Suffolk Dementia Needs Assessment: Final Report

November 2013

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## Contents

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Executive Summary</td>
<td>3</td>
</tr>
<tr>
<td>Section 1: Introduction</td>
<td>6</td>
</tr>
<tr>
<td>Section 2: Descriptive Epidemiology</td>
<td>9</td>
</tr>
<tr>
<td>Section 3: Existing Services</td>
<td>24</td>
</tr>
<tr>
<td>Section 4: Service User Experience</td>
<td>49</td>
</tr>
<tr>
<td>Section 5: Evidence of Effectiveness</td>
<td>58</td>
</tr>
<tr>
<td>Section 6: Information Gaps</td>
<td>66</td>
</tr>
<tr>
<td>Section 7: Key Findings and Recommendations</td>
<td>67</td>
</tr>
<tr>
<td>Acknowledgements</td>
<td>70</td>
</tr>
<tr>
<td>Glossary</td>
<td>71</td>
</tr>
<tr>
<td>Appendix 1: Summary of National Dementia</td>
<td>72</td>
</tr>
<tr>
<td>Policy</td>
<td></td>
</tr>
<tr>
<td>Appendix 2: Executive Summary of Debenham</td>
<td>76</td>
</tr>
<tr>
<td>Project Research</td>
<td></td>
</tr>
<tr>
<td>References</td>
<td>82</td>
</tr>
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</table>
Executive Summary

This needs assessment has been conducted to systematically review the needs of people with dementia and their family carers living in Suffolk county. The overall aim of the dementia needs assessment is to assess whether services for people with dementia and their family carers are meeting current and future need.

The needs assessment presents information and analysis about the descriptive epidemiology of dementia in Suffolk, description of current services and the use of these services, evidence of effective services and national best practice, stakeholders’ experiences and information gaps. It identifies areas of unmet need and proposes 10 key recommendations to address these issues.

Key findings and recommendations:

**Early diagnosis:**

An early diagnosis of dementia enables the person with dementia and their family carers to make choices about their care. It allows access to specialist dementia services which provide care and support to the family, thereby reducing the likelihood of crises, admission to hospital and residential care.

In Suffolk, it is estimated that approximately 6,000 people with dementia remain undiagnosed. This needs to be urgently addressed. Diagnosis rates can be improved using a variety of interventions as identified in national research and policy such as ‘Unlocking diagnosis: the key to improving the lives of people with dementia’, a report produced by the All-Party Parliamentary Group on Dementia in 2012.

Since the launch of the national and local dementia strategies in 2009, local memory assessment services have been commissioned across Suffolk. Service activity data that is required to monitor and evaluate these services is not currently available.

**Recommendation 1:** the clinical commissioning groups in Suffolk should continue to focus on improving diagnosis rates and evaluate the impact of local interventions, such as the memory assessment services.

Link to Suffolk Joint Dementia Strategy:
- Objective 2: Good quality early diagnosis and intervention for all

**Joint commissioning of dementia services:**

The provision of dementia services in Suffolk is fragmented; this impacts negatively on people with dementia and their family carers who receive complex and confusing services. Although many of the services provided receive positive feedback from people with dementia and their family carers, only a small proportion of the total population have access to services and there is variation in the accessibility of services across the county. This must be addressed urgently in order to improve the quality of care and support, equity of access, and to meet the increasing demand on services.

National guidance recommends the joint commissioning of dementia services. Evidence and case studies of joint commissioning best practice can be used to inform the initiation of joint commissioning of dementia services in Suffolk.

**Recommendation 2:** As a starting point, commissioners of dementia services in the CCGs and Suffolk County Council should develop and implement one integrated commissioning plan that is informed by people with dementia and their family carers, and the findings of this needs assessment.

Learning from other parts of the country (including Scotland and Staffordshire) suggests that an integrated, community model of post-diagnosis support services can be effective. An important coordinator role lies at the heart of such a model, ensuring a single point of contact and coordination of care.
Recommendation 3: An integrated post-diagnosis support service should be commissioned that provides a named, single point of contact for people with dementia and their family carers who will lead their care, treatment and support. This service must address gaps identified in this needs assessment, such as the limited capacity of respite services.

The number of people with dementia in Suffolk is expected to increase by 33% by 2021. This will place significant strain on services that are not currently meeting the volume of need.

Recommendation 4: Commissioners must use the data to plan for the expected increase in demand when commissioning dementia services.

There are certain groups of people living in Suffolk who may have different levels of risk of dementia and specific needs, and may experience variation in access to services. This includes those with early onset dementia, people from BME groups, people with a learning disability and those living in rural, isolated areas of the county. The number of people from these groups who have dementia or care for someone who does is likely to increase.

Recommendation 5: The joint commissioning plan must outline how dementia services will meet the specific needs of people with early onset dementia, people from BME groups, people with a learning disability and those living in rural, isolated areas of the county.

Link to Suffolk Joint Dementia Strategy:
- Objective 4: Enabling easy access to care, support and advice following diagnosis

Funding of dementia services:

Information is not currently available to accurately calculate how much is spent on health and care services for people with dementia and their family carers. This is due to the complex nature of the delivery of dementia services. This financial information is essential in order to effectively commission services that will meet the needs of the increasing number of people with dementia in Suffolk.

Many dementia services are funded by short-term grants. This has serious implications for the sustainability and quality of services, and must be addressed.

Recommendation 6: Commissioners must urgently identify the current spend on dementia services in Suffolk.

Recommendation 7: The joint commissioning plan should identify long-term and sustainable funding sources for local dementia services.

Dementia friendly communities and services:

More can be done in Suffolk to raise awareness about dementia amongst the public and professionals. By raising awareness and creating communities that are ‘dementia-friendly’, we can reduce fear, stigma and social isolation that people with dementia and their family carers experience. It is also essential in order to improve diagnosis rates. There are communities in Suffolk that have taken huge strides to become ‘dementia-friendly’ and we can learn from their best practice.

Recommendation 8: Public Health Suffolk should lead a dementia awareness campaign and coordinate the development of dementia friendly communities.

People with dementia and their family carers use a range of generic services in addition to dementia-specific services. It is therefore important that staff across these services understand dementia and the needs of people with dementia and their family carers. This needs assessment has identified the following sectors that require focused dementia training:
- General practice (in order to improve diagnosis rates);
- Domiciliary care (to improve quality of care, thereby helping people to stay living in the community);
- Residential care (where approximately 3,000 people with dementia live in Suffolk); and, Hospitals (where stakeholders have identified a need for training).
Recommendation 9: The workforce development programme for dementia in Suffolk should be targeted at general practice, domiciliary care, residential care and hospitals.

Link to Suffolk Joint Dementia Strategy:
- Objective 1: Improving public and professional awareness and the understanding of dementia

Information about dementia services in Suffolk:

This needs assessment has identified that people with dementia and their family carers find current dementia services complex and confusing. The provision of simple, timely and accessible information about services therefore remains a priority. The provision of integrated post-diagnostic services that use a single, named care co-ordinator should remove the need for large volumes of information about current services.

The needs assessment has also identified significant gaps in information about dementia services for use by commissioners. This includes gaps in information about the true prevalence of disease, characteristics of people with dementia, incidence of dementia and the number of family carers. There is also missing information about service activity, such as the number of referrals and diagnoses made at memory assessment services.

This information is necessary in order to monitor the effectiveness, cost-effectiveness, quality and outcomes of existing services, plan future services and identify any areas of inequity.

Recommendation 10: Commissioners must develop a dementia information dashboard that is regularly monitored to evaluate dementia services.
Section 1: Introduction

1 What is the issue and why is it important for Suffolk?

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 their loved ones. The condition is complex and can cause extensive physical, psychological, emotional and financial stresses to those with dementia, their family carers and the wider community.

The number of people living with dementia in Suffolk is expected to rise as the population ages. The population aged 65 and over is expected to increase by over 75,000 people (49%) from 2012 to 2030. As a result, there will be a rise in the number of people living with health problems and in particular dementia, placing even more pressure on dementia services in Suffolk.

A needs assessment is a systematic method for reviewing the health and wider issues facing a population, leading to agreed priorities and resource allocation that will improve health and reduce inequalities. In order to respond to the growing demand and ensure that dementia services have sufficient capacity and are of high quality, a needs assessment must be completed.

1.1 National context:

There are a wide range of national policies that influence dementia services and set standards for care. The following key policies and guidelines are summarised in appendix 1:

- Living well with dementia – A National Dementia Strategy
- Prime Minister’s Challenge on Dementia
- Recognised, valued and supported – Next steps for the Carers Strategy
- NICE Dementia Clinical Guidelines CG42
- Dementia Quality Standard QS1
- Quality standard for supporting people to live well with dementia QS30
- NHS, social care and public health outcomes frameworks

A broad range of important themes that affect people with dementia and their family carers have been identified from the national policy:
These themes were carefully considered when scoping the Suffolk dementia needs assessment.

1.2 Local context:

Improving outcomes for people with dementia and their family carers has been a priority in Suffolk for a number of years. Following the publication of the National Dementia Strategy in 2009, the local community and organisations worked together to produce the Suffolk Joint Dementia Strategy entitled ‘Living well with dementia: Transforming the quality and experience of dementia care for the people of Suffolk’. The strategy considers local needs and proposes a number of recommendations in line with the overarching national objectives which aim to raise awareness and understanding, improve early diagnosis and support, and ensure a high quality of care for people with dementia and their family carers.

<table>
<thead>
<tr>
<th>TABLE 1: Suffolk Joint Dementia Strategy Objectives (2009)</th>
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<tbody>
<tr>
<td>Objective 1</td>
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<tr>
<td>Objective 2</td>
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<td>Objective 3</td>
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<td>Objective 4</td>
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<td>Objective 5</td>
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<td>Objective 6</td>
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<td>Objective 7</td>
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<td>Objective 8</td>
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<td>Objective 9</td>
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<td>Objective 10</td>
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<td>Objective 11</td>
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</tbody>
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This needs assessment will assess local progress made in the achievement of the Suffolk Joint Dementia Strategy recommendations. The findings of the needs assessment can therefore be used to refresh the Suffolk Joint Dementia Strategy, thereby improving the quality of life of people with dementia and their family carers.

The needs assessment has been completed during a time of change in local services, including NHS reforms and the establishment of the Suffolk Health and Wellbeing Board, who have prioritised improving the quality of life of older people in Suffolk. The local mental health trust (Norfolk and Suffolk Foundation Trust) which delivers community mental health services in Suffolk is currently undergoing a review which is likely to impact local dementia services. In addition, Suffolk adult social care is implementing the Supporting Lives Connecting Communities programme which aims at ensuring that people are supported to find ways of looking after themselves within their communities, but are provided with immediate short-term help at moments when they need additional support and offered on-going support as and when they need it.

These significant changes to local services have informed this needs assessment and emphasise the importance of continuing to assess the changing need of the population and the services provided to them in the future.

2 Which population is this needs assessment about?

This needs assessment will examine the needs of people with dementia and their family carers living in Suffolk county. This includes the areas covered by West Suffolk Clinical Commissioning Group (CCG), Ipswich and East Suffolk CCG and Waveney, which is served by Great Yarmouth and Waveney CCG (Health East).

3 Aims and objectives

The overall aim of the dementia needs assessment is to assess whether services for people with dementia and their family carers are meeting current and future need. The objectives of the needs assessment are to:

I. Ascertain the size of the dementia challenge in Suffolk, using descriptive and comparative epidemiological techniques.
II. Map the current dementia services in Suffolk and identify any gaps.
III. Review evidence of best practice.
IV. Engage stakeholders, including both professionals and the public, in identifying need and finding solutions.
V. Make recommendations for actions that will address unmet need in order to improve the quality of life of people living with dementia and their family carers.

A population’s ‘need’ for a service can be defined as the capacity to benefit from that service; this may differ from the demand for services and the services supplied. This needs assessment aims to outline the needs of the population and consider any mismatches between need and supply.
### Descriptive Epidemiology – Summary

This section presents the *expected* numbers, distribution and pattern of people 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. The information is broken down by person, place and time.

 solt is affected by dementia?

- It is estimated that there are approximately 11,000 people with dementia living in Suffolk. It is likely that many of these people will receive some unpaid care from a friend or family member.
- If we apply national estimates of incidence to the local population, we would expect to see approximately 435 new cases of dementia per year.
- The risk of developing dementia increases with age - 85% of people with dementia in Suffolk are over the age of 75 years.
- Overall, there are more women with dementia in Suffolk than men.
- Alzheimer’s disease is the most common sub-type of dementia, followed by vascular dementia.
- There are some groups of people affected by dementia who may have different levels of risk and specific needs:
  - Although relatively rare, people with early onset dementia (occurring before the age of 65) may have specific needs (for instance in relation to employment and childcare). In Suffolk, early onset dementia is more common in men than women.
  - 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 in relation to differing levels of vascular risk, access to services and awareness/stigma attached to the condition.
  - There are approximately 3,150 people over 65 years who have a learning disability and this number is expected to grow by 700 by 2020. These people are at increased risk of developing dementia.

What are the patterns over time?

- The number of people with dementia in Suffolk is expected to rise by approximately 33% over the next 10 years to approximately 14,400 by 2021.
- The greatest absolute increase will be in the ‘oldest old’ age groups.

Where do people affected by dementia live?

- The number of people with dementia varies between CCG and local authority areas. Of the three key areas (the two CCGs 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 are expected in the districts of Mid Suffolk and Babergh.
- An estimated 70% of people in Suffolk with dementia live in the community and 30% live in residential care.
1 Person

1.1 Prevalence:

Prevalence is a measure of the proportion of a population that has a condition at a specific point in time.

We do not know the true number of people with dementia in Suffolk due to people living with the condition who have not been diagnosed as having dementia. This means that we have to use ways 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 (2007) to the Office of National Statistics (ONS) population estimates and projections. Unless specifically stated, this is the technique used in most sections of the report. Using 2011 population figures, it is estimated that there are 10,799 people with dementia living in Suffolk.

(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. In 2011/12, it estimates there are 11,319 people with dementia living in Suffolk. The report specifically states when the dementia calculator has been used.

1.2 Number of family carers:

Although we know that caring for someone with dementia can have a significant impact physically, emotionally, socially and economically on a person’s life, information about how many unpaid family carers care for someone with dementia is not currently available.

The national census data set includes information about the number of people who provide unpaid care for friends or family members. However, this data is not dementia-specific.

1.2.1 Census information:

At the 2011 Census, a total of 10.7% of usual residents in Suffolk County reported that they provided 1 or more hours of unpaid care per week. This compared with 10.2% in East of England and 10.2% in England as a whole.

In local authority districts in Suffolk, percentages of usual residents reporting that they provided 1 or more hours of unpaid care per week ranged from 11.9% in Suffolk Coastal to 8.3% in Forest Heath.

Figure 1 shows the distribution of usual residents of all ages in wards in Suffolk County reporting providing 1 or more hours of unpaid care a week in the 2011 Census.
1.3 Incidence:

Incidence is a measure of new occurrences of a condition within a specific time period. Local incidence data for dementia is not collected.

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 435 new cases of dementia per year in the 65+ age group.¹

1.4 Mortality:

The mortality data presented in figure 2 describes the number of people who have died with dementia listed on the death certificate. As expected, it shows that the majority of deaths occur in the over 85 age group. It also shows that more people died with vascular and unspecified dementias than with Alzheimer’s disease, despite Alzheimer’s disease being more common. This may be a true difference or due to differences in recording practices.

Mortality data such as this should be interpreted with caution. It is likely there are some people with dementia that die of other causes and do not have dementia listed on their death certificate. These people will not be represented in the data below.

¹ Based on 2011 census population figures which states that there were 145,039 people aged 65 and over living in Suffolk in 2011.
1.5 Characteristics of the population affected

1.5.1 Age

The age distribution of people with dementia in Suffolk is shown in figure 3.

Figure 2: Age-specific mortality rates for Alzheimer’s disease, vascular and unspecified dementia, Suffolk, 2007 – 2011

Figure 3: Estimated number of cases of dementia by age group, Suffolk, 2011
Figure 4: Estimated cases of dementia by age group (proportion of total), Suffolk, 2011

The data shows that dementia is more common in older people: 98% of people with dementia are over the age of 65 and 85% of people with dementia are over the age of 75.

