, notably in improving dementia diagnosis rates and the ongoing development of dementia friendly communities, dementia action alliances and dementia friendly employers, there remains work to do to meet all of the recommendations in full.

Recommendation 1: Commissioners should review the progress made against the 2013 Needs Assessment recommendations and, if still relevant, continue to make plans to address them.

6.2 Risk Factors and the Prevention of Dementia

The estimates of overall dementia prevalence in England have been revised downwards by a statistically significant 1.8%, compared to estimates made 20 years ago. This decline suggests that there is a cohort effect in dementia prevalence, with later-born populations having a lower risk of prevalent dementia than those born earlier in the last century.

There is a growing consensus that more dementias contain a vascular element than previously thought; therefore, actions to prevent or reduce cardiovascular risk are also important in reducing the prevalence of dementia. However, the importance of cardiovascular risk management for the promotion of brain health is not widely understood and needs to be explicitly communicated. Recent NICE guidance on “Dementia, Disability and Frailty in Later Life – Mid-life Prevention Approaches” highlights the need for people to stop smoking, be more physically active, reduce alcohol consumption, eat healthily and maintain a healthy weight in order to optimise their brain health in later life. Although the precise roles of loneliness and isolation as risk factors for dementia are not fully understood, they may reduce resilience to the onset and progression of dementia, so are also important to consider within the context of prevention.

Recommendation 2: The Commissioners of dementia services in the Suffolk CCGs and Suffolk County Council should note that more dementias have a vascular element than previously thought, and may therefore be amenable to prevention through the recognition and effective treatment of risk factors as part of the Suffolk Prevention Strategy.
6.3 Descriptive Epidemiology of Dementia in Suffolk

Since the 2013 Needs Assessment was published, the Office for National Statistics has updated the population projections for Suffolk, and the national prevalence estimates for dementia by age-band have been updated by the Alzheimer’s Society in their recent report Dementia UK:2014².

These revised data suggest that there are currently approximately 12,800 people with dementia living in Suffolk. By 2035, it is estimated that there will be nearly 25,000 people with dementia in Suffolk, an increase of 90% compared to the current prevalence. Despite recent rises in local dementia diagnosis rates, it is estimated that 40 - 45% of people with dementia in Suffolk have still not received a formal diagnosis, and therefore do not have access to therapeutic interventions and support; this equates to over 5,000 people.

Although relatively rare, the number of people estimated to have early onset dementia in Suffolk (occurring between the ages of 60 and 69) has doubled compared with the 2013 estimates; these younger people may have specific needs relating to employment and family life.

**Recommendation 3:** The Commissioners of dementia services in the Suffolk CCGs and Suffolk County Council should take account of the newly increased estimates for dementia prevalence in Suffolk, both now and in the coming years, and plan accordingly.

There is a three and a half-fold variation in the rates of dementia diagnosis between GP practices in Suffolk; this level of variation is unlikely to be explained by clinical variation alone, and may be contributing to health inequalities. Alzheimer’s disease remains the most common sub-type of dementia, followed by vascular dementia, but rates of death attributed to vascular dementia in Suffolk in 2009-13 have risen compared to 2007-2011, possibly indicating greater awareness of this type of dementia

**Recommendation 4:** The Commissioners of dementia services in the Suffolk CCGs and Suffolk County Council should support GP practices to reduce the current variation in dementia diagnosis rates, with the underlying aim of reducing potential inequalities in access to care and support.

As well as considering people with dementia alone, it is important to recognise that many people with dementia will also be frail. Recognition and understanding of the concept of clinical frailty is increasing, and as services develop to prevent deterioration and manage crises in those with frailty, there is also an opportunity to recognise, assess and support more people with dementia and their carers.

**Recommendation 5:** The recognition of frailty as a clinical syndrome is becoming easier to achieve and more widespread. The Commissioners of dementia services in the CCGs and Suffolk County Council should consider the extent to which the needs of people with dementia and their carers overlap with the needs of people with frailty, and ensure there are effective links between services when required.
6.4 Evidence review – Diagnosis and Post-diagnostic Support

Systematic reviews were conducted to review the evidence base published since 2013 for the diagnosis of dementia and the provision of post-diagnostic support. Very few recent systematic reviews were found regarding diagnosis, but there were a sizeable number of publications relating to post-diagnostic support. While some of this evidence was of a very low quality, there is recent evidence of better quality which found a number of different types of post-diagnostic intervention to be clinically effective.

**Recommendation 6:** The Commissioners of dementia services in the Suffolk CCGs and Suffolk County Council should note the evolving evidence base for post-diagnostic interventions, and ensure that commissioned services take account of the recent research findings with relation to support for carers, case management, interventions within care homes, withdrawal of antipsychotic medication, and occupational therapy.

6.5 Policy review – Recommendations for Post-Diagnostic support services in England

There is NICE guidance in place for the provision of post-diagnostic support, but it was published in 2006 and will not be updated until 2017. While this guidance should be adhered to, there is also additional guidance from the Royal College of Psychiatrist’s Memory Services National Accreditation Programme (MSNAP) Service Standards, which is recommended for use by NHS England.

**Recommendation 7:** The Commissioners of dementia services in the Suffolk CCGs and Suffolk County Council should ensure that commissioned service specifications meet current NICE guidance and the MSNAP service standards, including the non-mandatory standards covering psychosocial intervention.

In addition to the service standards, the Royal College of Psychiatrist’s Memory Services National Accreditation Programme also offers an accreditation service. Services follow a process of self-assessment and eventual peer review. Service criteria are assessed at one of three levels, Type 1, where failure to meet these criteria would result in a significant threat to patient safety, rights or dignity and/or would breach the law; Type 2, which are criteria that an accredited service would be expected to meet; or Type 3, which are criteria that an excellent service should meet or criteria that are not the direct responsibility of the service. An increasing number of memory services across the country are now Members of MSNAP and are being accredited through the programme, allowing assurance of service quality and recognition and support with areas where improvements are required. None of the three memory services in Suffolk are currently Members of MSNAP, or undergoing accreditation.

**Recommendation 8:** The Commissioners of dementia services in the Suffolk CCGs and Suffolk County Council should strongly encourage all three locally commissioned memory services to join and seek accreditation with the RCP MSNAP programme, aiming to achieve accreditation at level 2 by all three local services within an agreed timescale.

In addition to service accreditation, NHS England also recommends the creation of an online Dementia Roadmap specific to different areas, typically counties. Navigating so-called dementia “pathways” feels more like trying to navigate a labyrinth for many people with dementia and their carers. While it is recognised that online provision is not the right method of communication for everyone, many older people and their carers are increasingly active online, as are health and social
care professionals. The Roadmaps are hosted on a common software platform for an annual fee, and can be easily updated as statutory and third sector services change and develop in each area.

**Recommendation 9:** The Commissioners of dementia services in the Suffolk CCGs and Suffolk County Council should consider the difficulties reported by people with dementia and their families both nationally and locally in understanding and navigating dementia services; consider whether the creation of a Dementia Roadmap for Suffolk would meet the identified information needs of local residents and professionals; and commission accordingly.

### 6.6 Evidence review – Costs and Cost Effectiveness of Dementia Care

The evidence for cost-effectiveness in dementia interventions is again limited. However, recent systematic reviews have indicated that a number of post-diagnostic interventions, including cognitive stimulation therapy, tailored activity programmes, occupational therapy, carer support packages, and care or case managers, are cost effective.

**Recommendation 10:** The Commissioners of dementia services in the Suffolk CCGs and Suffolk County Council should consider the recent evidence on cost-effectiveness of services for people with dementia, and take account of this in their commissioning decisions.

NHS England has recently published a cost analysis for three different types of memory assessment and treatment models. Analysis to date of the primary care in-reach model suggests that it may be significantly cost-saving at CCG level, and that model is in the process of being rolled out from one practice to over CC. The other two models (primary care out-reach and specialist led and delivered) have not been assessed for cost-effectiveness, but costs per patient have been calculated for both approaches, which could provide useful comparators for an assessment of the efficiency of local services.