Early onset dementia is defined as dementia which occurs before the age of 65. Although there are smaller numbers of people living in Suffolk with early onset dementia, this group may have specific needs, such as support to stay in employment and childcare. Figure 5 shows that there are more men than women living with early onset dementia in Suffolk, and that the numbers of people with early onset dementia are expected to rise from 197 in 2012 to 211 in 2020.
1.5.2 Gender

Figure 6 shows that there are more women living with dementia in Suffolk than men. This is likely to be due to women living longer than men.

1.5.3 Dementia Subtype

The Dementia UK Report (2007) estimates that 62% of all cases of dementia are Alzheimer’s disease. The next most common subtypes of dementia are vascular dementia (17%) and mixed dementia (10%).
Applying these proportions to the estimated number of cases of dementia in Suffolk shows that there are approximately 6,700 people with Alzheimer’s disease in Suffolk in 2011 (see figure 7 below). This number is expected to grow to over 8,900 people by the year 2021.

![Estimated number of cases of dementia by sub-type and year, Suffolk, 2011 - 2016](image)

**Figure 7:** Estimated number of cases of dementia by sub-type and year, Suffolk, 2011 - 2016

1.5.4 **Ethnicity**

It is important to understand the needs of different BME groups with regards to dementia because they may have different levels of risk (e.g. vascular risk) and in order to meet their specific cultural and language needs. Table 2 shows the ethnicity of people aged 65 and over in Suffolk, measured by the 2011 census. The proportion of White British people decreased slightly from 97.1% in the 2001 census to 96.9% in the 2011 census.

As the number of older people from BME groups in Suffolk increases over the coming years, so will the number of people from BME groups that live with dementia or care for those that do. It is known that people from BME groups are under-represented in dementia services and some groups have lower levels of dementia awareness with high levels of stigma attached to the condition."
### TABLE 2: Number and percentage distribution of people aged 65 and over by ethnic group, Suffolk, 2011 (Source: Census)

<table>
<thead>
<tr>
<th>Ethnic Group</th>
<th>All persons</th>
<th>Males</th>
<th>Females</th>
<th>All persons</th>
<th>Males</th>
<th>Females</th>
</tr>
</thead>
<tbody>
<tr>
<td>All categories: Ethnic group</td>
<td>145,039</td>
<td>65,946</td>
<td>79,093</td>
<td>100.0%</td>
<td>100.0%</td>
<td>100.0%</td>
</tr>
<tr>
<td>White: English/Welsh/Scottish/Northern Irish/British</td>
<td>140,571</td>
<td>63,918</td>
<td>76,653</td>
<td>96.9%</td>
<td>96.9%</td>
<td>96.9%</td>
</tr>
<tr>
<td>White: Irish</td>
<td>1,187</td>
<td>492</td>
<td>695</td>
<td>0.8%</td>
<td>0.7%</td>
<td>0.9%</td>
</tr>
<tr>
<td>White: Gypsy or Irish Traveller</td>
<td>49</td>
<td>23</td>
<td>26</td>
<td>0.0%</td>
<td>0.0%</td>
<td>0.0%</td>
</tr>
<tr>
<td>White: Other White</td>
<td>1,719</td>
<td>731</td>
<td>988</td>
<td>1.2%</td>
<td>1.1%</td>
<td>1.2%</td>
</tr>
<tr>
<td>Mixed/multiple ethnic group: White and Black Caribbean</td>
<td>163</td>
<td>86</td>
<td>77</td>
<td>0.1%</td>
<td>0.1%</td>
<td>0.1%</td>
</tr>
<tr>
<td>Mixed/multiple ethnic group: White and Black African</td>
<td>36</td>
<td>12</td>
<td>24</td>
<td>0.0%</td>
<td>0.0%</td>
<td>0.0%</td>
</tr>
<tr>
<td>Mixed/multiple ethnic group: White and Asian</td>
<td>113</td>
<td>57</td>
<td>56</td>
<td>0.1%</td>
<td>0.1%</td>
<td>0.1%</td>
</tr>
<tr>
<td>Mixed/multiple ethnic group: Other Mixed</td>
<td>92</td>
<td>45</td>
<td>47</td>
<td>0.1%</td>
<td>0.1%</td>
<td>0.1%</td>
</tr>
<tr>
<td>Asian/Asian British: Indian</td>
<td>165</td>
<td>98</td>
<td>67</td>
<td>0.1%</td>
<td>0.1%</td>
<td>0.1%</td>
</tr>
<tr>
<td>Asian/Asian British: Pakistani</td>
<td>19</td>
<td>12</td>
<td>7</td>
<td>0.0%</td>
<td>0.0%</td>
<td>0.0%</td>
</tr>
<tr>
<td>Asian/Asian British: Bangladeshi</td>
<td>66</td>
<td>38</td>
<td>28</td>
<td>0.0%</td>
<td>0.1%</td>
<td>0.0%</td>
</tr>
<tr>
<td>Asian/Asian British: Chinese</td>
<td>125</td>
<td>56</td>
<td>69</td>
<td>0.1%</td>
<td>0.1%</td>
<td>0.1%</td>
</tr>
<tr>
<td>Asian/Asian British: Other Asian</td>
<td>142</td>
<td>58</td>
<td>84</td>
<td>0.1%</td>
<td>0.1%</td>
<td>0.1%</td>
</tr>
<tr>
<td>Black/African/Caribbean/Black British: African</td>
<td>42</td>
<td>21</td>
<td>21</td>
<td>0.0%</td>
<td>0.0%</td>
<td>0.0%</td>
</tr>
<tr>
<td>Black/African/Caribbean/Black British: Caribbean</td>
<td>434</td>
<td>231</td>
<td>203</td>
<td>0.3%</td>
<td>0.4%</td>
<td>0.3%</td>
</tr>
<tr>
<td>Black/African/Caribbean/Black British: Other Black</td>
<td>44</td>
<td>29</td>
<td>15</td>
<td>0.0%</td>
<td>0.0%</td>
<td>0.0%</td>
</tr>
<tr>
<td>Other ethnic group: Arab</td>
<td>17</td>
<td>9</td>
<td>8</td>
<td>0.0%</td>
<td>0.0%</td>
<td>0.0%</td>
</tr>
<tr>
<td>Other ethnic group: Any other ethnic group</td>
<td>55</td>
<td>30</td>
<td>25</td>
<td>0.0%</td>
<td>0.0%</td>
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#### 1.5.5 Learning Disabilities

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 people with Down’s syndrome. People with learning disabilities and dementia may exhibit different symptoms from those without a learning disability and they may have specific needs. It is therefore important that tailored services are provided to people with learning disabilities and dementia that meet their specific needs. Figure 8 shows that there are currently approximately 3,150 people aged 65 and over with a learning disability in Suffolk. This number is anticipated to increase by 700 by the year 2020.
The Projecting Adult Needs and Service Information (PANSI) system produces local estimates of the number of people with Down’s syndrome and dementia. These predictions for Suffolk are presented in figure 9 below. The total number of people aged 45 to 64 predicted to have Down’s syndrome and dementia is expected to increase from 25 in 2012 to 27 in 2030. Although only a small number of people, this group of people will have specific health care and support needs.
1.6 Risk factors

Although it is known that age and genetics play a role in determining a person’s risk of developing dementia, little is known about other modifiable risk factors for most sub-types of dementia. An exception to this is vascular dementia, for which there is evidence about a number of modifiable risk factors.

1.6.1 Cardiovascular diseases

There are a number of modifiable factors that increase the risk of developing vascular dementia. These include:

- a medical history of stroke, high blood pressure, high cholesterol, diabetes (particularly type II), heart problems or sleep apnoea (where breathing stops for a few seconds or minutes during sleep)
- a lack of physical activity, drinking more than recommended levels of alcohol, smoking, eating a fatty diet, or leaving conditions such as high blood pressure or diabetes untreated
- a family history of stroke or cardiovascular disease
- an Indian, Bangladeshi, Pakistani, Sri Lankan ethnic background (differences in vascular risk factors, such as heart disease, in these communities contribute to the increased risk)
- an African-Caribbean ethnic background (more research is needed to know why African-Caribbean people have an increased risk of vascular dementia).

Figures 10 to 12 show the observed prevalence (measured using the general practice quality and outcomes framework disease registers) and estimated prevalence of coronary heart disease, stroke and hypertension in Suffolk, the East of England and England. The graphs show that the prevalence of all three conditions is greater in Suffolk than the regional and national averages.

![Coronary heart disease observed and estimated prevalence](chart.png)

**Figure 10:** Observed and estimated prevalence of coronary heart disease in Suffolk, East of England and England, 2011/12
In 2014, the cardiovascular disease directly-standardised mortality rate in Suffolk for persons under 75 years is predicted to be 41.1 per 100,000, which would be a 10 year decrease of 44.9% (from 2004). The early CVD mortality rate for England is predicted to be 50.1 per 100,000 which would be a 10 year decrease of 44.2%.

1.6.2 Smoking

Using data from the Integrated Household Survey, smoking prevalence in Suffolk is estimated to be 20.1% which is marginally less than the national average of 20.7%.

1.6.3 Adult obesity

Using data from the Health Survey for England, the prevalence of adult obesity in Suffolk is estimated to be 24.3% which is marginally greater than the national average of 24.2%.

2. Place and time:
Using national prevalence estimates from the Dementia UK Report (2007), it is possible to estimate the number of people living with dementia in different areas of Suffolk (see table 3).

The number of people with dementia is expected to increase from 2011 to 2021 in all regions of Suffolk. In total, there is expected to be a 33% increase in the number of people with dementia in Suffolk between 2011 and 2021. This equates to approximately 3,600 more people.

### Table 3: Estimated number and year-on-year percentage change of people living with dementia in Suffolk, by CCG and Waveney local authority, 2011 - 2021

<table>
<thead>
<tr>
<th>Year</th>
<th>Ipswich &amp; East Suffolk CCG</th>
<th>West Suffolk CCG</th>
<th>Waveney LA</th>
<th>Suffolk</th>
</tr>
</thead>
<tbody>
<tr>
<td>2011</td>
<td>5742</td>
<td>-</td>
<td>3397</td>
<td>-</td>
</tr>
<tr>
<td>2016</td>
<td>6391</td>
<td>11%</td>
<td>3776</td>
<td>11%</td>
</tr>
<tr>
<td>2021</td>
<td>7460</td>
<td>17%</td>
<td>4397</td>
<td>16%</td>
</tr>
</tbody>
</table>

Table 4 and figure 13 shows that the estimated number of people living with dementia varies significantly by local authority with the lowest number in Forest Heath and the highest number in Suffolk Coastal. This reflects the size and age structure of the local population. The greatest proportional increases are expected in Mid Suffolk and Babergh districts.

### Table 4: Estimated number and year-on-year percentage change of people living with dementia by local authority and year, Suffolk, 2011 - 2021

<table>
<thead>
<tr>
<th>Year</th>
<th>Babergh</th>
<th>Forest Heath</th>
<th>Ipswich</th>
<th>Mid Suffolk</th>
<th>St. Edmundsbury</th>
<th>Suffolk Coastal</th>
<th>Waveney</th>
</tr>
</thead>
<tbody>
<tr>
<td>2011</td>
<td>1358</td>
<td>-</td>
<td>699</td>
<td>-</td>
<td>1581</td>
<td>-</td>
<td>1367</td>
</tr>
<tr>
<td>2016</td>
<td>1606</td>
<td>18%</td>
<td>792</td>
<td>13%</td>
<td>1635</td>
<td>3%</td>
<td>1643</td>
</tr>
<tr>
<td>2021</td>
<td>1909</td>
<td>19%</td>
<td>919</td>
<td>16%</td>
<td>1781</td>
<td>9%</td>
<td>1993</td>
</tr>
</tbody>
</table>

2 In tables 3 and 4, the ‘change’ column displays the proportional increase from the previous time period.
Figure 13: Estimated number of people living with dementia by local authority and year, Suffolk, 2011 - 2021

2.1 Accommodation

The dementia prevalence calculator\textsuperscript{vi} estimates the number of people living in an area in the community and in residential care. Figure 14 displays these estimates for Ipswich and East Suffolk CCG, West Suffolk CCG and Waveney local authority. It shows that the majority of people with dementia (70\%) live in the community. These people may not currently be known to services and may require support to remain living at home safely and to lead fulfilling lives in their communities.
As seen throughout these analyses, the number of cases of dementia is expected to increase over the next 10 years. The total number of people with dementia in Suffolk is expected to increase to approximately 14,400 by 2021 (33% increase).

Figure 15 shows that an increase is expected in all age groups with the highest absolute increase in the oldest old.
3. How does Suffolk compare with other regions?

Local data that describes the number of people with dementia in Suffolk is not available and national prevalence estimates have been applied to the Suffolk population to produce the information described here. This means that we are not able to compare the Suffolk burden of disease with the region and England as a whole.

However, the data presented here shows that Suffolk has a slightly higher proportion of people who provide 1 hour or more of unpaid care a week. We also know that a greater proportion of the Suffolk population have vascular risk factors that may put them at higher risk of developing vascular dementia.
Section 3: Existing Services

Existing Services – Summary

This section describes the current services provided to people with dementia and their family carers in Suffolk. It outlines what services are delivered, how they are accessed and where they are delivered. Where available, it presents activity data which describes the numbers and characteristics of people who have used the services.

There are a wide range of services available to care and support people affected by dementia. The commissioning of these services has been informed by local need and national guidance. However, there are a number of issues that must be addressed:

1. Despite Suffolk performing better than the regional average, a large number of people with dementia remain undiagnosed. Dementia diagnosis rates vary throughout the county. 2011/12 data suggests that Waveney has significantly higher diagnosis rates (61.1%) than Ipswich and East Suffolk CCG and West Suffolk CCG populations (42.3% and 42.9% respectively).

2. There is a complex web of services that is difficult for a person with dementia and their family carers to navigate. There needs to be improved coordination and cohesion between the many services on offer.

3. A widely held concern is the short term nature of the funding of many dementia services. This has potentially serious implications for the sustainability and quality of services and must be addressed.

4. There is a lack of information about the volume and characteristics of the users of many dementia services. The available activity data show that only a small proportion of the estimated number of people with dementia and their family carers currently receive services. This may be due to a number of reasons such as:

   - A large proportion of people remain undiagnosed.
   - There is lack of capacity of current services.
   - There is a lack of awareness about the available services amongst the public and professionals.
   - People with dementia and their family carers are not being referred to services.
   - People with dementia and their family carers do not require services and are managing their care and support themselves.

The data suggests that there may be mismatches between the need and supply of post diagnostic support and respite services.
A broad range of services are provided by a variety of organisations and local communities. However, local people and providers consistently state that there is a complex web of services that is difficult for a person with dementia and their family carers to navigate.

On behalf of the Suffolk Dementia Partnership, Sue Ryder recently completed a piece of work that has mapped all dementia-specific services within Suffolk. This includes those delivered by health, local authorities, the voluntary sector and by communities. However, it is important to note that not all community services are likely to be captured in this service mapping activity and further work may be needed to paint a full picture about the type and location of all community support services on offer. The majority of services, apart from primary care and those delivered by local communities, are commissioned by the CCGs and Suffolk County Council.

It is recognised that the workforce providing services to people with dementia and their family carers need considerable development to give them skills to provide an effective response to the needs of people affected by dementia. A number of programmes, such as the Dementia Care Coaches initiative, have been established to address these needs.

1. Summary of dementia services

The key components of the dementia care pathway in Suffolk are summarised below.

1.1 Raising awareness and dementia friendly communities
The Prime Minister’s Challenge on Dementia commits to creating dementia friendly communities that understand how to help people with dementia. Raising awareness and creating dementia friendly communities is essential to reduce fear and stigma, improve quality of life and diagnosis rates and reduce social isolation.

In Suffolk, a number of local communities (including Debenham, Elmswell, Halesworth, Haverhill and Wickham Market) have set up initiatives to support people with dementia and their family carers, making their communities more dementia friendly. The services are largely volunteer-led and include the provision of information, advice, activities and support sessions, such as lunch clubs and medication support. Age UK Suffolk have run a number of ‘Partnerships with Older People Forums’ in Leiston, Elmswell, Haverhill and other communities aimed at raising awareness and understanding of dementia, and promoting opportunities for peer support and structured learning networks. The Dementia-Enabled Villages project has focused particular attention in Aldeburgh and Shotley. Specific programmes have been run by the African and Caribbean Community Health Support Forum and the Bangladeshi Support Centre to bring such opportunities to these BME communities. In addition, the Norfolk and Suffolk Dementia Alliance will be funding the promotion of dementia-friendly hubs in a number of communities across Suffolk and the Alzheimer’s Society is rolling out the Dementia Friends Programme.

1.2 Primary care
Most people with dementia enter the care pathway via their GP who refer suspected cases of dementia to the memory assessment services. Early diagnosis is a key national priority and work is ongoing to improve diagnosis rates in all CCGs. The new directly enhanced service being introduced to the GP contract in 2013/14 will involve payment for the identification of patients at risk of dementia and opportunistic offers to assess them during a routine consultation. In addition to this, West Suffolk CCG has included dementia care quality points in the primary care Commissioning for Quality and Innovation payment (CQUIN), including the use of dementia champions and support for carers.

1.2.1 General practice dementia registers:
As part of the Quality and Outcomes Framework, general practices are required to keep registers of their patients with a diagnosis of dementia. Figure 16 shows that Suffolk has a greater prevalence of dementia (0.7%), as recorded on general practice registers, than the East of England and England as a whole.

The general practice registers do not represent the true prevalence of dementia within an area. It is known that a significant number of people with dementia remain undiagnosed and will not be on a general practice dementia register.

The general practice register prevalence varies across the county, with Waveney district having the highest prevalence and West Suffolk CCG the lowest. This is despite Waveney having lower levels of estimated true prevalence, and therefore reflects the greater rates of diagnosis in Waveney than other parts of the county.

![Crude prevalence of dementia (%), all ages, Suffolk, 2011/12 (QOF data)](image)

**Figure 16:** Crude prevalence of dementia (%) as recorded on general practice registers, all ages, Suffolk, 2011/12 (Data source: quality and outcomes framework)

### 1.2.2 Dementia diagnosis gap:

An early diagnosis of dementia enables the person with dementia and their family carers to make choices about their care. It allows access to specialist dementia services which provide care and support to the family, thereby reducing the likelihood of crises, admission to hospital and residential care.

Early diagnosis remains an important national priority as outlined in the National Dementia Strategy and the Prime Minister’s Challenge on Dementia. A recent report by the All-Party Parliamentary Group on Dementia makes nine recommendations for improving diagnosis rates. These include the use of an awareness raising campaign, quantified targets, workforce development and memory assessment services.

The dementia prevalence calculator can be used to estimate how many people with dementia remain undiagnosed in an area. It is also possible to enter a target diagnosis rate into the calculator in order to estimate the dementia diagnosis gap in the coming years. The tables and figures below present this information using a target diagnosis of 75% for Waveney district and Ipswich and East Suffolk CCG, and a target diagnosis of 66% for West Suffolk CCG.
The data show that although the total number of cases is expected to rise over the next 3 years, the number of people undiagnosed will be reduced if the diagnostic rates targets are met.

**TABLE 5:** Estimated total number of cases of dementia, number of cases on dementia register and number of undiagnosed cases, Ipswich and East Suffolk CCG, 2011 – 2015 (Data source: Dementia Prevalence Calculator)

<table>
<thead>
<tr>
<th></th>
<th>2011/12</th>
<th>2012/13</th>
<th>2013/14</th>
<th>2014/15</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Forecast number of cases</strong></td>
<td>5890</td>
<td>6028</td>
<td>6155</td>
<td>6280</td>
</tr>
<tr>
<td><strong>Diagnostic rate (%)</strong></td>
<td>42.3%</td>
<td>53.2%</td>
<td>64.1%</td>
<td>75.0%</td>
</tr>
<tr>
<td><strong>Result dementia register numbers</strong></td>
<td>2490</td>
<td>3205</td>
<td>3944</td>
<td>4710</td>
</tr>
<tr>
<td><strong>Dementia gap</strong></td>
<td>3400</td>
<td>2823</td>
<td>2211</td>
<td>1570</td>
</tr>
</tbody>
</table>

**Figure 17:** Predicted number of cases on the dementia register and number of undiagnosed cases, Ipswich and East Suffolk CCG, 2011 – 2015 (Data source: Dementia Prevalence Calculator)

**TABLE 6:** Estimated total number of cases of dementia, number of cases on dementia register and number of undiagnosed cases, West Suffolk CCG, 2011 – 2015 (Data source: Dementia Prevalence Calculator)

<table>
<thead>
<tr>
<th></th>
<th>2011/12</th>
<th>2012/13</th>
<th>2013/14</th>
<th>2014/15</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Forecast number of cases</strong></td>
<td>3265</td>
<td>3341</td>
<td>3411</td>
<td>3480</td>
</tr>
<tr>
<td><strong>Diagnostic rate (%)</strong></td>
<td>42.9%</td>
<td>50.6%</td>
<td>58.3%</td>
<td>66.0%</td>
</tr>
<tr>
<td><strong>Result dementia register numbers</strong></td>
<td>1401</td>
<td>1690</td>
<td>1988</td>
<td>2296</td>
</tr>
<tr>
<td><strong>Dementia gap</strong></td>
<td>1864</td>
<td>1651</td>
<td>1423</td>
<td>1184</td>
</tr>
</tbody>
</table>
**Figure 18:** Predicted number of cases on the dementia register and number of undiagnosed cases, West Suffolk CCG, 2011 – 2015 (Data source: Dementia Prevalence Calculator)

**TABLE 7:** Estimated total number of cases of dementia, number of cases on dementia register and number of undiagnosed cases, Waveney District Council, 2011 – 2015 (Data source: Dementia Prevalence Calculator)

<table>
<thead>
<tr>
<th>Year</th>
<th>2011/12</th>
<th>2012/13</th>
<th>2013/14</th>
<th>2014/15</th>
</tr>
</thead>
<tbody>
<tr>
<td>Forecast number of cases</td>
<td>2164</td>
<td>2214</td>
<td>2261</td>
<td>2307</td>
</tr>
<tr>
<td>Diagnostic rate (%)</td>
<td>61.1%</td>
<td>65.7%</td>
<td>70.4%</td>
<td>75.0%</td>
</tr>
<tr>
<td>Result dementia register numbers</td>
<td>1322</td>
<td>1454</td>
<td>1590</td>
<td>1730</td>
</tr>
<tr>
<td>Dementia gap</td>
<td>842</td>
<td>760</td>
<td>671</td>
<td>577</td>
</tr>
</tbody>
</table>

**Figure 19:** Predicted number of cases on the dementia register and number of undiagnosed cases, Waveney District Council, 2011 – 2015 (Data source: Dementia Prevalence Calculator)
When we compare Suffolk’s performance compared with the rest of the region (figure 20), we can see that all three areas perform better than the regional average (41.6%). It also shows that in 2011/12, Waveney had the best diagnosis rates in the East of England.

![Dementia diagnosis rates calculated using adjusted dementia prevalence estimates, by clinical commissioning group, East of England, 2011/12 (Source: Dementia Prevalence Calculator)](chart)

**Figure 20:** Comparison of dementia diagnosis rates calculated using adjusted dementia prevalence estimates, by clinical commissioning group, East of England Region, 2011/12 *(Source: Dementia Prevalence Calculator)*

### 1.3 Memory assessment services

Memory assessment services in Suffolk are commissioned by the CCGs and provided by the Norfolk and Suffolk NHS Foundation Trust. Patients are referred to the clinics by their GP and receive assessment and diagnosis of memory problems. The clinics also offer information, signposting to services and prescription of medication post-diagnosis.

#### 1.3.1 Referrals to memory assessment services

Referral data for Ipswich and East Suffolk CCG and West Suffolk CCG patients is not currently available. This gap in information must be urgently addressed.

In Waveney, there were 785 referrals in total between April 2012 and June 2013. Figure 21 shows that the greatest number of referrals was in the 85 and older age group.
Figure 21: Number of referrals to the memory assessment services by age groups, Waveney patients, April 2012 to July 2013

Information about the number of referrals compared with the number of diagnoses made at memory assessment services is not currently available. This information would be useful to evaluate the memory assessment services and the referral process.

Memory assessment service data is not published nationally and it is therefore not possible to compare Suffolk activity with other areas of the country.

1.4 Information and advice

1.4.1 Dementia Telephone Helpline
The Dementia Telephone Helpline provides information about dementia and signposting to services, in addition to a listening ear and emotional support. The service can be accessed by anyone via telephone and email and is currently provided during working hours, with plans to extend opening hours. The service is provided by Sue Ryder on behalf of the Suffolk Dementia Partnership.

The Dementia Helpline has received 480 calls since the service began on 17th September 2012 (as at 15th October 2013). 40% of these calls were from friends or family carers, 36% from professionals and 14% from people with concerns about themselves in relation to dementia. 46% of calls provided information, whilst 47% of calls provided information and emotional support. The areas of Suffolk with the greatest number of calls were Ipswich, Babergh and Suffolk Coastal districts.

1.4.2 Dementia Advisors
The Dementia Advisors enable people with dementia to find the help they need to live independently in their own homes by providing them with information and advice. People with a diagnosis of dementia are able to access the service via memory clinics, hospitals, GPs and the helpline. The service, which is provided by the Suffolk Dementia Partnership (with Age UK Suffolk as Lead Provider), works across the whole of Suffolk.

The recent evaluation of the Suffolk Dementia Advisor Service conducted by the Suffolk Dementia Partnership showed that over 800 families were supported by dementia advisors in the first 12 months of operation (the service commenced in September 2012). Other key findings include:
36% of referrals were from friends, relatives or family carers and 20% from memory assessment services.
35% of people were referred to the service within one month of diagnosis and 39% after being diagnosed 12 months or more.
Waveney and Suffolk Coastal districts had the highest number of referrals which is likely to be due to a large population size and a high proportion of older people.
The dementia advisors identified the following key issues which affect people with dementia and their family carers: accessing the right information, understanding the illness, continuity of care and support, dealing with other organisations, accessing support services, emotional support, planning for the future and transport.
96% of service users agreed that the service was helpful to them and 92% were very or fairly satisfied with the service.
92% of service users agreed or strongly agreed that the information given to them was helpful and 81% felt informed about services available to them.
72% of service users agreed or strongly agreed that the service had helped them to be more independent and in control.

The activity data show that there is a mismatch between the number of families receiving information and advice services (including the Dementia Helpline and Dementia Advisors) and the estimated number of families affected by dementia in Suffolk.

1.5 Support services for people with dementia and their family carers
There are a number of funded support services provided by the Suffolk Dementia Partnership. These services provide support to address issues that are creating difficulty for themselves or their family. In addition, there are growing numbers of emerging networks of support as communities respond to the needs of those living within those communities.

1.5.1 Dementia Advocacy Service
The Dementia Advocacy Service provides specialist advocacy services to family carers of people with dementia and is accessed via the Dementia Advisors. It is provided across the whole of Suffolk by Suffolk Family Carers and is commissioned as part of the Dementia Advisor Service. This is in addition to the advocacy service provided by a consortium of advocacy agencies, including the Alzheimer’s Society.

1.5.2 Befriending
Befriending services are offered by a number of organisations (including Alzheimer’s Society, Age UK Suffolk and Suffolk Acre) throughout Suffolk. Befriending is an important way of helping potentially isolated people with dementia lead active and fulfilling lives in the community. The services offered vary in terms of how they are funded, charges and access.

1.5.3 Carer support groups
A variety of carer support groups are run throughout the county including those set up and run by carers themselves. The Alzheimer’s Society provide peer support groups facilitated by a Dementia Support Worker. They encourage discussion about a range of topics and enable the opportunity to meet new friends and reduce social isolation.

1.5.4 Dementia cafés
Dementia cafés, such as the rotary club dementia café and the Synergy Cafés delivered by Sue Ryder, provide opportunities for people with dementia and their carers to come together in a café environment and access information, support and education.

1.5.5 Courses for family carers
Caring with confidence courses are provided by Suffolk Family Carers and Help for Dementia. These courses provide family carers with information about the condition and advice on how to care for their family member with dementia and themselves. Over 150 carers have attended these
courses since they started in March 2012. The courses receive positive feedback and there are a large number of family carers on a waiting list to attend the course.

1.5.6 Counselling
Providers such as Suffolk Mind and Headway Ipswich and East Suffolk offer one-to-one or group counselling sessions to people with dementia and their family carers.

1.5.7 Activities and leisure
A variety of leisure activities delivered specifically for people with dementia and their family carers are delivered throughout Suffolk. These include yoga, sailing, music therapy, art and reminiscence therapy. They are delivered by a range of different organisations and usually incur a charge.

1.5.8 Other services
In addition to the above specific services, information and help centres are provided by Alzheimer’s Society and Age UK Suffolk across Suffolk where people can drop in to receive support and meet others. Alzheimer’s Society Dementia Support Workers work directly with people with dementia and their family carers, providing them with one-to-one support and information during home visits or over the telephone.

1.5.9 Safeguarding:
People with dementia and their family carers may be vulnerable to neglect or physical, sexual, psychological, financial, discriminatory or institutional abuse. Commissioners and providers of health and social care services have a responsibility to safeguard vulnerable people against abuse.

We are aware that the Alzheimer’s Society has recently published research highlighting that inadequate support mechanisms increase the risk of people with dementia being vulnerable to abuse from their family carers. As a consequence it is vital that family carers are clear how they can access information/advice and staff understand their roles and responsibilities in relation to safeguarding. In order to do so it is important that the following are in place:

- Training and education: family carers need to gain skills in the best way of caring for a person with dementia. For example, an understanding of the behavioural and psychological symptoms of dementia and how to cope is vital. This training must include making family carers “abuse aware”.
- Peer support networks: family carers want to know that they are not alone and to get practical advice from others who are in the same situation.
- Short breaks: It is vital that family carers have access to flexible and responsive short breaks, provided in a variety of settings.
- Psychological support: family carers for people with dementia can experience significant emotional distress including depression, stress and guilt.
- Information: having access to timely, pertinent information about rights and entitlements, the role of the Safeguarding Team and how to access it is crucial.

It is also acknowledged that family carers themselves are likely to be affected by abuse, and that this can add to the stresses and strains of fulfilling the family carer role.

Suffolk County Council and healthcare commissioners play an important role in protecting people with dementia from abuse that may occur within health and social care organisations. Commissioners are responsible for ensuring that the services they purchase are safe and for investigating any safeguarding concerns. It is therefore essential that the expectations of the service provider, in relation to safeguarding vulnerable adults, are clearly specified in contracts for dementia services. Service providers have a responsibility to understand their duties and be familiar with local safeguarding policies and procedures.
1.6 Mental Health Services

1.6.1 Complexity in Later Life pathway
The Complexity in Later Life Pathway is delivered by the Norfolk and Suffolk NHS Foundation Trust and commissioned by the CCGs as part of the mental health block contract. This service includes assessment, diagnosis, care planning, care coordination and support in the following areas:

• Early detection and diagnosis of dementia
• Short term intensive interventions to reduce, avoid or manage crisis
• Long term care planning and coordination for those with the most complex needs

The pathway is for people with dementia of all ages and for people with other mental health needs who also have physical health need associated with aging that requires specialist input, interventions or management. The teams are made up of psychiatrists, community psychiatric nurses, occupational therapists, psychologists and support workers.

1.6.2 Psychiatric liaison
Ipswich and East Suffolk CCG and West Suffolk CCG are working with NSFT and Ipswich and West Suffolk Hospitals to extend and develop the availability of psychiatric liaison in the acute hospital setting. This service will offer a single point of access to assessment and intervention for patients in the hospital presenting with mental health, dementia, alcohol and substance misuse problems to the multidisciplinary team. The service focus is to prevent admission and reduce length of stay and will have a key role in working with people with dementia. The service is to be implemented during 2013/14 and will be evaluated during 2014.

1.6.3 Mental health clusters
Clustering is the process by which adults entering secondary mental health services are reviewed by clinicians and placed into one of 20 groups (known as clusters) of people with similar diagnoses, symptoms and needs. The process is in-depth and takes into consideration many factors (not just diagnosis) to ensure that people are placed into clusters that best fit both their current circumstances and also their previous history.

Suffolk services have been clustering people for some years; the next step is to agree the care packages which will be offered to people in each cluster and the outcomes the packages should be expected to produce. There is a price attached to each cluster, which in the longer term will be the basis of payment to providers under the provisions of Mental Health Payment by Results (PbR).