**Recommendation 11:** The Commissioners of dementia services in the Suffolk CCGs and Suffolk County Council should review the three service models suggested by NHS England as best practice, consider which model is the best approximation for local services, and compare current service costs against NHS England’s cost estimates to identify opportunities for optimising current service spend.
# 2015 Dementia Joint Strategic Needs Assessment Update: New Recommendations

<table>
<thead>
<tr>
<th>2015 Recommendations</th>
<th>Description</th>
<th>Rationale</th>
</tr>
</thead>
<tbody>
<tr>
<td>2015 - 1</td>
<td>The Commissioners of dementia services in the Suffolk CCGs and Suffolk County Council should review the progress made against the 2013 Needs Assessment recommendations and, if still relevant, continue to make plans to address them.</td>
<td>Many of the recommendations made in the 2013 Needs Assessment have not yet been implemented, or are only partially implemented. Although the evidence base for some interventions has been updated in this document, many of the recommendations made previously are still relevant to the meeting the needs of people with dementia, and their carers, in Suffolk.</td>
</tr>
<tr>
<td>2015 - 2</td>
<td>The Commissioners of dementia services in the Suffolk CCGs and Suffolk County Council should note that more dementias than previously thought have a vascular element and may be amenable to prevention through the recognition and effective treatment of risk factors as part of the Suffolk Prevention Strategy.</td>
<td>The recognition and mitigation of cardiovascular risk has an important part to play in the promotion of brain health and the prevention of future dementias, but this link is not widely understood amongst health and social care professionals or the general public.</td>
</tr>
<tr>
<td>2015 - 3</td>
<td>The Commissioners of dementia services in the Suffolk CCGs and Suffolk County Council should take account of the newly increased estimates for dementia prevalence in Suffolk, both now and in the coming years, and plan accordingly.</td>
<td>There are currently estimated to be 12,800 people with dementia in Suffolk; by 2035 this is predicted to increase to just below 25,000 people as the Suffolk population ages and increases. The number of people estimated to have early-onset dementia has also increased significantly compared to estimates in the 2013 report.</td>
</tr>
<tr>
<td>2015 - 4</td>
<td>The Commissioners of dementia services in the Suffolk CCGs and Suffolk County Council should support GP practices to reduce the current variation in dementia diagnosis rates, with the underlying aim of reducing potential inequalities in access to care and support.</td>
<td>With dementia diagnosis rates varying by three and half times between different practices, clinical variation is unlikely to explain all the variance. Variations in rates should be reduced to try and avoid lack of access to a dementia diagnosis compounding existing inequalities in health and care.</td>
</tr>
<tr>
<td>2015 - 5</td>
<td>The Commissioners of dementia services in the Suffolk CCGs</td>
<td>While the overall evidence base for interventions in dementia...</td>
</tr>
</tbody>
</table>
and Suffolk County Council should review the updated evidence base for post-diagnostic interventions presented in this report, and ensure that commissioned services take account of the recent research findings with relation to support for carers, case management, interventions within care homes, withdrawal of antipsychotic medication, and occupational therapy remains poor, the most recent systematic reviews are starting to identify evidence of effectiveness for these interventions.

<p>| 2015 - 6 | The Commissioners of dementia services in the Suffolk CCGs and Suffolk County Council should ensure that commissioned service specifications meet current NICE guidance and the MSNAP service standards, including the non-mandatory standards covering psychosocial interventions | Current NICE guidance on post-diagnostic support for people with dementia is in the process of being updated. Until updated NICE guidance is available in 2017, the RCP MSNAP service standards represent evidence-based best practice for assessment, diagnosis and interventions, and are updated annually. |
| 2015 - 7 | The Commissioners of dementia services in the Suffolk CCGs and Suffolk County Council should strongly encourage all three locally commissioned memory services to join and seek accreditation with the RCP MSNAP programme, aiming to achieve accreditation at level 2 by all three local services within an agreed timescale. | Level 2 accreditation simply means that a service is meeting the standards that would be expected of it, and as such provides assurance that a service is “fit for purpose” |
| 2015 - 8 | The Commissioners of dementia services in the Suffolk CCGs and Suffolk County Council should consider the difficulties reported by people with dementia and their families both nationally and locally in understanding and navigating dementia services; consider whether the creation of a Dementia Roadmap for Suffolk would meet the identified information needs of local residents and professionals; and commission accordingly So-called “dementia pathways” may give an illusion of certainty and clarity which is not matched by the personal experience of people with dementia and carers |
| 2015 - 9 | The Commissioners of dementia services in the Suffolk CCGs and Suffolk County Council should consider the recent evidence on cost-effectiveness of services for people with dementia, and | While the evidence base on cost-effective interventions in dementia remains thin, there is evidence that cognitive stimulation therapy, tailored activity programmes, occupational therapy, case |</p>
<table>
<thead>
<tr>
<th></th>
<th>take account of this in their commissioning decisions.</th>
<th>management and carer support programmes can all be cost-effective, and in some cases, cost-saving.</th>
</tr>
</thead>
<tbody>
<tr>
<td>2015 - 10</td>
<td>The Commissioners of dementia services in the Suffolk CCGs and Suffolk County Council should review the three service models suggested by NHS England as best practice, consider which model is the best approximation for local services, and compare current service costs against NHS England’s cost estimates to identify opportunities for optimising current service spend.</td>
<td>NHS England has costed three alternative service models; understanding how the models in place in Suffolk compare to this, in terms of structure, performance and cost, would inform effective local commissioning decisions.</td>
</tr>
<tr>
<td>2015 - 11</td>
<td>The recognition of frailty as a clinical syndrome is becoming easier to achieve and more widespread. The Commissioners of dementia services in the Suffolk CCGs and Suffolk County Council should consider the extent to which the needs of people with dementia and their carers overlap with the needs of people with frailty, and ensure there are effective links between services when required.</td>
<td>As frailty becomes more widely recognised and understood, there is an opportunity to use the networks, teams and services developed to assess, diagnose and support people with frailty to also support people with dementia. Ideally, staff working in services for people with dementia should be trained in the recognition of frailty and knowledgeable about local support available in this area, and staff working in services for people who are frail should be similarly knowledgeable about effective approaches and the available local support for people with dementia.</td>
</tr>
</tbody>
</table>
## Glossary

<table>
<thead>
<tr>
<th>Term</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Admiral Nurse</td>
<td>Admiral Nurses are specialist dementia nurses who give expert practical, clinical and emotional support to families.</td>
</tr>
<tr>
<td>Anti-psychotic medication</td>
<td>Medications used for some types of mental disorder, mainly schizophrenia and bipolar disorder. They can also be used to help with severe anxiety or depression.</td>
</tr>
<tr>
<td>Aromatherapy</td>
<td>The use of aromatic plant extracts and essential oils for healing and cosmetic purposes.</td>
</tr>
<tr>
<td>BME</td>
<td>Black and Minority Ethnic</td>
</tr>
<tr>
<td>Case conferences</td>
<td>A process of reviewing a person’s care with all professionals involved in their care.</td>
</tr>
<tr>
<td>CBT</td>
<td>Cognitive Behavioural therapy - a talking therapy that can help you manage your problems by changing the way you think and behave. It is most commonly used to treat anxiety and depression, but can be useful for other mental and physical health problems</td>
</tr>
<tr>
<td>Care Cluster</td>
<td>Care clusters are a way of measuring the outcome of a mental health assessment using a pre agreed set of key mental health assessment measures. Each Cluster has a set of corresponding scores that indicate a level of mental health need which is then linked to a specific care package attached to that cluster.</td>
</tr>
<tr>
<td>Case management</td>
<td>A system in which patients or families with particular needs are allocated a case manager (typically a nurse) who provides them with consistent and sustained support and advice, and acts as their advocate.</td>
</tr>
<tr>
<td>CCG</td>
<td>Clinical Commissioning Group – the new local organisations, led by local GPs, which are responsible for planning and designing local health services in England. CCGs took over the role of local commissioning from primary care trusts on 1 April 2013.</td>
</tr>
<tr>
<td>Cognitive training</td>
<td>Cognitive training consists of a variety of exercises designed to help improve functioning in areas such as sustaining attention, thinking before acting, visual and auditory processing, listening and reading.</td>
</tr>
<tr>
<td>CQUIN</td>
<td>Commissioning for Quality and Innovation payment – a payment scheme used by health care commissioners.</td>
</tr>
<tr>
<td>Dementia</td>
<td>Dementia is a syndrome due to disease of the brain, usually of chronic or progressive nature, in which there is disturbance of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language and judgement. The impairments of a cognitive function are commonly accompanied, and occasionally preceded, by deterioration in emotional control, social behaviour, or motivation.</td>
</tr>
<tr>
<td>Dementia Action Alliance</td>
<td>The Dementia Action Alliance is a movement with one simple aim: to bring about a society-wide response to dementia. It encourages and supports communities and organisations across England to take practical actions to enable people to live well with dementia and reduce the risk of costly crisis intervention.</td>
</tr>
<tr>
<td>Dementia Care Mapping</td>
<td>Dementia Care Mapping™ is an established approach to achieving and embedding person-centred care for people with dementia. Dementia Care Mapping™ is designed to empower staff teams to engage in evidence-based critical reflection in order to improve the quality of care for people living with dementia. It provides a direct and ongoing evidence base for</td>
</tr>
</tbody>
</table>
practice and practice change. It is an observational tool used within a practice development cycle in care settings including five phases:
- Preparation and briefing;
- Observation;
- Analysis;
- Feedback – written report and verbal feedback;
- Action planning.

| Dementia Friends | The Alzheimer’s Society’s ‘Dementia Friends’ programme aims to change people’s perceptions of dementia. Dementia touches the lives of millions of people across the UK. Dementia Friends was launched to tackle the stigma and lack of understanding that means many people with the condition experience loneliness and social exclusion. Nearly 1.5m people are now registered as being Dementia Friends. |
| Dementia Friendly Communities | This is a programme run by the Alzheimer’s Society which focuses on improving inclusion and quality of life for people with dementia. There is an accreditation process for communities to go through to be awarded Dementia Friendly Community status. |
| Dementia diagnosis rate | The number of people in a given population (for example, those who are registered with a specific GP practice) who have been diagnosed with dementia, as a proportion of the number of people expected to have dementia in that population. |
| Dementia Roadmap | An online platform setting out all the details of the available dementia services in a locality, for the use of the public and local professionals |
| Diagnosis | The identification of the nature of an illness or other problem by examination of the symptoms. |
| DIST | Dementia Intensive Support Teams – a service that aims to prevent avoidable acute hospital admissions, expedite discharge from acute hospitals and prevent premature admission to 24 hour care on discharge from acute hospital. |
| Early onset dementia | Dementia occurring in an individual who is aged between 60 and 69 years of age. |
| Frailty | Frailty is a common clinical syndrome in older adults that carries an increased risk of poor health outcomes including falls, incident disability, hospitalization, and mortality. Frailty is a clinically recognizable state of increased vulnerability resulting from aging-associated decline in reserve and function across multiple systems, such that the ability to cope with everyday or acute stressors, such as a minor infection, is comprised. |
| GP | General practitioner |
| Health inequalities | Health inequalities are preventable and unjust differences in health status experienced by certain population groups. People in lower socio-economic groups are more likely to experience chronic ill-health and die earlier than those who are more advantaged. |
| HSCIC | Health and Social Care Information Centre |
| ICD-10 | International Classification of Diseases – the standard diagnostic tool used worldwide. |
| Incidence | A measure of the number of new cases of a disease within a specified time period. |
| Interpersonal therapy | Interpersonal Therapy is a time-limited treatment that encourages the patient to regain control of mood and functioning typically lasting 12–16 weeks. IPT is |
based on the principle that there is a relationship between the way people communicate and interact with others and their mental health.

**Needs Assessment - NA**

A Needs Assessment (NA) looks at the current and future health and care needs of local populations to inform and guide the planning and commissioning (buying) of health, well-being and social care services within a local authority area. A Needs Assessment for a particular disease or population group forms part of the overall Joint Strategic Needs Assessment for Suffolk.

**Light therapy**

Light therapy is a way to treat seasonal affective disorder (SAD) by exposure to artificial light. Seasonal affective disorder is a type of depression that occurs at a certain time each year, usually in the fall or winter.

**LSOA**

Lower Super Output Area: this is an area of geography containing between 1000 and 1500 residents.

**MATS**

Memory Assessment and Treatment Services – the name of the mental health clinics which are dedicated to the assessment, diagnosis and treatment of people with memory problems, including dementia.

**Mini-COG**

The Mini-COG is a three minute test designed to screen for cognitive impairment in older adults in the primary care setting.

**MSNAP**

The Royal College of Psychiatrists’ Memory Services National Accreditation Programme.

**NICE**

National Institute for Health and Care Excellence – an organisation that provides guidance to ensure quality and value for money of health and social care.

**Occupational therapy**

Occupational therapists help people with mental, physical or social disabilities to independently carry out everyday tasks or occupations. They work with children and adults of all ages, whose difficulties may have been present since birth, or the result of an accident, illness, ageing or lifestyle.

**ONS**

Office for National Statistics - the recognized national statistical institute for the UK.

**PCT**

Primary Care Trust - the statutory bodies in England responsible for ensuring NHS services were available in a defined geographical area and for improving the health of people living in that area. These commissioning organisations ceased to exist on 31st March 2013.

**PET scan**

Positron Emission Topography scan – technique to produce detailed three-dimensional images of the inside of the body, which helps to show what tissues look like and how they are working.

**Prevalence**

A measure of the number (or proportion of a population) of people living with a condition.

**Primary Care**

Primary care is care provided in the community and is the level of a health services system that provides entry into the system for all new needs and problems; provides person-focused (not disease-oriented) care over time; provides care for all but very uncommon or unusual conditions, and coordinates or integrates care, regardless of where the care is received. In the NHS, primary care is typically delivered by a General Practitioner.

**QOF**

Quality and Outcomes Framework - a voluntary annual reward and incentive programme for all GP surgeries, detailing practice achievement results. It is a useful source of health information about a population.

**Reminiscence therapy**

People with dementia often have difficulty remembering what’s recently happened in their lives. This can leave them feeling confused, vulnerable and less confident. However, their memories from years ago often remain detailed and intact.

Reminiscence Therapy gives people the opportunity to meet as a group and share these rich stories and experiences. It’s very sociable and helps them...
remember that they are still a real person. The group will meet with a therapist who will encourage everyone to share their memories or stories one at a time. The therapist will often use items such as photographs, music and postcards to get the ball rolling or to jog peoples’ memories. One-to-one sessions can also take place and the therapist will often gather enough stories and memories to compile a ‘life history book’. Not only is this a nice object for that person, it is also a valuable tool in helping the individual remember who they are.

<table>
<thead>
<tr>
<th>RCP</th>
<th>Royal College of Psychiatrists – the professional body responsible for training and education, and setting and raising standards in psychiatry. Psychiatry is a medical field concerned with the diagnosis, treatment and prevention of mental health conditions.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Statins</td>
<td>A group of drugs which act to reduce levels of cholesterol in the blood.</td>
</tr>
<tr>
<td>Suffolk Dementia Partnership</td>
<td>A local partnership between Age UK Suffolk, Alzheimer’s Society, Sue Ryder and Suffolk Family Carers.</td>
</tr>
<tr>
<td>Vascular dementia</td>
<td>A common form of dementia caused by an impaired supply of blood to the brain, such as may be caused by a series of small strokes.</td>
</tr>
</tbody>
</table>
References


70. Hodge S, Hailey E, Orrell M. *Memory Services National Accreditation Programme (MSNAP): Standards for Memory Services*.; 2014.


### Appendix 1 – Public Health England Dementia Profiles for the County of Suffolk

#### Dementia Profile

**Overview**
- **Area type:** County & UA
- **Areas grouped by:** Region
- **Region:** East of England
- **CIPFA nearest neighbours to Suffolk**

**Search for an area**

**Benchmark:** England

#### Indicator

<table>
<thead>
<tr>
<th>Indicator</th>
<th>Period</th>
<th>Suffolk</th>
<th>Region</th>
<th>England</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dementia: Recorded prevalence (all ages)</td>
<td>2014/15</td>
<td>6.07%</td>
<td>0.89%</td>
<td>0.73%</td>
</tr>
<tr>
<td>Dementia: Recorded prevalence (aged 65+)</td>
<td>Sep 2015</td>
<td>6.07%</td>
<td>4.06%</td>
<td>3.95%</td>
</tr>
</tbody>
</table>

**Export table as image**

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#### Dementia Profile

**Overview**
- **Area type:** County & UA
- **Areas grouped by:** Region
- **Region:** East of England
- **CIPFA nearest neighbours to Suffolk**