There are 4 clusters into which people with dementia may be classified:

• **Care Cluster 18: Cognitive Impairment (Low Need)** – people who may be in the early stages of dementia (or who may have an organic brain disorder affecting their cognitive function) who have some memory problems, or other low level cognitive impairment, but who are still managing to cope reasonably well. Underlying reversible physical causes have been ruled out.

• **Care Cluster 19: Cognitive Impairment or Dementia Complicated (Moderate Need)** – people who have problems with their memory, and/or other aspects of cognitive functioning resulting in moderate problems looking after themselves and maintaining social relationships. Probable risk of self-neglect or harm to others and may be experiencing some anxiety or depression.

• **Care Cluster 20: Cognitive Impairment or Dementia (High Need)** – people with dementia who are having significant problems in looking after themselves and whose behaviour may challenge their carers or services. They may have high levels of anxiety or depression, psychotic symptoms, or significant problems such as aggression or agitation. They may not be aware of their problems. They are likely to be at high risk of self neglect or harm to others, and there may be a significant risk of their care arrangements breaking down.
Care Cluster 21: Cognitive Impairment or Dementia (High Physical or Engagement) – people with cognitive impairment or dementia who are having significant problems in looking after themselves, and whose physical condition is becoming increasingly frail. They may not be aware of their problems and there may be significant risk of their care arrangements breaking down.

Figures 22 and 23 show the number of patients in these mental health clusters in Ipswich and East Suffolk CCG and West Suffolk CCG between April and June 2013. As this is a new initiative, there is only data available for a short time period (3 months). The graphs show that, in both CCGs, the number of patients in each cluster has remained approximately stable over the 3 months. Cluster 19 (moderate need) has the greatest number of patients in both CCGs and cluster 21 has the lowest number of patients. This may be due to true differences (i.e. there are more people with moderate needs), differences in the proportion of people in different clusters accessing services or coding practices.

The number of patients in West Suffolk CCG is significantly less than in Ipswich and East Suffolk CCG. Although there are fewer people living with dementia in West Suffolk, this still represents a proportional under-activity and commissioners may wish to investigate this further.

![Figure 22: Number of mental health clusters 18 to 21 patients, Ipswich and East Suffolk CCG, April to June 2013](image-url)
1.7 Social care:

1.7.1 Social care teams:
Social care services for people with dementia and their carers are provided by Neighbourhood Teams and the four Suffolk County Council Dementia Clusters (North, South, East and West). These teams of social workers and community care practitioners provide assessment, access to personal budgets (including Enhanced Carers Budgets), coordination of discharges, and access to the Flexible Dementia Service. These teams support people to maintain their independence for longer and connect people to support within their communities. They provide short term help when needed as well as longer term care. These services are accessed via Customer First. A diagnosis of dementia is not required for assessment purposes but is necessary for referral to the Flexible Dementia Services. Social work teams also provide information and advice for people affected by dementia and will seek to link them with networks of support.

1.7.2 Respite
Suffolk County Council use spot purchase arrangements to provide respite to those in need. This service is accessed via Customer First. A number of care homes across Suffolk offer respite beds which are available for spot purchase by Suffolk County Council or by individual families using their own resources, which may be supplemented by a personal budget. There are a number of ways that respite can be achieved in addition to the use of respite beds which can be disruptive for people with dementia. This includes sitting services as well as opportunities provided through peer support networks and other services. Enhanced carers budgets are available to support people to arrange alternative respite arrangements.

1.7.3 Day services
People with dementia are able to access day services delivered specifically for those with dementia and generic day services for older people. These are delivered in Suffolk by Care UK and voluntary sector organisations such as Age UK Suffolk and Sue Ryder. Day services may be accessed directly or via Customer First.

1.7.4 Domiciliary care
Suffolk County Council arranges or facilities the provision of domiciliary or home care to support people to live at home and assist with daily living tasks. These services are provided by a number of private and voluntary sector agencies, and are supplemented by the Council Council’s Home
First service. This service is designed to re-able people, restoring their independence and self-confidence after a period in hospital or other event.

1.7.5 Residential care and nursing homes

The dementia prevalence calculator estimates that there are 1,879 people with dementia living in care homes in the Ipswich and East Suffolk CCG area, 889 living in care homes in the West Suffolk CCG area and 532 living in care homes in Waveney. This amounts to 3,300 people with dementia in Suffolk who live in care homes.

The Norfolk and Suffolk Dementia Alliance has established a dementia care coaching programme to address concerns about the need for dementia training for care home staff. This programme aims to develop a network of dementia care coaches to develop and support good practice in effective dementia care. Suffolk Brokerage (an independent, non-profit organisation) is providing funding support to improve dementia training for the Suffolk workforce. The Suffolk Dementia Care Provider Forum has been established to develop, promote and share good practice. Suffolk has secured investment as part of the Department of Health demonstrator programme to invest in care homes and other sectors to improve the environment for dementia care.

1.7.6 Social care activity

The activity information presented below is taken from the social care activity database ‘Care First 6’. It therefore reflects the number of people who are classified as having dementia who receive social care services. In addition to these people, it is likely that there are service users who are classified as being ‘frail’ who may also have dementia but are not coded as having dementia. This group of people will not be included in the activity data below and it is therefore likely that the activity data is an underestimation of the true number of people with dementia who receive social care services.

A quarterly snapshot of activity data for June 2013 shows that just over 1,800 people with dementia receive social care services. This suggests that approximately 16% of those people living with dementia in Suffolk (both diagnosed and undiagnosed) receive social care services.³

- Type of service:

Figure 24 shows that the most common social care services received by people with dementia are home care and residential care services.

³ This figure should be interpreted with caution due to the limitations of the data discussed throughout the report.
Figure 24: Number of people with dementia receiving services by type of service, Suffolk, June 2012 to June 2013 (quarterly snapshots)

Of those receiving residential and nursing care services, the majority are receiving non-respite services (as shown in figures 25 and 26). The small number of people receiving respite services is reflected by feedback from the public and professionals about a need for more respite services. The use of respite beds, however, may be disruptive to people with dementia and there are a number of other ways to achieve respite including use of sitting services, peer support networks and enhanced carers budgets.

Figure 25: Number of people with dementia receiving residential care services by type (respite or non-respite), Suffolk, June 2012 to June 2013 (quarterly snapshots)
The quarterly snapshot of activity data for June 2013 shows that a total of 634 people with dementia were receiving home care services. In Suffolk, homecare is delivered by both external and internal providers. Figure 27 shows that the majority of service users with dementia receive home care delivered by external providers.

**Figure 26:** Number of people with dementia receiving nursing care services by type (respite or non-respite), Suffolk, June 2012 to June 2013 (quarterly snapshots)

**Figure 27:** Number of people with dementia receiving home care services by type of provision (internal or external), Suffolk, June 2012 to June 2013 (quarterly snapshots)

- **Direct payments:**
  The quarterly snapshot for June 2013 shows that approximately 100 people with dementia receive a direct payment. This represents 6.5% of the total number of service users with dementia.
Figure 28: Number and percentage of service users with dementia receiving a direct payment, Suffolk, June 2012 to June 2013 (quarterly snapshots)

- **Number of services received:**
The quarterly snapshot of activity data for June 2013 shows that approximately 75% of service users with dementia receive 1 social care service (see figure 29). This means that just under 370 people with dementia received 2 or more services.

Figure 29: Pie chart showing the number of services received by dementia service users, Suffolk, June 2013 (quarterly snapshot)

- **Ethnicity:**
Table 8 shows that the majority of service users with dementia in Suffolk are White British (92.7% in June 2013). However, this proportion is less than the 2011 Suffolk population profile, which shows that 96.9% of the general population aged 65 and over are White British.

<table>
<thead>
<tr>
<th>Ethnicity</th>
<th>Number of people</th>
</tr>
</thead>
<tbody>
<tr>
<td>White British</td>
<td>15%</td>
</tr>
<tr>
<td>Other</td>
<td>15%</td>
</tr>
<tr>
<td>Asian</td>
<td>6%</td>
</tr>
<tr>
<td>African Caribbean</td>
<td>3%</td>
</tr>
<tr>
<td>Other Caribbean</td>
<td>2%</td>
</tr>
<tr>
<td>Irish</td>
<td>1%</td>
</tr>
<tr>
<td>Other Europeans</td>
<td>1%</td>
</tr>
<tr>
<td>Mixed</td>
<td>1%</td>
</tr>
<tr>
<td>Other</td>
<td>1%</td>
</tr>
<tr>
<td>Total</td>
<td>100%</td>
</tr>
</tbody>
</table>

4 Small numbers have been suppressed to protect anonymity.
<table>
<thead>
<tr>
<th>Ethnicity</th>
<th>Jun-12</th>
<th>Jun-13</th>
</tr>
</thead>
<tbody>
<tr>
<td>White British</td>
<td>1301</td>
<td>1412</td>
</tr>
<tr>
<td>White Irish</td>
<td>10</td>
<td>8</td>
</tr>
<tr>
<td>Any other white</td>
<td>13</td>
<td>11</td>
</tr>
<tr>
<td>Gypsy/Roma</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>White and Asian</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>White and Black African</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Bangladeshi</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Indian</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Any other Asian</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Black - Caribbean</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Black - African</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Black - Other</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Any other ethnicity</td>
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<td>25</td>
</tr>
<tr>
<td>Any other mixed background</td>
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<td>0</td>
</tr>
<tr>
<td>Chinese</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Information not yet obtained</td>
<td>21</td>
<td>49</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>1385</strong></td>
<td><strong>1522</strong></td>
</tr>
</tbody>
</table>
• **Age:**
Figure 30 shows that, between June 2012 and June 2013 there was the greatest increase in the number of service users with dementia in the ‘oldest old’ age group (85 and over). The number of service users with dementia in this age group increased by 13%.

This group of people may be more likely to have other co-morbidities and more complex health and social care needs. This may affect the capacity and type of services required.

![Number of people with dementia receiving a service by age band, Suffolk, June 2012 and June 2013 quarterly snapshots](image)

**Figure 30:** Number of people with dementia receiving a service by age band, Suffolk, June 2012 and June 2013 quarterly snapshot

1.8 Intermediate care:

1.8.1 Flexible dementia Service
The Flexible Dementia Service provides enhanced and flexible home care to people with dementia in Suffolk. By doing so, it aims to prevent admission to secondary care thereby minimising disruption and anxiety to the person with dementia. The service is accessed via the Dementia Clusters (see above) and operates 24 hours a day, 7 days a week.

1.8.2 Dementia intensive support teams (DIST)
The dementia intensive support teams began working in East and West Suffolk in August of 2012 and in Waveney in June 2013. The teams aim to prevent avoidable acute hospital admissions, expedite discharge from acute hospitals and prevent premature admission to 24 hour care on discharge from acute hospital. In East and West Suffolk, the community and hospital functions of the DIST will be carried out in future by the liaison psychiatry and complexity in later life pathway services. DIST services will remain operational in Waveney.

Figures 31 and 32 below show the number of DIST contacts from April 2012 to June 2013 for Ipswich and East Suffolk CCG and West Suffolk CCG patients. Both graphs show an increase in referrals since the service began in August 2012. As expected, there are a greater number of Ipswich and East Suffolk CCG contacts than West Suffolk (as the number of people with dementia is greater in Ipswich and East Suffolk than West Suffolk). There are peaks in the number of contacts over the winter months which may be explained by seasonal variation in hospital activity. Data for the Waveney DIST are not yet available.
Figure 31: Number of Ipswich and East Suffolk CCG DIST contacts between April 2012 and June 2013.
Figure 32: Number of West Suffolk CCG DIST contacts between April 2012 and June 2013

Figures 33 and 34 display the DIST contacts by age band. They show that in both CCGs the 80 years and over age band has the greatest number of contacts and that the winter peak in contacts is mostly due to contacts aged 80 years and over.
Figure 33: Number of Ipswich and East Suffolk CCG DIST contacts, by age band, April 2012 to June 2013.
Figure 34: Number of West Suffolk CCG DIST contacts, by age band, April 2012 to June 2013
Figures 34 and 36 below show the number of DIST contacts by the referral source. These show that there is geographic variation in referral source with Ipswich and East Suffolk DIST receiving more referrals from the acute trust, and West Suffolk DIST receiving most referrals from GPs and 'other sources'. For both CCGs, the primary referral source in the ‘other’ category is social care.

**Figure 35:** Number of DIST contacts by referral source, Ipswich and East Suffolk CCG, April 2012 to June 2013

**Figure 36:** Number of DIST contacts by referral source, West Suffolk CCG, April 2012 to June 2013

### 1.9 Acute hospitals

The three main acute hospitals that provide care for people in Suffolk are Ipswich, West Suffolk and the James Paget. Acute hospitals have a responsibility to people with dementia that come into contact with their services, in terms of identification and assessment, standards of care and effective discharge back into the community. The National Dementia Strategy, Prime Minister’s...
Challenge on Dementia and NICE guidelines all emphasise the importance of the role of acute hospitals. In Suffolk, a variety of interventions are used in acute trusts including CQUINs, dementia champions, the dementia intensive support teams and specialist liaison services.

The acute trusts dementia leads have been implementing a number of initiatives to improve the care and experience of people with dementia and their family carers:

- Dementia friendly wards and hospital environment, including the use of signage and colours to help people find their way.
- Support to carers, including carers information pack, involvement in the patient’s care, flexible visiting hours and a ‘Carer’s Kitchen’.
- Purposeful activities such as reminiscence work and film clubs, and the provision of social spaces.
- Staff training and the use of dementia champions.
- Identification of patients with dementia throughout the hospital via the use of blue wrist bands and forget-me-not signage.
- Use of the ‘This is me’ document.

A ‘welcome home’ service is provided by voluntary sector organisations (Age UK in West Suffolk and British Red Cross in Ipswich and East Suffolk) to those returning from a period in hospital to help them with everyday tasks and support them to regain their confidence and independence.

2. Funding

In 2012, the Alzheimer’s Society estimated that dementia costs the NHS, local authorities and families £23 billion per year\textsuperscript{viii}. Over a third of these costs are due to informal care by family carers. The King’s Fund estimate that the total cost will rise to £27 billion per year by 2018\textsuperscript{ix}.

Information is not currently available to accurately calculate how much is spent on health and care services for people with dementia and their family carers in Suffolk. This is due to the complex nature of the delivery of dementia services. For example, community mental health services are delivered via a block contract with NSFT. People with dementia receive social care services from a range of different services, including generic older people services, and it is not possible to differentiate this spend. In addition, we know that a high proportion of people with dementia have not had this confirmed by a diagnosis, but care and support services are available to meet their needs. These difficulties in measuring dementia spend are common across the country.

A widely held concern in Suffolk is the short term nature of funding for many dementia services. This has potentially serious implications for the sustainability and quality of services and must be addressed.

Financial information would be useful to commissioners in order to plan effectively to meet the needs of the increasing number of people with dementia in Suffolk. It is therefore recommended that commissioners carefully consider the value and resource implications of collecting such information and take steps to initiate data collection if considered to be a priority.

3. Care Pathways

In 2009, a new dementia care pathway was agreed as part of the Suffolk Joint Dementia Strategy (figure 37).
The pathway has since evolved with the establishment of new services, and the commissioning partners (Great Yarmouth and Waveney CCG, Ipswich and East Suffolk CCG, West Suffolk CCG and Suffolk County Council) are currently working together to develop a model pathway that incorporates the following stages:

Stage 1: Raising awareness and understanding of dementia
Stage 2: Early intervention and support
Stage 3: Maintenance and daily living
Stage 4: Crisis and end stage

It is recognised that these stages are not linear and that people affected by dementia will need effective responses from each of these at different times within their experience with dementia. The pathway fits with the commissioning partners’ strategic aims.

4. How does Suffolk compare with other regions?

The services offered in Suffolk reflect the guidance provided in the National Dementia Strategy and other national standards and guidelines. This suggests that the services are likely to be similar to those offered throughout the country. In section 6 of this report, a number of case studies describing innovative services offered in other areas of the countries are presented.
# Section 4: Service User Experience

## Service User Experience - Summary

The needs assessment has been informed by a variety of engagement activities with people with dementia, their family carers and professionals. A number of common concerns have been identified:

- More work is needed to raise awareness about the condition and reduce stigma.
- We need to improve early diagnosis and reduce inequalities in diagnosis rates.
- This must be accompanied by increased capacity and improved post diagnostic services.
- The provision of post diagnosis support services is complex, uncoordinated and under-resourced.
- Information about services needs to be simplified and provided in an accessible way.
- Services should be integrated and jointly commissioned.
- Caring for someone with dementia can impact on family carers’ lives physically, psychologically, socially and financially; family carers therefore need more support, including respite services.
- More work is needed to improve the quality of care for people with dementia and their family carers in hospitals.
- Every effort should be taken to prevent crises and hospital admissions, and support people to stay at home.
- People with dementia and their family carers should receive high quality end of life care.
- There are inequalities in the experience of people with dementia and their family carers. People who live in isolated rural areas and those from BME groups may not have the same access to services.
- There needs to be greater consistency in the training of staff who work with people with dementia and their family carers.