**Search for an area**

**Benchmark:** England

#### Indicator

<table>
<thead>
<tr>
<th>Indicator</th>
<th>Period</th>
<th>Count</th>
<th>Value</th>
<th>Value</th>
<th>Value</th>
<th>Lowest</th>
<th>Range</th>
<th>Highest</th>
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<tbody>
<tr>
<td>Smoking Prevalence in adults - current</td>
<td>2014</td>
<td>-</td>
<td>20.2%</td>
<td>17.9%</td>
<td>18.0%</td>
<td>9.8%</td>
<td>26.9%</td>
<td></td>
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<tr>
<td>smokers (HTH)</td>
<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Percentage of physically active and</td>
<td>2014</td>
<td>-</td>
<td>25.5%</td>
<td>25.9%</td>
<td>27.7%</td>
<td>16.7%</td>
<td>39.3%</td>
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<tr>
<td>inactive adults - inactive adults</td>
<td></td>
<td></td>
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<td></td>
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</tr>
<tr>
<td>Excess Weight in Adults</td>
<td>2012</td>
<td>-</td>
<td>65.3%</td>
<td>65.1%</td>
<td>63.8%</td>
<td>45.9%</td>
<td>78.8%</td>
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<td>Admission episodes for alcohol-related</td>
<td>2013/14</td>
<td>4,244</td>
<td>575</td>
<td>582</td>
<td>645</td>
<td>368</td>
<td>1,231</td>
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<tr>
<td>conditions (Narrow)</td>
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<tr>
<td>People receiving an NHS Health Check</td>
<td>2013/14 G1</td>
<td>63,969</td>
<td>27.3%</td>
<td>25.6%</td>
<td>22.9%</td>
<td>8.3%</td>
<td>50.2%</td>
<td></td>
</tr>
<tr>
<td></td>
<td>2015/16 G2</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Hypertension: Recorded prevalence (all</td>
<td>2013/14</td>
<td>113,713</td>
<td>14.9%</td>
<td>14.1%</td>
<td>13.7%</td>
<td>7.9%</td>
<td>17.7%</td>
<td></td>
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<tr>
<td>ages)</td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stroke: Recorded prevalence (all ages)</td>
<td>2013/14</td>
<td>14,991</td>
<td>2.0%</td>
<td>1.7%</td>
<td>1.7%</td>
<td>0.6%</td>
<td>2.5%</td>
<td></td>
</tr>
<tr>
<td>Diabetes: Recorded prevalence (aged 17+)</td>
<td>2013/14</td>
<td>37,840</td>
<td>6.1%</td>
<td>6.8%</td>
<td>6.2%</td>
<td>3.7%</td>
<td>8.7%</td>
<td></td>
</tr>
<tr>
<td>CHD: Recorded prevalence (all ages)</td>
<td>2013/14</td>
<td>29,549</td>
<td>3.7%</td>
<td>3.2%</td>
<td>3.3%</td>
<td>1.4%</td>
<td>5.0%</td>
<td></td>
</tr>
<tr>
<td>Depression: Recorded prevalence (aged 18+)</td>
<td>2013/14</td>
<td>46,036</td>
<td>7.3%</td>
<td>6.5%</td>
<td>6.5%</td>
<td>3.1%</td>
<td>12.7%</td>
<td></td>
</tr>
</tbody>
</table>
Dementia Profile

Social Isolation: % of adult carers who have as much social contact as they would like

<table>
<thead>
<tr>
<th>Indicator</th>
<th>Period</th>
<th>Suffolk</th>
<th>Region</th>
<th>England</th>
</tr>
</thead>
<tbody>
<tr>
<td>Social Isolation</td>
<td>2014/15</td>
<td>-25.6%</td>
<td>42.2%</td>
<td>36.5%</td>
</tr>
</tbody>
</table>
### Appendix 2 - Public Health England Dementia Profiles for Great Yarmouth & Waveney CCG

#### Dementia Profile

<table>
<thead>
<tr>
<th>Indicator</th>
<th>Period</th>
<th>Great Yarmouth And Waveney</th>
<th>Region</th>
<th>England</th>
<th>England</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dementia: Recorded prevalence (all ages)</td>
<td>2014/15</td>
<td>2,169</td>
<td>0.9%</td>
<td>0.7%</td>
<td>0.3%</td>
</tr>
<tr>
<td>Dementia: Recorded prevalence (aged 65+)</td>
<td>Sep 2015</td>
<td>2,207</td>
<td>3.98%</td>
<td>3.96%</td>
<td>4.27%</td>
</tr>
</tbody>
</table>

#### Dementia Profile

<table>
<thead>
<tr>
<th>Indicator</th>
<th>Period</th>
<th>Great Yarmouth And Waveney</th>
<th>Region</th>
<th>England</th>
<th>England</th>
</tr>
</thead>
<tbody>
<tr>
<td>Smoking: Recorded prevalence (aged 15+)</td>
<td>2014/15</td>
<td>42,062</td>
<td>21.0%</td>
<td>18.5%</td>
<td>10.4%</td>
</tr>
<tr>
<td>Obesity: Recorded prevalence (aged 16+)</td>
<td>2014/15</td>
<td>21,287</td>
<td>10.9%</td>
<td>9.9%</td>
<td>9.0%</td>
</tr>
<tr>
<td>Hypertension: Recorded prevalence (all ages)</td>
<td>2014/15</td>
<td>39,617</td>
<td>16.9%</td>
<td>14.2%</td>
<td>13.8%</td>
</tr>
<tr>
<td>Stroke: Recorded prevalence (all ages)</td>
<td>2014/15</td>
<td>5,005</td>
<td>2.1%</td>
<td>1.7%</td>
<td>1.7%</td>
</tr>
<tr>
<td>Diabetes: Recorded prevalence (aged 17+)</td>
<td>2014/15</td>
<td>14,304</td>
<td>7.4%</td>
<td>6.1%</td>
<td>6.4%</td>
</tr>
<tr>
<td>CHD: Recorded prevalence (all ages)</td>
<td>2014/15</td>
<td>9,465</td>
<td>4.0%</td>
<td>3.2%</td>
<td>3.2%</td>
</tr>
<tr>
<td>Depression: Recorded prevalence (aged 15+)</td>
<td>2014/15</td>
<td>16,619</td>
<td>8.2%</td>
<td>7.2%</td>
<td>7.3%</td>
</tr>
</tbody>
</table>
Dementia Profile

**Prevalence**

- Overview
- Compare Indicators
- Map
- Trends
- Compare Areas

**Preventing Well**

- Overview
- Compare Indicators
- Map
- Trends
- Compare Areas

**Diagnosing Well**

- Overview
- Compare Indicators
- Map
- Trends
- Compare Areas

**Living Well**

- Overview
- Compare Indicators
- Map
- Trends
- Compare Areas

**Supporting Well**

- Overview
- Compare Indicators
- Map
- Trends
- Compare Areas

**Dying Well**

- Overview
- Compare Indicators
- Map
- Trends
- Compare Areas

**Indicator**

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<thead>
<tr>
<th>DEM003: Blood tests recorded (den.incl.exc.)</th>
<th>Period</th>
<th>Great Yarmouth and Waveney</th>
<th>Region</th>
<th>England</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>2014/15</td>
<td>337</td>
<td>76.1%</td>
<td>71.4%</td>
</tr>
</tbody>
</table>

**Indicator**

<table>
<thead>
<tr>
<th>DEM002: Dementia care has been reviewed last 12 months (den.incl.exc.)</th>
<th>Period</th>
<th>Great Yarmouth and Waveney</th>
<th>Region</th>
<th>England</th>
<th>England</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>2014/15</td>
<td>1,032</td>
<td>75.2%</td>
<td>76.0%</td>
<td>85.0%</td>
</tr>
</tbody>
</table>
## Dementia Profile

### Overview

- Area type: CCG
- Areas grouped by: Region
- Region: East of England
- Benchmark: England

### Indicators

<table>
<thead>
<tr>
<th>Indicator</th>
<th>Period</th>
<th>Great Yarmouth And Waveney</th>
<th>England</th>
</tr>
</thead>
<tbody>
<tr>
<td>Directly Age Standardised Rate of Mortality: People with dementia aged 20+</td>
<td>2013</td>
<td>411</td>
<td>185.8</td>
</tr>
<tr>
<td>Directly Age Standardised Rate of Mortality: People with dementia aged 65+</td>
<td>2013</td>
<td>404</td>
<td>748</td>
</tr>
<tr>
<td>Deaths in Usual Place of Residence: People with dementia aged 65+</td>
<td>2013</td>
<td>278</td>
<td>69.8</td>
</tr>
<tr>
<td>Place of death - care home: People with dementia aged 65+</td>
<td>2013</td>
<td>245</td>
<td>60.6</td>
</tr>
<tr>
<td>Place of death - hospital: People with dementia aged 65+</td>
<td>2013</td>
<td>122</td>
<td>30.2</td>
</tr>
<tr>
<td>Place of death - home: People with dementia aged 65+</td>
<td>2013</td>
<td>35</td>
<td>8.7</td>
</tr>
</tbody>
</table>
## Dementia Profile

### Prevalence

**Indicator:** Ratio of inpatient service use to recorded diagnoses  
**Period:** 2013/14  
**Great Yarmouth and Waveney:** 1,035 54.5 67.4 65.1 39.6  
**England:** 306  

**Indicator:** DSR of emergency admissions (aged 65+)
**Period:** 2013/14  
**Great Yarmouth and Waveney:** 1,261 587 712 779 406  
**England:**  

**Indicator:** DSR of emergency admissions (aged 65+)
**Period:** 2013/14  
**Great Yarmouth and Waveney:** 1,214 2,277 2,764 3,046 1,579  
**England:**  

**Indicator:** DSR of short stay emergency admissions (aged 20+)
**Period:** 2013/14  
**Great Yarmouth and Waveney:** 232 19.5% 24.3% 25.5% 10.5%  
**England:**  

**Indicator:** DSR of short stay emergency admissions (aged 65+)
**Period:** 2013/14  
**Great Yarmouth and Waveney:** 228 18.6% 24.2% 25.4% 10.7%  
**England:**  

**Indicator:** Alzheimer’s disease: DSR of inpatient admissions (aged 65+)
**Period:** 2013/14  
**Great Yarmouth and Waveney:** 251 118.5 127.4 146.2 60.2  
**England:**  

**Indicator:** Alzheimer’s disease: DSR of inpatient admissions (aged 65+)
**Period:** 2013/14  
**Great Yarmouth and Waveney:** 241 467.5 495.2 574.5 232.2  
**England:**  

**Indicator:** Vascular dementia: DSR of inpatient admissions (aged 20+)
**Period:** 2013/14  
**Great Yarmouth and Waveney:** 197 92.1 104.7 127.5 56.6  
**England:**  

**Indicator:** Vascular dementia: DSR of inpatient admissions (aged 65+)
**Period:** 2013/14  
**Great Yarmouth and Waveney:** 193 361.9 416.6 506.2 223.6  
**England:**  

**Indicator:** Unspecified dementia: DSR of inpatient admissions (aged 20+)
**Period:** 2013/14  
**Great Yarmouth and Waveney:** 567 264.8 319.5 336.1 186.1  
**England:**  

**Indicator:** Unspecified dementia: DSR of inpatient admissions (aged 65+)
**Period:** 2013/14  
**Great Yarmouth and Waveney:** 558 1,045.2 1,266.0 1,327.3 737.3  
**England:**  

---
# Dementia Profile

## Prevalence

<table>
<thead>
<tr>
<th>Indicator</th>
<th>Period</th>
<th>Great Yarmouth And Waveney</th>
<th>Region</th>
<th>England</th>
<th>England</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Count</td>
<td>Value</td>
<td>Count</td>
<td>Value</td>
</tr>
<tr>
<td>Directly Age-Standardised Rate of Mortality: People with dementia aged 65+</td>
<td>2013</td>
<td>411</td>
<td>169.3</td>
<td>179.1</td>
<td>187.2</td>
</tr>
<tr>
<td>Deaths in Usual Place of Residence: People with dementia aged 65+</td>
<td>2013</td>
<td>273</td>
<td>69.8</td>
<td>68.4</td>
<td>66.6</td>
</tr>
<tr>
<td>Place of death - care home: People with dementia aged 65+</td>
<td>2013</td>
<td>245</td>
<td>50.6</td>
<td>59.7</td>
<td>55.6</td>
</tr>
<tr>
<td>Place of death - hospital: People with dementia aged 65+</td>
<td>2013</td>
<td>122</td>
<td>32.2</td>
<td>31.1</td>
<td>32.6</td>
</tr>
</tbody>
</table>

* A note is attached to the value, hover over to see more details.*

Export table as image
Appendix 3 - Public Health England Dementia Profiles for Ipswich & East Suffolk CCG

Dementia Profile

<table>
<thead>
<tr>
<th>Indicator</th>
<th>Period</th>
<th>Ipswich And East Suffolk</th>
<th>Region</th>
<th>England</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dementia: Recorded prevalence (all ages)</td>
<td>2014/15</td>
<td>3,566</td>
<td>0.9%</td>
<td>0.7%</td>
</tr>
<tr>
<td>Dementia: Recorded prevalence (aged 65+)</td>
<td>Sep 2015</td>
<td>3,524</td>
<td>4.23%</td>
<td>3.96%</td>
</tr>
</tbody>
</table>

Dementia Profile

<table>
<thead>
<tr>
<th>Indicator</th>
<th>Period</th>
<th>Ipswich And East Suffolk</th>
<th>Region</th>
<th>England</th>
</tr>
</thead>
<tbody>
<tr>
<td>Smoking: Recorded prevalence (aged 15+)</td>
<td>2014/15</td>
<td>57,150</td>
<td>17.3%</td>
<td>17.6%</td>
</tr>
<tr>
<td>Obesity: Recorded prevalence (aged 15+)</td>
<td>2014/15</td>
<td>32,172</td>
<td>9.9%</td>
<td>8.9%</td>
</tr>
<tr>
<td>Hypertension: Recorded prevalence (all ages)</td>
<td>2014/15</td>
<td>57,665</td>
<td>14.5%</td>
<td>14.2%</td>
</tr>
<tr>
<td>Stroke: Recorded prevalence (all ages)</td>
<td>2014/15</td>
<td>7,941</td>
<td>2.0%</td>
<td>1.7%</td>
</tr>
<tr>
<td>Diabetes: Recorded prevalence (aged 17+)</td>
<td>2014/15</td>
<td>18,758</td>
<td>8.8%</td>
<td>8.1%</td>
</tr>
<tr>
<td>CHD: Recorded prevalence (all ages)</td>
<td>2014/15</td>
<td>14,706</td>
<td>3.7%</td>
<td>3.2%</td>
</tr>
<tr>
<td>Depression: Recorded prevalence (aged 15+)</td>
<td>2014/15</td>
<td>25,334</td>
<td>8.0%</td>
<td>7.2%</td>
</tr>
</tbody>
</table>
# Dementia Profile

## Indicators

<table>
<thead>
<tr>
<th>Indicator</th>
<th>Period</th>
<th>Ipswich And East Suffolk</th>
<th>Region</th>
<th>England</th>
<th>Lowest</th>
<th>Range</th>
<th>Highest</th>
</tr>
</thead>
<tbody>
<tr>
<td>Directly Age-Standardised Rate of Mortality: People with dementia aged 65+</td>
<td>2013</td>
<td>642</td>
<td>726</td>
<td>179.1</td>
<td>187.2</td>
<td>419</td>
<td>362.0</td>
</tr>
<tr>
<td>Directly Age-Standardised Rate of Mortality: People with dementia aged 65+</td>
<td>2013</td>
<td>642</td>
<td>726</td>
<td>179.1</td>
<td>187.2</td>
<td>419</td>
<td>362.0</td>
</tr>
<tr>
<td>Deaths in Usual Place of Residence: People with dementia aged 65+</td>
<td>2013</td>
<td>483</td>
<td>75.9%</td>
<td>68.4%</td>
<td>66.6%</td>
<td>58.6%</td>
<td>25.0%</td>
</tr>
<tr>
<td>Place of death - care home: People with dementia aged 65+</td>
<td>2013</td>
<td>428</td>
<td>66.7%</td>
<td>59.7%</td>
<td>58.6%</td>
<td>19.5%</td>
<td>77.0%</td>
</tr>
<tr>
<td>Place of death - hospital: People with dementia aged 65+</td>
<td>2013</td>
<td>155</td>
<td>24.1%</td>
<td>31.1%</td>
<td>32.6%</td>
<td>16.5%</td>
<td>66.2%</td>
</tr>
<tr>
<td>Place of death - home: People with dementia aged 65+</td>
<td>2013</td>
<td>56</td>
<td>8.7%</td>
<td>8.6%</td>
<td>7.4%</td>
<td>1.5%</td>
<td>17.2%</td>
</tr>
</tbody>
</table>
# Dementia Profile