Over the past year in Suffolk, there has been significant engagement with people with dementia, their carers and those that provide services to them. This includes:

- Partnership with Older People in Suffolk forums focused on dementia
- Ipswich and East Suffolk clinical scoping exercise
- Ipswich and East Suffolk CCG dementia consultation workshop
- Ipswich and East Suffolk primary care engagement
- The Debenham Project – research into the dementia/memory loss journey for the cared-for and carer
- Dementia Advisor Service evaluation

Stakeholders have also provided input into the dementia needs assessment via the Dementia Needs Assessment Steering Group and one-to-one meetings with key stakeholders, including service providers.

The Dementia Advisory Reference Group was established in 2010 to ensure that the experience of people affected by dementia is available to influence the implementation of Suffolk’s Joint Dementia Strategy. The group has membership from current and former carers of people with dementia, user representatives as well as members from organisations supporting people affected by dementia. One of the key focuses for the group has been to highlight current deficits in the dementia pathway. The Dementia Advisory Reference Group has representation on the Dementia Needs Assessment Steering Group.
The findings from these engagement activities are summarised below:

1. Living Today, Remembering Yesterday – Partnership with Older People in Suffolk Forums (April 2012 to March 2013)

The engagement exercise consisted of four forums in Elmswell, Haverhill, Leiston and Sudbury. The focus of the forums was to raise awareness and understanding of dementia, and to discuss how Suffolk communities can enable people with dementia to remain independent and active.

1.1 Participants
A total of 80 people attended the forums, 50% of whom had experience of caring for someone with dementia. The attendees were aged between 50 and 99 years old, with 45% of attendees being in their 70s. 71% of attendees were female.

1.2 Key findings
- When asked about the ease of getting a diagnosis of dementia, 44% said it was very easy, 12% easy, 22% difficult and 22% very difficult.
- 70% of the attendees in Leiston and Haverhill were aware of assistive technology. None of the attendees in Sudbury were aware of assistive technology.
- When asked if routine screening by GPs for dementia would put you off going to see the GP, the majority of attendees (87%) answered that it would not put them off going to see their GP.

1.3 Common recommendations from all forums
- There is a need for more information about dementia to be available from GP surgeries and various places around the community. This information needs to include the signs and symptoms, support that is available and how to access support and the importance of early diagnosis.
- Community groups need to be welcoming and supportive to people with dementia and their family carers. In order to achieve this, there needs to be a mechanism to support and train volunteers in community groups to increase awareness of dementia, how best to support people with dementia in a group setting and how to cope with challenging behaviour.
- There is a need to provide support/respite for carers and this support needs to be available sometimes at short notice and locally.
- A dedicated drop in cafe style meeting place would provide somewhere for carers and the cared for to go together, meet others and have resources available to do activities and opportunities to pick up leaflets and relevant information.

1.4 Area-specific recommendations
- Peer support within community groups and for volunteers was something that Leiston and Haverhill felt were important to enable community groups to welcome people with dementia and their carers.
- Leiston recognised the need to work with the whole community in order to combat the stigma associated with dementia and raise awareness of dementia amongst children and families.
- The residents of Banham Drive in Sudbury felt that a befriending service would enable people with dementia to have regular contact with the community.
- The Haverhill forum discussed the diagnosis and support of a person with dementia and it was felt that having support services based around the GP practice would give familiarity and continuity to the support.

Following the forums, Age UK Suffolk has worked with the local communities to take action to address the issues raised (see the summary report for more details).

2. Ipswich and East Suffolk Clinical Scoping Exercise (December 2012)

2.1 Participants
The clinical scoping exercise involved professionals from the memory assessment service, Ipswich and East Suffolk CCG and Adult and Community Services at Suffolk County Council.

2.2 Key findings
Two key issues were identified during the clinical scoping exercise (i) the capacity to diagnose increasing dementia cases, and (ii) the need for more post diagnosis services.

3. Ipswich and East Suffolk CCG Dementia Consultation Workshop (February 2013)

The aim of the workshop was to gather in-depth views from a wide range of people who provide frontline dementia services.

3.1 Participants
52 people attended the event including representatives from community organisations, the voluntary sector, home care agencies, nursing and residential care homes, Suffolk County Council, Norfolk and Suffolk NHS Foundation Trust, Ipswich Hospital, GPs and Ipswich and East Suffolk CCG.

3.2 Key findings
The key findings from the workshop are summarised in table 9. For a full description of the findings of the workshop, please see the ‘Redesigning Dementia Services: Report of the Consultation Workshop of 26 February 2013’.

<table>
<thead>
<tr>
<th>Theme</th>
<th>Key issues identified</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diagnosis</td>
<td></td>
</tr>
</tbody>
</table>
| Recognition of dementia symptoms in the community | Public information campaign needed to address stigma of dementia and encourage people to seek diagnosis.  
Need for pre-diagnosis element of care.  
More information needed about post diagnosis care.  
Need to address benefits of a diagnosis and risks of a false positive diagnosis. |
| Encouraging the GP to diagnose more patients | Concerns about diagnosis delays and the practice of ‘wait and see’.  
Need for communication of diagnosis to patient and family.  
Need for GPs to stop being reluctant to diagnose. |
| Information at GP surgeries | Better information for primary care staff and family carers can prevent crises.  
Issues with dissemination of information. |
| Equality matters | Rurality – poor transport links, difficulty getting information.  
Need to take services close to communities.  
Need to identify couples where both have dementia.  
Accessibility of information for those with specific needs (e.g. vision, hearing and mobility).  
BME groups present late for services and may require interpretation and translation. Need to overcome language and cultural barriers. |
| Secondary care | Inadequate information given to patients on discharge from acute hospital.  
Community mental health teams should be more involved in diagnosis.  
Hospital clinicians may be unwilling to make or confirm diagnosis.  
Issues with differential diagnosis between delirium and dementia. |
| Memory assessment service | Ipswich Hospital memory clinic is working at full capacity.  
Inadequate patient information on GP referral forms.  
Patient needs to attend with a carer and arrange transport which can be difficult for those with no friends/family and those who live in rural areas. |
<p>| Nursing and | Campaign to diagnose people living in care and nursing homes. |</p>
<table>
<thead>
<tr>
<th><strong>Residential Settings</strong></th>
<th>Improved training for care home staff. Greater involvement of GP in staff training and medication support.</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>General</strong></td>
<td>Not enough people to diagnose – therefore GPs and nurses should be trained to meet this need.</td>
</tr>
<tr>
<td><strong>Post Diagnosis Services</strong></td>
<td></td>
</tr>
<tr>
<td><strong>National Frameworks</strong></td>
<td>Need to monitor Suffolk progress against national targets.</td>
</tr>
<tr>
<td><strong>Knowledge and Understanding</strong></td>
<td>Need for more dementia advisors. Need for community groups to support people with dementia post diagnosis.</td>
</tr>
<tr>
<td><strong>Range of Services</strong></td>
<td>Unclear what services the different providers offer. More community services in primary care and access to services through one central point. Services are uncoordinated and overwhelming. Some patients would benefit from cognitive rehabilitation in community hospitals.</td>
</tr>
<tr>
<td><strong>Dementia Service Users</strong></td>
<td>Medical reviews are not always done. Memory assessments over the phone do not always represent what is really happening. People with dementia and co-morbidities need to be aware of their choices. Some people have no family carers, some have partners who also have dementia (therefore need for services in community). Patients with delirium need to be followed up after hospital discharge. There is less dementia provision in nursing and residential care homes. People who are first diagnosed in secondary care tend to arrive in crisis.</td>
</tr>
<tr>
<td><strong>Equality Matters</strong></td>
<td>Rurality and isolation: suggestion of a dementia awareness bus with information and support services. Need to increase cultural awareness and training to support BME groups.</td>
</tr>
<tr>
<td><strong>Family Carers</strong></td>
<td>Not enough respite or transparency about how it is allocated. Lack of coordination of respite services. Need to include a sitting service. Support for family carers allows people to stay in the community for longer. Sustainability of funding of befriending service. Understanding that some family carers are private and do not seek help, but there is an issue with waiting until a crisis to engage.</td>
</tr>
<tr>
<td><strong>Information</strong></td>
<td>Directory of services would be beneficial and provide clarity. Need accessible formats of information. Too much information on organisations that provide the same services. Dementia Advisors needed to navigate this information. Need information sharing between IT systems of different organisations.</td>
</tr>
<tr>
<td><strong>Training</strong></td>
<td>Inadequate training for hospital, primary care, domiciliary, nursing and residential care home staff, and family carers. Need to have an agreed training strategy across all providers.</td>
</tr>
<tr>
<td><strong>Coordination of Services</strong></td>
<td>Need for joined up working. Proposal of a local coordinator role in each locality – providing consistency for patients and family carers (more detail available on role). Importance of having patients’ notes in one place, like end of life care yellow folder. Currently, there are too many referral forms.</td>
</tr>
<tr>
<td><strong>Joint Commissioning</strong></td>
<td>General desire for the joint commissioning, coordination and co-location of post diagnosis services. Current funding model using short term grants is not sustainable.</td>
</tr>
<tr>
<td><strong>What Would Success Look Like</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Public Health Campaign</strong></td>
<td>Important for improving diagnosis rates. Key messages: recognition of symptoms, presenting diagnosis positively, information about post diagnosis services, should address negatives head on (e.g. lack of recovery, medication issues), living well with dementia, dementia is everybody’s business. Should target young people.</td>
</tr>
</tbody>
</table>
| **Diagnosis**           | 100% diagnosis rates. Everybody should know where to go for an early diagnosis within 2-3 weeks of
| Post-diagnosis | Fewer crises in the community and hospitals. Services locally embedded in communities. Good communication between providers (inc. primary and secondary care). Improved access to services for those in rural areas and BME groups. |
| Information | Dementia directory. One dementia telephone number for the public/patients/family carers. Less signposting to services and more actual services. Accessible formats of information. |
| Service co-ordination | Single GP practice with named worker responsible for all cases in the locality – local accountability. All patients allocated a service co-ordinator and never discharged from this service. Information sharing between providers. Jointly developed care pathways. Service integration between community health services, DIST and other services. Service co-ordination would allow people to stay at home for longer. |
| Service co-location | New dementia hubs with co-location of a range of services and professionals which cut across confusing geographical boundaries that currently exist. Led by a Consultant in Older People’s Mental Health which will meet NICE guidance. |
| Services | Services should develop and promote dementia champions to work with communities and help develop dementia friendly communities. More dementia advisors. Cognitive rehabilitation for patients in the community. Mobile unit providing support and advice. Good quality respite care with co-ordination and support from social care professionals. More access and use of assistive technology. |
| Residential and nursing care homes | Knowledge of offer from homes to dementia patients and what training is delivered. 100% diagnosis rates of people living in homes. Activity coordinators in care homes providing sessions. Less reluctance from BME family carers for their family members with dementia to go into care homes. |
| Training | Joint training across sectors. More skills training in care homes. Use of 12 week dementia medication course. Training for community mental health team support workers. |
| Joint commissioning | Joint commissioning with pooled budgets between health and social care. This would reduce duplication of services. Learning from pilots informs commissioning. Voluntary sector spend less time fundraising and more time delivering services. Long term funding of voluntary sector increases sustainability. Under spend of enhanced care budget addressed. Provider agencies work in partnership. Learning from successful models in Sweden and the Netherlands. |

4. Ipswich and East Suffolk Primary Care Engagement (February 2013)

The Ipswich and East Suffolk CCG engaged with GPs using two techniques: (i) a letter informing them of the need for a more sustainable dementia service and asking them to express an interest in being one of 10 practices that might offer a diagnostic service in their
locality, and (ii) a GP education event during which GPs were consulted about the proposed redesign of dementia services.

4.1 Participants
150 GPs took part in the GP education event. 41 GP practices were written to about the redesign of dementia services and 20 practices expressed an interest in taking part in the initiative.

4.2 Key findings
The GPs raised a number of issues regarding diagnosis in primary care including issues around capacity, financing, the use of screening tools, the aim of early diagnosis and concerns about overdiagnosis. In addition to this, they identified that it would be useful to have a contact list of all post-diagnosis service providers and expressed concern about a lack of resources and post-diagnosis services. The needs of patients with early onset dementia were also raised.

5. The Debenham Project: Research into the dementia / memory loss journey for the cared-for and carer, 2012/13

In 2012/13, the Norfolk and Suffolk Dementia Alliance funded the Debenham Project to conduct research into the dementia/memory loss journey for people with dementia and their family carers in the village of Debenham, Mid-Suffolk. The Debenham Project (www.the-debenham-project.org.uk) is a community-based project which has, of its own initiative, developed a comprehensive range of local services to support people with dementia and their family carers.

The researchers used various methods (including questionnaires and interviews with family carers, volunteers and professionals) to obtain information about:

- The dementia/memory loss journey;
- A profile of people with dementia and their family carers;
- The experiences of people with dementia and their family carers; and,
- Positive and negative aspects of early diagnosis and interventions.

The research provides unique insight into the key issues affecting people with dementia and their family carers. These can be summarised as:

- Lack of knowledge and unpreparedness of carers;
- Greater range and depth of person-centred support;
- Addressing the needs of a rural community e.g. transport to and distance from care homes;
- Financial worries of carers;
- Isolation of carers and the burden of caring;
- The focus on the diagnosis as the gateway to services and support;
- Obtaining services before diagnosis;
- A single point of contact for carers and people with dementia/memory loss; and,
- Training needs of GPs, other health and social care professionals.

Further details of the research methods and findings are presented in the research executive summary which is attached to this report as appendix 2. The full report can be found at http://www.the-debenham-project.org.uk/downloads/research/reports/DebProjResearch_Final_Report311013.doc.

6. Dementia Advisor Service Evaluation
The evaluation of the Dementia Advisor Service conducted by the Suffolk Dementia Partnership involved identification of areas of unmet need. In total, unmet need was recorded on assessment forms in 141 instances. The unmet need, reason given and district where the unmet need has been identified are summarised in table 10 below:
TABLE 10: Areas of unmet need identified by the Dementia Advisor Service

<table>
<thead>
<tr>
<th>Unmet need identified</th>
<th>Reason given</th>
<th>District</th>
</tr>
</thead>
<tbody>
<tr>
<td>Specialist befriending</td>
<td>• Unavailable locally</td>
<td>All areas</td>
</tr>
<tr>
<td>Specialist Support Worker</td>
<td>• Unavailable locally</td>
<td>Suffolk Coastal Ipswich</td>
</tr>
<tr>
<td>Respite</td>
<td>• Cost</td>
<td>Mid Suffolk Babergh St Edmundsbury Ipswich</td>
</tr>
<tr>
<td></td>
<td>• Unavailable locally</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Client/Carer reluctant to be separated</td>
<td></td>
</tr>
<tr>
<td>Cognitive Stimulation Therapy</td>
<td>• Unavailable locally</td>
<td>Suffolk Coastal</td>
</tr>
<tr>
<td>Transport</td>
<td>• Cost</td>
<td>Babergh</td>
</tr>
<tr>
<td></td>
<td>• Unavailable locally</td>
<td></td>
</tr>
<tr>
<td>Social Groups/Activities</td>
<td>• Unavailable locally</td>
<td>Babergh Forest Heath Ipswich</td>
</tr>
<tr>
<td></td>
<td>• No transport</td>
<td></td>
</tr>
<tr>
<td>Appropriate Day Care</td>
<td>• Cost</td>
<td>Ipswich Babergh St Edmundsbury</td>
</tr>
<tr>
<td></td>
<td>• Age (young client)</td>
<td></td>
</tr>
<tr>
<td>Sitting Service at Night</td>
<td>• Long waiting list</td>
<td>Babergh Forest Heath St Edmundsbury</td>
</tr>
<tr>
<td>Customer First Urgent Assessment</td>
<td>• High Priority assessment requested – no contact from Customer First until chased by DA</td>
<td>Babergh Ipswich</td>
</tr>
<tr>
<td>Help with Dispensing Medication</td>
<td>• Unavailable locally</td>
<td>Mid Suffolk Ipswich</td>
</tr>
<tr>
<td></td>
<td>• Domiciliary carers not allowed to dispense</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Cost</td>
<td></td>
</tr>
<tr>
<td>Carer Support Group</td>
<td>• Unavailable locally</td>
<td>St Edmundsbury</td>
</tr>
<tr>
<td></td>
<td>• Unable to leave spouse</td>
<td></td>
</tr>
<tr>
<td>Residential Care Provision</td>
<td>• Refused by Customer First</td>
<td>Babergh</td>
</tr>
<tr>
<td>Help with POA</td>
<td>• Cost</td>
<td>Ipswich</td>
</tr>
<tr>
<td>Home Instead – Dementia Companion</td>
<td>• Unavailable locally</td>
<td>Suffolk Coastal</td>
</tr>
</tbody>
</table>

7. Stakeholder Interviews

As the needs assessment is part of the commissioning cycle and is feeding into the commissioners’ 2014/15 commissioning intentions, the work has been led by public health and commissioners. In order to understand some of the key issues which Suffolk service providers encounter, one-to-one interviews have been conducted with a number of providers and other key stakeholders including representatives from the mental health trust, acute trusts, the ambulance trust, Healthwatch Suffolk, Norfolk and Suffolk Dementia Alliance, Suffolk Family Carers and Suffolk Community Healthcare. Age UK Suffolk, Alzheimer’s Society and Sue Ryder are represented on the steering group.