## Prevalence

<table>
<thead>
<tr>
<th>Indicator</th>
<th>Period</th>
<th>Count</th>
<th>Value</th>
<th>Value</th>
<th>Lowest</th>
<th>Range</th>
<th>Highest</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dementia: Ratio of inpatient service use to recorded diagnoses</td>
<td>2013/14</td>
<td>1,674</td>
<td>54.7</td>
<td>67.4</td>
<td>65.1</td>
<td>39.6</td>
<td>96.4</td>
</tr>
<tr>
<td>Dementia: DSR of emergency admissions (aged 65+)</td>
<td>2013/14</td>
<td>2,590</td>
<td>739</td>
<td>712</td>
<td>779</td>
<td>406</td>
<td>1,479</td>
</tr>
<tr>
<td>Dementia: DSR of emergency admissions (aged 65+)</td>
<td>2013/14</td>
<td>2,502</td>
<td>2,662</td>
<td>2,794</td>
<td>3,046</td>
<td>1,579</td>
<td>6,875</td>
</tr>
<tr>
<td>Dementia: Short stay emergency admissions (aged 65+)</td>
<td>2013/14</td>
<td>670</td>
<td>25.9%</td>
<td>24.3%</td>
<td>26.5%</td>
<td>10.5%</td>
<td>45.1%</td>
</tr>
<tr>
<td>Dementia: Short stay emergency admissions (aged 65+)</td>
<td>2013/14</td>
<td>636</td>
<td>25.5%</td>
<td>24.2%</td>
<td>25.4%</td>
<td>10.7%</td>
<td>45.3%</td>
</tr>
<tr>
<td>Alzheimer’s disease: DSR of inpatient admissions (aged 20+)</td>
<td>2013/14</td>
<td>456</td>
<td>129.7</td>
<td>127.4</td>
<td>149.2</td>
<td>60.2</td>
<td>364.2</td>
</tr>
<tr>
<td>Alzheimer’s disease: DSR of inpatient admissions (aged 65+)</td>
<td>2013/14</td>
<td>443</td>
<td>506.7</td>
<td>499.2</td>
<td>574.6</td>
<td>232.2</td>
<td>1,436.9</td>
</tr>
<tr>
<td>Vascular dementia: DSR of inpatient admissions (aged 20+)</td>
<td>2013/14</td>
<td>341</td>
<td>97.1</td>
<td>104.7</td>
<td>127.5</td>
<td>56.6</td>
<td>294.3</td>
</tr>
<tr>
<td>Vascular dementia: DSR of inpatient admissions (aged 65+)</td>
<td>2013/14</td>
<td>339</td>
<td>388.6</td>
<td>416.6</td>
<td>585.2</td>
<td>223.6</td>
<td>1,169.3</td>
</tr>
<tr>
<td>Unspecified dementia: DSR of inpatient admissions (aged 20+)</td>
<td>2013/14</td>
<td>1,053</td>
<td>298.3</td>
<td>319.5</td>
<td>336.1</td>
<td>186.1</td>
<td>769.1</td>
</tr>
<tr>
<td>Unspecified dementia: DSR of inpatient admissions (aged 65+)</td>
<td>2013/14</td>
<td>1,035</td>
<td>1,178.2</td>
<td>1,206.0</td>
<td>1,327.3</td>
<td>737.3</td>
<td>3,853.5</td>
</tr>
</tbody>
</table>
# Appendix 4 - Public Health England Dementia Profiles for West Suffolk CCG

## Dementia Profile

### Prevalence

<table>
<thead>
<tr>
<th>Indicator</th>
<th>Period</th>
<th>West Suffolk</th>
<th>Region</th>
<th>England</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dementia: Recorded prevalence (all ages)</td>
<td>2014/15</td>
<td>1.967</td>
<td>0.8%</td>
<td>0.7%</td>
</tr>
<tr>
<td>Dementia: Recorded prevalence (aged 85+)</td>
<td>Sep 2015</td>
<td>1.884</td>
<td>3.73%</td>
<td>3.96%</td>
</tr>
</tbody>
</table>

### Prevalence

<table>
<thead>
<tr>
<th>Indicator</th>
<th>Period</th>
<th>West Suffolk</th>
<th>Region</th>
<th>England</th>
</tr>
</thead>
<tbody>
<tr>
<td>Smoking: Recorded prevalence (aged 15+)</td>
<td>2014/15</td>
<td>36.690</td>
<td>17.6%</td>
<td>17.5%</td>
</tr>
<tr>
<td>Obesity: Recorded prevalence (aged 16+)</td>
<td>2014/15</td>
<td>17.564</td>
<td>8.7%</td>
<td>8.9%</td>
</tr>
<tr>
<td>Hypertension: Recorded prevalence (all ages)</td>
<td>2014/15</td>
<td>36.203</td>
<td>14.9%</td>
<td>14.2%</td>
</tr>
<tr>
<td>Stroke: Recorded prevalence (all ages)</td>
<td>2014/15</td>
<td>4.266</td>
<td>1.8%</td>
<td>1.7%</td>
</tr>
<tr>
<td>Diabetes: Recorded prevalence (aged 17+)</td>
<td>2014/15</td>
<td>12.363</td>
<td>6.2%</td>
<td>6.1%</td>
</tr>
<tr>
<td>CHD: Recorded prevalence (all ages)</td>
<td>2014/15</td>
<td>8.269</td>
<td>3.4%</td>
<td>3.2%</td>
</tr>
<tr>
<td>Depression: Recorded prevalence (aged 15+)</td>
<td>2014/15</td>
<td>15.564</td>
<td>7.9%</td>
<td>7.2%</td>
</tr>
</tbody>
</table>
Dementia Profile

**Indicator:** DEM002: Dementia care has been reviewed last 12 months (den incl exc.)

<table>
<thead>
<tr>
<th>Period</th>
<th>West Suffolk</th>
<th>Region</th>
<th>England</th>
<th>Lowest</th>
<th>Range</th>
<th>Highest</th>
</tr>
</thead>
<tbody>
<tr>
<td>2014/15</td>
<td>1,479</td>
<td>75.2%</td>
<td>75.6%</td>
<td>77.0%</td>
<td>45.3%</td>
<td>85.8%</td>
</tr>
</tbody>
</table>

**Indicator:** DEM003: Blood tests recorded (den incl exc.)

<table>
<thead>
<tr>
<th>Period</th>
<th>West Suffolk</th>
<th>Region</th>
<th>England</th>
<th>Lowest</th>
<th>Range</th>
<th>Highest</th>
</tr>
</thead>
<tbody>
<tr>
<td>2014/15</td>
<td>864</td>
<td>73.1%</td>
<td>71.4%</td>
<td>74.7%</td>
<td>57.3%</td>
<td>86.6%</td>
</tr>
</tbody>
</table>
## Dementia Profile

### Prevalence

<table>
<thead>
<tr>
<th>Indicator</th>
<th>Period</th>
<th>West Suffolk</th>
<th>Region</th>
<th>England</th>
<th>Range</th>
<th>Highest</th>
</tr>
</thead>
<tbody>
<tr>
<td>Directly Age Standardised Rate of Mortality: People with dementia aged 20+</td>
<td>2013</td>
<td>329</td>
<td>179.2</td>
<td>179.1</td>
<td>187.2</td>
<td>362.8</td>
</tr>
<tr>
<td>Directly Age Standardised Rate of Mortality: People with dementia aged 65+</td>
<td>2013</td>
<td>328</td>
<td>719</td>
<td>713</td>
<td>746</td>
<td>1,461</td>
</tr>
<tr>
<td>Deaths in Usual Place of Residence: People with dementia aged 65+</td>
<td>2013</td>
<td>250</td>
<td>77.2</td>
<td>68.4</td>
<td>66.6</td>
<td>25.0</td>
</tr>
<tr>
<td>Place of death - care home: People with dementia aged 65+</td>
<td>2013</td>
<td>219</td>
<td>58.6</td>
<td>60.0</td>
<td>58.6</td>
<td>77.0</td>
</tr>
<tr>
<td>Place of death - hospital: People with dementia aged 65+</td>
<td>2013</td>
<td>73</td>
<td>22.3</td>
<td>31.1</td>
<td>32.6</td>
<td>66.2</td>
</tr>
<tr>
<td>Place of death - home: People with dementia aged 65+</td>
<td>2013</td>
<td>33</td>
<td>10.1</td>
<td>8.0</td>
<td>7.4</td>
<td>17.2</td>
</tr>
</tbody>
</table>
Appendix 5 – Mid-life risk indicators, England, HSCIC

Smoking in middle age
Cigarette smoking decreased in those in middle age between 2004 and 2014 (45-64), showing decreases of six percentage points for 45-54 year olds and one percentage point for those aged 55-64.