The interviews were conducted either in person or over the telephone and used the following questions as prompts:
- What currently works well?
• What are areas that require improvement?
• What does future success look like?

The following issues were identified as needs which may not be currently addressed:

**Raising awareness and understanding:**
• We need to tackle stigma and increase awareness about dementia, including the message that people can live well with dementia.
• We need to learn from best practice examples of communities in Suffolk that have worked to become ‘dementia-friendly’.
• Everyone who comes into contact with a person with dementia (e.g. people who work in local shops and banks) should receive training about dementia.

**Early diagnosis:**
• Early diagnosis is important in order to identify those who need support.
• There is concern that some GPs are reluctant to diagnose people with dementia.
• There are inequalities in diagnosis rates across the county.

**Good quality information:**
• Providers need to have accurate, simple information about other services available to support people in the community (e.g. directory of services).

**Improved community support services:**
• There are many different services available which is confusing and difficult to understand.
• Many people with dementia and their family carers receive very little support after being diagnosed.
• There should be one integrated service provided to the person with dementia which is personalised to them.
• There is variation in the post diagnostic support services offered throughout the county.
• Health and social care services need to be integrated.
• Services should be delivered locally and integrated at a local level (e.g. GP practice).
• Many services are not available out of hours – this means that people who have a crisis out of hours do not receive sufficient services.
• Those who live in rural areas may have difficulty accessing services. Rurality can also affect continuity of care.
• Day services are not always appropriate for people with dementia and need to offer a wider variety of ‘real world’ activities.
• There is a lack of befriending services with varying availability in different regions of the county.
• Care packages need to be more flexible to meet the individual needs of the person with dementia. Direct payments may offer a solution to this, although the person with dementia needs to have support to manage their budget.
• There is a significant problem with short-term funding of services.
• More needs to be done to help people with dementia live at home in the community. This may involve adaptation of the home environment, use of technology and support for family carers. It is important that people who are supported to stay at home and their family carers are safe and have a good quality of life.
• There is a concern about lack of support for families during a crisis (both in and out of hours).
• People with dementia and their family carers need to be actively involved in the commissioning and design of dementia care and support services.
• It is not always useful to consider dementia services alone as people are likely to use generic services and have co-morbidities.
Support for family carers:
- Family carers may neglect their own health needs whilst caring for someone with dementia.
- Family carers would benefit from a sitting service and other forms of respite.
- There is an issue with the sustainability of funding of family carer support services.
- The Dementia Advisor service is valued by family carers and is currently under resourced.

Improved quality of care for people with dementia in hospitals:
- More needs to be done to prevent crises and hospital admission which can be extremely stressful for people with dementia.
- It is felt that people with dementia who enter hospital from their home are likely to be discharged to residential care.
- There are difficulties diagnosing dementia and planning discharge whilst the patient has delirium.
- The ‘This is Me’ document is very useful to ambulance and hospital staff but people may need support to complete these. A list of medication would also be useful.
- If a family carer is taken ill and needs urgent care, the ambulance crew may have to take their family member with dementia to hospital as well which can be stressful for both the carer and person with dementia. A sitting service may be useful to address this issue.
- It is important that health care staff are aware that a patient has dementia so they can meet their needs. This may be addressed by expanded use of initiatives such as the blue wrist band or forget me not signage.
- There can be difficulty releasing front line staff to attend dementia training.
- More needs to be done to support people with dementia and their family carers following discharge from hospital.

Improved end of life care:
- We need to understand how we are supporting people with dementia during end of life care and consider what best practice is happening in the county and elsewhere. Some expressed concern about the use of anti-psychotics during end of life care.

Workforce development:
- Training is needed for all professionals who work with people with dementia and their family carers, to ensure high standards of health and social care. Although many organisations in Suffolk invest in dementia training, there is concern that there is variation in the availability of training in some sectors, including domiciliary and residential care.
- There needs to be continued focus on workforce development and identification of sectors that need improvement in this area.
- The barriers to effective workforce development, such as services being unable to backfill attendees, must be considered and addressed.

8. Needs Assessment Steering Group

The Dementia Needs Assessment Steering Group is a small group of key stakeholders who have led the delivery of the needs assessment. The group includes representation from public health, adult social care, the clinical commissioning groups and the Dementia Advisory Reference Group (representing people with dementia and their carers). This group has enabled key stakeholders to provide input from the very beginning, thereby shaping the needs assessment and ensuring it is fit for purpose.
Section 5: Evidence of Effectiveness

Evidence of Effectiveness - Summary

This needs assessment has identified that there is a lack of coordination and integration of dementia services in Suffolk and this is negatively impacting people with dementia and their family carers. This section of the report therefore presents evidence of how these issues can be effectively addressed and case studies of innovative practice from other areas in the country.

Joint Commissioning:
- Due to the complexity of the needs of people with dementia, joint commissioning between health and social care is recommended by national guidelines.
- Commissioners of dementia services must influence commissioners of other health and social care services to help them understand the requirements of people with dementia.
- Joint commissioning may be achieved through a stepped process, moving from collaboration to shared and integrated services, and finally to operational merger.

Integrated Models of Dementia Services:
- National guidelines state that memory assessment services are the preferred model of care for the assessment and diagnosis of dementia.
- Memory assessment services should include a full range of assessment, diagnostic, therapeutic and rehabilitation services.
- These services should be integrated with other elements of care for people with dementia and may be located in primary care in order to move away from intimidating hospital settings, and by doing so break down barriers and reduce stigma.
- The Alzheimer Scotland 8 Pillars Model of Community Support includes a Dementia Practice Coordinator who is a named, skilled practitioner who will lead the care, treatment and support for the person with dementia and their family care. This role ensures that the services delivered to the patient are fully coordinated.
- The Gnosall Primary Care Memory Clinic use a similar role called the ‘Eldercare Facilitator’. A key feature of the Gnosall model is that the patient is never discharged from the service and continues to receive support from the facilitator until death.

1. Evidence of effectiveness - joint commissioning of dementia services:

1.1 National Dementia Strategy

Objective 14 of the Living well with dementia: A National Dementia Strategy is a joint commissioning strategy for dementia.
- It states that local commissioning and planning mechanisms should be established to determine the services needed for people with dementia and their carers, and how best to meet these needs.
- These services should be informed by the World Class Commissioning guidance developed to support the strategy.

1.2 Dementia Joint Commissioning Framework

The strategy is supported by the Dementia Joint Commissioning Framework which provides best practice guidance on commissioning.
- The framework recommends joint commissioning between health and social care as the health and care needs of people with dementia are often inseparable.
• A key principle of dementia commissioning is that commissioners should work across the commissioning community. The framework recommends that commissioners leading on dementia should work in partnership with commissioning colleagues, notably commissioners of acute general healthcare, mental healthcare, PCT primary and community services, practice-based commissioning, learning disabilities services, end of life care, public health and health promotion services, social care and housing services.

• Working collaboratively should result in services that are connected and provide a joined-up pathway for people with dementia and their carers.

• Commissioners of dementia services should work with other commissioners to co-ordinate budgets to maximise the impact of services for people with dementia and their carers.

1.3 NICE Support for Commissioners of Dementia Care (CMG48)

The NICE support for commissioners of dementia care (CMG48) is a resource that supports commissioners, clinicians and managers to commission high-quality evidence-based care for people with dementia and their carers that are in line with the NICE guidelines and quality standards.

• The guide states that commissioning for dementia is complex and therefore requires a whole systems approach with collaboration between all relevant health and social care stakeholders.

• Lack of integration between health and social care is the biggest barrier to the delivery of high quality care for people with dementia.

• Moving towards integration is a gradual process that begins with collaboration, moving towards a shared and integrated service and finally operational merger (figure 38).

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**Figure 38:** Schematic diagram of steps towards joint commissioning (NICE Commissioning Guide: support for commissioning dementia care).

• Joint needs assessments and commissioning plans: as a minimum, commissioners should work together to ensure that health and social care commissioning plans for dementia are complementary. Ideally, commissioners should develop and implement one integrated commissioning plan.
Integrating commissioning teams: given the national priority attached to improving dementia services, commissioners may wish to propose to senior managers that: (i) there is a written commitment to collaborative working between the relevant commissioners, or (ii) they establish a joint commissioning post or team for dementia across health and social care.

Case study 1: Salford

Salford has taken an integrated approach to commissioning dementia services.

- The Older People’s Mental Health Programme Board manages the delivery of the joint strategy for older people’s mental health services, incorporating a dementia action plan.
- This multi-agency group reports into both the Older People’s Partnership Board and the Mental Health Partnership Board.
- It has representation from health and social care managers and trainers, acute health trust, mental health trust, University of Manchester, service users and voluntary sector representatives, service providers, general practitioners and housing and residential care.
- Several key roles make integrated commissioning work well in Salford:
  - Integrated Commissioning Manger (older people) – jointly funded by the PCT and Council, employed through the council and reports to the Assistant Director for Integrated Commissioning (also a joint appointment).
  - GP commissioning lead – works with the Integrated Commissioning Manager and is the GP representative on the Older People’s Mental Health Programme Board.
  - Joint funded research role – collaborates on research and evaluation of services. Part funded through the local university and apart through the mental health trust. Sits on the Older People’s Mental Health Programme Board.

Case study 2: Walsall

Walsall has established a joint commissioning unit for unplanned care, mental health, dementia, learning disabilities and older people, with a post of Joint Commissioner for Dementia.

- The joint commissioner has led work to design integrated care pathways, re-specify existing services, jointly tender for new services and develop a partnership approach across providers.
- These improvements have only been possible with high level agreement from the NHS and local council, and a unified approach to the commissioning of services.
- A section 75 agreement allows Commissioners from health and social care to be co-located and work together on all commissioning areas.
- As part of the joint commissioning arrangements, commissioners are required to engage with council health scrutiny committees, PCT professional executive committees, joint partnership boards, service user groups, service users/patients, carers, their dementia commissioners and clinicians.
- Difficulties encountered include lack of pooled budgets, having two masters (health and social care) and the council not having a purchaser-provider split.

2. Evidence of effectiveness - integrated models of dementia services (including memory assessment and post-diagnosis services):

2.1 NICE Dementia Clinical Guideline (CG42)

The NICE Dementia Clinical Guideline (CG42) provides specific guidance about memory assessment services and taking an integrated approach to the provision of dementia services.
• The guideline states that memory assessment services should be the single point of referral for all people with a possible diagnosis of dementia.
• People who show signs of mild cognitive impairment should be referred to memory assessment services.
• These services should include a full range of assessment, diagnostic, therapeutic and rehabilitation services.
• The memory assessment services should ensure an integrated approach.

2.2 Prime Minister's Challenge on Dementia
The Prime Minister’s challenge on dementia aims to deliver major improvements in dementia care and research by 2015. It makes specific recommendations regarding memory assessment services.
• In order to improve early diagnosis rates, GPs should be encouraged to refer those in need of assessment to memory assessment services.
• Memory assessment services will be established in all parts of the country.
• The proportion of memory services accredited through the Royal College of Psychiatrists national Memory Accreditation Programme will be increased. This will enable individual organisations to benchmark and report their own performance to drive improvement.

2.3 Dementia Quality Standard (QS1)
The Dementia Quality Standard (QS1) defines a high standard of dementia care and states that people with suspected dementia are referred to a memory assessment service specialising in the diagnosis and initial management of dementia (statement 2).

2.4 NICE Commissioning Guide for Memory Assessment Services
The NICE Commissioning Guide for memory assessment services provides support for the local implementation of NICE clinical guidelines through commissioning.
1. The guide outlines some key clinical issues in providing effective memory service: (i) accurately identifying and referring all people who present with signs and symptoms of possible early diagnosis, (ii) ensuring that appropriate referral pathways are in place, (iii) providing comprehensive assessment and diagnosis of dementia, including subtype diagnosis, (iv) providing an integrated approach to care coordination and implementation across all agencies involved in the treatment and care of people with dementia and support of their carers, and (v) providing a quality assured service.
2. The key components of a memory assessment service are: (i) early identification and referral of people with a possible diagnosis of dementia and (ii) developing a high quality service for dementia assessment diagnosis and management.
3. Commissioners may wish to consider the potential for locating memory assessment services (or aspects of such services) in primary care, where they may be provided by practitioners with a special interest in dementia. Moving away from intimidating psychiatric or other hospital settings to a primary care environment may help to break down barriers and reduce stigma.
4. Commissioners may wish to consider delivering a memory assessment service in a number of different ways, and mixed models of provision may be appropriate across a local health economy.
5. Local stakeholders (including service users, family carers and the voluntary sector) should be involved in determining what is needed by a memory assessment service.
6. Memory assessment services should be integrated with other elements of care for people with dementia.
7. Commissioners should consider joint local planning with joint funding or pooled budgets to achieve a whole-systems approach.

2.5 South West Dementia Partnership Evaluation of Dementia Support Worker Roles
The South West Dementia Partnership has conducted an evaluation of community-based support for people with dementia and their family carers. They reviewed different models of community support and present the benefits and costs of a number of case studies. The evaluation found that most dementia support workers function as named contacts for people with dementia and their family carers and assist with navigating through or signposting to suitable support services at times which suit service users best. Some models provide other services including pre-diagnosis support and liaison between health services.

The evaluation found that community-based support services delivered a number of outcomes, including improved quality of care, reduction in the time taken to diagnosis, increased diagnosis rates, reassurance to service users and prevention of crises, helping people stay in their homes for longer and improved access to services. Locating dementia support workers in primary care is thought to improve the quality of the service and improve diagnosis rates. Overall, the evaluation found that a tiered model of service delivery offering differing intensity of support is most effective at delivering care.

**Case study 1: Alzheimer Scotland 8 Pillars Model of Community Support for People with Dementia**

The 8 Pillars Model of Community Support for people with dementia has been developed by Alzheimer Scotland and tackles the full range of factors that influence the experience and impact of the illness. Figure 39 summarises the 8 Pillars Model.

![Schematic diagram of the 8 Pillars Model of Community Support for Dementia (Alzheimer Scotland)](figure39.png)

*Figure 39: Schematic diagram of the 8 Pillars Model of Community Support for Dementia (Alzheimer Scotland)*

The first pillar of community support is the Dementia Practice Coordinator who is a named, skilled...
practitioner who will lead the care, treatment and support for the person with their dementia and their family carer. They will ensure access to all pillars of support and coordinate between all the practitioners delivering services, accompanying each person with dementia throughout their journey.

The rationale for this element of support is that there is currently no coordinated approach to providing support and no joint practice intervention when people start to decline. People with dementia and their carers do not receive the range of interventions required to support them in the community.

The symptoms of the illness mean that the care, support and treatment needed spans health and social care. It requires a single practitioner to hold responsibility for ensuring all needs are met and that those working with the person do so in a coordinated way.