Alcohol consumption in middle age
Alcohol consumption in 2014 was highest for those aged 55–74. The Chief Medical Officers’ proposed new guidelines¹ for both men and women is that you are safest not to drink regularly more than 14 units per week, to keep health risks from drinking alcohol to a low level.

Obesity in middle age
The proportion of the population who are overweight or obese¹ increases with age. Within the 45-64 age group it was 12 percentage points higher for men than women.
Physical inactivity in middle age

It is recommended adults undertake at least 150 minutes moderate intensity physical activity or 75 minutes vigorous activity per week or an equivalent combination of these.

In 2012 this was met by 66 per cent of 45-54 year olds and 55 per cent of 55-64 year olds.

<table>
<thead>
<tr>
<th>Levels of activity by age group, 2012</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
<tr>
<td>Meets recommendations</td>
</tr>
<tr>
<td>Some activity</td>
</tr>
<tr>
<td>Low activity</td>
</tr>
</tbody>
</table>

Poor diet in middle age

The proportion of those in middle age (45-64) consuming the recommended amount of fruit and vegetables (five portions daily) was:

28% in 2003
27% in 2013

In 2013 women in middle age ate on average 3.9 portions daily compared to men’s 3.5.

High blood pressure

Between 2005 and 2014, the percentage of adults aged 45-54 with high blood pressure\(^1\) remained around or below the overall rate for all adults. However for those aged 55-64, it remained consistently higher\(^2\). Rates increase with age and men suffer more from high blood pressure than women until age 75.

<table>
<thead>
<tr>
<th>Percentage of people by age group, gender, and high blood pressure type, 2014</th>
</tr>
</thead>
<tbody>
<tr>
<td>Men</td>
</tr>
<tr>
<td>Overall rate for all adults men and women (30 per cent)</td>
</tr>
<tr>
<td>Hypertensive controlled</td>
</tr>
<tr>
<td>Hypertensive untreated</td>
</tr>
<tr>
<td>Hypertensive uncontrolled</td>
</tr>
<tr>
<td>All with high blood pressure</td>
</tr>
</tbody>
</table>
**Appendix 6 – Mapping NICE Quality Standard for Dementia to MSNAP Service Standards**

The NICE quality standard for dementia requires that dementia services should be commissioned from and coordinated across all relevant agencies encompassing the whole dementia care pathway. An integrated approach to provision of services is fundamental to the delivery of high quality care to people with dementia.

<table>
<thead>
<tr>
<th>Number</th>
<th>Quality statements</th>
<th>MSNAP standards</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>People with dementia receive care from staff appropriately trained in dementia care.</td>
<td>2.7; 2.7.1-2.7.3; 2.8; 2.8.1 – 2.8.11</td>
</tr>
<tr>
<td>2</td>
<td>People with suspected dementia are referred to a memory assessment service specialising in the diagnosis and initial management of dementia.</td>
<td>2.9; 2.10; 3.1; 3.1.1; 1.1.1</td>
</tr>
<tr>
<td>3</td>
<td>People newly diagnosed with dementia and/or their carers receive written and verbal information about their condition, treatment and the support options in their local area.</td>
<td>3.8; 3.8.6.1 – 3.8.6.8</td>
</tr>
<tr>
<td>4</td>
<td>People with dementia have an assessment and an ongoing personalised care plan, agreed across health and social care that identifies a named care coordinator and addresses their individual needs.</td>
<td>2.9; 3.1; 3.5; 4.1; 4.1.1; also see psychosocial intervention standards (in development)</td>
</tr>
</tbody>
</table>
| 5      | People with dementia, while they have capacity, have the opportunity to discuss and make decisions, together with their carer/s, about the use of:  
  - advance statements  
  - advance decisions to refuse treatment  
  - Lasting Power of Attorney  
  - Preferred Priorities of Care. | 3.3.7; 3.8.6.5; 4.2.15                                  |
<p>| 6      | Carers of people with dementia are offered an assessment of emotional, psychological and social needs and, if accepted, receive tailored interventions identified by a care plan to address those needs. | 3.6.1; 4.2.3; 4.2.8; 4.2.10; 4.2.14; also see psychosocial intervention standards (in development) |
| 7      | People with dementia who develop non-cognitive symptoms that cause them significant distress, or who develop behaviour that challenges, are offered an assessment at an early opportunity to establish generating and aggravating factors. Interventions to improve such behaviour or distress should be recorded in their care plan. | 3.5.8; 4.2.1; also see psychosocial and pharmacological intervention standards (both in development) |
| 8      | People with suspected or known dementia using acute and general hospital inpatient services or general hospital inpatient emergency departments have access to a liaison service that specialises in the diagnosis and management of dementia and older people's mental health. | Not covered by current CCQI audit of dementia in acute and general hospitals and the Psychiatric Liaison Accreditation Network (PLAN) |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>People in the later stages of dementia are assessed by primary care teams to identify and plan their palliative care needs.</strong></td>
<td><strong>Not covered.</strong></td>
</tr>
<tr>
<td><strong>Carers of people with dementia have access to a comprehensive range of respite/short-break services that meet the needs of both the carer and the person with dementia.</strong></td>
<td><strong>4.2.13</strong></td>
</tr>
</tbody>
</table>
Appendix 7: MSNAP 2014 Service Standards for Ongoing Care Management and Follow up, Pharmacological Interventions and Psychosocial Interventions

### Care management

<table>
<thead>
<tr>
<th>NUMBER</th>
<th>STANDARD/CRITERION</th>
<th>TYPE</th>
</tr>
</thead>
<tbody>
<tr>
<td>4.1</td>
<td>The memory service ensures that each person with memory problems/dementia has a care plan</td>
<td></td>
</tr>
<tr>
<td>4.1.1</td>
<td>The service supports personalised care planning that incorporates appropriate agencies/services if necessary</td>
<td>1 Ref 6</td>
</tr>
</tbody>
</table>

4.2 Professionals working within the memory service ensure that the person (and their carer, where appropriate) is able to access a range of post-diagnostic supports and interventions

| 4.2.1 | Services that will offer assessment and intervention for people who develop non-cognitive symptoms | 1 Ref 15 |
|       | **Guidance:** e.g. mood disorders, psychotic symptoms and behaviour that challenges           |       |
| 4.2.2 | Services that will offer information, advice and support to assess and manage pharmacological treatment | 1 Ref 15 |
| 4.2.3 | Voluntary organisations and support groups such as Age UK, Dementia UK and the Alzheimer’s Society, for follow up support and information | 2 Ref 6 |
| 4.2.4 | Services that will offer information, advice and support with communication problems       | 2 Ref 15 |
| 4.2.5 | Services that will offer information, advice and support on modifiable risk factors for dementia | 2 Ref 5, 13, 22 |
|       | **Guidance:** e.g. smoking, excessive alcohol consumption, obesity, diabetes, hypertension and raised cholesterol |       |
| 4.2.6 | Services that will offer information, advice and support on dietary interventions to help the person adapt dietary intake to help achieve full nutritional requirements | 2 | Ref 15 |
| 4.2.8 | Services that provide individual or group psychoeducation | 2 | Ref 15 |
| 4.2.9 | Services that can advise on welfare benefits | 2 | Ref 14 |
| 4.2.10 | Peer support/self-help groups, e.g. befriending schemes, memory cafés | 2 | Ref 4 |
| 4.2.11 | Dementia advisor and support services for patients and carers (including Admiral Nurses, dementia navigators, or other specialist practitioners) | 3 | Ref 4 |
| 4.2.12 | A range of respite/short break services | 2 | Ref 15 |
| 4.2.13 | Services that will offer carers a full assessment of their needs | 1 | Ref 15 |
| 4.2.14 | Services that offer information, advice and support on a range of legal matters associated with the loss of capacity, including: power of attorney, managing finances, advance directives etc. | 2 | Ref 15 |
| 4.2.15 | Genetic counselling for people and their unaffected relatives (where there is likely to be a genetic cause for their dementia) | 3 | Ref 15 |
| 6.5.2 | Specialist services for rare and/or complex care needs (e.g. regional/tertiary neurology/neuropsychiatry services) | 2 | Ref 38 |
## Follow up