The role will involve effective communication with the GP, psychiatry and the wider community mental health team. The Dementia Practice Coordinator will facilitate the transfer of this knowledge and expertise into the design of effective social care interventions.

In Scotland, everyone diagnosed with dementia from 1st April 2013 is entitled to a minimum of one year’s worth of post-diagnostic support which will be coordinated by a Link Worker. This initiative is part of Scotland’s National Dementia Strategy (2013-2016).
Case study 2: Gnosall Primary Care Memory Clinic

The Gnosall Primary Care Memory Clinic was set up in 2006 and aims to remove delays and the potential stigma associated with referral to traditional mental health based memory services by providing all necessary expertise (including a Consultant Psychiatrist) within primary care, referring people on to mental health or other specialist services only when matters were too complex or stressful to cope with locally.

The Eldercare Facilitator runs the memory clinic and liaises with those using the service. The facilitator is a dementia expert who coordinates all activities to identify, investigate, treat and support people with dementia and their families from within the practice. The facilitator allocates one 3.5 hour session on site every month to the practice of 8,000 people for a primary care memory clinic and is available by telephone and email between times. This means that patients, their families and professionals always have someone to turn to for consultation and direct help. The facilitator can use the expertise of colleagues in the practice and other agencies when needed.

The Gnosall memory clinic pathway is summarised here:

Once a person has been seen at the memory clinic and been diagnosed with dementia, the patient and family become registered under the supervision of the Eldercare Facilitator who will remain in touch and available to them. The facilitator arranges follow up care and modifies support and
treatment according to their changing needs in agreement with the patient, their family, the GP and Consultant Psychiatrist. The facilitator identifies and accesses appropriate resources to the patient’s and family’s needs from other agencies including social care, voluntary and independent organisations. The patient and family are informed of benefits and legal matters relevant to their situation. Support from this point is continuous and iterative until death.

Key outcomes:
- Time from referral to being seen is one month.
- The number of people on the dementia register is at or above the predicted prevalence.
- Satisfaction amongst patients, their families and those referring is high.
- There has been minimal use of secondary care mental health services with consequent cost savings.
- The use of secondary care physical health services has been reduced which has also led to savings.
- It has been estimated that Gnosall’s service to older people with memory disorders or frailty provides more for these patients at a cost which is £1,000,000 less than equivalent practices in South Staffordshire.

Case study 3: West Sussex Memory Assessment Service

The West Sussex Memory Assessment Service (MAS) aims to provide timely high quality diagnostic assessment and cognitive treatment as well as ongoing information, advice and support via Dementia Advisors and Dementia Support Workers.

- The service is delivered in a variety of locations including Assessment and Treatment Centres and GP surgeries.
- The patient is offered a post-diagnostic meeting with the Alzheimer’s Society Dementia Advisor who provide clear, comprehensive and accurate information on (i) forms of dementia, (ii) caring, legal and financial matters, (iii) social and health services, and (iv) benefits.
- This also includes a carers assessment and information, advice and signposting for carers.
- The MAS also provides pharmaceutical and psychological treatment interventions.
- The Dementia Support Workers provide ongoing emotional support to people with dementia and their carers where necessary and through times of crisis.
- People who continue treatment and those with mild cognitive impairment who require follow up remain on the caseload of MAS. They have access to and regular support and advice from the Dementia Advisors and Dementia Support Workers.
- Patients who are not on dementia treatments and who do not have complex neuropsychiatric needs are discharged back to primary care with a comprehensive management plan and access to a Dementia Advisor.
- Those with more complex needs are transferred to the care of the Living Well with Dementia Team.

Key benefits:
- Early diagnosis, treatment and management planning prevents crisis hospital admissions and delays residential and nursing home placement.
- Single point of referral – MAS delivers expertise across the disciplines of psychiatry, neurology and care of elderly medicine within one service, reducing the need for multiple referrals.
- Seamless interface with secondary mental health services, voluntary sector and social services to streamline patient’s journey.
Section 6: Information Gaps

There are a number of gaps in information about the epidemiology of dementia in Suffolk, service provision and the effectiveness of these services.

1. Epidemiology of dementia in Suffolk:
   - 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 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 what services are provided to people with dementia and their family carers in Suffolk. However, 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.
   - 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.

Commissioners in Surrey have been working with the Department of Health to develop a tool\(^5\) to assess progress at improving outcomes for people with dementia and their family carers. The tool uses health information and the findings from a survey to monitor progress, and also presents a set of aspirational measures that could be used in the future.

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Section 7: Key Findings and Recommendations

This needs assessment shows that some progress has been made in achieving the objectives of the Suffolk Joint Dementia Strategy which was launched in 2009. This includes the provision of services such as the memory assessment service, dementia advisors, flexible dementia service and dementia intensive support teams. However, it has also highlighted a number of areas of unmet need which are having a significant negative impact on the quality of life of people with dementia and their family carers in Suffolk.

The key findings from the needs assessment are presented here, alongside recommendations of how to address the issues and links to the Suffolk Joint Dementia Strategy.

Early diagnosis:

An early diagnosis of dementia enables the person with dementia and their family carers to make choices about their care. It allows access to specialist dementia services which provide care and support to the family, thereby reducing the likelihood of crises, admission to hospital and residential care.

In Suffolk, it is estimated that approximately 6,000 people with dementia remain undiagnosed. This needs to be urgently addressed. Diagnosis rates can be improved using a variety of interventions as identified in national research and policy such as ‘Unlocking diagnosis: the key to improving the lives of people with dementia’, a report produced by the All-Party Parliamentary Group on Dementia in 2012.

Since the launch of the national and local dementia strategies in 2009, local memory assessment services have been commissioned across Suffolk. Service activity data that is required to monitor and evaluate these services is not currently available.

Recommendation 1: the clinical commissioning groups in Suffolk should continue to focus on improving diagnosis rates and evaluate the impact of local interventions, such as the memory assessment services.

Link to Suffolk Joint Dementia Strategy:
- Objective 2: Good quality early diagnosis and intervention for all

Joint commissioning of dementia services:

The provision of dementia services in Suffolk is fragmented; this impacts negatively on people with dementia and their family carers who receive complex and confusing services. Although many of the services provided receive positive feedback from people with dementia and their family carers, only a small proportion of the total population have access to services and there is variation in the accessibility of services across the county. This must be addressed urgently in order to improve the quality of care and support, equity of access, and to meet the increasing demand on services.

National guidance recommends the joint commissioning of dementia services. Evidence and case studies of joint commissioning best practice can be used to inform the initiation of joint commissioning of dementia services in Suffolk.

Recommendation 2: As a starting point, commissioners of dementia services in the CCGs and Suffolk County Council should develop and implement one integrated commissioning plan that is informed by people with dementia and their family carers, and the findings of this needs assessment.
Learning from other parts of the country (including Scotland and Staffordshire) suggests that an integrated, community model of post-diagnosis support services can be effective. An important coordinator role lies at the heart of such a model, ensuring a single point of contact and coordination of care.

**Recommendation 3: An integrated post-diagnosis support service should be commissioned that provides a named, single point of contact for people with dementia and their family carers who will lead their care, treatment and support. This service must address gaps identified in this needs assessment, such as the limited capacity of respite services.**

The number of people with dementia in Suffolk is expected to increase by 33% by 2021. This will place significant strain on services that are not currently meeting the volume of need.

**Recommendation 4: Commissioners must use the data to plan for the expected increase in demand when commissioning dementia services.**

There are certain groups of people living in Suffolk who may have different levels of risk of dementia and specific needs, and may experience variation in access to services. This includes those with early onset dementia, people from BME groups, people with a learning disability and those living in rural, isolated areas of the county. The number of people from these groups who have dementia or care for someone who does is likely to increase.

**Recommendation 5: The joint commissioning plan must outline how dementia services will meet the specific needs of people with early onset dementia, people from BME groups, people with a learning disability and those living in rural, isolated areas of the county.**

Link to Suffolk Joint Dementia Strategy:
- Objective 4: Enabling easy access to care, support and advice following diagnosis

**Funding of dementia services:**

Information is not currently available to accurately calculate how much is spent on health and care services for people with dementia and their family carers. This is due to the complex nature of the delivery of dementia services. This financial information is essential in order to effectively commission services that will meet the needs of the increasing number of people with dementia in Suffolk.

Many dementia services are funded by short-term grants. This has serious implications for the sustainability and quality of services, and must be addressed.

**Recommendation 6: Commissioners must urgently identify the current spend on dementia services in Suffolk.**

**Recommendation 7: The joint commissioning plan should identify long-term and sustainable funding sources for local dementia services.**

**Dementia friendly communities and services:**

More can be done in Suffolk to raise awareness about dementia amongst the public and professionals. By raising awareness and creating communities that are ‘dementia-friendly’, we can reduce fear, stigma and social isolation that people with dementia and their family carers experience. It is also essential in order to improve diagnosis rates. There are communities in Suffolk that have taken huge strides to become ‘dementia-friendly’ and we can learn from their best practice.
Recommendation 8: Public Health Suffolk should lead a dementia awareness campaign and co-ordinate the development of dementia friendly communities.

People with dementia and their family carers use a range of generic services in addition to dementia-specific services. It is therefore important that staff across these services understand dementia and the needs of people with dementia and their family carers. This needs assessment has identified the following sectors that require focused dementia training:

- General practice (in order to improve diagnosis rates);
- Domiciliary care (to improve quality of care, thereby helping people to stay living in the community);
- Residential care (where approximately 3,000 people with dementia live in Suffolk); and,
- Hospitals (where stakeholders have identified a need for training).

Recommendation 9: The workforce development programme for dementia in Suffolk should be targeted at general practice, domiciliary care, residential care and hospitals.

Link to Suffolk Joint Dementia Strategy:

- Objective 1: Improving public and professional awareness and the understanding of dementia

Information about dementia services in Suffolk:

This needs assessment has identified that people with dementia and their family carers find current dementia services complex and confusing. The provision of simple, timely and accessible information about services therefore remains a priority. The provision of integrated post-diagnostic services that use a single, named care co-ordinator should remove the need for large volumes of information about current services.

The needs assessment has also identified significant gaps in information about dementia services for use by commissioners. This includes gaps in information about the true prevalence of disease, characteristics of people with dementia, incidence of dementia and the number of family carers. There is also missing information about service activity, such as the number of referrals and diagnoses made at memory assessment services.

This information is necessary in order to monitor the effectiveness, cost-effectiveness, quality and outcomes of existing services, plan future services and identify any areas of inequity.

Recommendation 10: Commissioners must develop a dementia information dashboard that is regularly monitored to evaluate dementia services.
Acknowledgements:

Many people have contributed to the production of this needs assessment, including representatives from the following organisations:

- Age UK Suffolk
- Alzheimer’s Society
- The Debenham Project
- East of England Ambulance Service NHS Trust
- Great Yarmouth and Waveney Clinical Commissioning Group
- Ipswich and East Suffolk Clinical Commissioning Group
- Ipswich Hospital NHS Trust
- Healthwatch Suffolk
- Norfolk and Suffolk Dementia Alliance
- Norfolk and Suffolk NHS Foundation Trust
- Sue Ryder
- Suffolk Community Healthcare
- Suffolk County Council
- Suffolk Dementia Advisory Reference Group
- Suffolk Family Carers
- West Suffolk Clinical Commissioning Group
- West Suffolk NHS Foundation Trust

Special thanks to the following people who provided data and analytical support: Chris Hughes, Patrick Forrest, Paul Higham, Tanya Kimber and Stephen Patterson.
Glossary:

<table>
<thead>
<tr>
<th>Term</th>
<th>Description</th>
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<tbody>
<tr>
<td>BME</td>
<td>Black and Minority Ethnic</td>
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<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>CQUIN</td>
<td>Commissioning for Quality and Innovation payment – a payment scheme used by health care commissioners.</td>
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<tr>
<td>DIST</td>
<td>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.</td>
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<tr>
<td>GP</td>
<td>General practitioner</td>
</tr>
<tr>
<td>ICD-10</td>
<td>International Classification of Diseases – the standard diagnostic tool used worldwide.</td>
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<tr>
<td>Incidence</td>
<td>A measure of the number of new cases of a disease within a specified time period.</td>
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<tr>
<td>NICE</td>
<td>National Institute for Health and Care Excellence – an organisation that provides guidance to ensure quality and value for money of health and social care.</td>
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<td>ONS</td>
<td>Office for National Statistics - the recognized national statistical institute for the UK)</td>
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<tr>
<td>PCT</td>
<td>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.</td>
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<tr>
<td>Prevalence</td>
<td>A measure of the number (or proportion of a population) of people living with a condition.</td>
</tr>
<tr>
<td>QOF</td>
<td>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.</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>
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</table>
Appendix 1: Summary of National Dementia Policy

In 2009, the government published ‘Living well with dementia – A National Dementia Strategy’. The strategy aims to ensure that significant improvements are made to dementia services across three key areas (improved awareness, earlier diagnosis and intervention, and a high quality of care). The strategy identifies 17 key objectives (outlined in table 1) which should result in significant improvements in the quality of services provided to people with dementia and promote a greater understanding of the causes and consequences of dementia.

<table>
<thead>
<tr>
<th>TABLE 1: Key objectives of the national dementia strategy</th>
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<tbody>
<tr>
<td><strong>Objective 1:</strong> Improving public and professional awareness and understanding of dementia.</td>
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<tr>
<td><strong>Objective 2:</strong> Good-quality early diagnosis and intervention for all.</td>
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<td><strong>Objective 3:</strong> Good-quality information for those with diagnosed dementia and their carers.</td>
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<tr>
<td><strong>Objective 4:</strong> Enabling easy access to care, support and advice following diagnosis.</td>
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<tr>
<td><strong>Objective 5:</strong> Development of structured peer support and learning networks.</td>
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<tr>
<td><strong>Objective 6:</strong> Improved community personal support services.</td>
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<tr>
<td><strong>Objective 7:</strong> Implementing the Carers’ Strategy.</td>
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</tbody>
</table>
are available for carers of people with dementia. Carers have a right to an assessment of their needs and can be supported through an agreed plan to support the important role they play in the care of the person with dementia. This will include good-quality, personalised breaks. Action should also be taken to strengthen support for children who are in caring roles, ensuring that their particular needs as children are protected.

<table>
<thead>
<tr>
<th>Objective 8:</th>
<th>Improved quality of care for people with dementia in general hospitals.</th>
<th>Identifying leadership for dementia in general hospitals, defining the care pathway for dementia there and the commissioning of specialist liaison older people’s mental health teams to work in general hospitals.</th>
</tr>
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<tr>
<td>Objective 9:</td>
<td>Improved intermediate care for people with dementia.</td>
<td>Intermediate care which is accessible to people with dementia and which meets their needs.</td>
</tr>
<tr>
<td>Objective 10:</td>
<td>Considering the potential for housing support, housing-related services and telecare to support people with dementia and their carers.</td>
<td>The needs of people with dementia and their carers should be included in the development of housing options, assistive technology and telecare. As evidence emerges, commissioners should consider the provision of options to prolong independent living and delay reliance on more intensive services.</td>
</tr>
<tr>
<td>Objective 11:</td>
<td>Living well with dementia in care homes.</td>
<td>Improved quality of care for people with dementia in care homes by the development of explicit leadership for dementia within care homes, defining the care pathway there, the commissioning of specialist in-reach services from community mental health teams, and through inspection regimes.</td>
</tr>
<tr>
<td>Objective 12:</td>
<td>Improved end of life care for people with dementia.</td>
<td>People with dementia and their carers to be involved in planning end of life care which recognises the principles outlined in the Department of Health End of Life Care Strategy. Local work on the End of Life Care Strategy to consider dementia.</td>
</tr>
<tr>
<td>Objective 13:</td>
<td>An informed and effective workforce for people with dementia.</td>
<td>Health and social care staff involved in the care of people who may have dementia to have the necessary skills to provide the best quality of care in the roles and settings where they work. To be achieved by effective basic training and continuous professional and vocational development in dementia.</td>
</tr>
<tr>
<td>Objective 14:</td>
<td>A joint commissioning strategy for dementia.</td>
<td>Local commissioning and planning mechanisms to be established to determine the services needed for people with dementia and their carers, and how best to meet these needs. These commissioning plans should be informed by the World Class Commissioning guidance for dementia developed to support this Strategy.</td>
</tr>
<tr>
<td>Objective 15:</td>
<td>Improved assessment and regulation of health and care services and of how systems are working for people with dementia and</td>
<td>Inspection regimes for care homes and other services that better assure the quality of dementia care provided.</td>
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</table>
Objective 16: A clear picture of research evidence and needs. Evidence to be available on the existing research base on dementia in the UK and gaps that need to be filled.