### 4.3
The memory service ensures that each person with memory problems/dementia is followed up

### 4.3.1
The service provides follow up based on clinical need (or refers people on to appropriate agencies/services for follow-up) taking into account local protocols and the preferences of patients and their carers

1 Ref 5

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## Pharmacological interventions

<table>
<thead>
<tr>
<th>NUMBER</th>
<th>STANDARD/CRITERION</th>
<th>TYPE</th>
</tr>
</thead>
<tbody>
<tr>
<td>5.1</td>
<td>The memory service provides equal and timely access to antidementia medication in accordance with individual needs</td>
<td>2 Ref 91, 92</td>
</tr>
<tr>
<td>5.1.1</td>
<td>The service has a locally agreed protocol, based on NICE/SCIE guidance (or equivalent), which ensures that people with dementia have access to anti-dementia medication in accordance with their needs</td>
<td>2 Ref 91, 92</td>
</tr>
<tr>
<td>5.2</td>
<td>Antipsychotics are only prescribed as a last resort, after a thorough assessment of risk factors, and their use is reviewed regularly</td>
<td></td>
</tr>
<tr>
<td>5.2.1</td>
<td>People with dementia who develop psychotic symptoms or behaviour that challenges, are only offered antipsychotic medication when the severity and associated risks are high and when other options have been considered and excluded</td>
<td>2 Ref 91, 92</td>
</tr>
<tr>
<td>5.2.2</td>
<td>Where antipsychotic medication is given, this prescription is recorded and a single, named individual is responsible for undertaking a review. Guidance: when stabilised on medication, review should take place at least every three months</td>
<td>2 Ref 88</td>
</tr>
<tr>
<td>5.2.3</td>
<td>A local audit surrounding the prescription of antipsychotic drugs for people with dementia has been carried out in the last year</td>
<td>3 Ref 88, 91</td>
</tr>
</tbody>
</table>
# Psychosocial interventions

<table>
<thead>
<tr>
<th>NUMBER</th>
<th>STANDARD/CRITERION</th>
<th>TYPE</th>
</tr>
</thead>
<tbody>
<tr>
<td>6.1</td>
<td><strong>Access to psychosocial interventions is based on the needs and preferences of the person with dementia and, where appropriate, their carer</strong></td>
<td></td>
</tr>
<tr>
<td></td>
<td>The service has access to a range of evidenced-based psychosocial interventions</td>
<td>2</td>
</tr>
<tr>
<td>6.1.1</td>
<td><strong>Guidance:</strong> e.g. individual and group therapies for adjustment to dementia diagnosis and life changes in people with dementia/carers; psychological therapies for depression or anxiety in the person with dementia; coping strategies and stress management for carers; life story work; reminiscence</td>
<td></td>
</tr>
<tr>
<td>6.1.2</td>
<td><strong>Guidance:</strong> An audit should be carried out of the diagnoses of people offered/participating in psychosocial interventions and support groups</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Psychosocial interventions and post-diagnostic support are available regardless of dementia subtype</td>
<td></td>
</tr>
<tr>
<td>6.2</td>
<td><strong>The service provides access to psychosocial interventions for cognitive aspects of dementia</strong></td>
<td></td>
</tr>
<tr>
<td></td>
<td>People with dementia have access to a local programme of group cognitive stimulation therapy (CST)</td>
<td>2</td>
</tr>
<tr>
<td>6.2.1</td>
<td><strong>Guidance:</strong> i.e. engagement in a range of activities and discussions aimed at general enhancement of cognitive and social functioning</td>
<td>Ref 15, 30</td>
</tr>
<tr>
<td>6.2.2</td>
<td>People who have participated in group cognitive stimulation therapy have access to a maintenance CST programme</td>
<td>2</td>
</tr>
<tr>
<td>6.2.3</td>
<td>People with dementia have access to cognitive rehabilitation according to their clinical needs</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td><strong>Guidance:</strong> i.e. an individualised approach where personally relevant goals are identified and the therapist works with the patient and his/her family to devise strategies to address these. The emphasis is on improving performance in everyday life rather than on cognitive tests, building on the patient’s strengths and developing ways of compensating for impairments</td>
<td>Ref 31</td>
</tr>
<tr>
<td>6.2.4</td>
<td>People with dementia and their carers have access to a group reminiscence programme</td>
<td>3</td>
</tr>
<tr>
<td>6.3</td>
<td>The service provides access to psychosocial interventions for emotional aspects of dementia</td>
<td></td>
</tr>
<tr>
<td>6.3.1</td>
<td>People with dementia have access to interventions to address their emotional needs</td>
<td></td>
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<tr>
<td></td>
<td><strong>Guidance:</strong> e.g.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Life story work</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Cognitive behaviour therapy</td>
<td></td>
</tr>
<tr>
<td>6.4</td>
<td>The service provides access to psychosocial interventions for occupational and functional aspects of dementia</td>
<td></td>
</tr>
<tr>
<td>6.4.1</td>
<td>People have access to personally tailored occupational therapy to assist them with their occupational and functional needs and to help maintain their health and wellbeing, independence and community living</td>
<td>2</td>
</tr>
<tr>
<td>6.4.2</td>
<td>The memory service has access to advice and support on assistive technology and telecare solutions</td>
<td>2</td>
</tr>
<tr>
<td>6.5</td>
<td>The service provides or can signpost/refer people and their carers on to interventions for more complex needs, if required</td>
<td></td>
</tr>
<tr>
<td>6.5.1</td>
<td>People with dementia and their carers have access to tailored psychosocial interventions for behaviour that challenges</td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>Guidance:</strong> e.g. <em>Functional Analysis-based intervention as part of a multi-component psychosocial intervention</em></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Ref 15, 29</td>
<td></td>
</tr>
<tr>
<td>6.6</td>
<td>The service provides access to psychosocial interventions for carers of people with dementia</td>
<td></td>
</tr>
<tr>
<td>-----</td>
<td>------------------------------------------------------------------------------------------</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Carers of people with dementia are offered an assessment, and intervention/s if appropriate, for their emotional, psychological and social needs.</td>
<td></td>
</tr>
</tbody>
</table>
| 6.6.1 | **Guidance:** e.g.  
|      | • Family interventions  
|      | • Cognitive behaviour therapy  
|      | • Counselling |
|     | 2 |

<table>
<thead>
<tr>
<th>6.7</th>
<th>People with dementia and their carers are made aware of other non-pharmacological interventions that they may wish to consider</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>The service provides information and signposting to other possible non-pharmacological interventions that the person with dementia and their carer may wish to consider</td>
</tr>
</tbody>
</table>
| 6.7.1 | **Guidance:** e.g.  
|      | • Music and/or dance therapy  
|      | • Animal-assisted therapy  
|      | • Art therapy  
|      | • Social engagement groups  
|      | • Walking groups  
|      | • Creative activities |
|     | 3 |

<table>
<thead>
<tr>
<th>6.8</th>
<th>Staff delivering psychosocial interventions are appropriately trained and supervised</th>
</tr>
</thead>
<tbody>
<tr>
<td>6.8.1</td>
<td>Staff involved in delivering psychosocial interventions receive appropriate training</td>
</tr>
<tr>
<td></td>
<td>2</td>
</tr>
<tr>
<td>6.8.2</td>
<td>Staff involved in delivering psychosocial interventions receive appropriate supervision</td>
</tr>
<tr>
<td></td>
<td>2</td>
</tr>
<tr>
<td>6.9</td>
<td>The service monitors people’s responses to interventions</td>
</tr>
<tr>
<td>-----</td>
<td>----------------------------------------------------------</td>
</tr>
<tr>
<td><strong>6.9.1 M</strong></td>
<td>The service has a strategy for monitoring each person’s response to a pharmacological or psychosocial intervention and adapts the person’s care plan accordingly</td>
</tr>
</tbody>
</table>

**Guidance:** This could include use of standardised outcome measures, quality indicators, quality of life assessments, carer questionnaires, or other appropriate measures and monitoring of adverse reactions such as excessive distress | 2 |