Objective 17: Effective national and regional support for implementation of the Strategy. Appropriate national and regional support to be available to advise and assist local implementation of the Strategy. Good-quality information to be available on the development of dementia services, including information from evaluations and demonstrator sites.

The national strategy was followed in 2012 by the publication of the ‘Prime Minister’s challenge on dementia’ which aims to deliver major improvements in dementia care and research by 2015. The report delivers key commitments in three main areas: (i) driving improvements in health and care, (ii) creating dementia friendly communities that understand how to help and (iii) better research.

It is recognised that unpaid carers play a key role in helping people with dementia to live well. The national carers strategy, ‘Recognised, valued and supported – Next steps for the Carers Strategy’, published in 2010, is a key national strategy that directly relates to improving outcomes for people with dementia and their carers. The carers strategy sets out an ambitious agenda for change, identifying four priority areas: early identification, recognition and involvement in care planning, enabling carers to fulfil their educational and employment potential, personalising support for carers and those they care for and supporting carers to remain mentally and physically well. Objective 7 of the national dementia strategy is to implement the carers strategy for those caring for people with dementia. NHS Midlands and East and Enable East have published a good practice guide entitled ‘Commissioning for Carers’ which demonstrates the excellent practice that has been developed in the East of England.

The National Institute for Health and Care Excellence (NICE) has also been instrumental in setting clinical guidelines and quality of care for the diagnosis and management of people with dementia. The ‘NICE Dementia Clinical Guideline CG42’ was originally published in 2006 and updated in 2012. It makes recommendations for the identification, treatment and care of people with dementia and the support of carers. Key priorities within the guideline include: non-discrimination, valid consent, assessment and support for carers, health and social care integration, memory services, structural imaging for diagnosis, behaviour assessment, workforce training and mental health needs in acute hospitals.

In 2010, NICE published its ‘Dementia Quality Standard (QS1)’ which defines a high standard of dementia care. It covers the care provided by health and social care staff in direct contact with people with dementia in hospital, community, home-based, group care, residential or specialist care settings. The quality standard statements are outlined in table 2 below:

<table>
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<th>TABLE 2: Dementia quality standard statements</th>
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<tr>
<td>Statement 1</td>
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<td>Statement 2</td>
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<td>Statement 3</td>
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<td>Statement 4</td>
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</table>
Statement 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.

Statement 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.

Statement 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.

Statement 8
People with suspected or known dementia using acute and general hospital inpatient services or emergency departments have access to a liaison service that specialises in the diagnosis and management of dementia and older people’s mental health plan.

Statement 9
People in the later stages of dementia are assessed by primary care teams to identify and plan their palliative care needs.

Statement 10
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.

This quality standard was followed in 2013 by the publication of the ‘Quality standard for supporting people to live well with dementia (QS30)’ which covers care and support of people with dementia and applies to all social care settings and services working with and caring for people with dementia. The 10 statements cover the following areas: involvement in diagnosis, choice and control in their care and support, participation in leisure activities, development of relationships, accessing and involvement in the development of services, appropriate housing, the use of advocacy services and involvement in their community.

The ‘NICE support for commissioners of dementia care (CMG48)’ is a resource that supports commissioners, clinicians and managers to commission high-quality evidence-based care for people with dementia and their carers that are in line with the NICE guidelines and quality standards.

The new NHS, social care and public health outcomes frameworks include two dementia-specific outcome indicators.

(i) The number of people diagnosed with dementia as a proportion of the estimated dementia prevalence: this indicator is a joint indicator, included in both the NHS and public health outcomes framework.

(ii) A measure of the effectiveness of post-diagnosis care in sustaining independence and improving quality of life: this indicator is currently being developed and will be a joint indicator, included in both the NHS and social care outcomes framework.

In addition to these key national policies, guidelines and outcomes frameworks, there are a wide range of other national organisations and initiatives that will influence this dementia needs assessment. These include the National Dementia Audit of the care of people with dementia in acute trusts, work done by the All Party Parliamentary Group on Dementia and by national charities such as the Alzheimer’s Society, Dementia UK and Age UK.
The Debenham Project
Research into the Dementia/Memory Loss Journey for Cared-For and Carer - 2012-13

Including investigation of the advantages & disadvantages of early diagnosis and early engagement with care/support services.

Commissioned and Funded by:
This report lays out the findings of research carried out between July 2012 and August 2013 for The Debenham Project in Suffolk, funded by the Norfolk & Suffolk Dementia Alliance.

1. **The Debenham Project**

The Debenham Project is based in the eponymous village in mid-Suffolk. It is a unique, community-based project which has, of its own initiative, developed a comprehensive range of local services to support carers of those with symptoms of dementia, and those they care for.

2. **The Research**

The research sought to obtain information from family carers and cared-for about the memory loss/dementia journey; a profile of the carers and cared-for; their experiences; and also views from them and others on the positive and negative aspects of early diagnosis and early intervention of/by services.

The principal survey group was forty-two family carers of people with memory loss/dementia living either presently or in the recent past in the area covered by the Debenham GP practice including its two surgeries in Otley and Grundisburgh.

The aim of this research is to inform the funders; local and regional authorities and national government as well as the Debenham Project and partners to enable robust planning of future services and support for people with dementia and their carers.

This report lays out the responses to the family carer questionnaire, question by question; it examines and computes these responses, categorising where clearly possible & helpful. It also incorporates experiences and views from structured interviews with the family carers, Debenham Project volunteer questionnaires and relevant professionals in social care and health services, including the voluntary sector; and discusses the findings and draws conclusions.

The research is believed to be unique in its person-focused methodology and approach, and this is evidenced through the high returns and response rates.

The researchers are independent of the Debenham Project, and have a background in non-instructed advocacy, engaging empathetically to elicit information from those who are not necessarily able to give it verbally. They also are experienced in older people’s services and other support and housing.

3. **Context**

This research has taken place at a time of change. The researchers have therefore set it against the background of these changes, which include national and local dementia strategies and changed ways of working among health, social care and the voluntary sector.

4. **Data**

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6 [www.the-debenham-project.org.uk](http://www.the-debenham-project.org.uk)
4.1. PROFILE OF THE CARER & CARED-FOR

The carers indicated physical and/or mental strain and money are problems. Carers and cared-for are mainly older – three-quarters of cared-for are over 80. 19% of cared-for had moved into the area in the last five years – a higher proportion than for carers. Half the cared-for had poor physical health, a third of carers had financial problems. Roughly half lived with the carer. Changes were noted in the cared-for including character, mood, frustration, and for the carer the strain & sense of loss and sadness.

Key issues & concerns:-
   a. Many carers have physical health issues that can impede looking after the cared-for
   b. One in three carers report financial difficulties
   c. One-third of cared-for had moved to a care setting, but there is no such provision within the vicinity, causing hardship for some carers and families
   d. There is severe physical and emotional cost to the carer.

4.2. EVOLUTION OF MEMORY LOSS/DEMENTIA

Each responder was at very different stages of the memory loss/dementia journey. The most frequent first signs reported were forgetfulness; difficulty doing familiar things; misplacing things; and changes in mood. Signs that it was more than age-related included memory loss; personality change; problem or inability with familiar tasks; lack of motivation.

Key issues & concerns:-
   a. Some carers and cared-for found it difficult to grasp, confront or accept the changes to the cared-for – and the burden of caring was seen as heavy.

4.3. AWARENESS, KNOWLEDGE & UNDERSTANDING OF DEMENTIA AND THOSE FIRST TURNED TO FOR HELP

Numbers stating there were signs that could have been detected earlier, point to the lack of understanding, information or pathway that carers state elsewhere. Family ties are very important and they are typically turned to first for help. The GP is first 'external' port of call – often after consultation with the family. Three-quarters of carers saw the GP’s input here as beneficial.

Key issues arising:
   a. More education & training is clearly needed for carers to understand what is happening and what to expect and how to care & live with it.
   b. Given they are typically the first port of call beyond the family, GP practices could perhaps be the place for this role and offer advice and information
   c. Literature & publicity could be further developed to highlight likely first signs, what to look for, what to expect and where to seek help7.

4.4. IMPACT OF CARING FOR SOMEONE WITH DEMENTIA

The impacts are emotional/psychological; social/lifestyle; then practical. Chief factors are fear/worry, guilt, exhaustion, constant vigilance & attendance, and isolation. Physical health deterioration is also reported. Commitment from carers is high, despite the frequent lack of support reported beyond the family or GP.

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7 This could be similar to the stroke leaflet When Stroke Strikes, Act F.A.S.T: NHS, 2009, 293293a 1p 1050K Feb 09 (Colibri), http://www.nhs.uk/actfast/documents/act-fast-a5-leaflet-white-woman.pdf
Key points/concerns:

a. These impacts are crucial to supporting particularly the carer. Is current support here appropriate & sufficient?

4.5. AWARENESS OF HOW TO ACCESS HELP, CARE & SUPPORT & WHO FROM

Carers contacted the GP first, for help, services or signposting. Next came the Debenham Project and carers’ use of their own initiative. Social Care then Health were next. The media was a source of information for some. Some help was difficult and took unacceptably long to obtain. There was too much paperwork and too little personal contact. Carers are typified by one comment: “I learnt as I went along” – a recurrent theme.

Key points or issues

a. Carers felt not supported but isolated, perplexed & ignorant. Some fell back on their own resources (initiative, family etc) or had to wait for a crisis.
b. Responsive, adequate and trusted local services, advice, care & support are required.
c. Carers reported too many agencies to deal with – one gateway is needed, to ensure people have the knowledge and tools to identify what they need at the right time.
d. Given the proportion spontaneously seeking help from the GP, there could be a wider role for the GP as the access point or gateway. However, concerns were raised about the GP’s knowledge, and improved training is needed
e. Help/support from other agencies was of mixed value

4.6. DIAGNOSIS, ITS EFFECT, EFFECTIVENESS & TIMELINESS

Most diagnoses were given by a consultant but 14% were reported as given by the GP. There was a mixed view about whether an early diagnosis is of value: 42% positive, 31% negative & 23% a mixed blessing. Main benefits seen were the ability to plan for the future; confirmation of the problem; early medical and other intervention; the delaying effect medication can have; improved quality of life. Main drawbacks were that it made little or no difference; confirmed worst fears; & that it provoked a sense of ignorance or helplessness about dementia. Understandably, it had mostly a negative effect.

Key Points or issues

a. There is a need for enhanced training for professionals and education of carers to ensure greater clarity about what constitutes a diagnosis, who gives it and what it gives access to.
b. Dementia is often diagnosed as a result of another presenting problem which requires eg hospital admission
c. The diagnosis is seen as the primary gateway to services but people with memory loss/dementia can have needs before the point of diagnosis. This raises questions about the formal diagnosis-led approach.

4.7. SERVICES, SUPPORT & HELP: ACCESSIBILITY, USEFULNESS & TIMELINESS

As a result of diagnosis, 50% of responders were offered a service (but for 2 out of 5 it was insufficient or late), while 40% reported they were not. One-third of services offered were from the voluntary sector, a quarter from Health and less than a fifth from Social Care. Half the carers were positive in some way about the help or service offered as a result of the diagnosis, while just under half said it was not helpful in at least some way, and nearly three times as many saw some benefit in early support. Prime responses to what early support would have helped were: peer support, knowledge of who to ask & what is available, and training. Most of the reasons why early support was seen as not beneficial stemmed from the cared-for baulking at it.

Key points/issues

Local means “within the community” e.g. the local GP practice or community support project.

2. The most frequent service offered from the diagnosis was a list of organisations to contact.

3. It is of concern that the proportion of social care services offered/provided\(^9\) is so low (16%), not least since this should include a benefits check.

4. The health services offered/provided figure is also comparatively low (26%), considering it includes the GP service.

5. A majority saw the services or help offered/provided as of benefit, and a strong majority saw early help & support as beneficial. Peer support, greater knowledge, and training were the key benefits foreseen of early support intervention.

6. Other health conditions precipitated a hospital admission which led to a diagnosis of dementia

4.8. CARERS’ VIEWS ABOUT IMPROVEMENTS THAT COULD BE MADE & WHAT MIGHT ENCOURAGE OR DISCOURAGE SEEKING HELP

Scope for improvement was seen by carers in the services offered by professionals, mostly in the statutory sector. 2.6 times more reasons were given that discourage seeking help than encourage, chiefly a) emotive & reactive (eg guilt, pride, fear, denial); b) problems between cared-for/family/carer; c) problems with services; and d) the issues causing or steming from isolation. The main areas seen as potentially encouraging seeking help were: a) emotive/reactive (eg desperation or dealing with the fears); b) greater publicity and awareness; c) upskilling volunteers, NHS staff & GPs; and d) increased peer support, knowledge and education of carers. Overall, half said, in different ways, that they wished they had acted sooner and/or have been more assertive.

Key points & issues

1. Even though there were fair levels of satisfaction with the services provided following the diagnosis, there is evidence that additional services were needed along with improvements to existing. 1 in 5 cases reported the dementia situation is directly exacerbated by a perceived shortcoming of the statutory health and/or care/support agencies.

2. Frustration, feelings of inadequacy, isolation, unsupportedness and bleakness are common among carers. The existence of a clear care pathway for dementia (comparable for example to that for cancer) could have eased these.

3. The encouragements & discouragements (above) to seeking help point very directly to areas needing development – publicity and awareness, improved services, greater education.

4. Obtaining results and action (eg for appropriate support) takes energy, assertiveness and tenacity. However, carers were frequently exhausted, depressed or demotivated.

4.9. THE DEBENHAM PROJECT & ENGAGEMENT WITH IT/ITS USEFULNESS

Responders had mainly heard of the Debenham Project through informal local networks, most commonly through the GP. Other sources were local publicity, the Debenham Project itself, and some other professionals were also making referrals to it. Principal benefits were seen as: contact with other people in the same situation, friendships and reduction of isolation; support, reassurance & understanding; and advice and information. There was overwhelming (but not unanimous) praise for it.

Key points/issues

1. The Debenham Project’s penetration of the memory loss/dementia population appears to be reasonably effective in the light of the estimates. Responders had heard through a variety of methods.

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\(^9\) Notwithstanding the shift by social care away from direct provision & towards sub-contracted services via the voluntary sector.
2. There is room for greater penetration. The more informal, local networks appear relatively effective but referral from other agencies appears very low in this (historic) research sample. So there is scope for further work here.

3. In terms of the Debenham Project’s helpfulness, the sample group reported a wide range of ways the Project had helped them to cope. In essence these were through the meeting of needs through services not available elsewhere.

4. Given this – and also the climate of service provision and funding – it is very important that a project which is voluntary, for and inspired by the community, continues to provide and expand its services, to work towards as close to 100% penetration as possible of the group in its area affected/likely to be affected by memory loss/dementia. However, in practice it is difficult to envisage such a community-based organisation reaching or supporting more than about 75% to 85% of this target population.

5. **Conclusions**

A new methodology was developed which achieved high response rates and depth of information. The purpose of the research was to illuminate the dementia ‘journey’ by the carers and cared-for; to investigate the pros and cons of early diagnosis and early engagement with services. The following issues emerge as the main concerns:-

- Lack of knowledge and unpreparedness of carers
- Greater range and depth of person-centred support
- Addressing the needs of a rural community e.g. transport to, and distance from, care homes
- Financial worries of carers
- Isolation of carers and the burden of caring
- The focus on the diagnosis as the gateway to services and support
- Obtaining services before diagnosis
- A single point of contact for carers and people with dementia/memory loss
- Training needs of GPs, other health and social care professionals
References:


v *What is Vascular Dementia?* Alzheimer’s Society. Factsheet 402LP: December 2011


vii All-Party Parliamentary Group on Dementia, *Unlocking diagnosis: the key to improving the lives of people with dementia*. 2012


xvi Community Care. *Bridging the health-social care gap: life as a joint commissioner for dementia*. [http://www.communitycare.co.uk/2013/05/08/bridging-the-health-social-care-gap-life-as-a-joint-commissioner-for-dementia/#.UpMq0TC9W8Z](http://www.communitycare.co.uk/2013/05/08/bridging-the-health-social-care-gap-life-as-a-joint-commissioner-for-dementia/#.UpMq0TC9W8Z)


